

# PERSONAL OUTCOME MEASURES®

Measuring Personal Quality of Life





For over 45 years CQL has provided international leadership in designing progressive practices in services for people with intellectual and developmental disabilities and people with mental illness. Our work remains focused on organizations and helping them make real change.

## MISSION

CQL is dedicated to the definition, measurement, and improvement of personal quality of life.

## VISION

A world of dignity, opportunity, and community for all people

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# INTRODUCTION

CQL | The Council on Quality and Leadership is an international not-for-profit organization that provides training, accreditation, and customized consultation to human service organizations and systems.

## MISSION

CQL is dedicated to the definition, measurement, and improvement of personal quality of life.

## VISION

A world of dignity, opportunity, and community for all people.

## OUR WORK

CQL has demonstrated international leadership for over 45 years in the definition, measurement, and improvement of services and supports.

For almost five decades, CQL has taken the leadership initiative in developing progressive measures and indicators of quality in services and supports, personal quality of life outcome measures, and measures of recovery and social capital. We provide a range of services, products, and tools to enhance the capacity of individuals, organizations, and communities to achieve person-centered excellence.

CQL achieves its mission by working in partnership with public and private organizations.

## OUR GOALS & OBJECTIVES

- Develop and implement person-centered quality measures, performance indicators, and evaluation methods
- Conduct an international accreditation program
- Provide training, consultation, and education to build individual and organizational capacity
- Conduct research and disseminate information to enhance policy making
- Provide access to information, innovation, and emerging ideas in quality of life

# CQL HISTORY

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

## 1970s & 1980s Past Contributions, Current Foundations, 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 of people with disabilities in large public institutions. During the 1970s and 1980s, CQL led national efforts in developing consensus standards for organizations providing services to people with intellectual disabilities in the community. 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 has 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 are self-determination, choice, and self-advocacy.

CQL's experience in promoting personal outcomes, however, leads us to new challenges. We recognize that personal outcomes are not realized in isolation but within communities of concerned and supportive people. Our work focuses 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 family, 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 foundation 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.

## 2010s What Really Matters Initiative

More than fifteen years of research using the CQL *Personal Outcome Measures*® national database has 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 redefined quality within the context of community inclusion. We've 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.

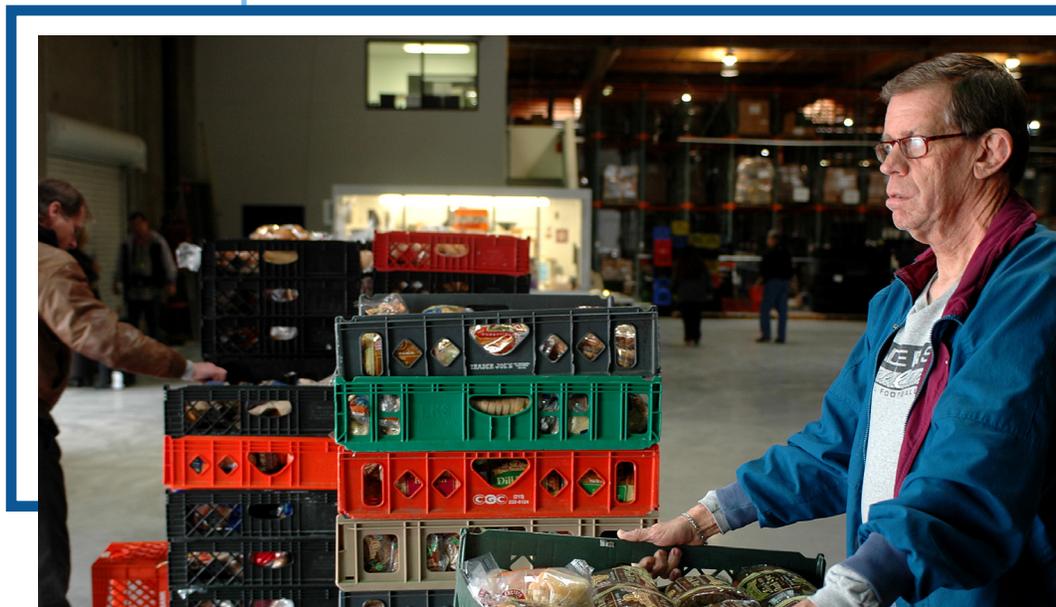
This led CQL to embark on the development of new definitions, metrics, and improvement methods focused on person-centered supports through the *What Really Matters* initiative in 2009. We took a new look at the challenges and solutions in realizing person-centered services and supports across a range of human services. CQL redefined quality in terms of person-centered 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.

While we are committed to a central set of indicators, we recognize that the fields of aging, mental health, and intellectual and developmental disabilities each have their own culture, language, assumptions, and priorities. For that reason, we developed three different applications for each setting – services and supports for older adults, people with mental illness, and people with intellectual and developmental disabilities.

Over a 12-month period, CQL 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

In 2015, CQL restructured the accreditation process to pay closer attention to the Basic Assurances® and whether they were in place in organizations, not only in policy, but in practice. Additionally, the accreditation process was modified to be applicable to networks (regional public systems and/or groups of provider organizations working together), and in 2015 Tennessee became the first state to achieve statewide CQL Network Accreditation. We continue to adapt our methodologies as our expectations change in response to what really matters to people.



# OVERVIEW OF CQL ACCREDITATION

CQL Accreditation promotes excellence in person-centered services and supports that lead to increased quality of life. It's about continuous improvement. CQL Accreditation facilitates your organizational improvement in person-centered services and supports and personal quality of life outcomes.

CQL's Accreditation is grounded in more than 45 years of CQL leadership and peer-reviewed research. We focus on the critical elements that lead to increased quality of life for people.

Our learning about your organization is based on three important foundations:



BASIC ASSURANCES®



PERSONAL OUTCOME MEASURES®



PERSON-CENTERED EXCELLENCE

## 1. Health, Safety, and Human Security

CQL's **Basic Assurances**® promote accountabilities for fundamental and non-negotiable requirements for all service and support providers. We look at systems and practices and their effectiveness, person by person.

- Do your systems and practices promote accountability and transparency?
- Are they both person-centered and system-linked?

## 2. Personal Quality of Life

CQL's **Personal Outcome Measures**® are used to identify people's quality of life outcomes, plan supports, and gather information and data about individual outcomes. We conduct *Personal Outcome Measures*® interviews to demonstrate the linkage between personally defined quality of life and excellence in person-centered services and the importance of data in planning and making change.

- Are people achieving their priority life outcomes?
- What organizational practices are in place to ensure that people are supported to achieve their outcomes?

## 3. Evidence-based Practices

CQL Accreditation contains a set of key factors and success indicators that lead to excellence in person-centered supports and promote personal quality of life outcomes. We guide your stakeholders through an onsite experience that results in priorities and concrete actions. This plan becomes the basis of your commitment to continued CQL Accreditation.

- What are the priority person-centered practices that will produce the greatest results for people supported?
- How will the organization implement or enhance those practices going forward?

## Getting Started

CQL Accreditation offers broad choices to organizations, providing the experience that best fits you. Whether your organization is just starting the journey or continuing it, we will help identify the path that's right for you. Learn more: [www.c-q-l.org](http://www.c-q-l.org)

# INTRODUCTION TO PERSONAL OUTCOME MEASURES®

CQL | The Council on Quality and Leadership first introduced personal outcomes in the 1993 Edition of the Outcome Based Performance Measures. We refined and published the revised outcomes as the *Personal Outcome Measures*® in 1997 and 2005.

Beginning in 1991, we held individual and focus group meetings with people representing diverse backgrounds and challenges in their lives (including people with intellectual and developmental disabilities, mental illness, brain injury, and physical disabilities). During these interviews, people told us about their priority outcomes.

These personal outcomes provided the basis for assessing personal quality of life for people and reflected a significant change in thinking about service delivery and quality. CQL moved the quality focus from complying with organizational processes to learning about and supporting individual choice and preferences. Choice and self-determination form the foundation for personal quality of life. When people receive services and supports, they expect real outcomes based on those choices.

## International Personal Outcomes Database

CQL has maintained an international *Personal Outcome Measures*® database since 1993. During this time, CQL has demonstrated the validity and reliability of our *Personal Outcome Measures*® interview and information gathering methodology. CQL has published information and analysis of the *Personal Outcome Measures*® and their application in national and international journals. The CQL database currently includes over 10,000 personal outcome interviews from certified interviewers. CQL has relied on this valid and reliable database as it has revised and updated the *Personal Outcome Measures*®.

## Refinement of the Personal Outcome Measures®

CQL has continually refined the *Personal Outcome Measures*® since their introduction in the early 1990s. The refinements have been based on data and information analysis from individual and focus group meetings with people, service and support providers, and public officials. In addition, CQL field tested the applications of the *Personal Outcome Measures*® at a range of organizations in the United States and Canada which provide services and supports to people with diverse needs.

CQL has regularly conducted factor analyses and proposed revisions of the *Personal Outcome Measures*® with published results in 1997 and 2005. During the period 2003-2005, CQL again conducted a series of individual and focus group meetings with people with disabilities, support and service providers, and international leaders in the fields of research and service evaluation.

## Further Refinement, 2005

CQL revised and reformatted the 2005 edition of the *Personal Outcome Measures*® into the following factors:

### My Self

Who I am as a result of my unique heredity, life experiences and decisions.

### My World

Where I work, live, socialize, belong or connect.

### My Dreams

How I want my life (self and world) to be.

## Revalidation, 2017

As a data driven organization, CQL continuously reexamines the reliability and validity of our tools to reflect the real-world changes in quality of life for people who receive human services and supports, as well as ever changing service systems.

As part of the continuing refinement of the *Personal Outcome Measures*® the tool was revalidated in 2017 using a principal components factor analysis. According to the analysis, the revised *Personal Outcome Measures*® has been reformatted into the following factors:

### **My Human Security**

Non-negotiable human and civil rights

### **My Community**

Access to be in, a part of, and included in the community

### **My Relationships**

Social support, familiarity, intimacy, and belonging

### **My Choices**

Decisions about one's life and community

### **My Goals**

Dreams and aspirations for the future

*Personal Outcome Measures*® focus on the choices people have in their lives. CQL emphasizes emergence and new opportunities for tomorrow that occur for all people. This means that for all of us there is a possibility of choices and opportunities that did not exist yesterday and cannot be predicted for tomorrow. Some organizations, however, set up barriers to emergence by allowing people only limited choices. They deny, rather than create, the opportunities and alternatives that enable people to learn, grow and explore new outcomes. In contrast, social capital, natural support networks, and close friends promote emergence and new possibilities for tomorrow.

Choice and personal control in one's own life remains at the heart of personal quality of life; these concepts drive the content of all our work. The focus is one of making connections to people and places and building trusting relationships to promote personal and community quality of life.

## **Using Personal Outcomes**

The *Personal Outcome Measures*® are a powerful tool for evaluating personal quality of life and the degree to which organizations individualize supports to facilitate outcomes. People define outcomes for

themselves. The outcomes are non-prescriptive; they have no norms. Each person is a sample of one. We all define friendship, health, or respect uniquely. Thus, the meaning and definition of personal outcome indicators will vary from person to person. As a result, an organization can only design and provide the needed supports after it figures out how the person defines his or her outcomes.

Personal outcomes are important because they put listening to and learning from the person at the center of organizational life. *Personal Outcome Measures*® enable us to learn about people in new and different ways. They provide a guide to person-centered planning. The suggested questions on the information gathering page for each of the outcomes provide an information pathway to knowledge about the person. *Personal Outcome Measures*® enable organizations to identify people's priorities. Knowing about people's priority outcomes directs planning efforts.

Information gathered about outcomes in the factors *My Human Security*, *My Community*, *My Relationships*, *My Choices*, and *My Goals* guides person-centered planning. As organizations support people in developing person-centered plans, they learn about the person's focus. Organizations listen to the person's perspective and put his or her focus at the center of their efforts. Since personal definitions of outcomes will vary, supports must be individualized. The supports that facilitate a particular outcome for one person may not do so for another. Supports chosen by one person may be a burden for someone else. Organizations use *Personal Outcome Measures*® to understand, measure, and improve personal quality of life.

## **Three Part Application**

**Learning** — Individual employees, teams, and organizations use the outcomes to learn about people. Organizations discover what and how much an outcome means to each person. The choice of priority outcomes is very personal and grounded in people's current and past life experiences. Employees, teams, and organizations can use the *Personal Outcome Measures*® and other strategies in learning about people and discovering individual outcomes. But people's own experiences, preferences, challenges, and personalities always guide the learning process.

**Facilitating** — Once an organization has learned a person’s definition of the outcomes, resources are organized to provide the services and supports to facilitate outcome achievement. These services and supports are processes focused on outcomes, not ends in themselves. Frequently the process begins with a person-centered plan. Those who support people are provided with tools to assist people in achieving personal goals.

Organizations may use a variety of methods to facilitate outcomes. Varied experiences result in the most practical mixture of supports. In some cases, we don’t know what will work before we try an approach. We learn by doing.

**Measuring** — After the organization aligns supports to facilitate personal outcomes, it determines if the outcomes were achieved. This occurs after extensive interactions and communication with people and those who know them best. CQL has developed a series of questions that follow a logic chain to guide decisions about the presence of outcomes. From this perspective, the measurement of the outcome defined by the person is a very objective process.

### Two important axioms apply to personal outcome quality evaluation:

1. It is not possible to measure individualized organizational supports without first identifying the personal outcome toward which the process will be directed.
2. Measuring individualized organizational supports alone creates the possibility of measuring a process that is no longer relevant because the person’s definition of the original outcome has changed. Personal outcome and organizational support questions go together.

## The Importance of Outcome Measurement

Outcome measures change organizational behavior. Staff change behaviors when they know and understand people as individuals with priority outcomes similar to their own. Staff learn which organizational activities are not focused on what is important to people. Organizational planning, resource allocation, and evaluation also change

with outcomes. The organization’s role moves from providing programs and services to supporting people in achieving the outcomes they value.

Outcomes focus attention on the whole person. The personal outcome approach does not allow staff to apply different standards and criteria to different areas of the person’s life. For example, certain standards associated with employment services apply to a person’s work environment. Standards for medications and therapy may apply when the person receives psychiatric services. Other regulations define quality in the person’s home. Each of these sets of regulations applies only to a part of the person’s life. The person’s existence is literally divided among the various agencies and programs that provide supports and services. In contrast, *Personal Outcome Measures*® apply to the whole person across services and settings.

The personal outcome approach also results in a different perspective on organizational process. When organizations realize that supports are methods, not ends in themselves, they become more thoughtful in connecting services with priority outcomes. They start to question whether they should continue services and supports that may have a strong constituency, but are unconnected to personal outcomes. Using personal outcomes, organizations often find new methods to increase flexibility in making management decisions. These organizations, for example, give service and support personnel more responsibility and thus blur the lines between professional and direct support staff.

A focus on outcomes changes the way an organization looks at itself. Often, organizations link their strategic planning to personal outcomes. The leadership begins to examine the alignment between people’s priority outcomes, services that connect to those outcomes and resources allocated to supporting those outcomes. During this reflection process it is not uncommon for organizations to implement changes to better align their practices and resources with what is important to the individuals they support.

## Principles of the Personal Outcome Measures®

The specific meaning of the personal outcomes is defined by each person. We must discover how each person defines the outcome for him or herself.

- No standard definition of any outcome applies to a group of people.
- It is unlikely that any two people will define an outcome in the same manner.
- People define their own outcomes based on their own experiences.
- Personal outcomes are defined from the person's perspective.
- Personal outcomes reinforce "differentness" and diversity.

Because the individual outcomes assume a different level of importance for each person, they cannot be ranked or weighted without input from the person. Thus, all of the *Personal Outcome Measures*® are considered of equal importance until the person prioritizes them. Also, specific outcomes may be more important for some people at particular times in their lives. People determine these changes for themselves by sharing information about their personal situations.

## Choice and Decision-Making

*Personal Outcome Measures*® are applied to each person. They do not, however, prescribe a specific outcome. All of the outcomes consider individual choice and decision-making as key variables. For example, a person who stays home every night and a person who goes out every night could both have the outcome "People participate in the life of the community," present. The presence of the outcome depends on the person's preferences and definition of the outcome. Three dimensions of choice and decision-making must be present for people to make meaningful choices and decisions.

**Experiential context for choice** — To make meaningful choices, people need concrete life experiences. Organizations provide people with training and opportunities to experience choice-making. People with significant limitations may require additional supports and experiences to make outcomes possible and relevant.

**Social support context for choice** — Social support networks assist people in choice-making. People seek advice from family, friends, and peers when faced with significant or difficult choices. We all need regular access to groups of trusted peers, friends, and family members to share feelings and information and to seek support and counsel. For some, the belief systems and values of a spiritual community influence their decisions. They turn to those who share this community when they need support and advice.

**Creative context for choice** — Choices and decisions seldom consist of an "either-or" situation. People look for creative alternatives to either "Choice A" or "Choice B". Creative compromises ensure a flexible approach to choice and decision-making. We are usually more satisfied with our decisions when we choose from an array of options. Organizations assist people in identifying creative alternatives that meet their individual needs and expectations, yet fit with obtainable or available resources.

## Rights and Responsibilities

*Personal Outcome Measures*® stress both the rights and responsibilities that apply to all people. People are protected by basic national or constitutional rights, laws, and court decisions. The people we support have the same rights and accompanying responsibilities as other people.

Rights are balanced by responsibilities and include an obligation to act responsibly. The importance of rights does not diminish people's responsibilities for their own lives. At the same time, people have responsibilities toward others. People cannot exercise rights when the results would burden someone else. Organizations assist people to both exercise their own rights and be responsible for the outcomes or consequences of their actions.

## Holistic Approach

Organizations define their own unique roles in supporting people to achieve outcomes. They have some role in supporting a person to achieve each outcome. Each organization's mission and purview defines its scope of responsibility. Some organizations may provide direct action through supports and services; others may address outcomes through referral, advocacy, or consultation.

A shift in the definition of organizational responsibility has accompanied the shift from “process” to “outcome”. In the past, an organization could ignore an outcome area because it was not directly related to its mission. With a focus on individual outcomes, the organization can no longer do so. If an organization cannot provide the necessary direct service, it still has a responsibility for supporting the person to find the support elsewhere.

This approach is more holistic. It acknowledges that daily events are interconnected and that seemingly random and unconnected events merge when they impact a single person. A commitment to holistic patterns of support and service is demonstrated either through direct service or through service coordination involving support staff, providers, public agencies, and natural supports.

## How This Manual Is Organized

This manual is designed to guide you in using personal outcomes as one aspect of an integrated quality management system. The key to understanding outcomes is learning about people. People live their lives and discover their own priority outcomes. The role of formal and informal service and support systems is to assist people to achieve these outcomes. First, we provide people the opportunity to have a variety of life experiences so they can identify their priority outcomes. Then, we use our resources and creativity to facilitate those outcomes.

This manual describes 21 personal outcomes presented within five factors —My Human Security, My Community, My Relationships, My Choices, and My Goals. We use the term ‘factor’ to refer to the main topic area. “People are safe,” is an example of a personal outcome (or indicator) under the factor of My Human Security.

The narrative accompanying each factor provides an overview of its meaning. Following this narrative, we present three sections of important information about each of the personal outcomes in each factor. The first section contains a narrative description and statements of values and principles. Reading this section will help you understand the meaning behind the personal outcome.

In Values, we highlight the beliefs and principles expressed in each outcome. In Principles for Organizations, we define the core practices that support a personal outcomes approach.

