WHAT REALLY MATTERS

A GUIDE TO PERSON-CENTERED EXCELLENCE

Application for Services for People with Mental Illness and People with Substance Use Disorder
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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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>List of Key Factors and Success Indicators</td>
<td>6</td>
</tr>
<tr>
<td>Factor 1 – Person-centered Assessment and Discovery</td>
<td>9</td>
</tr>
<tr>
<td>Factor 2 – Person-centered Planning</td>
<td>13</td>
</tr>
<tr>
<td>Factor 3 – Supports and Services</td>
<td>17</td>
</tr>
<tr>
<td>Factor 4 – Community Connection</td>
<td>23</td>
</tr>
<tr>
<td>Factor 5 – Workforce</td>
<td>25</td>
</tr>
<tr>
<td>Factor 6 – Governance</td>
<td>29</td>
</tr>
<tr>
<td>Factor 7 – Quality and Accountability</td>
<td>33</td>
</tr>
<tr>
<td>Factor 8 – Emerging Practices in Individual Budgets</td>
<td>37</td>
</tr>
<tr>
<td>Glossary of Terms</td>
<td>40</td>
</tr>
<tr>
<td>Background about CQL and the What Really Matters Initiative</td>
<td>42</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>46</td>
</tr>
</tbody>
</table>
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 behavioral health services and supports. These best practices and the resulting quality improvement initiatives can be applied across the range of supports and services for people with mental illness and substance use disorder.

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 urge organizations to use them as part of their own internal quality improvement program. 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.

These success indicators in person-centered behavioral health services and supports acknowledge the person’s life story. Support 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, dreams and fears.

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:
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 7 Quality and Accountability
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 8 Emerging Practices in Individual Budgets
Indicators:
8a People control their budget allocations
8b Individual budgets are both fair and ample
8c Budget, money and services/supports are portable

Key Factors and Success Indicators
APPLICATION FOR SERVICES FOR PEOPLE WITH MENTAL ILLNESS OR SUBSTANCE USE DISORDER

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

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 – PERSON-CENTRED ASSESSMENT AND DISCOVERY

FACTOR 1 INDICATORS

1. **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.

2. **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.

...AND THEIR APPLICATIONS

A person-centered organization meets people “where they are,” reaching out to demonstrate that it sees them, hears them and respects them. The organization acknowledges that individuals know their strengths and vulnerabilities, as well as their goals, hopes and expectations better than anyone else. The organization works with individuals to elicit these strengths and capacities throughout the assessment process and beyond. From the moment of first contact, a person-centered organization provides a way to engage and welcome consumers continuously and respectfully, promoting the values of choice, self-determination and empowerment.

In a person-centered environment, an individual’s involvement as a partner in care and supports extends beyond being heard to being in control of decision-making processes that lead toward self-discovery and, ultimately, to recovery. By definition, the path toward recovery for an individual with a mental illness or substance use disorder is self-directed; the individual defines his or her life goals and determines the route toward those goals.

In a person-centered environment, each person receives unconditional acceptance as he or she is – unique and special, with a singular life history and outlook, body of experiences, feelings and emotions. The organization’s values, structure, education, orientation and personnel reflect the focus on the individual and on that person’s dignity and right to self-direction. Formal and informal communications and interactions are respectful, compassionate and avoid judgments, predictions, put downs, labels, blaming or shamming. Each individual is recognized by the organization and its staff as the foremost expert on him or herself. Other stakeholders in an individual’s journey toward recovery, including family and peers as well as those within the organization and its network of consumer supports, share information and interact with respect, and also with the knowledge that the consumer is the final decision-maker in a person-centered environment.
In a person-centered environment, the process of assessment is not simply a matter of establishing a behavioral diagnosis. An organization providing a person-centered system of care for people with mental illness and substance use disorders begins by identifying and building on an individual’s assets, strengths and areas of health and competence, that, together, support an individual’s sense of mastery over his or her condition while working toward a meaningful sense of community belonging and a self-defined quality of life.