The Information Gathering section identifies the process and suggested questions for discovering personal outcomes. It has a series of suggested questions, both for the person receiving services and for others who know the person best (family, friends, and staff who work with and for each person). This is, above all, only a guide. It is not a script to be followed. You may find that other questions or different words are more comfortable for the person, you, or the situation.

The third section presents a series of questions that lead to a decision about whether the outcome is present for each person. This Decision-Making section presents the questions and decision matrices for measuring personal outcomes. Another sequence of questions provides answers to how the organization individualizes and sustains supports for each person. In some cases, you will find a section labeled Additional Considerations. These statements help to clarify circumstances that may arise during the decision-making process.

## A Note About Language

Throughout this manual, we include examples to clarify and illustrate the principles and meanings of the outcomes. These examples are neither all-inclusive nor definitive. Each person with whom we come in contact will bring unique experiences, circumstances, and stories.

- People or person refers to those receiving services and supports.
- Organization refers to the entity that provides services and supports. Organizations function as bridges for people to their communities. Organizations can be large or small, public or private, single entity or networks, regional, state, or federal. Organizations can provide minimal or infrequent supports as well as comprehensive, around the clock services.

# PERSONAL OUTCOME MEASURES® FACTORS & INDICATORS



## MY HUMAN SECURITY

### Factor 1 Indicators:

- 1 People are safe
- 2 People are free from abuse and neglect
- 3 People have the best possible health
- 4 People experience continuity and security
- 5 People exercise rights
- 6 People are treated fairly
- 7 People are respected



## MY COMMUNITY

### Factor 2 Indicators:

- 8 People use their environments
- 9 People live in integrated environments
- 10 People interact with other members of the community
- 11 People participate in the life of the community



## MY RELATIONSHIPS

### Factor 3 Indicators:

- 12 People are connected to natural support networks
- 13 People have friends
- 14 People have intimate relationships
- 15 People decide when to share personal information
- 16 People perform different social roles



## MY CHOICES

### Factor 4 Indicators:

- 17 People choose where and with whom they live
- 18 People choose where they work
- 19 People choose services



## MY GOALS

### Factor 5 Indicators:

- 20 People choose personal goals
- 21 People realize personal goals



# MY HUMAN SECURITY

## FACTOR 1

---

Human Security indicators are essential non-negotiable human and civil rights. While this includes a wide range of rights, from the right to access one's possessions to the right to privacy, there is also a requirement of freedom from physical or mental harm, including abuse, neglect, and mistreatment. People who receive services must be treated the same as people who do not; they must have dignity and respect, social stability, continuity, and security. People must have sufficient resources to meet their basic needs, as well as have person-centered services.

## INDICATORS

- 1 People are safe
- 2 People are free from abuse and neglect
- 3 People have the best possible health
- 4 People experience continuity and security
- 5 People exercise rights
- 6 People are treated fairly
- 7 People are respected

# 1 PEOPLE ARE SAFE

Feeling safe and free from danger concerns all of us. Threats to personal safety come from a variety of sources. Concerns about safety apply to our home, workplace, neighborhood, and community. Personal safety may be threatened by physical surroundings, other people, or lack of supports.

In some settings, we rely on regulations and inspections to ensure that safety standards are met. In other situations, we take personal actions to feel safer: for example, install smoke detectors or security systems, practice fire escape routes, or learn first aid or CPR. We memorize emergency fire and police numbers and post the poison control number near the telephone.

Living, working, and leisure time environments must meet all applicable health and safety standards. Places where we spend our time are clean and sanitary. Provisions for handling and securing toxic materials are in place. Plans exist for effectively meeting emergencies, including an evacuation plan that is rehearsed regularly.

Exploitation and situations of actual or potential abuse and neglect are also serious threats to personal safety. Organizations address all safety concerns, even when people may not recognize danger, such as in situations in which people may cause harm to themselves.

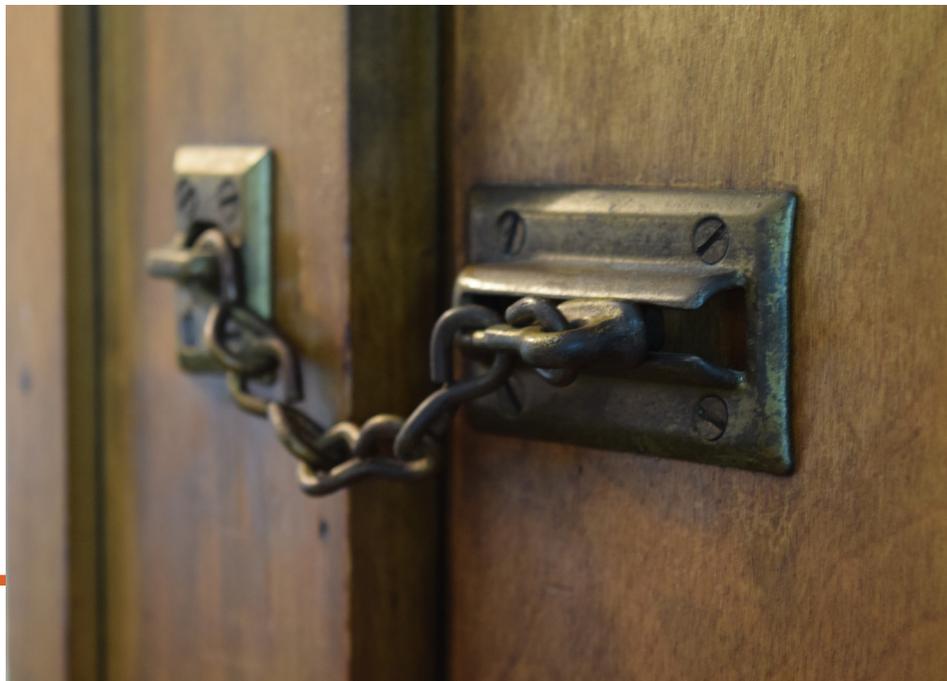
Typical environments contain a reasonable amount of risk. Overprotection prevents people from learning. However, people do not face major decisions that have potential for significant risk without first having the opportunity to make decisions with less significant risk. By learning through real life experiences that evolve from less to more significant consequences, people learn to make progressively more complex decisions responsibly.

## Values

- People live and work in environments that meet expectations for safety, sanitation, and emergency evacuation.
- People feel safe in all environments.

## Principles for Organizations

- Assist people to anticipate, recognize, and respond to safety issues.
- Provide support to keep people's environments clean and hazard free.
- Ensure that people who depend on others to identify and respond to emergencies have support and special equipment in order to anticipate, recognize, and respond to safety concerns.



# 1 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

## Conversation with the Person

### **SUGGESTED QUESTIONS FOR THE PERSON:**

- What kinds of safety risks are you concerned about? In your home? In your community?
- Do you feel safe at home? At work?
- Is there any place you don't feel safe?
- What would you do if there were an emergency (fire, illness, injury, severe weather)?
- Do you have safety equipment at home (smoke alarm, fire extinguisher, a way to see who is at the door before you open it)?
- Do you have safety equipment at work (protective eye and ear wear, safety devices on machinery)? Is this equipment maintained in good working order?
- Do you feel safe in your neighborhood?
- How do you react if a stranger approaches you?
- Are your living and working environments clean and free of health risks?

## Follow-up | Suggested Questions for Those Who Know the Person Best

### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Does the person know what to do in emergencies?
- If the person doesn't know, what do you do to ensure safety?
- Does the person need any special equipment in order to respond to emergencies? If so, does the person have these things?

### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you know that the person is safe (at home, work, school, neighborhood, and in vehicles)?
- How do you learn about safety issues that concern the person?
- What do you do to ensure that places where the person spends time are safe?
- Are there any barriers to the person's safety?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

# 1 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

## PERSONAL OUTCOME QUESTIONS:

- 1.1. Does the person live, work, and pursue leisure activities in environments that are safe?
- 1.2. Does the person know how to respond in the event of an emergency at home, at work, and in the community?
- 1.3. Are all the person's safety concerns addressed at home, at work, and in the community?

 If the answers to #1.1, 1.2 and 1.3 are Yes, the outcome is present.

## INDIVIDUALIZED SUPPORT QUESTIONS:

- 1.A. Has the organization identified safety issues for the person at home, at work, and in the community?
- 1.B. Is the person provided with supports to address identified safety concerns, if needed and requested, at home, at work, and in the community?

 Based on the answers to these questions, are individualized supports in place that facilitate this outcome at home, at work, and in the community?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

## Additional Considerations

- If the person cannot evacuate independently, but receives assistance to evacuate in emergency situations, the outcome is present.



## 2 PEOPLE ARE FREE FROM ABUSE AND NEGLECT

People are not subjected to abuse, neglect, mistreatment, and/or exploitation of any kind. No one threatens or intimidates people to make them comply with organizational policies or individual staff preferences. People live and work free from the fear of physical or mental harm. Abuse, neglect, exploitation, and any form of mistreatment are unacceptable.

The organization's policies define and prohibit abuse and neglect. Many actions (or failures to act) may constitute abuse and neglect. Abuse can take many forms — verbal, physical, sexual, and psychological. Neglect includes the lack of basic sustenance (food, clothing, shelter, etc.), failure to provide needed services, and failure to provide or maintain necessary adaptive equipment. Exploitation can include taking advantage of someone financially or sexually. Mistreatment is a broad category that includes abuse, neglect, exploitation, and any other action that is cruel or hurtful to the person.

The organization develops a program of supports designed to prevent all forms of abuse, neglect, and exploitation. To ensure people's safety, the organization screens staff appropriately before hiring them, then trains them to recognize and prevent abuse. Staff are aware of what the organization and the local governing entities define as harm and know what to do should they witness abuse, neglect, and/or exploitation.

Abuse and neglect are defined from the person's perspective. Organizations therefore identify people's personal definitions of abuse and neglect. A person may consider some actions, environments, and circumstances abusive and neglectful, even though they may not rise to the level of a legal or reportable requirement. They are nonetheless important for each person. Staff who support people are familiar with each person's definition so as to avoid any harm, no matter how inadvertent.

The organization also needs to think beyond the present situation. People may continue to experience pain, physical or mental, from previous instances of abuse. Whenever the organization is aware of any harm, past or present, it offers appropriate, individualized supports to assist the person in coping with the event.

If safeguards against abuse fail, the organization actively responds to each situation. The organization implements processes for investigating all allegations of neglect or abuse wherever they occur.

Follow-up actions also focus on supporting the victim. Although formal processes for reporting and investigating abuse and neglect are effective management tools, these procedures do not always result in a positive outcome for the person. Supports help the person overcome the physical and emotional impact of the abuse or neglect. Organizations inform people about community resources (such as spousal abuse centers, shelters, and support groups) to support them in dealing with physical and emotional challenges associated with abuse.

### Values

- People are not subjected to actions, by anyone, that cause them physical or emotional harm.
- People are able to recognize and report all forms of abuse, neglect, and exploitation.

### Principles for Organizations

- Expressly prohibit all forms of abuse, neglect, and exploitation.
- Address all allegations of abuse and neglect regardless of the source.
- Educate staff to recognize and report any suspected incidents of abuse and neglect.
- Provide support for the person who has been potentially victimized.

## 2 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Do you have any complaints about how you are treated by anyone?
- Have you been hurt by anyone?
- Has anyone taken advantage of you?
- Does anyone yell or curse at you? If so, who do you tell?
- What was done to address your concerns?
- Who would you tell if someone hurt you or did something to you that you didn't like?
- Do you know what abuse is? Do you know what neglect is?
- Do you know what exploitation is? Do you know what mistreatment is?
- Have you been abused? Have you been neglected? Have you been a victim of exploitation or mistreatment?
- Where are the safe places, people, or other resources that you can get in touch with if you have been abused, mistreated, or feel threatened?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Has the person ever indicated or reported concerns about how he or she was treated by others?
- If so, to whom were those complaints reported?
- What was done about the complaints?
- If allegations were substantiated, what action was taken?
- What is the area of greatest risk for the person?
- If the person cannot verbalize concerns, what do you do to determine whether or not abuse or neglect has occurred?
- What is done to inform people about abuse and neglect and what to do if it occurs?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- Does the person understand abuse, neglect, and exploitation? If yes, how do you know that?
- What has been done to inform the person?
- What activities/practices are in place for the person to prevent abuse and neglect, including any mistreatment or exploitation?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 2 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 2.1. Does the person understand the meaning of abuse, neglect, exploitation, and mistreatment?
- 2.2. Have there been any allegations of abuse, neglect, exploitation, and/or mistreatment by or on behalf of the person?
- 2.3. Is there any evidence that the person has been abused, neglected, exploited, and/or mistreated?
- 2.4. Is the person experiencing personal distress from any occurrence of abuse, neglect, exploitation, and/or mistreatment?



If the answers to #2.2, 2.3, and 2.4 are No, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 2.A. Does the organization know about the person's concerns regarding abuse, neglect, exploitation, and/or mistreatment?
- 2.B. Does the organization provide the person with information and education about abuse, neglect, exploitation, and/or mistreatment?
- 2.C. Does the organization provide support for the person if there have been concerns expressed or occurrences of abuse, neglect, exploitation, and/or mistreatment (recent or in the past)?
- 2.D. Does the organization provide support if the person is in danger or at risk of harm (e.g., threats of suicide, threats of physical harm, inability to handle crisis without assistance)?
- 2.E. Are any/all allegations of abuse, neglect, exploitation, and/or mistreatment reported and investigated (regardless of the source) according to organizational policy and procedure, and applicable law?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome at home, at work, and in the community?

YES— Supports in Place

NO— Developing Plans

NO— Aware, but No Plans

NO— Not in Place

### Additional Considerations

- A method to correct a situation of abuse or neglect must include provision of support necessary for the person to cope with the situation no matter when it occurred and to take legal action, if necessary.
- Any allegation of abuse and neglect must be reported and investigated regardless of the source according to organizational policy and procedure and applicable law in order for the individualized supports to be present.
- Lack of intervention in situations where staff have knowledge that the person is in danger or at risk of harm (for example, threats of suicide, threats of physical harm from others including family, inability to handle personal crisis without assistance) constitutes abuse or neglect.
- If the person continues to feel distress related to an allegation or occurrence of abuse/neglect regardless of when it occurred, the outcome is not present.
- If we are unable to determine the person's definition of the outcome, the outcome is not present.

### 3 PEOPLE HAVE THE BEST POSSIBLE HEALTH

Everyone has a personal definition of best possible health. Some of us might describe good health as freedom from a serious illness. Others may be concerned about their weight or smoking. Some people may want to reduce the use of a particular medication. Whatever our personal definitions might be, feeling healthy helps us to achieve other goals in life.

We look for support from health professionals to help us define options and interventions. Health care interventions are personalized and effective. The goal of the health intervention is for people to have the best possible health given their own health status.

The definition of “best possible health” depends on the current health status of a person and the possibility of health interventions to restore lost capacity, stabilize a condition, or minimize further loss of function. Best possible health is defined in terms that are satisfactory for the person. Organizations provide support to obtain a second opinion if the person is dissatisfied with the first. Failure to accept several “second” opinions may indicate that the person needs more information about his or her condition and treatment expectations.

A person’s decision to decline treatment is viewed as one point in the dialogue about treatment options. With support from their health care professionals, people determine if services facilitate their “best possible health.” For some people, effectiveness is measured by how well services assist them in preventing illness or injury, for others, by how well the services manage a condition’s rate of progression or keep a chronic condition stable.

People have access to health care services of the same variety and quality available to others. These services address physical, mental and dental health needs, including those related to nutrition, eye care and hearing. Organizations provide referrals as needed for specialized services such as physical, occupational, and speech therapies; psychiatric evaluation; psychotherapy, counseling, self-help and support groups.

The organization assists people to stay informed about, and to access, preventive screenings and evaluations that are consistent with their age and risk factors.

#### Values

- Best possible health is individually defined by each person, given his or her unique characteristics.
- A definition of best possible health is the foundation for selecting health services.
- Health care interventions for people are personalized and effective.

#### Principles for Organizations

- Provide education about the availability of the range of health services and the process for making decisions.
- Support people to manage and direct their own health care.
- Support and assist people to access all recommended health services.
- Continue to address health care concerns, even if preliminary interventions are not suited to the person’s preferences and lifestyle, or are not effective.

### 3 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

#### Conversation with the Person

##### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Do you feel healthy? If no, what bothers you?
- What do you do to stay healthy?
- What health concerns (physical and mental) do you have?
- Do you discuss your health concerns with anyone? How are your questions or concerns addressed?
- Are you seeing a doctor, dentist, and other health care professionals?
- Do you receive regular exams? What kind?
- Do you take any medication? If so, what is it and how does it help?
- What advice has your health care professional given you? Are you following it? If yes, is it working? If no, what do you think the problem is?
- If you think the medications, treatments, or interventions are not working, what is being done?

#### Follow-up | Suggested Questions for Those Who Know the Person Best

##### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- How has the person defined best possible health?
- What preventive health care measures are in place for the person?
- How is the person involved in his or her own health care?
- Is the person following the health care professional's recommendations? If no, why do you think that is?
- Do you think the person feels health interventions are working?
- If not, what is being done about it?

##### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How have you explored health issues with the person?
- What supports does the person need to achieve or maintain best possible health?
- Who provides the support?
- How was this decided?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 3 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 3.1. Does the person see health care professionals?
- 3.2. Have health care professionals identified the person's current best possible health situation, addressing any health care issues or concerns, and interventions?
- 3.3. Has health intervention been selected by the person in consultation with the health care professional?
- 3.4. Have health interventions, as desired by the person, been effective?
- 3.5. If the person needs devices or equipment such as glasses, hearing aids or dentures, are these available and in good repair?
- 3.6. Is the person receiving health care as recommended for their sex, age and health risks?
  - Complete physical exam
  - Dental exam
  - Eye exam/vision screening
  - Hearing test/screening
  - Pap test screening (if female and over 18)
  - Mammogram (if female and over 40)
  - PSA test for prostate cancer (if male and over 50)
  - Screening for colorectal cancer (if over 50)
  - Any other screenings, tests, etc. as needed



If the answers to #3.1, 3.2, 3.3, 3.4, 3.5, and 3.6, are Yes, the outcome is present.

If the answers to any of the questions (#3.1, 3.2, 3.3, 3.4, 3.5, and 3.6) are No, was this due to informed personal choice?

If due to informed personal choice, the outcome is present.

## 3 DECISION-MAKING

### INDIVIDUALIZED SUPPORT QUESTIONS:

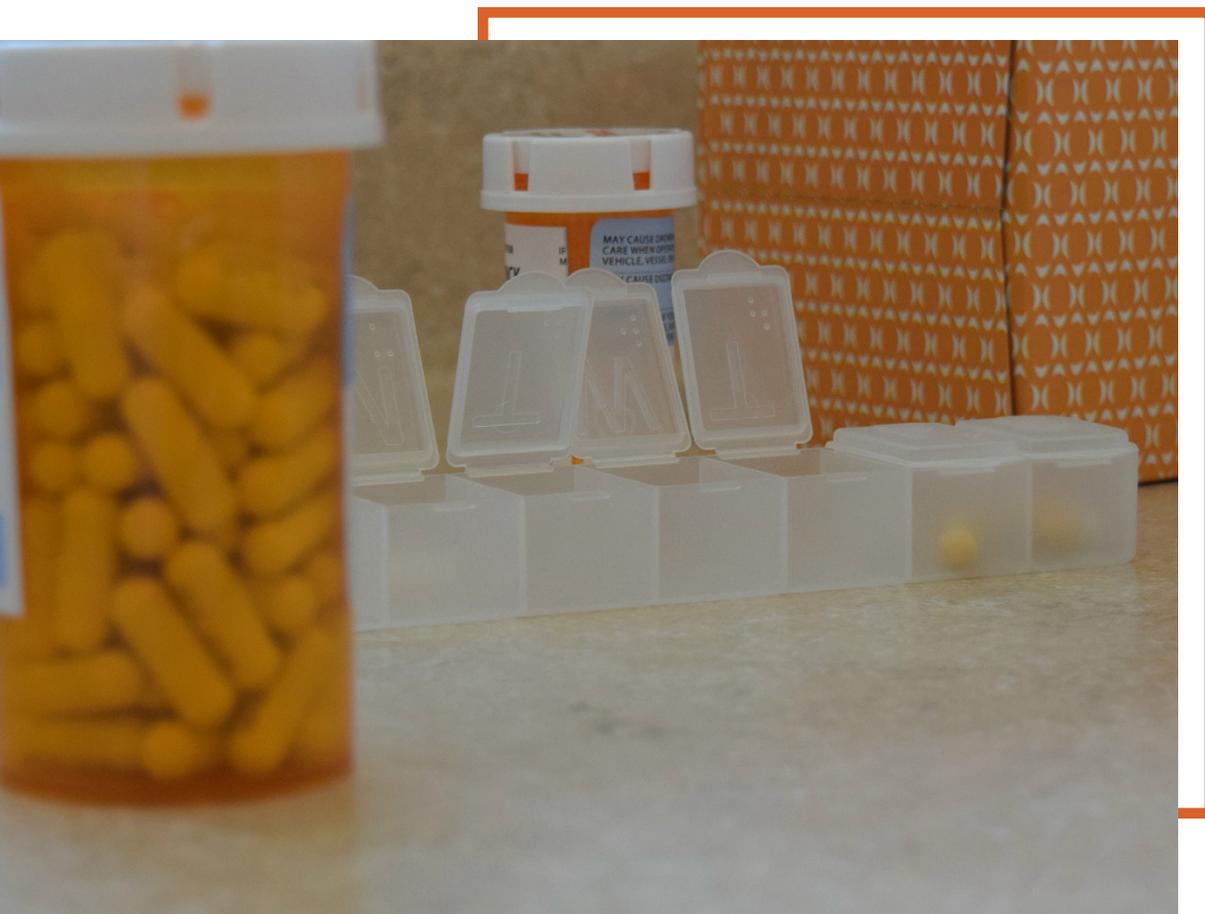
- 3.A. Does the organization know the person's definition of best possible health?
- 3.B. Are supports provided for the person to promote and maintain best possible health if needed and requested?
- 3.C. Does the organization assure that the person has support to obtain regular medical and health services?
- 3.D. Does the organization respond to the person's changing health needs and preferences?
- 3.E. Is the person supported to be aware of their medical issues and their impact?
- 3.F. Is the person supported to self-manage their health?

 Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- If people are not aware of their medical issues and their impact, and self-management of personal health is not addressed, the individualized supports are not present.
- If the person does not have support to obtain regular medical and health services, the individualized supports are not present.



## 4 PEOPLE EXPERIENCE CONTINUITY AND SECURITY

Change is a fact of life. The amount and type of change that we experience can contribute to happiness or discontent. Some of us welcome change — we look forward to new jobs, new places, and new people. Others find comfort in the familiar and reliable. We cannot always control change. Our employer relocates and we might have to move to a new home or even a new town. Or we might lose a job and be faced with financial worries. The loss of someone we love or depend on can cause feelings of uncertainty about the future.

Understanding how each person defines and reacts to change is vital to providing outcome-based services and supports. For this reason, organizations include people in all relevant decisions that impact their lives.

People who experience a disability, mental illness, or other conditions frequently depend on human service organizations for shelter, food, clothing, work, transportation, and other forms of support. Dependence on the organization often links changes in people's lives to organizational changes. Organizations provide continuity and security for people through the service process.

Changes in programs and services come from issues related to each person. Thus, people do not move from their homes or out of work settings because of concerns about funding or administration. Funding for supports and services follows the person.

Aspects of organizational operations, such as staffing turnover, can affect the stability and continuity people experience. The organization considers how change impacts people's continuity and security and acts to minimize its emotional effect on people.

Economic security plays a significant role in enabling people to plan for the future. Economic resources cover the basic requirements for a place to live, food, clothing, transportation, and leisure. People need the same cushion in difficult times or unexpected situations as everyone else. People have insurance to protect their resources. These may include health, life, casualty/property, unemployment and disability insurance.

### Values

- People control the type and amount of change and disruption that occurs in their lives.
- Economic security enables people to plan their own lives and futures.
- People have the economic resources that cover the basic requirements for a place to live, food, clothing, shelter, transportation, and leisure.
- People have protections for their personal resources.

### Principles for Organizations

- Provide supports and services to minimize disruption to people's lives.
- Assist people to gather the economic resources to support basic life activities.
- Maintain stability in the person's home and work, unless the change is made to enhance the person's life (with the person's involvement).
- Take action to correct the situation when changes occur due to factors other than individual choice.
- Engage in systems advocacy to promote greater security for people.

## 4 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- How long have your support staff worked with you?
- Do you have the consistency you need in the staff who work with you?
- What would cause you to make changes in your current situation?
- Is there anything you do not want to change?
- What is your source of income?
- Do you have enough money to pay expenses (food, rent, clothing, health care, insurance, transportation, leisure activities)?
- How do you protect your personal property and other resources?
- Are there things you have to do without? If so, what are they and why can't you have them?
- Is your financial situation acceptable? If yes, why? If no, what do you want to change?
- Have you experienced any changes?
- How do you feel about these changes?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What does the person consider to be important issues that would affect his or her continuity and security?
- Does the person feel secure in his or her living and working situations?
- Does the person feel secure financially?
- What has the person told you is important for continuity and security?
- If the person has indicated concerns, what are they and what was done about them?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How are changes handled and planned for?
- How is the importance of staff continuity defined for the person and addressed through the support process?
- How is the sufficiency of the person's economic resources determined?
- What supports are provided if they are insufficient?
- How is the person assisted to obtain additional resources?
- How does the organization ensure that the person has protections for his or her personal resources?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 4 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 4.1. Does the person have economic resources to meet his or her basic needs?
- 4.2. Has the person done any of the following to protect themselves or their belongings? (power of attorney for health-related issues; power of attorney for financial-related reasons; will; homeowner/renter insurance; savings account; retirement plan; burial plan; other)?
- 4.3. Have changes occurred over the past two years in any of the following areas: change in place of residence; change in roommate/housemate; change in employment/employer; change in other daytime activities; change in relationship status; change in guardian; change in natural support network; change in provider organization; change in direct support staff; change in financial resources available; other changes important to the person?
- 4.4. Who was responsible for the change (person, guardian, family, provider, employer, or other)?
- 4.5. Are changes to the following areas anticipated in the next two years (change in place of residence; change in roommate/housemate; change in employment/employer; change in other daytime activities; change in relationship status; change in guardian; change in natural support network; change in provider organization; change in direct support staff; change in financial resources available; other changes important to the person.)?
- 4.6. Is the control over changes similar to that exercised by other people?

 If the answers to #4.1 and 4.6 are Yes and the change either had no impact, was due to informed personal choice, or planned for to minimize the disruption to the person, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 4.A. Does the organization know what is required for the person to experience continuity and security or are efforts being made to learn about the person's preferences?
- 4.B. Are supports provided to assist the person in attaining and maintaining continuity and security?

 Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

## 5 PEOPLE EXERCISE RIGHTS

People exercise their human and civil rights. Each person defines which rights are most important. Rights include basic protections, personal freedoms, and guarantees afforded to everyone. The Universal Declaration of Human Rights of the United Nations and the constitutions of nations and states apply to all people. These rights include freedom of speech, freedom of religion, freedom of association, equal opportunity, and equal protection under the law.

Families, friends, and close associates provide supports in preparing people to exercise rights responsibly. Just as for all of us, those closest to people help increase their abilities for decision-making and exercising rights.

Exercising rights and personal freedoms are a natural part of our daily lives. We worship at the place of our choosing. We might serve on a jury or get help with a legal matter. We can choose to be actively involved in a political cause or be content to vote or decide to abstain from voting. We read the newspaper and feel free to write a letter to the editor. We travel around our community, read our mail, and engage in similar routines without giving much thought to the rights and personal freedoms these actions represent. Most of us would not tolerate intrusions or restrictions on our ability to engage in these kinds of activities. How active we are about exercising our rights depends on our personal situations and priorities.

Organizations assist people to exercise their rights. People with limited experience or knowledge about their rights receive training and support to make choices and exercise rights. Assistance also includes opportunities to exercise the responsibilities that accompany rights. People demonstrate respect for the rights of others as they assert and exercise their individual rights. Learning about individual freedom and rights of others is a part of the service process.

Some people may need guardians or other substitute decision-makers. Assessments help determine a person's specific abilities with regard to decision-making. Guardianship does not extend beyond the areas needed by the person.

The need for guardianship is periodically reviewed. If the person's skills improve or a change in situation occurs, the person resumes making decisions. On the other hand, when someone has been found legally incompetent to make basic decisions, an authorized surrogate represents the person's interests and protects all rights. Although guardianship puts legal limits on the person's exercise of certain rights, it does not prevent the person from influencing decisions or exercising other rights.

### Values

- People with disabilities have the same rights as everyone.
- The exercise of rights is a function of informed personal choice. People may decide not to exercise certain rights, such as voting or free speech, at certain times.
- The exercise of all rights is not limited when a person has a guardian.

### Principles for Organizations

- Assist the person to fully exercise rights and make choices.
- Provide training and supports to help people recognize and understand personal freedoms and the rights of others.

## 5 ADEQUATE DUE PROCESS PROCEDURES

Organizations are responsible for ensuring that the rights of people supported and protected. When rights are limited, it is typically due to the person's specific needs but sometimes a person's rights may be limited due to formal or informal practices, lack of resources, or a desire to keep the person safe or to mitigate risk. Whenever there is a rights limitation or restriction, the organization must follow strict safeguards to promote and protect people's rights:

- Limitations/Restrictions are based on a specific need as demonstrated by the person.
- People are informed of options, the expected outcomes of each option, and the risks of each option.
- The person and the legally authorized representative (if there is one) give informed consent.
- The organization demonstrates that less intrusive interventions were tried but were not successful.
- The organization ensures each restriction is temporary.
- There is a plan to promote skill development or other strategies to reduce the need for, or reliance on, the restriction.
- The organization demonstrates that the restriction will cause no harm.
- The person has a fair and impartial hearing. Typically, this is accomplished by inviting the person to a Human Rights Committee (HRC) meeting. At the time of the meeting, at least one-third of the members are not affiliated with the agency, people supported must be an active member of the committee, and there should be a least one person with prior experience with rights (e.g. legal, religion, advocacy, or civil rights.)



## 5 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- What do you know about your rights as a citizen?
- Do you have access to information about your rights as a citizen? As an employee? As a person receiving services?
- What rights are most important to you?
- Are you able to exercise your rights without difficulty?
- What information or support do you need to help you to exercise your rights?
- With whom can you talk about your questions or concerns regarding rights?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What rights are important to the person?
- How do you know that?
- What rights does the person exercise most?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How is the person supported to learn about his or her rights?
- Does the person need support to exercise rights?
- If so, what are the supports and who provides them?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?



## 5 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

**5.1.** Indicate whether the person exercises their rights in the following areas:

- Personal possessions
- Fair wages
- Voice an opinion
- Vote
- Practice religion
- Privacy
- Freedom from coercion and restraint
- Access to money - as a possession
- Personal decision-making
- Move about the community
- File complaints about services
- Access to food
- Have visitors at any time



The various rights listed are compiled through the United Nation's (UN) *Universal Declaration of Human Rights*, the UN Convention on the Rights of Persons with Disabilities (CRPD), and other legislation and regulations.

In addition to these specific rights, are there other rights that are limited or restricted?

**5.2.** For each of the rights the person does not exercise, who most limits their ability to exercise each of these rights (guardian, family, provider organization/support staff, employer/co-worker, other, person elects not to exercise this right through informed personal choice)?

**5.3.** For each of the rights the person does not exercise, was adequate due process provided?

 If each right in #5.1 is Yes (note: keep in mind a person may choose to not exercise some rights), including others important to the person, the outcome is present.

For all rights not exercised in #5.1, if due to informed personal choice, or if the limitations are approved with adequate due process, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

**5.A.** Are the person's preferences and desires about the exercise of rights solicited by the organization?

**5.B.** Have the rights that are important to the person been identified or are there efforts being made to learn about the person's preferences?

**5.C.** Is the person provided with the support needed to exercise his or her rights?

 Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

## 6 PEOPLE ARE TREATED FAIRLY

Within any society, community or group of people, situations exist where total freedom to act, do, or decide is not possible. Limitations may occur as a result of laws, community or group norms, and the needs of other people. When limitations are imposed, we expect that we will have the opportunity to be heard, fairly and impartially.

Rights limitations may occur as a result of the supports needed by a person, organizational policies or rules, lack of resources, or a desire to protect people from possible harm or risk. Regardless of the source or intent, people are entitled to have these limitations reviewed and possibly removed.

People are treated fairly if and when rights limitations are imposed, there is adequate due process. People are informed of options, consent is obtained, and they are listened to. Due process procedures are applied when limitations on personal freedoms or rights have occurred or are contemplated. A fair and impartial hearing in disputes is provided.

Rights limitations are always viewed as temporary measures. Organizations provide training and support to people so that restrictions and limitations are removed. Organizations also review and change policies, practices, or programmatic decisions that limit or restrict people.

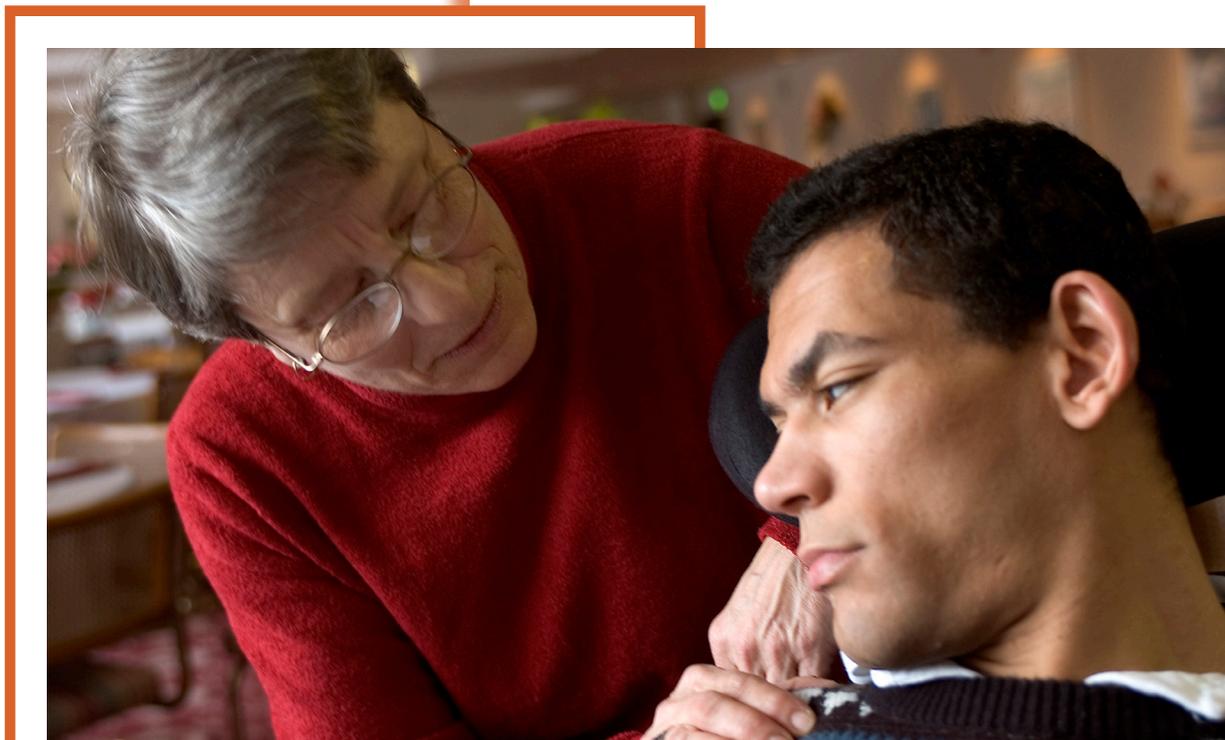
People have the right to least restrictive training and treatment alternatives, freedom of movement, communication, access to personal possessions (including money), and positive behavior interventions, when necessary. Other critical areas include guardianship decisions, denial of opportunity (such as employment or services), and restrictive procedures and limitations imposed by others.

### Values

- People have the right to be heard, to be informed, and to give consent.
- People with disabilities have the right to be treated the same as anyone.

### Principles for Organizations

- Provide people with access to a fair and impartial hearing of grievances and an independent review of limitations to personal freedoms.
- Provide people with training and support so that limitations can be reversed or removed.
- Review and change policies and practices that limit or restrict people.



## 6 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Have there been times when you thought you were treated unfairly or that your rights were violated?
- With whom can you talk when you have concerns about your rights or how you are treated?
- Are any of your rights formally limited?
- If yes, did you agree to the limitation?
- What is being done to change the situation?
- What assistance are you getting so that you can exercise this right in the future?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Has the person shared any concerns about his or her treatment or violation of rights?
- What recourse does the person have when he or she has concerns?
- Have any rights limitations been imposed on this person?
- What is the reason for the limitation (Individual need; Staff practices; Organizational policy)?
- Who consented to the limitation?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- Does the person have rights limitations?
- What is the reason for the limitation?
- How was it decided that the limitation was necessary?
- Who consented to the limitation?
- Who reviewed the limitation? What is the plan to remove the limitation (training; support; change in policy or practice)?
- How long will the limitation be in place?
- What are the barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 6 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 6.1. Have fair treatment or rights limitations been identified?
- 6.2. If the answer to #6.1 is Yes, for each rights limitation - identified in the *People Exercise Rights* section - was adequate due process provided?

In addition to those specific rights, are there *other* rights that are limited or restricted? If so, was adequate due process provided?

- 6.3. For any fair treatment issue, was the issue addressed so the person's concerns were resolved to their satisfaction?



If the answers to #6.2 and 6.3 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 6.A. Has the organization solicited information about rights violations or fair treatment issues from the person?
- 6.B. Have procedures for adequate due process for any identified rights limitation been implemented?
- 6.C. Are the procedures used by the organization consistent with due process principles?
- 6.D. Does the organization respond to the person's fair treatment issues to address any concerns?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

## Additional Considerations

- The type and extent of the due process depends on which right is to be limited or restricted. The greater the impact on the person's life, the greater the requirement for review and protection.
- Some rights limitations are due to criminal behavior that results in restrictions to rights such as being unable to own a gun, vote, or live near a school. When a rights limitation is imposed by law, the due process is through the court system. If the only rights limitations are imposed by law, the outcome is present due to adequate due process.
- Some rights limitations, such as guardianship or commitment to a facility, are put in place through the legal system. The organization is expected to regularly review the restriction, and implement strategies to reduce the need or reliance on the restriction.

## 7 PEOPLE ARE RESPECTED

Respect is how we show our regard for each other. Respect indicates that we believe someone is a valued person. Everything we do and say to people makes a statement about their perceived importance. People are treated with respect and dignity.