Person-centered assessment obtains holistic information about the individual and environment, including a valuation of both physical and behavioral health that can disclose any co-occurring disorders (whether behavioral problems such as substance use or physical ailments). It uses measures that carefully and accurately evaluate an individual from the perspectives of treatment, service and support needs, coupled with strengths and capacities. Assessment also hears the individual’s voice in identifying strengths and challenges, service preferences and identified needs.

The conduct of an initial evaluation of an individual seeking care and supports within a person-centered organization is the first opportunity an organization has to build the respectful, collaborative partnership that is the hallmark of a person-centered philosophy. The content of the assessment is sufficiently deep and insightful – and aware of the consumer’s expressed wants and needs – that it sets the groundwork for the ready development of an individualized, person-centered plan and budget for services and supports that are consistent with the individual’s age, gender, race, ethnicity and other personal characteristics. The assessment also discloses both provider and consumer assumptions about recovery and its sustainability. Importantly, assessment results are not static; they change over time as do care and support needs, emphasizing the value of ongoing connectedness with the consumer to collaboratively assess progress and changing needs.
In a person-centered organization, the values of an individual and that person’s own roadmap toward recovery are the foundation on which services and supports are built. When an individual is able to choose his or her own path to recovery and the tools he or she needs to get there, it allows for a more self-determined life. It grants an individual a greater sense of both control and responsibility.

Person-centered organizations work with individuals with mental illness and substance use disorders to engage in dialogue about the consumer’s personal meaning of recovery and how it can be achieved in practical and specific terms. Working with the organization’s staff, the consumer defines his or her own life goals; together, they design a unique path toward these goals, working within the values of both the person-centered organization and those of the consumer. In doing so, organizations may discover that while organizational goals and values emphasize freedom from symptoms, the individual may define recovery as a home of one’s own, a job, a circle of friends and a sense of self-value.
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
AN D THEIR A PPLICATI O N S

Treatment usually works best when it is consumer-led and controlled. When the individual determines a personal path to recovery, it allows for a self-determined life. The individual defines personal life goals with the service provider and together they design a unique path toward these goals. Individual pathways to recovery reflect the individual’s unique strengths and resilience, needs, preferences, experiences, and cultural and ethnic background. The focus is on increasing the consumer’s ability to cope successfully with life’s challenges, on facilitating recovery, and on building resilience – not just on managing symptoms.

The partnership among healthcare provider, consumer and family determines services and treatments based on the consumer’s needs and choices, not on the convenience of service systems. This includes choosing the health care providers who are on the team. The treatment plan is updated based on changing needs across the stages of life.

Included in the treatment plan is an individualized back-up plan for what is to be done in the event of a crisis. An individual may want to create an advance directive, a legal document that describes the services desired if an illness reduces the ability to make decisions.

All services, whether paid or unpaid, are integrated into a coordinated treatment plan designed to lead to improved health and quality of life.

Beyond specific behavioral health care services, individuals may choose or need other supports that should be considered as part of the plan, such as housing, supported employment and peer counseling, among others.

Budgets are managed collaboratively according to the training, counseling and assistance desired by the individual participants. Individuals accept responsibility for taking a direct role in managing their own care.

**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**
CONSUMERS

Consumers self-help and family involvement are an important part of effective mental illness and substance use disorder treatment. Consumers network with peers to find solutions to their problems, avoid isolation and learn about available social supports in the community. Consumers participating in self-help programs often experience increased independence, refine their coping skills and obtain feelings of empowerment. Families, in particular, play a role in the care and development of systems of care for children with serious emotional disturbances, identifying and helping to connect needed supports and services.

Behavioral healthcare plans that emphasize recovery include a commitment to personal independence and integration into community life. They identify supports that may be of assistance, such as supported housing, vocational rehabilitation and consumer-run activities that promote recovery. These plans can help an individual increase independence and participation in community life, and improve functioning at work or school.

Above all, individual needs dictate services. Two people with the same diagnosis may have distinctly different needs. Further, as the needs of consumers change, the services provided change with them. Consumers are empowered to control their own life choices.

Mental illness and physical health are connected and are considered together in planning. Older adults with major physical health issues often develop depression. Likewise, mental illness and substance use disorder often contribute to deterioration of physical health. Thus, supports are beneficial to help address physical health issues, when needed, and to address co-occurring mental illness and substance use disorder. Co-occurring mental illness and substance use disorder are resolved most successfully when addressed simultaneously.