Respect is more than the absence of negative comments or actions. Respect is demonstrated in how we interact with people. Interactions that promote respect do not draw undue attention to a person's condition or differences. Supports, in fact, emphasize and capitalize on the person's capabilities. Respect means listening and responding to the person's needs with the same promptness and urgency that anyone would expect. When people ask for assistance, they are entitled to receive a meaningful response.

Supports reflect concern for enhancing people's status. Staff respect and defer to people's opinions and preferences throughout the planning and decision-making process. People are challenged by the service activities and encouraged to try new things.

Respect is reflected, directly or indirectly, in everything that occurs in a service relationship. Positive regard and respect is demonstrated by providing people with meaningful work and activities, privacy, and advocacy.

References to, and interactions with, people promote self-esteem. Patterns of interaction reflect what is typically expected for most people. Expectations for achievement are high and supports are not intrusive or demeaning. Staff show significant concern for each person's feelings and avoid anything that might cause the person any personal, physical, or social discomfort.

### Values

- People are always treated as people first.
- Respectful treatment and interactions enhance the person's self-esteem and result in positive perceptions by others.

### Principles for Organizations

- Ensure that staff behavior reflects sensitivity to the needs of people for privacy and dignity, and that undignified displays, exhibitions, or exposure of people do not occur.
- Exercise confidentiality and sensitivity when speaking about people.
- Provide access to the materials and supports that will assist people in gaining competencies and participating fully in preferred activities.



## 7 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- How do staff treat you?
- How do people talk to and about you?
- Do people call you by your preferred name?
- How do you know if your opinions are valued and respected?
- What do you think about the things you do at home, school, work? Are they interesting? Boring?
- What do you think about the activities that you do? Are you learning or gaining things from these activities? Do they make you feel important? Is it a good use of your time?
- Do people listen to your comments and concerns?
- Do you think people treat you as important?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What is important to the person with regard to respect?
- What has been done to personalize the activities or interventions for the person?
- What benefits will these activities or interventions provide for this person?
- Is the person involved in all decisions affecting his or her life?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you know if the person feels respected?
- How is respect considered in decisions regarding supports, services, and activities?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 7 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

**NOTE:** Due to the nature of this outcome, decisions about both the outcome for the person and the supports provided by the organization will not typically be made until after the other twenty outcomes have been assessed.

### PERSONAL OUTCOME QUESTIONS:

- 7.1.** Is this person treated with respect by: family members; residential support staff; roommates/housemates; employment support staff; day staff; co-workers; medical professionals; adult education staff; classmates; business community members; therapists/counselors; neighbors; others?
- 7.2.** Do interactions with others reflect concern for the person's opinions, feelings, and preferences?
- 7.3.** Does the person have opportunities to participate in challenging and interesting activities?



If the answers to #7.1, 7.2, and 7.3 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 7.A.** Does the organization know what is important to the person with regard to respect?
- 7.B.** Does the organization act to ensure that interactions with the person are respectful?
- 7.C.** Have supports needed to enhance the person's self-image been identified and implemented?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- An isolated example of disrespectful interactions or practices does not automatically mean the outcome is not present.
- Services, supports, activities, and interactions must enhance the person's self-image and promote a positive image to others in order for the outcome to be present.



# MY COMMUNITY

## FACTOR 2

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People with disabilities have a right to be in the community, to access and interact with the world around them. Both the *Americans with Disabilities Act* (1990) and *Olmstead v. LC* (1999) require people receive services in the most integrated settings possible – people who are receiving human services and supports must have the same opportunities to access the community as other citizens. CQL recognizes the difference between community access and community inclusion, with the latter being the ultimate goal. While the characteristics of community may vary depending on personal preferences, as with all people, people who receive supports are integral community members and should be supported to fulfill multiple social roles in the community.

## INDICATORS

- 8 People use their environments
- 9 People live in integrated environments
- 10 People interact with other members of the community
- 11 People participate in the life of the community

## 8 PEOPLE USE THEIR ENVIRONMENTS

Our environment includes the places where we live, work, and spend time. Full access and use of those environments support a variety of experiences and activities. We choose what we will do and when. People use their environments with specialized training, adaptations, and modifications, as needed.

Some people may need specialized training and exposure to an environment before they feel comfortable. People increase the use of their environments when they have opportunities for a variety of experiences, learn about ways to control the environment, and have supports.

Equipment, technology, and computer advancements make dramatic changes in the control people have over environments. Technology increases control of personal movement and communication. Simple switches and computer applications control lighting, sound, temperature, and access.

Environmental modifications also increase people's control and independence. Examples include: ramps; grab bars; bathrooms and kitchens that are totally accessible to people who use wheelchairs; visual and vibrating alarm systems, and telephones for people with deafness; emergency notification devices and telephones with automatic dialing features; mobile apps; and computer or voice-activated devices.

Personal assistance is another way to support people to use their environments. Transportation services provide access to the larger environment and community. Organizations either make the necessary modifications and adaptations directly or help people access the resources they need in the community.

Organizations examine whether their rules, practices, or procedures prevent people from accessing and using the environment. Some examples of these situations include: locking laundry rooms or doors; locating staff offices and telephones in people's homes; and establishing rules about when people can use the kitchen.

### Values

- People are not limited in what they do because of environmental or regulatory barriers.
- Modifications and adaptations increase independence.

### Principles for Organizations

- Modify or adapt environments to meet people's needs.
- Assess the need for modifications and adaptations.
- Orient people to new environments and provide specialized training to increase their functional control and capacity.
- Ensure that rules and practices, or a lack of modifications or equipment, do not limit what people do at home, work, or school.

## 8 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Is there something you wish you could do, but can't?
- Is there anything you can't do or use because you don't have the proper equipment or modifications (use the kitchen, bathroom, or telephone; perform job duties; take care of personal needs)?
- Do you know how to use appliances and equipment (microwave, stove, telephone, washer, dryer)?
- Are there things that you are prevented from doing due to rules, practices, regulations, or staff behavior?
- Are there locked areas? If so, do you have a key?
- Is there anything that would make it easier for you to get around your home, school, place of work, or community?
- Is transportation available when you want to go somewhere?
- Do you decide how to furnish and decorate your home/room?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Is there anything the person has difficulty doing or cannot do because of the lack of modifications or adaptations?
- What assistance do you provide to the person when modifications or adaptations are needed?
- What resources are available within the organization and the community when modifications and adaptations are needed?
- Is transportation available to help the person access places and activities?
- How has the person been supported to furnish or decorate their home/room?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you determine the extent to which the person can use his or her environments?
- How do you determine if adaptations or assistive technologies are needed?
- What adaptations or modifications have been made for the person?
- How do you support the person in decorating and furnishing their home/room?
- Are there rules, practices, or staff behaviors that interfere with the person using his or her environments?
- How are barriers to this outcome being addressed through supports for the person?
- What organizational practices, values, and activities support this outcome for the person?

## 8 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 8.1. Does the person have maximum access to each of the physical environments they frequent: at home; at work; in the community?
- 8.2. For each of the environments, if the answer to #8.1 was No, what most limits the person's ability to access the environment (lack of staff supports, lack of training, lack of equipment/technology, lack of environmental modifications, lack of transportation, organizational rules/practices)?
- 8.3. Does the person use the physical environments he or she frequents?



If the answer to #8.1 and 8.3 are both Yes, the outcome is present.

If the answer to #8.1 and 8.3 is No, is this due to informed personal choice?

If due to informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 8.A. Does the organization know if the person can access his or her environments at home, at work, and in the community?
- 8.B. Has the organization assessed the person's interest and ability for personal access and use of environments at home, at work, and in the community?
- 8.C. Have modifications been made to promote maximum access and use for the person, if needed and requested, at home, at work, and in the community?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

### Additional Considerations

- If the limitations in the person's maximum use of the environment are based solely on individual limitations and needs, then the outcome is present.
- If the person's maximum use of the environment is prevented through rules, architecture or other means, then the outcome is not present.

## 9 PEOPLE LIVE IN INTEGRATED ENVIRONMENTS

Living in the community helps us become a part of the world around us and keeps us from feeling isolated and separate. Activity and participation increase when we are part of the life of the community. Our lives are connected to others and to the community. We live in the context of our community and become a part of its fabric. Our choices and opportunities are more diverse and abundant. Integration provides exposure to, and acceptance of, a wide diversity in people, including people of different racial and ethnic backgrounds, religions, ages, nationalities, and mental and physical disabilities.

For most people, home, work, educational, and leisure activities occur in diverse environments. People live and carry out routine activities in typical settings. Community integration provides people with opportunities to learn and grow and to obtain and use social capital.

Where people live, work, and spend their leisure time is often determined by where supports are located. Thus, organizations locate themselves where other community members engage in these same activities and provide any needed support. Organizations do not require people to demonstrate a certain skill in order to “graduate” into an integrated setting. Living in an integrated world does not depend on a person having certain knowledge or the capability of performing a particular behavior.

Physical integration is not the same as social integration, although it can lead to greater social inclusion. Physical integration requires that people are physically present in the community. This might occur based on the location of a person’s home: Is the home part of a typical neighborhood? Who are the neighbors? Is the home labeled or identified in a way that sets it apart from the surrounding residences? Physical presence also happens when people are engaged in activities or work: Where does the person see a doctor, get a haircut, go to a place of worship, or see a movie? Where is the person’s job located?

### Values

- People with disabilities have the right to access the same environments as anyone else.
- Integration increases exposure to, and acceptance of, a wide diversity in people.
- Opportunities for building social capital are increased when people live within their community.

### Principles for Organizations

- Ensure that the environments where people spend time are determined by their preferences.
- Provide supports so that an array of options about where people live and work is available.
- Promote people’s use of social capital.



## 9 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Where do you live and work?
- Do other people receiving services live and work with or near you?
- Where do you go to have fun?
- Are these places where other people living in your community would go?
- Do you spend time in other places used by people in your community?
- How did you select these places?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Does the person live in typical community housing?
- Does the person work in a building in which people from their community work?
- Do leisure activities take place in settings used by people from their community?
- Do sports and work teams consist of a diverse group of people from their community?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How have you determined what integration means to and for the person?
- How do services, supports, and activities promote and encourage integration?
- What supports are provided to increase efforts toward physical integration in public education programs, work, social activities and/or leisure activities?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 9 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

**9.1.** Does the person use the same environments used by people without disabilities?  
(for living, work, school, community [leisure, shopping, banking, places of worship, other])?



If the answer to #9.1 is Yes, the outcome is present.

If the answer to #9.1 is No, is this based on informed personal choice?

If due to informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

**9.A.** Does the organization know what integration means to the person, or are efforts being made to learn about the person's preferences?

**9.B.** Do services and supports for the person promote opportunities for integration (for living, work, school, and community [leisure, shopping, banking, places of worship, other])?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

“Community is a place  
**where you live**  
surrounded by people  
**WHO CARE ABOUT YOU.**”

-Sarah

## 10 PEOPLE INTERACT WITH OTHER MEMBERS OF THE COMMUNITY

Being in the community brings us into contact with other people on many levels in a variety of settings. Some of our contacts are casual (greeting a neighbor or chatting with a clerk in a store). Some are more formal (seeing the dentist or working with others on the job). Sometimes these contacts develop into closer relationships over time. With these contacts, people can more easily use the currency of social capital. Sometimes, social capital is the only currency readily available to people receiving services and supports. Interacting with others provides the person opportunities to engage in reciprocal relationships with members of their community.

People interact with a variety of others who do not receive services, or who are not staff of the organization or paid to be with them. Spending time with others in the community who are not affiliated with the organization is a critical means by which people can obtain and use meaningful social capital. These opportunities may occur at work, during leisure activity, or in the person's home.

Participation in the community results in meaningful interaction with other people, leading to enhanced personal relationships, expanded social roles, and deeper involvement in community activities. These opportunities broaden the person's social capital network. Through family members, friends, and co-workers, connections to even more people within the community become possible.

The organization facilitates these contacts in ways that match the person's preferences or requests. Opportunities for meaningful contacts are enhanced when they focus on an individual, rather than on groups of people. Service activities (schedules, rules, or resources) do not limit the type and number of available contacts. A broad array of opportunities is always available, unless the person specifically requests otherwise.

### Values

- People have contact with a broad range of other people.
- People are supported to “earn” social capital in reciprocal relationships.
- People have opportunities to meet and spend time with others outside the organization.
- People have the opportunity, freedom and support to define what level of contact they want for themselves. There is no predetermined level of interaction expected.
- People with limited experiences in meeting others have the opportunities and support needed to meet and interact with other people.

### Principles for Organizations

- Provide services and supports so that contacts with others in the community are facilitated.
- Facilitate people's understanding and use of social capital networks.
- Provide opportunities and support according to people's preferences.
- Ensure that services do not limit opportunities to have contact with others.

## 10 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Who do you know in your community?
- With whom do you like to spend time? With whom do you spend most of your time?
- When you go places, whom do you meet? Talk with?
- What kinds of interactions do you have with people (order food in restaurants; pay for purchases; talk with people at church, synagogue, or other places of worship; visit with neighbors)?
- If you work, what kinds of social contacts do you have there (lunches, breaks, parties after work)?
- What barriers do you face? With whom do you talk about this?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What opportunities does the person have to interact with others?
- Do you know if the person's current situation is satisfactory to him or her?
- Is there anything the person needs to support current relationships or develop new ones?
- What is the person's preference for interaction?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you support the person to have opportunities to meet and interact with others?
- How do you determine the person's preferences for interactions?
- How do you know if the type and frequency of interactions are satisfactory to the person?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this and encourage the person to interact with others?

## 10 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 10.1. Is there direct interaction between the person and others in the community?
- 10.2. Is the type of interaction satisfactory to the person?
- 10.3. Is the frequency of interaction satisfactory to the person?



If the answers to #10.1, 10.2, and 10.3 are Yes, the outcome is present.  
 If the answer to #10.1 is No, is this based on informed personal choice?  
 If based on informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 10.A. Has the organization assessed the type of interactions the person has with other members of the community?
- 10.B. Has the organization assessed the frequency of the person's interaction with other members of the community?
- 10.C. Does the organization know the person's preferences for interaction, or are efforts being made to learn about the person's preferences?
- 10.D. Does the organization provide support for the person to access opportunities for interaction with others, if needed and requested?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- There must be direct social contact between people for this outcome to be present.
- Social contacts that occur during work or other supported activities are considered for this outcome.
- Family members can be considered with regard to this outcome, if family members enable the person to have contacts with other members of the community.

## 11 PEOPLE PARTICIPATE IN THE LIFE OF THE COMMUNITY

The community offers a rich array of activities and experiences where we find and develop interests, take care of our personal needs, and enjoy leisure activities. The community has many resources for personal support, enjoyment, and development.

Consider the places you typically go during the week: you might visit the doctor or dentist's office, go to the bank, shop for groceries, get a haircut, or stop by the gym or health club. On the weekend, you might take in a movie, sporting event, or concert; attend your church, synagogue, or other place of worship; eat out in a restaurant; spend time at the mall, and so on. When we go out into the community, we meet other people, learn, and broaden our experiences.

Organizations provide people with easy access to community resources. Generic community resources, such as doctors, restaurants, banks, and grocery and retail stores, are the best options for health, leisure, and routine daily living activities.

Organizations support people to participate in many varied activities, according to their interests. When the number of options is limited by the location or size of the community, the type and variety of participation matches that of others in the community.

Training and supports are provided so that people actively join and share in the life of the community. Information about community events and resources is readily available to people. Assistance with transportation to and from different activities also plays a role in facilitating participation. Supports and training reflect individual differences concerning the nature, duration, and frequency of community participation. Organizations match people with opportunities by discovering individual interests.

### Values

- People decide the extent and type of their participation based on their preferences and interests.
- People have support to take part in a variety of activities in the community.
- The less experience a person has with life in the community, the more likely he or she is going to need support and opportunities to try different activities.

### Principles for Organizations

- Provide tangible supports for people to participate in the community.
- Individualize supports according to each person's interests and preferences

"We need to get out  
**in the community**  
in order to meet

**NEW FRIENDS."**

- Patrick

## 11 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- What kinds of things do you do in the community (shopping, banking, church, synagogue, mosque, school, hair care)? How often?
- What kinds of recreational or fun things do you do in your community (movies, sports, restaurants, special events)? How often?
- How do you know what there is to do?
- Who decides where and with whom you go?
- Is there anything you would like to do in your community that you don't do now? What do you need to make this happen?
- What supports do you need to participate as often as you'd like in community activities?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Do you know what the person would like to do in his or her community?
- Is the person encouraged and assisted to use a broad variety of community resources?
- Is training provided if the person needs it?
- Is support provided if the person needs it?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How is the person informed of options available in his or her community?
- How do you learn about what the person prefers to do?
- How do you learn about how often the person likes to be involved in community activities?
- What supports does the person need to participate in community activities? How are those provided?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 11 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 11.1. Does the person participate in the life of their community?
- 11.2. Is the person satisfied with the type of participation they have?
- 11.3. Is the person satisfied with the frequency of their participation?



If the answers to #11.1, 11.2, and 11.3 are Yes, the outcome is present.  
 If the answer to #11.1 is No, is this based on informed personal choice?  
 If based on informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 11.A. Does the organization know what the person would like to do in their community or are efforts being made to learn about the person's preferences?
- 11.B. Does the organization know how often the person would like to engage in community activities or are efforts being made to learn about the person's preferences?
- 11.C. Does the organization provide the person with access to information about options for community participation?
- 11.D. Does the organization provide support for the person to do the things he or she wants to do?

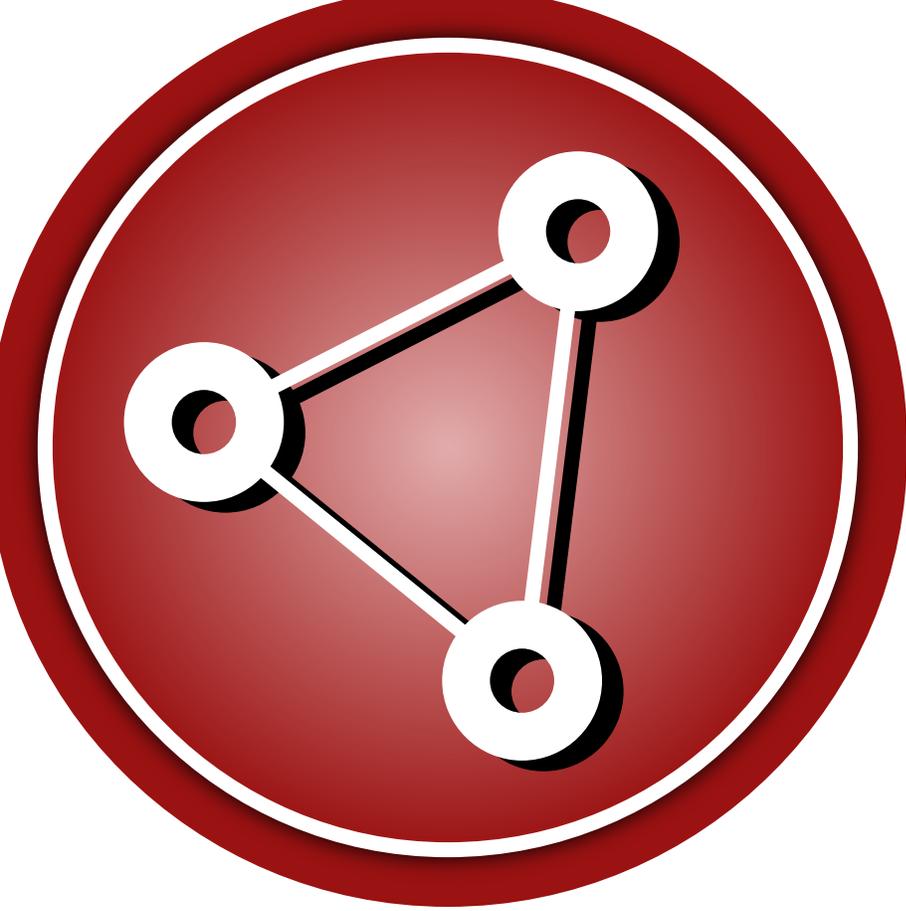


Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

## Additional Considerations

- If the person is aware of the options available to others in the community, and his or her opportunities to participate in the life of the community are limited only by the size and location of the community, then the outcome is present.
- The outcome is present when there is physical presence and engagement in community activities, regardless of who is part of the activity.
- The person does not have to also participate in integrated work or educational settings to achieve this outcome.
- A generic resource is no longer generic when other members of the community are excluded from using the resource.



# MY RELATIONSHIPS

## FACTOR 3

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Relationships, be they with biological or chosen family, friends, or romantic partners, produce a sense of belonging. Relationships are personally defined, ranging from who one chooses to share information with, to a deep level of familiarity and intimacy. CQL believes relationships create links to the greater world that create a blanket of security and help people who receive supports develop and maintain social roles. Social capital, the impact of social ties and relationships, promotes personal outcomes.

## INDICATORS

- 12** People are connected to natural support networks
- 13** People have friends
- 14** People have intimate relationships
- 15** People decide when to share personal information
- 16** People perform different social roles

## 12 PEOPLE ARE CONNECTED TO NATURAL SUPPORT NETWORKS

Most of us have a natural support network. This includes our family members (such as parents, spouses, brothers, sisters, aunts, uncles, nieces, nephews, grandparents, and foster/adoptive parents) and very close friends. For some of us, this network includes many people, and for others, it may be a smaller group. Sometimes we all live near each other and we see or talk to each other often. For other people, the network of family and friends is spread out, but the closeness and support is still there when we need it.

Natural support networks are groups of people whose commitment to support each other is usually lifelong. These support networks cannot be manufactured or created. They can only be nurtured as they grow and evolve over time. Families provide lifelong support and a safety net for many people. Lifelong relationships with non-family members are also part of the support network.

We see differences in how closely connected people are. Time, age, and distance can affect how well people stay connected. These and other factors can also determine how functional and supportive the networks are. The type and extent of these relationships at any particular time is determined by each person or by the interactions between members of the support group.

Organizations assist people to continue and strengthen existing connections and to stimulate potential connections whenever possible. People may need support to develop, enhance, or renew relationships. Supports that facilitate connections can be limited and informal, or extensive and formalized. Examples include telephones, communication devices, personal care assistants, and transportation. Specific care is taken not to disrupt or limit these connections. Family relationships are always encouraged, unless the person specifically requests otherwise.

### Values

- Connection to a natural support network of family and very close friends provides a sense of security and a safety net for people.
- People choose the extent and frequency of contact with their support network.

### Principles for Organizations

- Facilitate continuity in people's existing relationships and build the capacity of potential support networks, consistent with people's choices and preferences.
- Provide, or assist people, to access the supports that will enable them to maintain connections to people in their support network.
- Assist people who may have lost contact with family members to re-establish communication and develop their natural support network, if desired.



## 12 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Who are the people in your life that you can count on?
- Who do you want to talk to or be with when you go through tough times?
- Who do you want to share your successes with? How do you maintain contact with these people?
- Have you lost contact with family members or others?
- Is the contact you have enough for you? If not, what is the reason?
- What type or frequency of contact would you prefer?
- What do you think could be done to change the situation?
- Where do you get emotional strength?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Do you know who is part of the person's natural support network?
- Do you know if the person is satisfied with his or her contact with these people?
- What assistance is provided to maintain the person's contact with his or her family and others who provide emotional support?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you learn about the person's support network?
- What do you do to support contact?
- If there is no contact, what is done to assist the person to re-establish contact if desired?
- If contact is with parents only, what do you do to expand the network to extended family?
- What do you do if the extent and frequency of contact is unsatisfactory to the person?
- Are there any barriers that prevent the person from remaining connected with the people he or she identifies as part of their support network?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 12 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

**12.1.** Does the person have a natural support network?

**12.2.** If the answer to #12.1 is Yes, does the person have enough contact with the people in their natural support network?



If the answer to #12.1 and 12.2 is Yes, the outcome is present.

If the person does not have a natural support network (the answer to #12.1 is No), is this due to informed personal choice?

If due to informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

**12.A.** Has the person's natural support network been identified by the organization?

**12.B.** Does the organization know the status of relationships within the person's support network?

**12.C.** Does the organization provide support for the person's relationships within the network, if needed and requested?

**12.D.** Does the organization recognize and promote opportunities for people to develop natural support networks?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

### Additional Considerations

- Natural supports are typically people who have a lasting commitment and/or connection to each other and not a casual support by a neighbor or co-worker.
- If the extent and frequency of contact with people in the support network is decided by the person in conjunction with those people, then the outcome is present.
- If the person has no natural support network with which to be connected, and does not desire a relationship with a natural support network, then the outcome is present.
- Natural supports for some people may be related to spirituality.

## 13 PEOPLE HAVE FRIENDS

Friends provide us emotional support and enjoyment. Friendships are mutual; they are based on a two-way relationship between people who choose to spend time with each other. While casual contacts with other community members and relationships with paid staff are important, they do not replace friendships.

Personal relationships bring variety and richness to our lives. Friends are neighbors, co-workers, and peers who provide acceptance, support, and emotional closeness. Friends can be a significant source of comfort and support during difficult times. They bring us companionship and share our joy in the best of times. Friends are the people we confide in and share special events with. They are the people we call on when good or bad things happen.

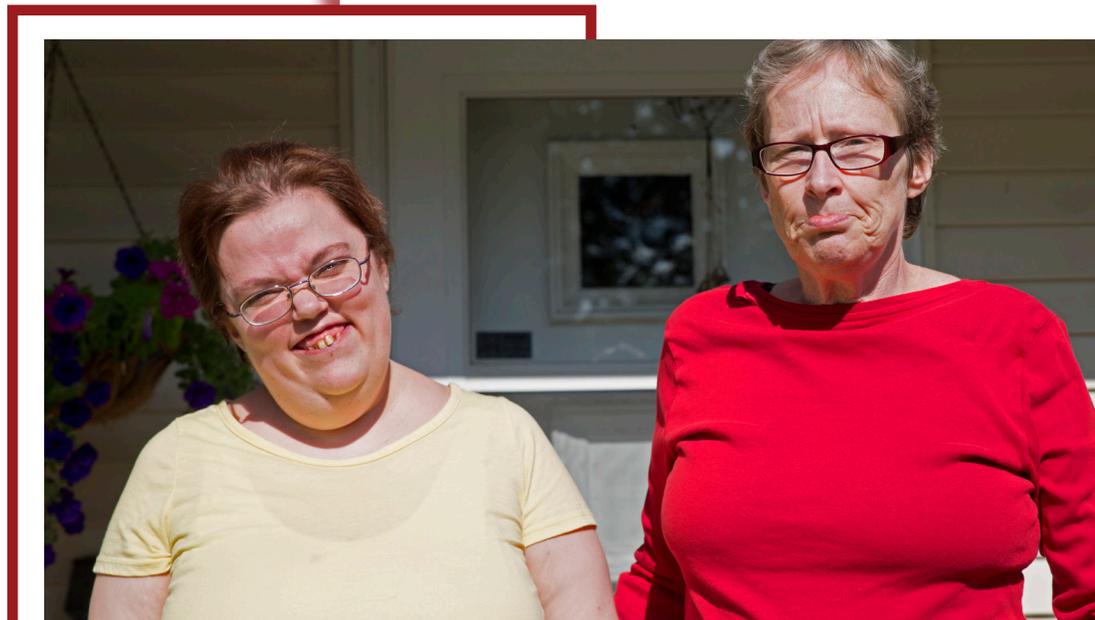
Organizations support people to maintain existing friendships. Planning includes a discussion of what can be done to support people to continue and expand their friendships. While people are not required to have friends, organizations support social opportunities for people to develop and maintain friendships. Service delivery reflects respect for individual preferences in social activities and the expectation that people will, in fact, develop friendships. Supports to maintain friendships might include finding transportation, encouraging telephone calls, access to email and social media, and writing letters or cards. Organizations honor people's preferences and use them as a guide to assist people to develop and maintain friendships.

### Values

- For children, adolescents, and adults, social relationships beyond the family are essential.
- Friendship is a voluntary, reciprocal relationship.

### Principles for Organizations

- Support people in forming and maintaining friendships with neighbors, co-workers, and peers, including people who are not receiving services.
- Provide support through training or assistance, such as transportation for visits, or help with email, social media, written communications, and telephone calls.



## 13 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- How do you define friendship? Who are your friends?
- With whom do you like to spend time?
- What do you like to do with friends?
- How often do you see your friends?
- Do you spend enough time with them?
- Besides seeing your friends, what other kinds of things do you do to stay in contact?
- Do you have enough friends? Would you like more?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- With whom does the person choose to spend time?
- Who are the person's friends? How do you know?
- What contact does the person have with his or her friends?
- Are the interactions and contacts the person has with friends similar to typical friendships that you or people you know have? Are they voluntary, mutual, and interactive?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you determine the importance of friendship to the person?
- How do you know if the person needs support to develop or maintain friendships?
- How do you determine satisfaction with the extent and frequency of contact?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 13 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

**13.1.** Does the person have friends?

**13.2.** Is the person satisfied with the number of friends they have?

**13.3.** Is the person satisfied with the amount of contact with their friends?



If the answers to #13.1, 13.2, and 13.3 are Yes, the outcome is present.

If the person has no friends (#13.1), is this due to informed personal choice?

If this is due to informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

**13.A.** Does the organization know the person's preference and need for friends?

**13.B.** Are supports provided to assist the person with developing, maintaining, and enhancing friendships, if needed?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

### Additional Considerations

- If the person has no prior experience with friendships or has not expressed a clear choice in making friendships, then support and opportunity to make friends are provided in order for the individualized supports to be present.
- Friends are people apart from family members and staff.

## 14 PEOPLE HAVE INTIMATE RELATIONSHIPS

We define intimacy as sharing ourselves with another person in a way we would only share with those whom we deeply trust. Intimate relationships include intellectual, social, emotional, and physical components. Intimacy is present when people care and feel deeply about each other. They talk about important events or changes in their lives. Intimacy can also be spiritual. People in prayer, confession, or meditation may be reflecting a dimension of intimacy. Intimate relationships mean that people are committed to one another, trust each other, and know that they will not be rejected by the other person.

Sometimes intimate relationships result in physical affection and sexuality. Intimacy should not be confused with casual sexual relationships, even though the term “intimate” is often used to mean sexual contact in today’s society. Physical closeness is only one aspect of intimacy.

People have choices and opportunities to develop close personal relationships. These options match those available to all people. Organizations do not prohibit or present barriers to close, personal relationships. They respect and support personal desires for intimacy.

Relationships with family and close friends may meet some people’s needs for intimacy. Others have a different level of need for intimacy that goes beyond friendships and family ties. People define the meaning of intimacy in their own lives. They are not required to have intimate relationships.

People are not prevented from pursuing intimate relationships. Organizations support people to safely explore their intimacy needs. People are assisted in making choices and accessing opportunities for enhancing relationships. More broadly, organizations provide assistance for people to learn about relationships.

### Values

- People define their own requirements for personal relationships and types of intimacy.
- The choices people make are respected by all who support them.
- People have the right to develop and express their sexuality.
- Each person is responsible for his or her relationships and sexuality. No person can dominate or exploit another.

### Principles for Organizations

- Assist people to explore feelings and desires, evaluate experiences, and make choices about intimate relationships.
- Support people in forming, pursuing, and maintaining intimate relationships.
- For people who lack experience with, or knowledge about, intimate relationships and sexuality, present options for training and support in expressing intimacy and sexuality.

## 14 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Who are you closest to?
- Is there someone with whom you share your personal thoughts or feelings?
- Whom do you trust to talk with about private concerns and feelings?
- Who is there for you when you need to talk?
- With whom do you share your good and bad feelings?
- Is this enough for you?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Do you know how the person defines intimacy?
- What is that definition?
- Do you know if the person has the type and degree of intimacy desired?
- How do you support the person's choices for intimate relationships?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you learn about the person's desires for intimacy?
- How do you know if the person needs support to develop or maintain intimate relationships?
- If the person needs support, what has been arranged?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to forming intimate relationships with others?
- What organizational practices, values, and activities support this outcome for the person?

## 14 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

**14.1.** Does the person have intimate relationships?

**14.2.** If yes, are they satisfied with the type and scope of intimate relationships?



If the answers to #14.1 and 14.2 are Yes, the outcome is present.

If the answer to #14.1 is No, is this due to informed personal choice?

If due to informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

**14.A.** Does the organization know and understand the person's preferences for intimate relationships?

**14.B.** Does the organization assist the person to explore and evaluate experiences in order to make informed choices about intimate relationships?

**14.C.** Does the organization provide support for the person to pursue, form, and maintain intimate relationships?

**14.D.** Has the organization addressed any barriers to the person having intimate relationships?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

## Additional Considerations

- For some people, the involvement and closeness of family relationships may meet intimacy needs. Family relationships that address intimacy needs go beyond the typical family contact and interaction. They show evidence of emotional closeness and personal reliance that result in a positive outcome for the person.
- For some people, the expression of spirituality may meet some of their intimacy needs.
- If the person has not indicated a desire for intimate relationships in any way (including behavioral and verbal) and if the person's preferences for intimacy are known and supports are available, then the outcome is present.

## 15 PEOPLE DECIDE WHEN TO SHARE PERSONAL INFORMATION

Organizations often keep personal information about people. Whatever is contained in those records is personal and confidential. People know what information is kept and access it whenever they want. People decide when and how the information is shared with others.

Before sharing information, the organization obtains permission from the person and/or a legally authorized representative. The organization educates people and their legally authorized representative about the meaning of confidentiality and their right to refuse to share information. In this way, they can give consent or withhold it.

Sometimes information is shared informally without proper consent. Staff may not be aware that casual conversations reveal personal information about people without their permission. Posting personal information in the living or work environment can also violate the person's privacy. This can cause people discomfort and embarrassment.

In certain situations, people may be part of a committee or a group where confidential information about others is discussed. Organizations make clear the importance of maintaining confidentiality in these situations.

Even with permission, organizations provide only the information that is relevant. Consents should be limited to certain pieces of information, for a particular purpose, and be in effect for a specified time period.

People can limit what information anyone knows and shares about them. In situations where their wishes cannot be respected for legal reasons, or because of concerns related to professional ethics, the reasons are explained to them.

### Values

- People have access to their records and know what information is included.
- Information is shared only with consent of the person or legally authorized representative.
- People decide who participates in meetings where personal information is discussed.
- People decide what happens to their record when services are terminated.

### Principles for Organizations

- Request only the information necessary to provide supports and/or services.
- Limit access to people who need information and to others identified by the person or legally authorized representative.
- Ensure that staff are knowledgeable about confidentiality laws.
- Make personal records available to people on request and assist them with interpretation, as needed.

## 15 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Do you know if there is a record (journal, file, book, electronic file) that has information about you?
- What is in that record? Have you looked at it? Has anyone told you what information is in it?
- How do you know if anyone reads, hears, or receives information about you?
- How do you decide who reads or gets information about you?
- Is there information about you posted where others can read it?
- Has anyone talked with you about confidentiality?
- Is there any personal information about you that you do not want shared with others?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- Does the person know that information about him or her is kept on file?
- Who has access to information about the person?
- Has information about the person been shared with others? With whom? For what purpose?
- Does the person know what specific information is shared with others?
- Do you know if there is specific information the person does not want shared with others?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How is the person informed about what is in his or her record?
- Who consents to the sharing of information about the person?
- How is the person protected from violations of confidentiality, both within and outside the organization?
- Are there any barriers that affect the outcome for the person?
- How are barriers to this outcome addressed?
- What organizational practices, values, and activities support this outcome for the person?

## 15 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 15.1.** Does the person know what personal information the provider organization has collected about them?
- 15.2.** What personal information is the person most concerned about protecting [personal (name, address, birthdate, race, etc.); services and supports; medical (issues, medications, treatments, etc.); behavior (issues, behavior plans, etc.); relationships (family, friends, intimate relationships, etc.); financial (earnings, savings, etc.); legal/criminal background; abuse, neglect, exploitation, mistreatment; other]?
- 15.3.** Are the person's desires about the sharing of information respected?
- 15.4.** Is personal information shared with others only at the request of, or with the consent of, the person or his or her legally authorized representative?



If the answers to #15.1, 15.3, and 15.4 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 15.A.** Does the organization know the person's preferences for confidentiality regarding personal information?
- 15.B.** Does the organization obtain the person's consent or that of the legally authorized representative prior to the release of any personal information?
- 15.C.** Are procedures implemented to respect the person's wishes about the sharing of personal information?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- The sharing of information through both written and verbal means is considered in determining whether the outcome is present. If the person requires assistance to understand and/or share personal information, and adequate supports are in place, then the outcome is present.

## 16 PEOPLE PERFORM DIFFERENT SOCIAL ROLES

The roles we fill in life (child, parent, sister, nephew, spouse, worker, volunteer, congregation member, etc.) express what is important to us. They define the expectations we have for ourselves and that others have for us.

Most of us play a number of different roles depending on the time, place, and circumstances. For instance, during the day our primary roles might be as student, worker, or manager. At home, our roles change to parent, spouse, or friend. At other times, we have additional roles, such as team athlete or coach, PTA volunteer, theatergoer, or choir member. The opportunity to play all of these roles enriches our lives and the lives of others.

Society assigns various levels of status to particular roles. Some roles are valued and some are not (e.g. criminals). Most of us would not choose to play less-valued roles. People play valued social roles to increase their status. Playing a variety of roles helps people express their unique qualities. Common roles can be neighbor, volunteer, family member, and friend/confidant. Roles related to religious activity or spiritual beliefs are very important to some people. These roles, like many others, offer people an opportunity to contribute and give something back to a larger community.

Social roles are active, rather than passive. Not only do people recognize the roles they play, but others do as well. One way to define a social role is to ask “Would the person be missed in the role if he or she was not there?” When we fill a particular role, we take on the responsibilities and actions that go with it.

People give back to the community. They participate in activities that best fit their interests and skills or allow them to learn and fill new social roles. People have roles in their places of worship by singing in the choir, serving on a committee or working in the office. Other people may work on a committee to revise service standards because they want to advocate for a particular change or learn more about the workings of the government.

People receiving services may need supports to give back to their communities. People who have never participated on a committee may ask for support to understand how committees work, or to read the agenda and other documents. People may also need support to understand their options for community involvement, or to match their interests and skills with opportunities. Organizations assist people to overcome barriers by providing access to opportunities, information, technology, and skill development.

### Values

- People who fill a variety of social roles are more likely to be treated as valued members of the larger community.
- People have opportunities to experience and perform different roles in their communities.
- People decide which social roles they would like to perform.

### Principles for Organizations

- Ensure that a broad array of role options is available to people.
- Provide supports to assist people to learn additional skills and behaviors necessary for filling a variety of social roles.