When programs and their funding are fragmented and limited in number, individuals often are slotted into whatever is available rather than into services or supports they have chosen themselves. Consumers and families need the ability to choose the support services and treatments most relevant to them and most likely to lead to recovery. Consumers seek mental health and substance use disorder practitioners who provide support and education that enable consumers to take responsibility for controlling their symptoms to achieve recovery. Consumers are encouraged to set personal goals and work toward them. Practitioners provide facts and planning strategies, gather necessary supports and help target these efforts.

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

Consumer self-help and family involvement are an important part of effective mental illness and substance use disorder treatment. Consumers network with peers to find solutions to their problems, avoid isolation and learn about available social supports in the community. Consumers participating in self-help programs often experience increased independence, refine their coping skills and obtain feelings of empowerment. Families, in particular, play a role in the care and development of systems of care for children with serious emotional disturbances, identifying and helping to connect needed supports and services.

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KEY FACTOR

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

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
People-centered organizations ensure that in every way, from the first time an individual steps through a door for assessment, he or she is respected as an equal and an integral part of the care and support team and in the mapping and conduct of a recovery strategy.

People with mental illness and substance use disorders want to take personal responsibility for their own self-care and journey of recovery. By directing their own service needs, individuals develop better illness self-management skills, including greater knowledge of mental illness and substance use disorder, coping skills and relapse prevention skills, all of which play a key role in recovery. Specifically, in a person-centered system, individuals are empowered by being able to make choices not only about their care and supports, but also about where they live and work, how they spend their time and manage their resources and finances, and with whom they share their life stories.

Person-centered systems and organizations support shared decision-making, an interactive and collaborative process between individuals and their chosen health care providers that is consistent with the values of choice, self-determination and empowerment. When individuals have opportunities for choice and negotiation in selecting a doctor, therapist or case manager; have accurate, complete information on all available interventions and supports; and experience real collaboration in the development and conduct of a care and support plan, they are participating in a person-centered environment that can foster sustained recovery.

The process of recovery from mental illness or substance use disorder is not a linear process. Rather, recovery is based on continual growth, occasional setbacks and learning from experience. Beginning from the recognition that change is possible, a consumer can move forward to fully engage in the work of recovery. The pathway to recovery is highly individualized for those with mental illness and substance use disorders, based on each person’s unique strengths and resilience, as well as his or her needs, preferences, experiences (including past trauma) and cultural background in all of its diverse representations.

Thus, to meet individual needs and desired outcomes in recovery, both services and supports are flexible in nature, number, duration and scope in ways that correspond to an individual’s unique pathway to recovery. The organization also recognizes that the types and nature of supports made available are reassessed and refined over time as the process of recovery unfolds. At times, an individual may benefit from fewer or different supports and services. At other times, particularly in the event of relapse, an individual may desire more intensive...
Self-determination and person-centered supports are possible and most successful when individuals with mental illness and substance use disorders are empowered with the ability to choose the services and supports they would find most beneficial at any given time, and to realign, reconfigure and revise elements of that care and support over time.

A person-centered organization that has examined its structures, processes, programs, activities and overall culture is able to assess the extent to which individuals have real, ongoing opportunities to choose, to participate and to provide feedback and input about the types of services and supports available. A real dialogue with consumers helps organizations identify gaps and impediments – as well as strengths – that affect participation and person-centered supports one way or another. Organizations learn what would make the environment and the organization’s services and supports most accessible and appropriate.

Organizations with limited services and supports, such as those focused solely on crisis stabilization and medication, find opportunities to coordinate a person-centered approach with other community organizations.

The path toward recovery is a changing landscape of services and supports that are not always specific to treatment. An individual’s particular need for supports and providers includes many aspects of life: housing, employment, education, physical and behavioral health care and treatment, spirituality, creativity, social networks and peers, involvement in the community. Person-centered organizations, as well as family, individual providers, peers and the community at large, each play a role in ensuring individuals have access to and the ability to freely choose among these supports, as needed at a particular moment in time. Consumers and organizations together ensure that those supports are grounded in trust-based, respectful relationships.