## 16 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- Do you know about different groups, clubs, organizations, etc., to be involved in?
- What kinds of involvement and responsibilities do you have in your neighborhood or community (neighborhood watch, civic groups, social clubs, volunteer, church, synagogue, other place of worship)?
- What kinds of things do you do with other people?
- Is there something you would like to be doing that you don't do now?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What social roles do you think the person performs?
- Why do you think these are social roles for the person?
- What roles do you see the person having the potential or interest to perform?
- If the person stopped participating, would he or she be missed?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How have the person's interests been identified?
- How do you know what social roles the person would like to perform?
- What opportunities have been provided?
- What supports does the person need to develop or maintain social roles?
- Have those supports been provided?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 16 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 16.1.** Does the person have a social role(s)?
- 16.2.** Does the person fill a variety of social roles?
- 16.3.** Is the person satisfied with the type of social roles they have?
- 16.4.** Is the person satisfied with the number of social roles they have?



If the answers to #16.1, 16.2, 16.3, and 16.4 are Yes, the outcome is present.  
 If the answers to #16.1 and 16.2 is No, is this the result of an informed personal choice?  
 If due to informed personal choice, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 16.A.** Does the organization know what social roles the person currently fills?
- 16.B.** Has the organization assessed the person's interests in assuming additional roles or expanding current roles and responsibilities?
- 16.C.** Are supports provided to assist the person with performing chosen social roles if needed and requested?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- The person must be acknowledged and recognized in the particular social role and supported to assume all aspects and responsibilities that typically accompany that role in order for the outcome to be present.
- A greater range of type and complexity of social roles is expected of people who have greater capabilities and supports to perform those roles.



# MY CHOICES

## FACTOR 4

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Choice is the ability to make decisions that affect one's life and community. Central to choice are self-determination, participation, and autonomy. Organizations must accommodate peoples' preferences so they can get what they want and need.

## INDICATORS

- 17 People choose where and with whom they live
- 18 People choose where they work
- 19 People choose services

## 17 PEOPLE CHOOSE WHERE AND WITH WHOM THEY LIVE

Home is where we find comfort, support, pleasure, and privacy. Therefore, we all cherish our ability to choose for ourselves where and with whom we live.

Organizations learn about each person's preferences for a place to live — whether in the local community, near family or friends, in the city, or in the country. Just as important, organizations discover with whom the person might like to live, if anyone. Some people prefer to live alone, others enjoy sharing their home with another person, and some feel more comfortable living with several people who can provide them support and companionship.

People learn about the range of choices by having opportunities to see what is available. They do so by visiting houses, apartments, and other living situations. They also need to meet potential roommates to learn about interests, habits, and overall compatibility. People can then choose with whom and where they would like to live. Organizations assist people with these decisions by finding out what they would like, providing opportunities for them to see what is available, and then honoring their choices. Some people will need more help than others to make decisions.

Most important to remember, the person is the key decision-maker. His or her preferences and individual characteristics are the priority. Organizations assist in matching what the person wants with what is available.

Sometimes options are limited. A person may, for instance, prefer a specific location where no apartments or homes are available. The organization works with the person to find the next best situation. Organizations actively plan with the person to look for ways to eventually honor the person's preferences.

When options for living arrangements are limited, organizations have a responsibility for community advocacy. Organizations focus on expanding options for the future by working with other community members to identify the barriers. Often the barriers are related to socio-economic status. At the systems level, the organization works to increase options for everyone who lives in the community.

### Values

- People's choices about where and with whom they want to live are critical to providing supports.
- People have the same array of options of where to live that is available to everyone.
- People have an array of options of where and with whom they live.
- People have control of decisions regarding their living situations.

### Principles for Organizations

- Discover people's preferences for living arrangements.
- Use personal choices and characteristics to guide how you assist people to find where and with whom to live.
- Serve as an advocate to enhance and expand options for all people.

## 17 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### SUGGESTED QUESTIONS FOR THE PERSON:

- How did you choose where to live?
- What options did you have to choose from?
- How did you decide who would live with you?
- What do you like about your living situation?
- What would you like to be different?

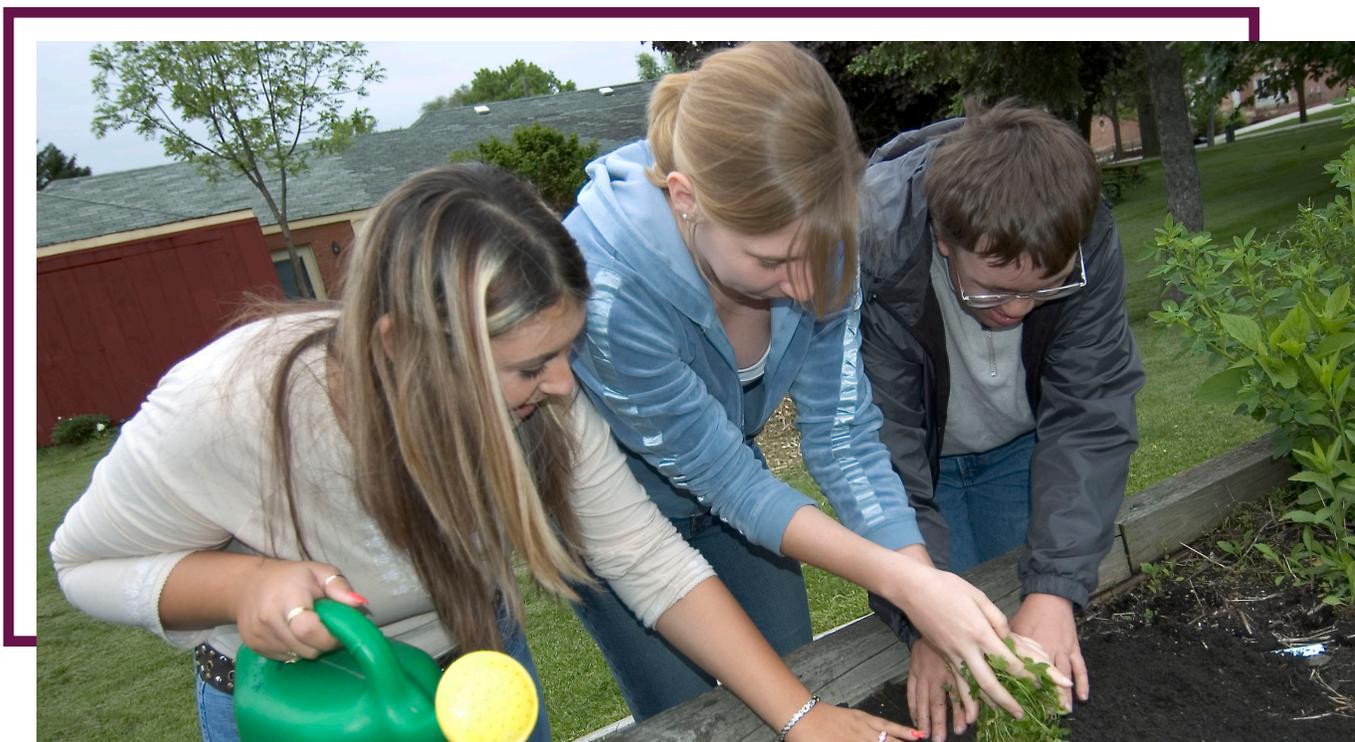
### Follow-up | Suggested Questions for Those Who Know the Person Best

#### QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:

- Who decided where and with whom the person would live?
- What options and experiences did the person have in order to make choices?
- If the person did not choose, why not?

#### QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:

- How do you learn about the person's preferences for type of living situation?
- How do you present options to the person so he or she can make informed choices?
- Is the person living where and with whom he or she wishes? If not, what is the barrier?
- What are you doing to overcome this barrier?
- What organizational practices, values, and activities support the person to maintain or achieve this outcome?



## 17 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 17.1. Does the person have options about where and with whom to live?
- 17.2. If #17.1 is Yes, do the options include generic (non-disability specific) community settings and the possibility of a private room or home?
- 17.3. Does the person decide where to live?
- 17.4. Does the person select with whom he or she lives?



If the answers to #17.1, 17.2, 17.3, and 17.4 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 17.A. Does the organization know where and with whom the person wants to live or are there efforts being made to learn about the person's preferences?
- 17.B. Does the organization support the person to explore all options so he or she can make informed choices?
- 17.C. Does the organization provide an array of options that includes generic (non-disability specific) options and a private room or home?
- 17.D. Does the organization acknowledge the person's preferences and support the person to address any barriers that prevent him or her from choosing where and with whom to live?
- 17.E. Were the person's preferences and unique characteristics used as the home was selected?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- If the person has not been presented with options about where and with whom to live and his or her preferences have not been determined, then the outcome is not present.
- If the person chooses to remain in a situation he or she did not originally choose, after options have been presented through a process of exploration, the outcome is present.
- For minor children living at home with the natural family, this outcome is present. For children placed out of the birth or adoptive home, the outcome is present if the preferences of the child and guardian are part of decision-making.

## 18 PEOPLE CHOOSE WHERE THEY WORK

Work provides a source of income, an opportunity to meet other people, a sense of accomplishment, and self-esteem. Finding and choosing a job and a career is an important life decision.

People have productive lives whether or not they have paid employment. Some people do not work because they are too young, do not need the money, or because they have retired. For children, we define work as going to school and doing household chores. During adolescence, we begin to look at career development and planning for work. When people are retired or do not work, they have meaningful activities that provide the same social and personal rewards that a paid job offers. This can be accomplished through volunteering, continued learning, or leisure activities.

Organizations learn about people's preferences for work, the type of job, the hours, the location, and the responsibilities. People learn what is available and consider a wide range of work choices. People's preferences, interests, and desires are key to job and career selection.

With access to supports and technology, most people can enter the job market. Options for jobs and places to work increase when people have support services, assistive technology, and environmental adaptations. Organizations assist people to make work-related decisions by finding out what they would like, providing opportunities to see what is available, and honoring the final choice. Some people will need more help than others to make these decisions.

Organizations use a variety of methods to learn about people's preferences. Decisions about work involve matching individual characteristics and preferences with available options, since we cannot always control what options are available.

Options for work may be limited due to particular circumstances that are beyond the person's or organization's control, such as no job openings at a given company. Organizations assist people to identify the "next best" alternative. Planning addresses ways to change the circumstances, while the person experiences the "next best" option.

### Values

- The same array of options for work available to others is available to people.
- For most adults in our society, work provides a significant amount of economic support and self-esteem.
- If people have alternate means of support and do not wish to work, that choice is respected.
- People who do not work spend their time in meaningful and productive activities.
- Assistive technology enhances people's employment potential and productivity.

### Principles for Organizations

- Assist people to locate employment that matches their goals, desires, skills, and aptitudes.
- A full array of work, training, and other opportunities is made available to people.
- Provide opportunities for different experiences and explore and respect individual preferences.

## 18 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- What do you do for work or your career?
- What options did you have?
- Who chose what you do?
- Can you do something different if you want to?
- How did others help you with this?
- Are you satisfied with the decision either you or others made?
- If not, what would you like instead?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- How was it decided where the person would work?
- What options/experiences did the person have?
- Who made the decision about where the person works? If it wasn't the person, why not?
- Is the current work situation satisfactory to the person? If not, what is being done?
- How are the person's concerns addressed if there is not a good match?
- How does the person's current job relate to his or her preferences, skills, and interests?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you learn about the person's preferences for work?
- How do you present options to the person so he or she can make informed choices?
- Is the person working where he or she wishes? If not, what is the barrier?
- What are you doing to overcome the barrier?
- How do you learn about the person's job satisfaction?
- What organizational practices, values, and activities support the person to maintain or achieve this outcome?

## 18 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 18.1.** What does the person do for work and/or other daytime activities? (For example, school/education, competitive employment, supported community employment, sheltered work, enclave work, day program/activities, community-based day activities, retirement, no scheduled work/day activities.) For each of the options, is the person engaged in the work and/or other daytime activities full or part time?
- 18.2.** Does the person have opportunities to experience different options?
- 18.3.** If #18.2 is Yes, do the options include generic community work/day activities?
- 18.4.** Does the person decide where to work or what to do (e.g., type of job/employer, or daytime activity and amount of time spent engaged)?



Question #18.1 is for information gathering purposes only.  
If the answers to #18.2, 18.3, and 18.4 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 18.A.** Does the organization know the person's interests for work, or are efforts being made to learn what the person would like to do?
- 18.B.** Does the organization provide the person with access to varied job experiences and options?
- 18.C.** Do the options include generic non-disability specific community work/day activities?
- 18.D.** Has the organization responded to the person's desires for pursuing specific work or career options with supports?
- 18.E.** Has the organization supported the person to address any identified barriers to achieving this outcome?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- If the person has not been presented with options about where to work, and his or her preferences have not been determined, then the outcome is not present.
- Planning for work begins during high school years. For preadolescent children, this outcome is present as long as they are involved in educational activities.
- Choice may mean exploring options, expressing preferences, and finally choosing the only option available at that time.

## 19 PEOPLE CHOOSE SERVICES

Services help us get what we want and need. In the business world, companies that don't fill customers' needs soon fail. We don't shop in a clothing store that does not carry our size or go to a restaurant that serves food we don't like. We choose, instead, places that give us what we are looking for.

Organizations afford people an array of options in services and then honor people's choices.

Organizations accommodate people's preferences about who provides services, where, and when.

People may, for instance, get services at a bank or a grocery store, or from doctors, dentists, hair stylists, personal care assistants, therapists, and service coordinators. Organizations ensure people's service options match what is available to other members of the community. People may need assistance to explore and understand information about options. Organizations provide support by assisting people to gather information, discuss benefits and drawbacks of different services, visit the service settings, and meet the people who work there.

Services and interventions assist people to realize personal goals and achieve individualized outcomes. Organizations customize services for each person. They do not place people into program "slots". Organizations do not omit possible options because they have decided (independent of the person) that the option is not a "good" one. They do not, for the convenience of the organization, require people to accept services that do not match their needs. They consider individual preferences when making decisions about the type, intensity, location, and provider of service. They modify services whenever possible to accommodate requests and preferences. Organizations support people if they change their minds about choices they have made.

Services and supports are not outcomes themselves; rather, they facilitate outcomes. They are processes that enable people to achieve their goals. Assessment information describes the services that would benefit people in achieving their goals and identifies the options available for those services.

### Values

- Services and interventions focus on personal goals and desires.
- To promote choice, options are presented and explained to the person. These options are well matched to the person's goals.
- A person's ability to choose and make decisions changes throughout life.

### Principles for Organizations

- Explain all available options.
- Identify what decisions the person makes and provide support to expand that capability over time.
- Provide the support and opportunities people need to make choices.

## 19 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- What services are you receiving?
- When, where, and from whom do you receive the services?
- Who decided what services you would receive?
- If you did not decide, what was the reason?
- How did you decide who would provide the service?
- Are these the services you want?
- Do you have enough services? Are they meeting your needs and expectations?
- Can you change services or providers if you so choose?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What services does the person use?
- What services were identified as beneficial by the person?
- What options for services were presented to the person?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you determine the services desired by the person?
- How were options for services and providers presented to the person?
- How were the person's preferences considered when presenting options?
- If the person has limited ability to make decisions or limited experience in decision-making, what do you do?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

"I like to make as many

**CHOICES**

**as I can."**

- Amy

## 19 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations, and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 19.1.** Does the person select the services and/or supports that they receive? (For example, residential/in-home, employment/day, health, case management, generic community [dentist, doctor, bank, stores, etc.] )
- 19.2.** Do the services and/or supports focus on the person's goals? (For example, residential/in-home, employment/day, health, case management; generic community)
- 19.3.** Does the person have choices about service provider organizations? (For example, residential/in-home, employment/day, health, case management, generic community)
- 19.4.** Does the person have choices about direct support professionals/staff? (residential/in-home; employment/day)



If the answers to #19.1, 19.2, 19.3, and 19.4 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 19.A.** Does the organization actively solicit the person's preferences about services, provider organizations, and direct support professionals/staff in: residential/in-home, employment/day, health, case management, other?
- 19.B.** Does the organization provide options to the person about services, provider organizations, and direct support professionals/staff in: residential/in-home, employment/day, health, case management, other?
- 19.C.** Does the organization honor the person's choices about services, provider organizations, and direct support professionals/staff in: residential/in-home, employment/day?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- Even though the person may not have chosen the services or providers of service initially, if he or she is now choosing to maintain the service after options have been presented, the outcome is present.
- The choice of place of work or place of residence is not the issue in this outcome. In relation to work and home, the outcome refers to choice in services received while the person is at home or at work.



# MY GOALS

## FACTOR 5

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Goals reflect aims for the future, including direction, dreams, and aspirations. While goals do not need to be realistic or achievable, they do need to be person-centered. Organizations need to support people who receive services to have experiences and opportunities that help them meet personal milestones.

## INDICATORS

- 20 People choose personal goals
- 21 People realize personal goals

## 20 PEOPLE CHOOSE PERSONAL GOALS

Our goals reflect what we want for the future. Each of us has a unique way of expressing our dreams, directions, hopes, and desires. Goals can be formal statements about what we want to do or accomplish in the years ahead. They can be informal expectations, wishes, and hopes about the future. When we have a variety of experiences and opportunities to try different things, our options and choices increase and our goals and hopes for the future are enriched.

The following examples show how we might describe our goals:

- “I want to live in my own apartment.”
- “I hope to have my own house.”
- “I’d like to live on a farm.”
- “I want to move near my sister.”
- “I want to work as a ...”
- “I want to stay out of the hospital.”
- “I would like to take a trip to ...”
- “I want to have a boyfriend.”
- “I want to get married.”
- “I want to finish school.”
- “I’d like to drive a car.”
- “I want to be a...”
- “I want to play basketball.”
- “I’d like to play the guitar.”

Learning about personal goals requires that we talk to the person and, when appropriate, to others who know the person well. We listen and acknowledge what people tell us. Finally, we do not prejudge what people say they want as “unrealistic” or “unachievable”. Rather, we respect that what we learn is important to each person and why. Understanding a person’s goals may require more than just asking. Taking statements at face value may misrepresent the real meaning and hope the person has for his or her life.

People’s experiences, social connections, creativity, and often their spiritual beliefs not only influence goal choice, but also the priority and importance placed on those goals. Organizations explore the complex interplay between all these factors to understand why a person is choosing to pursue a particular life path.

People’s goals serve as the basis for interacting with them and providing supports. Using many tools and techniques, organizations learn and discover people’s goals. The learning process occurs in all aspects of a person’s life — not just where the person lives, works, or spends time. We often learn about a person through assessments. Assessment is an ongoing process; learning is continuous. These are not one time events — something that happens at a meeting, by filling out a form, or by answering a questionnaire.

Person-centered plans flow from what we learn about the person’s goals and desires for the future. Plans can be written, displayed in charts and diagrams, or drawn with pictures. The format of the plan is not as important as how it relates to a person’s goals. Planning guides the way supports are provided and ensures that they match the person’s unique priorities.

### Values

- Each person directs the process of choosing personal goals.
- People have the support they need to experience a variety of options to make choices about the future.
- The person’s desires and goals are the focus of supports and services.

### Principles for Organizations

- Actively solicit personal goals, needs, and wants.
- Provide people with experiences and options in making choices.
- Ensure that planning is person-centered and ongoing.
- Focus services and supports on the person’s goals and desires.

## 20 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these, or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- How do you want your life to be in the future?
- What is important to you to accomplish or learn?
- Whom do you talk with about your future?
- What are your hopes and dreams for yourself?
- What assistance (if any) do you need to make these things happen?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What are the person's goals?
- What leads you to think that?
- How is the person working toward the attainment of personal goals?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How have you explored hopes, dreams, and desires for the future with the person?
- What are you doing to support the person?
- Why did you select this action?
- How do you learn if the supports/activities are effective?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

“One thing that  
I would like to do  
**IN MY LIFE**  
is to get married.”

- Raji

## 20 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

- 20.1. Have the person's priorities regarding goals been solicited?
- 20.2. Does the person choose personal goals?
- 20.3. Are these the goals the person is working toward?



If the answers to #20.1, 20.2, and 20.3 are Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

- 20.A. Does the organization know the goals the person has identified for him or herself or are efforts being made to learn about the person's goals?
- 20.B. Does the organization provide supports and services to assist the person in pursuing personal goals?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

- YES — Supports in Place
- NO — Developing Plans
- NO — Aware, but No Plans
- NO — Not in Place

### Additional Considerations

- A formal service planning process is not required for the outcome to be present.

## 21 PEOPLE REALIZE PERSONAL GOALS

We define success when we achieve what we set out to do. Sometimes success means that we get exactly what we wanted (for example, to graduate from college in four years). Sometimes we meet the goal, but not exactly as planned (maybe it took five years because you changed your major). Still, we are proud of the result and the path we took to get there.

We all identify personal goals, directions, dreams, and aspirations. These add meaning and value to life. We also define when and how we measure success and attainment. When we realize personal goals, we celebrate.

People define their personal milestones, significant events, goals, or accomplishments. Although various activities, objectives, and actions contribute to the process of realizing personal goals, they are the means or steps to the end, not the ends in themselves. Assisting each person to reach his or her goals is the focus of services and supports. Organizations individualize the assessment and planning process. This planning and support process continues as the person realizes personal goals and moves on to the next challenge.

People may need to learn new skills and competencies to achieve personal goals. People achieve their goals with individualized supports. These may include specialized and generic supports. Even without new skills, people may maintain or increase their functional capabilities through support. They may, for instance, use personal attendants, medical services, therapies or adaptive technology, and have environmental alterations.

### Values

- Achieving goals gives people a sense of accomplishment and enhances personal image.

### Principles for Organizations

- Provide supports and training to target those skills, resources, and experiences that will facilitate realization of personal goals.



## 21 INFORMATION GATHERING

Use the following questions to guide your discussion with the person and those who know the person and their supports best. You may ask all of these, some of these or none of these questions. Your goal is to be able to answer the decision-making questions.

### Conversation with the Person

#### **SUGGESTED QUESTIONS FOR THE PERSON:**

- What have you done that you feel good about?
- What have you accomplished over the past few (one or two) years that has made you feel good about yourself?
- What accomplishments have pleased you most?
- Sometimes things happen that make life better. Has that happened to you?
- If you did not accomplish something important to you, what got in your way?
- What assistance or support do you think you need?

### Follow-up | Suggested Questions for Those Who Know the Person Best

#### **QUESTIONS ABOUT THIS OUTCOME FOR THE PERSON:**

- What personal goals has the person achieved?
- If any were not achieved, what is the reason?

#### **QUESTIONS ABOUT INDIVIDUALIZED SUPPORTS:**

- How do you know if the person accomplished something personally significant?
- What did you do to assist the person to experience personal success?
- What barriers to goal attainment does the person face?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 21 DECISION-MAKING

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

### PERSONAL OUTCOME QUESTIONS:

**21.1.** Has the person accomplished something that is significant to him or her, in the past year or two?



If the answer to #21.1 is Yes, the outcome is present.

### INDIVIDUALIZED SUPPORT QUESTIONS:

**21.A.** Has the organization identified accomplishments the person sees as significant?

**21.B.** Does the organization assist the person to celebrate the achievement of personal milestones?



Based on the answers to these questions, are individualized supports in place that facilitate this outcome?

YES — Supports in Place

NO — Developing Plans

NO — Aware, but No Plans

NO — Not in Place

### Additional Considerations

- The person must have accomplished a personal milestone within the past year or two for this outcome to be present.

“My goal is to get my driver's permit.

PERSONAL OUTCOME MEASURES®

helped me to succeed.”

- Amanda

# PERSONAL OUTCOME MEASURES®

Guide and Tools



# ADDITIONAL TOPICS TO COVER

## ABOUT THE INTERVIEW

- Date of interview
- Person interviewed (legal name)
- Person's unique ID (assigned by organization, if applicable)
- Primary interviewer's certification status and name
- Second interviewer's certification status and name
- People present to support the person (as requested by the person)
- Provider staff interviewed for follow-up

## ABOUT THE PERSON

- Date of birth
- Gender
- Race/ethnicity
- Primary language
- Marital status
- Primary method of communication
- Diagnosis
- Decision-making authority/guardianship

## ABOUT THE PERSON'S LIVING SITUATION

- City/town
- State/province
- Zip code
- Country
- Type of residence
- Number of housemates receiving paid services/supports (e.g., people with disabilities, include person interviewed)
- Number of housemates not receiving paid services/supports (e.g., people without disabilities)
- Total number in household (include person being interviewed)

## ABOUT THE SERVICES & SUPPORTS

- Name of provider organization.
- Is it a managed care organization?
- Services the person currently receives and if each of those services is provided by this organization
- Does the person have medical and behavioral support needs?
- Does the person receive psychotropic medications?
- Average hours per week person receives support
- Funding for services

# TECHNIQUES FOR DISCOVERY

## A FOCUS ON PEOPLE

Learning about personal outcomes requires interaction with people. The primary tool used for learning about individual priorities is interaction and conversation with the person you want to get to know. This direct interaction with the person is the best way to gather information about the person's preferences, goals, desires, and particular method of communication. It is only through interaction and exchange that we can begin to understand each person as a unique individual.

## FAMILIARITY WITH THE OUTCOMES

The person facilitating the information gathering needs to have knowledge of CQL's *Personal Outcome Measures*<sup>®</sup> in order to conduct a personal outcome interview in a conversational fashion. Critical knowledge includes the key ideas for each of the outcome measures. An understanding of the key ideas for each outcome assists the person asking questions to learn about the person's definition and status for each outcome. During an initial interaction, the goal is to gather as much information about personal outcomes as possible directly from the person. This provides a foundation of understanding about the person and his or her sense of priorities. Follow-up interactions and interviews with the person and others provide opportunities to gather additional information.

## REAL COMMUNICATION

One difficulty that many of us experience when interacting with people is clarifying what the person is trying to tell us. To accomplish this, we have to understand the concept of communication. Focusing only on the exchange of words as the core of communication does not ensure that understanding will follow. Communication is much more than just talk.

Communication refers to all the ways people provide and use information. It is not a simple process. Each person brings his or her unique style, values, experience, personal characteristics, and skills into the exchange. The interviewer's challenge is to listen and learn from everything the person says and does. If we want to communicate, we must start with a focus on

the person with whom we want an exchange to occur. There is no short cut or substitute for direct interaction with the person. We can learn something from every interaction. Although some people have difficulty expressing their thoughts and feelings, the interviewer must believe that every person communicates.

Success with the process of learning from people requires a great deal of skill and practice. The required skills can be learned, but are not necessarily skills routinely learned through professional training. Talking with people about personal outcomes is a skill learned through experience. Each person is different. There is no substitute for meeting with the person and working through a process for information exchange and understanding. Over time and with experience, a greater comfort is developed.

The goal of any *Personal Outcome Measures*<sup>®</sup> conversation is to learn as much as possible about what the person values most. This process helps the organization identify the person's expectations, define his/her desired outcomes, assess when and how the person's expectations are met, and gather suggestions for improvement. By learning about the person's life priorities and personal preferences, the interviewer gains an understanding of the person's perspective. This personal perspective assists those who provide supports and services to understand how each outcome is defined by that person. The organization uses the personal outcome definition to guide service activities.

## COMMUNICATION WITHOUT WORDS

People communicate with actions as well as words. Our patterns of behavior communicate our personal preferences and priorities in life. The information gathering process may require extra attention to non-verbal communication. Spending time with the person to develop rapport and observing how the person interacts (or doesn't interact) in several different settings may provide key information for people who have difficulty with language and verbal expression due to physical or cognitive limitations. People who are most familiar with the person may be able to assist the interviewer in understanding the person's own communication method and style. They may also offer suggestions and guidance to enhance interactions.

## DEVELOPING AND ASKING QUESTIONS

Learning about people requires listening not only to what is said, but what is not said. At times, people have difficulty expressing themselves directly and clearly. When this happens, the challenge is to assist the person to express information and issues by probing and asking questions.

There are two basic types of questions that can be asked: open and closed. Open questions are questions that must be answered with an explanation or opinion. They are useful for starting a discussion and learning about the person's unique perspective. Closed questions are used when a specific response is needed. Closed questions often result in a "yes", "no" or single word answer. Learning about outcomes requires that both types of questions be used to gain the best understanding possible.

### Open Questions:

- What can you tell me about where you live?
- How did you find your current job?
- Why have you decided not to move?
- Would you tell me more about your hobbies?
- What do you enjoy most about cooking?

Open questions help to provide an overall understanding of the person by promoting an open exchange of information. They help define the person's issues and concerns and clarify the person's requests and desires because they allow for a variety of viewpoints and responses. Open questions provide more information and detail on specific issues and often begin with: What, How, Why, and Would you tell me more about.

We offer a word of caution about using questions that begin with "Why". Although these questions can be useful in follow-up, "Why" questions can also be perceived as asking the person to justify his or her statements or feelings. Framing the question as a follow-up request for more information (for example: "I'm not sure I understand. Can you tell me more about why that was so important to you?"), reduces the chance of communicating judgment to the person.

Closed questions are used to get specific information or clarify what the person has said. They can be useful to get confirmation or agreement and to validate understanding. Closed questions are also used to summarize the information that is learned during the interaction.

### Closed Questions:

- How old are you?
- Where do you live?
- Who is your best friend?
- Are you happy with your job?

When 'yes or no' questions are the primary source of information, there may not be a complete or accurate picture of what is important to the person. When 'yes or no' questions are used, follow-up questions such "Is there anything else you can tell me about ..?" can help to open up the conversation. These additional questions will help the interviewer to get more information about the person's perspective.

In general, questions need to be as specific and clear as possible. This is difficult because what may seem clear to one person is not clear to someone else. If the person does not seem to understand the question, re-stating the question in a different way may be necessary. Reassuring the person throughout the process that there are no right or wrong answers is often helpful.

## A SUCCESSFUL INTERACTION

When you engage a person in discussion for the purpose of learning, you are asking for something of value. The person sharing information is risking his or her personal privacy, as well as sharing personal experiences. Making the person feel comfortable and in control of the process, and assuring the person's privacy and confidentiality of information, are requirements for going ahead.

## THINGS TO DO BEFORE YOU MEET WITH THE PERSON

### Contact the person to request time to talk.

Participation should always be voluntary for the person. If the person is hesitant or unsure about taking part, support for the person to say ‘no’ should be provided. The value of the information will be diminished if the person is uncertain about participating.

### Ask if special accommodations or arrangements are desired or needed.

For the person’s comfort, the facilitator should make sure that any accommodations the person needs to feel comfortable are made.

### Have the person choose where and when the conversation will take place.

The easiest way to ensure that the person is comfortable is to ask for direction about where and when it is best to meet. This means that the time and location of the meeting is set by the person. Meetings can happen anywhere: at the person’s home, near the workplace, in a restaurant, or another place selected by the person.

### Offer options to make the person feel more comfortable.

People are often hesitant to ask for what they need, so it is useful to provide options and examples.

### Direct interaction and contact with the person is a requirement.

Even if conversation is difficult, interaction with the person before talking with someone else provides a starting point to guide discussions with others. It is possible to get a sense of the person’s capabilities through interaction and observation. People who may have difficulty with conversation may have no difficulty showing you around their home or workplace. Spending time with the person can also reveal some of the difficulties that the person lives with day-to-day. For example, by visiting with a person who has limited mobility or uses a wheelchair, you may observe some environmental barriers that interfere with the person’s personal outcomes. Observations also reveal information about the supports being provided.

## WHAT TO DO IF YOU HAVE DIFFICULTY COMMUNICATING:

- Meet with the person
- Spend time observing how the person interacts (or doesn’t interact) with other people
- Find out who knows the person best
- Enlist the assistance of the people most familiar with the person and his or her style of communication
- Look to the person for direction and ideas
- Interview as many people as possible who are close to the person

Always seek to include the person in the conversation even if the primary information is provided by someone else. It is always best to begin with a topic that is familiar and comfortable when trying to engage someone in conversation.

Asking the person for suggestions about where to start may work; however, identifying the person’s preferred topic is not always that easy. After reviewing the range of topics that will be discussed, ask the person which of the issues is most interesting or important. If the person does not identify a preference, the interviewer can then make a suggestion. If the conversation topic is selected by the interviewer, be sure to watch for non-verbal cues about how comfortable the person is with the conversation.

## STARTING THE CONVERSATION:

- Explain the purpose of your meeting with the person and what you intend to talk about
- Provide the person with a copy of the Personal Outcomes and/or questions you will use to guide the conversation
- Affirm that the person is in control of the conversation and can choose to answer or not answer questions
- Ask about preferences and things you can do to make the person comfortable (again!)

Another approach to starting the conversation is to ask the person to tell you something about home, work, or family. Most people are eager to share this kind of personal information. This approach also puts the person in control of what information is shared.

Attention to the person's comfort and needs for support does not stop during the conversation. The facilitator is responsible for directing the process in whatever way will best meet the needs of the person. The following are some general practices that will support people and demonstrate respect for the information they are willing to share.

- Be open to hearing whatever the person has to tell you
- Follow-up on anything that is unclear or may have more than one meaning
- Don't be afraid to modify the format during the interview
- Stop the interview when the person requests or if you sense signs of discomfort
- Ask permission to follow-up the interview by talking with other people
- Arrange to follow-up with the person later

### ACTIVITIES THAT ENHANCE UNDERSTANDING

After the initial conversation, organize and review the information collected. This review of information often reveals items that need further clarification. The "best" people/sources to provide the necessary clarification can then be identified and additional information obtained.

With the person's permission, interactions with the person's family, friends, and staff often provide additional details to clarify the person's situation.

#### Use these questions to guide the review of information:

- What did you learn from the person?
- What additional information do you need about this person?
- What are your best sources for getting the additional information you need?
  - the person
  - observation
  - people who know the person well
  - the person's service records

### FOLLOW-UP ACTIVITIES

- Visits with the person in more than one setting
- Observation of support activities and interactions
- Checking documentation

Follow-up activities include opportunities to interact with staff and the person in typical settings. These visits are informal but provide a chance to look for links between what has been said and what is really happening. Observations can also reveal additional issues to be explored.

Although documentation is not a primary source of information, there are things that may need to be verified by reviewing the person's service records. Information such as specific dates, names, medical and legal information may be too detailed for people to remember. Follow-up visits to the service setting provide an opportunity to check documents.

### INVOLVING OTHER PEOPLE IN THE INFORMATION GATHERING

There are times when other people are involved in the initial conversation. This must always occur at the request, or with the permission, of the person. It may be important to include others, if you have difficulty communicating with the person.

The facilitator must be clear about what kind of help to ask for from others. The biggest mistake made in gathering additional information from others is that questions focus on what other people think about the person, instead of asking what has been learned about the person through shared experiences. People who know the person well can confirm and enhance what has been learned through interaction with the person. Family, friends, and staff who know the person can share what they have learned about the person through interactions over time.

# STRENGTHENING DATA THROUGH A REPRESENTATIVE SAMPLE

Some agencies use the *Personal Outcome Measures*® with everyone they serve. However, other organizations utilize the *Personal Outcome Measures*® to interview a selection of the people they support. When this is the case, if there is flexibility in who can be interviewed, it presents an opportunity for a representative sample.

## WHAT IS A REPRESENTATIVE SAMPLE AND WHY IS IT IMPORTANT?

A representative sample is when data from a group of people (sample) reflects the members of an entire population. When exploring your *Personal Outcome Measures*® data for your entire organization you want the interviews you complete to be generalizable – accurately reflect what is really going on in your organization. A representative sample is a way to increase accuracy and reduce bias from potential “outliers.” Outliers are problematic because people that do much better or worse than average will skew findings to be a less accurate representation of your organization. Moreover, if certain groups are overrepresented, their experiences may be magnified causing others’ experiences to be underrepresented.

To have a representative sample you want to confirm a wide range of populations are included. You also want to confirm groups that may often be forgotten or left out are also included to ensure your agency’s data represents all types of people that you serve.

**When selecting your *Personal Outcome Measures*® interview participants, it’s important to pay attention to the following demographics:**

- Age
- Disability type
- Gender
- Primary communication method
- Primary language
- Race/ethnicity

## HOW TO MAKE YOUR INTERVIEW DATA MORE REPRESENTATIVE

If you only use the *Personal Outcome Measures*® with a selection of your organization rather than all of the people you support, ideally the best possible way to get a representative sample is to randomly select who will participate in the *Personal Outcome Measures*® interviews.

There are websites (e.g., <https://www.randomizer.org/>) that can help you select a sample randomly. However, we recognize it is not always possible to have a completely random sample.

### Other methods to make your sample more representative include:

- Try to make your interview sample as close as possible to the demographic makeup of the people your agency serves. For example, if 75% of the people you support have autism and 25% of the people have an intellectual disability, then  $\frac{3}{4}$  of your interviews should be with people with autism and  $\frac{1}{4}$  be with people with intellectual disability. If half of the people you support have Spanish as their primary language then half of your interviews should be with Spanish speaking people.
- Try to ensure none of the demographics are heavily distributed to one category. For example, the demographics of your interviews being 99% White would be concerning if this is radically different from the population you serve. Try to pick interviews with a more even distribution of demographics.
  - With characteristics such as gender, aim for a 50/50 representation of women to men.
  - With characteristics such as race, instead of following the demographic makeup of the people you support as mentioned above, you can aim for a representation that is similar to the breakdown of the population of the your state, or the United States as a whole.

- For example, here is the racial/ethnic breakdown of the United States from the 2010 Census you could compare against:

White	57.7%
Hispanic or Latino	16.8%
Black or African American	13.0%
Asian	4.9%
American Indian or Alaska Native	1.0%
Native Hawaiian or Other Pacific Islander	0.2%
Some Other Race	6.4%

- Even if you don't serve a lot of people with certain demographics (for example, nonverbal communication, Spanish speakers, etc.), you may be interested in purposefully interviewing a few people from those groups because then when you analyze across your data it will paint a fuller picture about the outcomes for who you serve. This also allows you to see if there are any disparities for any groups.

## HOW DO I USE PERCENTAGES TO SELECT INTERVIEW PARTICIPANTS?

Once you know what you want your representative sample to look like it's easy to calculate how many people you'll need to interview from each of the demographic categories. To do so, multiply the percentages you want to use (e.g., agency population, state population, census population, etc.) by the total number of people you want to interview..

For example, if you decide you want to have a racial makeup similar to the U.S. Census data multiply the number of people being interviewed (in this example 50) times the racial breakdown for each category. This will produce a number of people you want to aim for in each category.