A person-centered organization respects and acts with the knowledge that consumers have the right to change providers or supports to best meet their care and support needs, including the desire to add non-traditional providers and supports, such as peer counselors (sometimes called “experience experts”) and peer-run programs. These consumer-to-consumer connections provide social support, role models, shared experience and a sense of self-worth and empowerment that help advance the process of recovery.
Person-centered organizations and consumers both recognize that, at times, even though they have been proactive, individuals with mental illness or substance use disorder may find themselves in crisis. In advance, and with the encouragement and support of the person-centered organization, an individual develops an anticipatory self-directed plan of action delineating the circumstances that define a crisis, how the crisis will be managed and by whom. It also includes a post-crisis plan – another personally developed guide for the individual to use when getting over a crisis. To promote an environment that is respectful of consumers and consistent with the organization’s goals and values, the person-centered organization supports establishment of consumer-determined, individual crisis plans.

The plan may specifically identify the symptoms that would indicate to others that an individual is in crisis and needs others to step in; the names of trusted people who are to step in to be of assistance; the names of both current health providers and medications as well as the providers and medications of choice (as well as those of last resort and those to be avoided); preferred treatments; and a plan of care that includes the kinds of supports, services and facilities preferred in a crisis, as well as the steps other people (such as peers) could take to be of help. A plan may also include specific information that providers, supporters and peers might need to recognize when recovery has ended the need to use the crisis plan. A person-centered organization acknowledges and works within the bounds of such a crisis plan to facilitate the greatest amount of self-determination possible for the consumer.

In addition to a plan, organizations may encourage consumers to develop a formal legal document that facilitates self-determination during a crisis. It is known as an Advance Health Directive for Mental Health or a Psychiatric Advance Directive (PAD). In that document, an individual specifies his or her preferred treatment, what is and is not acceptable, how management should proceed, and who should be involved in care during that period, in the event the individual cannot speak for him or herself.
FACTOR 3 INDICATORS

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

Anyone who can help build hope – the catalyst for recovery – provides the unconditional support needed by a person with a mental illness or substance use disorder who is working toward health, independence, and a life of purpose and fulfillment. These personal champions may be family members, friends, health care providers, spiritual leaders or others. Foremost, they are trusted individuals, such as those a consumer entrusts with power of attorney or names in an advance directive. When stepping in they help carry out a consumer’s wishes for care and services. Importantly, these champions may also include peers. Peer support plays a key role in recovery and person-centered care. Peers, perhaps more often than anyone else, provide the unconditional support another consumer needs. Person-centered organizations help individuals identify these “personal champions,” encourage the value of such bonds, and also find that staff – particularly peer counselors – are actually serving in such a role.
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.

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 personalized plan includes treatment, supports and other assistance that enables consumers to integrate into their communities. Community participation enables people to identify and access mental health and substance use disorder services, opportunities for personal growth, and the people and resources to support them. Services are integrated and coordinated. Offering a full range of community-based alternatives to persons needing treatment for mental illness and substance use disorder is more effective than hospitalization and emergency room treatment.

Each consumer or child’s family needs information about services and supports, and opportunities to network with other consumers and families. Recovery-oriented services and supports are often successfully provided by consumers through consumer-run organizations and by consumers who work as providers in peer-support and psychosocial rehabilitation programs.

Consumers need information that takes into account the developmental, gender, linguistic or cultural aspects of providing and receiving services. As circumstances in life change, consumers may want to alter their service plans. That is why, in partnership, both consumer and organization staff review care and support plans on a regular basis. All communications are clear and easy to understand.

People with serious mental illness or substance use disorder or both need information on their illness, treatment and recovery options, and the range of available community resources, particularly housing and employment. Information and training, combined with peer support, direct persons in need of safe, decent housing to programs within the community.

The majority of adults with serious mental illness or substance use disorder want to work and many of them could work with help in the community. Job training support, for example, enables people with mental illnesses to participate in the work life of the community, with gains in self-esteem and financial rewards associated with meaningful employment. Being out in the work world can be one of the steps to recovery.
KEY FACTOR 5

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
The person-centered organization keeps up with new trends in evidence-based practices. Providers train support personnel in evidence-based practices and the most advanced thinking on diagnosis and treatments. Moreover, in the case of individuals working within a person-centered environment, they also are imbued with the knowledge and skills to work with consumers as partners in care.

Further, critical segments of the workforce, such as bachelor-level staff, paraprofessionals, primary care providers, as well as consumers and families, benefit from continuing education programs highlighting evidence-based practices and the value and elements of person-centered supports.

Organizations address retention and recruitment issues and concerns through a data-driven, continuous quality improvement process tailored to the problems being experienced. Organization leadership take part in a comprehensive public relations campaign promoting careers in behavioral health. This includes forming regional partnerships to create career ladders to ensure there is a set of educational steps linking advanced certification and licensure to increased reimbursement to providers of mental health and substance use disorder treatment. Financial incentives to recruit and retain qualified personnel include training stipends, tuition assistance and loan forgiveness.

Organizations implement strategies to develop a more stable workforce that is well-matched to consumers by engaging local residents who are culturally and linguistically diverse into entry-level positions and promoting their long-term professional growth.

Organizations take into account individual preferences and needs, including language, ethnic and cultural considerations, to ensure that all consumers have full access to effective care and supports and that their desires and needs are understood and are driving forces in decision-making. Thus, person-centered organizations are closely attuned to the development of a stable, highly skilled, culturally and linguistically competent behavioral health workforce. Behavioral health organizations consider their current connections to local groups and coalitions with the goal of creating a plan to increase and strengthen these ties.

Person-centered organizations are routinely working to eliminate rules and regulations that are not evidence-based and that impede the ability of staff to work with consumers to meet their individual needs. By providing staff autonomy and input into organizational decisions, person-centered organizations create a workforce that will be more stable. Organizations implement strategies to encourage the use of newly acquired skills and discourage the tendency for systems and supervisors to block constructive changes in practice.
Support for person-centered principles and practices are 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 to discuss 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.

Payments for community-based care and services take into account individually assessed differences in supports and needs, based on a standardized assessment and the identification of priority outcomes, while promoting the economical and efficient delivery of services. The service rates themselves are graduated to take into account differing intensities of service and support needs of individuals. The budgets awarded to individuals are sufficient to purchase the full number, duration and scope of services they are intended to pay for. Providers are likewise reimbursed sufficiently for the services they deliver.

Behavioral health systems collaborate with federal or state/provincial departments of labor to gain expertise in calculating wages and benefits across professions.

Since there is never enough money to adequately compensate providers and to provide needed services, adequate use is made of available peer supports that provide the individual with a unique perspective that enhances the overall relevance of the support provided.

When budgets are not sufficient to provide necessary services and supports, organizations undertake advocacy efforts to educate the public and its representatives about the unmet needs and the higher costs to society of less than adequate programs that do not have recovery as their goal or the consumer as a partner.
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
An organization’s commitment to and emphasis on person-centered supports for individuals with mental illness or substance use disorder is articulated in its mission, vision and values. The mission is the bedrock on which the organization’s work is built. It defines the organization’s purpose and the outcomes toward which it is working, spelling out in broad strokes the priorities, goals, orientation, culture and, above all, values on which the organization and its work are based.

The organization’s vision is the specific expression of the positive outcomes for the individuals with mental illness or substance use disorder (or both) who experience a person-centered approach that has been incorporated into every aspect of the organization’s day-to-day work.

Values are the core priorities on which day-to-day activities are grounded. Person-centered values include the engagement of people served by the organization as partners and peer service providers; the organization’s overall attention to culture, race, ethnicity, sexual orientation and gender; and the importance of collaborating with other organizations to expand the scope of care and supports to meet the full array of each individual’s needs. Values are most likely to be respected and adopted, if they are reflected in the mission and vision of the organization.

Without regard to where an organization resides or whether it is in the public or private sector, the mission, vision and values are evident in behaviors, actions, words and deeds of the entire staff, from corporate leaders and Boards of Directors to service providers and support staff of every level and skill-set. The development of an organization’s mission, vision and values includes representatives of all stakeholders in the organization – including those whom the organization serves. These priorities become part of the fabric of the daily operations of the organization.

**FACTOR 6 INDICATORS**

**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.
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).

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.

The organization involved with a “system of care” (or a support model for children with serious emotional disturbances) ensures that both care and supports not only are person-centered (and, if for a minor, also family-focused), but also that the care and supports are individualized. The organization ensures that service recipients (and, as appropriate, parents) are part of the team that helps structure the services, and tune and retune them over time, to ensure they remain consistent with a service plan and its desired goals. Moreover, support services, beyond clinical care and treatment to support the individual’s needs, are brought together – often through the collaboration of other service systems (for example, work or school, social welfare, criminal or juvenile justice, among others) – to create a fabric of care for that individual. Those supports, and others, may be needed by different individuals, but the goal is the same: to make available, at all times, the full range of services and supports that an individual needs for recovery.

That is the principle on which all organizations providing person-centered supports for people of all ages operates. A performance improvement process and regular evaluation ensures that the services and supports are of greatest benefit to the needs, goals and aspirations of the people with mental illness and substance use disorder it serves.

The person-centered organization engages mental health and substance use disorder consumers in leadership roles at all levels of the service delivery system, from outreach and assessment through recovery support and program evaluation. In a person-centered model, consumers, their families and the community are a valued voice and partner not only in delineating the mission, vision and values of the organization, but also in evaluating the organization’s progress toward meeting mission, vision and values, once established.

Mental health and substance use disorder consumers and individuals in recovery from substance use disorder play an important role in helping to empower their peers to recover. These peer leaders make valuable contributions as agency staff and as active members of a person-centered organization’s advisory board or leadership council. By acknowledging these contributions, organization leadership encourages the development and support of an ever-growing group of people involved in meaningful leadership roles in the organization.
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
The development of a program of integrated quality management is particularly important for a person-centered organization because behavioral health service systems tend to operate in separate realms with separate funding, quality assurance measures and evaluations. Adding to the complexity, supports – from housing and rehabilitation to education and employment – more often than not also function within separate arenas with separate outcome expectations, funding streams and evaluation criteria. Thus, evaluation of the full range of outcomes of a person-centered care model for individuals with mental illness and substance use disorder needs to be integrated. Not only are different measures collected, but even when measures are the same, they may be defined differently by different systems.

The challenge for the person-centered organization is to create and implement a consistent, quality management system that functions across all of the disparate parts of a network of services and supports. The quality management undertaken by a person-centered organization measures what is important to people, the impact on human needs and how well the program is meeting outcomes expected by the people receiving services and supports, in addition to outcomes related to cost efficiencies. Further, person-centered organizations’ quality management examinations of accountability include attention to such matters as instances of abuse, neglect and exploitation, all of which are antithetical to the person-centered model in behavioral health.

Evaluation assesses the impact of the quality of services and supports on the outcomes most desired by those consumers involved in a person-centered care model. The measures, above all, reflect indicators of progress toward recovery that are valued by consumers, among them social connectedness, employment or educational opportunity, and housing stability. For this reason, consumers are actively engaged in helping to identify evaluation criteria and in providing evaluation feedback. A person-centered organization places particular emphasis on the role and voices of consumers, their families and the community of peers and other concerned stakeholders in evaluating the organization’s progress toward meeting its mission, vision and values and the particular steps that may need to be taken to improve that effort.
Most mental illness and substance use disorder supports are provided by public sector organizations. Many of these service systems and support organizations have mandated quality measures through statute and regulation. Not all of those measures routinely reflect the focus on personal outcomes that are the hallmark in a person-centered system. The instruments used and data collected by a person-centered system measure the goals and outcomes established by individuals themselves. The measures assess how well the organization supports self-determination and recovery for the consumers it serves.

The work of monitoring consumer self-determination in a person-centered system is a component of a consumer report card that is oriented toward evaluating and understanding both quality assurance and consumer satisfaction. The measures assess both consumer experiences and infrastructure elements (policies, budgets, planning, staffing and values) that affect the robustness of the person-centered organization to advance consumer self-determination and, ultimately, recovery.

The organization includes all stakeholder groups — among them, consumers, peers and families — in ongoing evaluation of supports and services. The organization uses internal and external, formal and informal methods of evaluation. Outcomes and results are shared broadly in readily understandable language and graphics that convey not only point-specific outcomes, but also outcome trends over time. Results of the evaluation — outcomes — are reviewed closely by the organization and concerned stakeholders, including consumers. The information gained is used to collectively explore and make changes in organization policy and practice.

Organizations and communities can use questionnaires and report cards to gauge satisfaction with the organization's services and supports through questions about choice and self-determination.

In addition to evaluation, the organization has processes in place to receive and explore complaints or concerns raised by consumers or others engaged in the organization, whether as staff, service recipient, peer or other stakeholder. A non-punitive, confidential and accessible means of voicing concerns is well publicized and well known by everyone engaged in the delivery or receipt of supports. All concerns are carefully reviewed and addressed in a manner respectful of the consumers being served.
Many organizations serving individuals with mental illness or substance use disorder function within the public sector and are supported, often in large part, by public (local, state/provincial and federal) revenues and resources. Organizations receiving these public funds have a responsibility to the people they serve, to the public and to their funders to demonstrate they are good fiscal stewards and to ensure that resources are deployed appropriately and effectively. To that end, organizations conduct evaluations and assessments.

Person-centered organizations also make information about service outcomes readily available to other stakeholders, including individuals they serve, family, caregivers and the larger local community. They demonstrate accountability for service delivery and its human outcomes, as well as the cost efficiencies and effectiveness in meeting individualized person-centered needs that promote recovery. Organizational accountability can come in the form of reports on a range of person-focused measures and reports on the quality, effectiveness and person-centeredness of services and supports.

A person-centered organization serving people with mental illness or substance use disorder is transparent in many ways. Its structure is known to all, as is the full range of service and supports offered. Its mission, values and culture are broadly publicized and infused throughout its staff, from front desk through executive suite. The organization is evaluated from within and from the outside, with particular attention to its efficiencies and effectiveness in achieving person-centered outcomes, not just in terms of cost-effectiveness.

Transparency ends, however, where individual confidentiality begins, particularly when it regards individuals with mental illness and substance use disorder — who are still considered by too many in the general public as having stigma-laden illnesses or “personal defects.” A person-centered organization focused on behavioral health maintains the confidentiality of individual information and does not share it without permission. Only aggregate information about accomplishments and outcomes of those served by the organization is shared publicly.
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
When funding follows consumers, individuals have incentives and a vested economic interest to use resources wisely to obtain and sustain recovery. Funding that follows consumers results in consumers learning to become self-monitoring and to exercise accountability.

Practitioners recognize consumers as partners in the treatment process, rather than as the subjects of treatment. Consumers and families partner with their health care providers to play a shared role in managing the funding for their services, treatments and supports. Placing management of the budget for treatment and supports with consumers and families – where permitted by federal, state/provincial and local law – enhances consumer choices.

With a personal budget based on the assessment, consumers 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.

Consumer preferences determine the mix of services to be provided, considering the gender, age, language, development and culture of the individual. The burden of coordinating the mix of care chosen by the individual, however, should rest on the services system, not on the consumer and family who are attempting to deal with serious illness to achieve recovery.

Optimally, person-centered organizations give consumers full discretion over the use of budgets for their care and supports. Flexibility is one of the hallmarks of a person-centered support budget. It provides optional individual choice in the kinds of services and supports that can be secured. It also enables an individual to change options and services as his or her experiences and priorities toward recovery change. Person-centered organizations serving people with mental illness or substance use disorder link funding to the individual rather than the service or support. When service needs change, the funding follows the individual to the newly chosen service or support.

Three tools that promote the value of self-determination, characteristic of a person-centered organization, are individual budgets for each consumer, independent support coordination, and the use of fiscal intermediaries. Personal assistance services and brokered support offer other examples of person-centered...
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 needs, 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 arrange 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 – recovery is a journey of healing and transformation enabling a person with a mental health or substance use 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.
ACKNOWLEDGMENTS

CQL gratefully acknowledges the work of an international group of contributors to the development, design and implementation of the What Really Matters Initiative and to the Key Factors and Success Indications for Person-centered Excellence. We received the benefit of their critical input, creative thinking, practical advice and real-life experiences.

We express our appreciation to these individuals, organizations, staff and leaders for their guidance and support.

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