RACE / ETHNICITY	CALCULATION	# OF INTERVIEWEES
White	50 x 57.7%	29
Hispanic or Latino	50 x 16.8%	8
Black or African American	50 x 13.0%	7
Asian	50 x 4.9%	2
American Indian and Alaska Native	50 x 1.0%	1
Native Hawaiian or Other Pacific Islander	50 x 0.2%	0
Some Other Race	50 x 6.4%	3

**GENERAL GUIDELINES****Before the meeting:**

- Contact the person, explain the purpose of your visit and get permission to proceed.
- Find out if the person needs any special accommodations (seating, communication assistance, personal supports, etc.).
- Give the person options about the time and place.
- A location familiar to the person often contains environmental cues and symbols that contribute to a good information exchange.
- Check the person's comfort level with the setting — seating arrangements, open or closed doors, other people present.
- Do not form assumptions, perceptions, or opinions about the person ahead of time.

**During the conversation:**

- Explain why you are meeting with the person.
- Provide the person with a list of the *Personal Outcome Measures*<sup>®</sup>.
- Affirm the person's right to decline to answer questions and to end the meeting.
- Observe and listen to everything.
- Take notes on exactly what is communicated.
- Be aware of body language and other cues.
- Avoid making decisions at this time.

**Follow-up, redirect or reframe questions if answers are unclear or are inconsistent with previous answers:**

- Do not be afraid to say, "I don't understand."
- You may need to ask some questions a number of times in different ways to clarify your understanding.
- Do not be afraid to modify the questions or format.
- Ask permission to follow-up with friends, family, and staff.
- When inconsistencies or contradictions arise, redirect questions to the person and then to others until you clearly understand.

**When you have difficulty with communication:**

- Always begin by meeting the person with an expectation for success.
- Spend time with the person, observing how the person interacts (or does not) with you or other people.
- Find out who knows the person best.
- Enlist the assistance of the people most familiar with the person and the person's style of communication.
- Talk with as many people as possible who are very close to the person.
- Observe the person in as many different environments as possible.

**Afterward:**

- Review and organize information from the discussion.
- Make a list of items that need clarification.
- Identify other people who can provide clarification.
- Talk with the person's family, friends, and staff as needed.
- Visit with the person again in a different setting for further clarification.
- Observe support activities and interactions.
- Check documentation when you need details or verification of information.

Once you have completed the information gathering phase and have organized what you learned, you will be ready to move on to the measurement phase.

# PERSONAL OUTCOME MEASURES® FACTORS & INDICATORS



## MY HUMAN SECURITY

### Factor 1 Indicators:

- 1 People are safe
- 2 People are free from abuse and neglect
- 3 People have the best possible health
- 4 People experience continuity and security
- 5 People exercise rights
- 6 People are treated fairly
- 7 People are respected



## MY COMMUNITY

### Factor 2 Indicators:

- 8 People use their environments
- 9 People live in integrated environments
- 10 People interact with other members of the community
- 11 People participate in the life of the community



## MY RELATIONSHIPS

### Factor 3 Indicators:

- 12 People are connected to natural support networks
- 13 People have friends
- 14 People have intimate relationships
- 15 People decide when to share personal information
- 16 People perform different social roles



## MY CHOICES

### Factor 4 Indicators:

- 17 People choose where and with whom they live
- 18 People choose where they work
- 19 People choose services



## MY GOALS

### Factor 5 Indicators:

- 20 People choose personal goals
- 21 People realize personal goals

# SUGGESTED QUESTIONS FOR YOUR CONVERSATION WITH THE PERSON

## 1. People are safe

- What kinds of safety risks are you concerned about? In your home? In your community?
- Do you feel safe at home? At work?
- Is there any place you don't feel safe?
- What would you do if there were an emergency (fire, illness, injury, severe weather)?
- Do you have safety equipment at home (smoke alarm, fire extinguisher, a way to see who is at the door before you open it)?
- Do you have safety equipment at work (protective eye and ear wear, safety devices on machinery)? Is this equipment maintained in good working order?
- Do you feel safe in your neighborhood?
- How do you react if a stranger approaches you?
- Are your living and working environments clean and free of health risks?

## 2. People are free from abuse and neglect

- Do you have any complaints about how you are treated by anyone?
- Have you been hurt by anyone?
- Has anyone taken advantage of you?
- Does anyone yell or curse at you? If so, who do you tell?
- What was done to address your concerns?
- Who would you tell if someone hurt you or did something to you that you didn't like?
- Do you know what abuse is? Do you know what neglect is?
- Do you know what exploitation is? Do you know what mistreatment is?
- Have you been abused? Have you been neglected? Have you been a victim of exploitation or mistreatment?
- Where are the safe places, people, or other resources that you can get in touch with if you have been abused, mistreated, or feel threatened?

## 3. People have the best possible health

- Do you feel healthy? If no, what bothers you?
- What do you do to stay healthy?
- What health concerns (physical and mental) do you have?
- Do you discuss your health concerns with anyone? How are your questions or concerns addressed?
- Are you seeing a doctor, dentist, and other health care professionals?
- Do you receive regular exams? What kind?
- Do you take any medication? If so, what is it and how does it help?
- What advice has your health care professional given you? Are you following it?
- If yes, is it working? If no, what do you think the problem is?
- If you think the medications, treatments, or interventions are not working, what is being done?

#### 4. People experience continuity and security

- How long have your support staff worked with you?
- Do you have the consistency you need in the staff who work with you?
- What would cause you to make changes in your current situation?
- Is there anything you do not want to change?
- What is your source of income?
- Do you have enough money to pay expenses (food, rent, clothing, health care, insurance, transportation, leisure activities)?
- How do you protect your personal property and other resources?
- Are there things you have to do without? If so, what are they and why can't you have them?
- Is your financial situation acceptable? If yes, why? If no, what do you want to change?
- Have you experienced any changes?
- How do you feel about these changes?

#### 5. People exercise rights

- What do you know about your rights as a citizen?
- Do you have access to information about your rights as a citizen? As an employee? As a person receiving services?
- What rights are most important to you?
- Are you able to exercise your rights without difficulty?
- What information or support do you need to help you to exercise your rights?
- With whom can you talk about your questions or concerns regarding rights?

#### 6. People are treated fairly

- Have there been times when you thought you were treated unfairly or that your rights were violated?
- With whom can you talk when you have concerns about your rights or how you are treated?
- Are any of your rights formally limited?
- If yes, did you agree to the limitation?
- What is being done to change the situation?
- What assistance are you getting so that you can exercise this right in the future?

#### 7. People are respected

- How do staff treat you?
- How do people talk to and about you?
- Do people call you by your preferred name?
- How do you know if your opinions are valued and respected?
- What do you think about the things you do at home, school, work? Are they interesting? Boring?
- What do you think about the activities that you do? Are you learning or gaining things from these activities? Do they make you feel important? Is it a good use of your time?
- Do people listen to your comments and concerns?
- Do you think people treat you as important?

**8. People use their environments**

- Is there something you wish you could do, but can't?
- Is there anything you can't do or use because you don't have the proper equipment or modifications (use the kitchen, bathroom or telephone; perform job duties; take care of personal needs)?
- Do you know how to use appliances and equipment (microwave, stove, telephone, washer, dryer)?
- Are there things that you are prevented from doing due to rules, practices, regulations, or staff behavior?
- Are there locked areas? If so, do you have a key?
- Is there anything that would make it easier for you to get around your home, school, place of work, or community?
- Is transportation available when you want to go somewhere?
- Do you decide how to furnish and decorate your home/room?

**9. People live in integrated environments**

- Where do you live and work?
- Do other people receiving services live and work with or near you?
- Where do you go to have fun?
- Are these places where other people living in your community would go?
- Do you spend time in other places used by people in your community?
- How did you select these places?

**10. People interact with other members of the community**

- Who do you know in your community?
- With whom do you like to spend time? With whom do you spend most of your time?
- When you go places, whom do you meet? Talk with?
- What kinds of interactions do you have with people (order food in restaurants; pay for purchases; talk with people at church, synagogue or other places of worship; visit with neighbors)?
- If you work, what kinds of social contacts do you have there (lunches, breaks, parties after work)?
- What barriers do you face? With whom do you talk about this?

**11. People participate in the life of the community**

- What kinds of things do you do in the community (shopping, banking, church, synagogue, mosque, school, hair care)? How often?
- What kinds of recreational or fun things do you do in your community (movies, sports, restaurants, special events)? How often?
- How do you know what there is to do?
- Who decides where and with whom you go?
- Is there anything you would like to do in your community that you don't do now?
- What do you need to make this happen?
- What supports do you need to participate as often as you'd like in community activities?

**12. People are connected to natural support networks**

- Who are the people in your life that you can count on?
- Who do you want to talk to or be with when you go through tough times?
- Who do you want to share your successes with? How do you maintain contact with these people?
- Have you lost contact with family members or others?
- Is the contact you have enough for you? If not, what is the reason?
- What type or frequency of contact would you prefer?
- What do you think could be done to change the situation?
- Where do you get emotional strength?

**13. People have friends**

- How do you define friendship? Who are your friends?
- With whom do you like to spend time?
- What do you like to do with friends?
- How often do you see your friends?
- Do you spend enough time with them?
- Besides seeing your friends, what other kinds of things do you do to stay in contact?
- Do you have enough friends? Would you like more?

**14. People have intimate relationships**

- Who are you closest to?
- Is there someone with whom you share your personal thoughts or feelings?
- Whom do you trust to talk with about private concerns and feelings?
- Who is there for you when you need to talk?
- With whom do you share your good and bad feelings?
- Is this enough for you?

**15. People decide when to share personal information**

- Do you know if there is a record (journal, file, book, electronic file) that has information about you?
- What is in that record? Have you looked at it? Has anyone told you what information is in it?
- How do you know if anyone reads, hears, or receives information about you?
- How do you decide who reads or gets information about you?
- Is there information about you posted where others can read it?
- Has anyone talked with you about confidentiality?
- Is there any personal information about you that you do not want shared with others?

**16. People perform different social roles**

- Do you know about different groups, clubs, organizations, etc., to be involved in?
- What kinds of involvement and responsibilities do you have in your neighborhood or community (neighborhood watch, civic groups, social clubs, volunteer, church, synagogue, other place of worship)?
- What kinds of things do you do with other people?
- Is there something you would like to be doing that you don't do now?

**17. People choose where and with whom they live**

- How did you choose where to live?
- What options did you have to choose from?
- How did you decide who would live with you?
- What do you like about your living situation?
- What would you like to be different?

**18. People choose where they work**

- What do you do for work or your career?
- What options did you have?
- Who chose what you do?
- Can you do something different if you want to?
- How did others help you with this?
- Are you satisfied with the decision either you or others made?
- If not, what would you like instead?

**19. People choose services**

- What services are you receiving?
- When, where, and from whom do you receive the services?
- Who decided what services you would receive?
- If you did not decide, what was the reason?
- How did you decide who would provide the service?
- Are these the services you want?
- Do you have enough services? Are they meeting your needs and expectations?
- Can you change services or providers if you so choose?

**20. People choose personal goals**

- How do you want your life to be in the future?
- What is important to you to accomplish or learn?
- Whom do you talk with about your future?
- What are your hopes and dreams for yourself?
- What assistance (if any) do you need to make these things happen?

**21. People realize personal goals**

- What have you done that you feel good about?
- What have you accomplished over the past few (one or two) years that has made you feel good about yourself?
- What accomplishments have pleased you most?
- Sometimes things happen that make life better. Has that happened to you?
- If you did not accomplish something important to you, what got in your way?
- What assistance or support do you think you need?

# SUGGESTED FOLLOW-UP QUESTIONS FOR THOSE WHO KNOW THE PERSON BEST

## 1. People are safe

### Questions about this outcome for the person

- Does the person know what to do in emergencies?
- If the person doesn't know, what do you do to ensure safety?
- Does the person need any special equipment in order to respond to emergencies?
- If so, does the person have these things?

### Questions about individualized supports

- How do you know that the person is safe (at home, work, school, neighborhood, and in vehicles)?
- How do you learn about safety issues that concern the person?
- What do you do to ensure that places where the person spends time are safe?
- Are there any barriers to the person's safety?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 2. People are free from abuse and neglect

### Questions about this outcome for the person

- Has the person ever indicated or reported concerns about how he or she was treated by others?
- If so, to whom were those complaints reported?
- What was done about the complaints?
- If allegations were substantiated, what action was taken?
- What is the area of greatest risk for the person?
- If the person cannot verbalize concerns, what do you do to determine whether or not abuse or neglect has occurred?
- What is done to inform people about abuse and neglect and what to do if it occurs?

### Questions about individualized supports

- Does the person understand abuse, neglect, mistreatment, and exploitation? If yes, how do you know that?
- What has been done to inform the person?
- What activities/practices are in place for the person to prevent abuse and neglect, including any mistreatment or exploitation?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

### 3. People have the best possible health

#### Questions about this outcome for the person

- How has the person defined best possible health?
- What preventive health care measures are in place for the person?
- How is the person involved in his or her own health care?
- Is the person following the health care professional's recommendations? If no, why do you think that is?
- Do you think the person feels health interventions are working?
- If not, what is being done about it?

#### Questions about individualized supports

- How have you explored health issues with the person?
- What supports does the person need to achieve or maintain best possible health?
- Who provides the support?
- How was this decided?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

### 4. People experience continuity and security

#### Questions about this outcome for the person

- What does the person consider to be important issues that would affect his or her continuity and security?
- Does the person feel secure in his or her living and working situations?
- Does the person feel secure financially?
- What has the person told you is important for continuity and security?
- If the person has indicated concerns, what are they and what was done about them?

#### Questions about individualized supports

- How are changes handled and planned for?
- How is the importance of staff continuity defined for the person and addressed through the support process?
- How is the sufficiency of the person's economic resources determined?
- What supports are provided if they are insufficient?
- How is the person assisted to obtain additional resources?
- How does the organization ensure that the person has protections for his or her personal resources?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

### 5. People exercise rights

#### Questions about this outcome for the person

- What rights are important to the person?
- How do you know that?
- What rights does the person exercise most?

#### Questions about individualized supports

- How is the person supported to learn about his or her rights?
- Does the person need support to exercise rights?
- If so, what are the supports and who provides them?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 6. People are treated fairly

### Questions about this outcome for the person

- Has the person shared any concerns about his or her treatment or violation of rights?
- What recourse does the person have when he or she has concerns?
- Have any rights limitations been imposed on this person?
- What is the reason for the limitation (Individual need; Staff practices; Organizational policy)?
- Who consented to the limitation?

### Questions about individualized supports

- Does the person have rights limitations?
- What is the reason for the limitation?
- How was it decided that the limitation was necessary?
- Who consented to the limitation?
- Who reviewed the limitation? What is the plan to remove the limitation (Training; Support; Change in policy or practice)?
- How long will the limitation be in place?
- What are the barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values and activities support this outcome for the person?

## 7. People are respected

### Questions about this outcome for the person

- What is important to the person with regard to respect?
- What has been done to personalize the activities or interventions for the person?
- What benefits will these activities or interventions provide for this person?
- Is the person involved in all decisions affecting his or her life?

### Questions about individualized supports

- How do you know if the person feels respected?
- How is respect considered in decisions regarding supports, services and activities?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 8. People use their environments

### Questions about this outcome for the person

- Is there anything the person has difficulty doing or cannot do because of the lack of modifications or adaptations?
- What assistance do you provide to the person when modifications or adaptations are needed?
- What resources are available within the organization and the community when modifications and adaptations are needed?
- Is transportation available to help the person access places and activities?
- How has the person been supported to furnish or decorate their home/room?

### Questions about individualized supports

- How do you determine the extent to which the person can use his or her environments?
- How do you determine if adaptations or assistive technologies are needed?
- What adaptations or modifications have been made for the person?
- How do you support the person in decorating and furnishing their home/room?
- Are there rules, practices, or staff behaviors that interfere with the person using his or her environments?
- How are barriers to this outcome being addressed through supports for the person?
- What organizational practices, values, and activities support this outcome for the person?

## 9. People live in integrated environments

### Questions about this outcome for the person

- Does the person live in typical community housing?
- Does the person work in a building in which people from their community work?
- Do leisure activities take place in settings used by people from their community?
- Do sports and work teams consist of a diverse group of people from their community?

### Questions about individualized supports

- How have you determined what integration means to and for the person?
- How do services, supports and activities promote and encourage integration?
- What supports are provided to increase efforts toward physical integration in public education programs, work, social activities and/or leisure activities?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 10. People interact with other members of the community

### Questions about this outcome for the person

- What opportunities does the person have to interact with others?
- Do you know if the person's current situation is satisfactory to him or her?
- Is there anything the person needs to support current relationships or develop new ones?
- What is the person's preference for interaction?

### Questions about individualized supports

- How do you support the person to have opportunities to meet and interact with others?
- How do you determine the person's preferences for interactions?
- How do you know if the type and frequency of interactions are satisfactory to the person?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this and encourage the person to interact with others?

## 11. People participate in the life of the community

### Questions about this outcome for the person

- Do you know what the person would like to do in his or her community?
- Is the person encouraged and assisted to use a broad variety of community resources?
- Is training provided if the person needs it?
- Is support provided if the person needs it?

### Questions about individualized supports

- How is the person informed of options available in his or her community?
- How do you learn about what the person prefers to do?
- How do you learn about how often the person likes to be involved in community activities?
- What supports does the person need to participate in community activities? How are those provided?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 12. People are connected to natural support networks

### Questions about this outcome for the person

- Do you know who is part of the person's natural support network?
- Do you know if the person is satisfied with his or her contact with these people?
- What assistance is provided to maintain the person's contact with his or her family and others who provide emotional support?

### Questions about individualized supports

- How do you learn about the person's support network?
- What do you do to support contact?
- If there is no contact, what is done to assist the person to re-establish contact if desired?
- If contact is with parents only, what do you do to expand the network to extended family?
- What do you do if the extent and frequency of contact is unsatisfactory to the person?
- Are there any barriers that prevent the person from remaining connected with the people he or she identifies as part of their support network?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 13. People have friends

### Questions about this outcome for the person

- With whom does the person choose to spend time?
- Who are the person's friends? How do you know?
- What contact does the person have with his or her friends?
- Are the interactions and contacts the person has with friends similar to typical friendships that you or people you know have? Are they voluntary, mutual, and interactive?

### Questions about individualized supports

- How do you determine the importance of friendship to the person?
- How do you know if the person needs support to develop or maintain friendships?
- How do you determine satisfaction with the extent and frequency of contact?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 14. People have intimate relationships

### Questions about this outcome for the person

- Do you know how the person defines intimacy?
- What is that definition?
- Do you know if the person has the type and degree of intimacy desired?
- How do you support the person's choices for intimate relationships?

### Questions about individualized supports

- How do you learn about the person's desires for intimacy?
- How do you know if the person needs support to develop or maintain intimate relationships?
- If the person needs support, what has been arranged?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to forming intimate relationships with others?
- What organizational practices, values, and activities support this outcome for the person?

**15. People decide when to share personal information****Questions about this outcome for the person**

- Does the person know that information about him or her is kept on file?
- Who has access to information about the person?
- Has information about the person been shared with others? With whom? For what purpose?
- Does the person know what specific information is shared with others?
- Do you know if there is specific information the person does not want shared with others?

**Questions about individualized supports**

- How is the person informed about what is in his or her record?
- Who consents to the sharing of information about the person?
- How is the person protected from violations of confidentiality, both within and outside the organization?
- Are there any barriers that affect the outcome for the person?
- How are barriers to this outcome addressed?
- What organizational practices, values, and activities support this outcome for the person?

**16. People perform different social roles****Questions about this outcome for the person**

- What social roles do you think the person performs?
- Why do you think these are social roles for the person?
- What roles do you see the person having the potential or interest to perform?
- If the person stopped participating, would he or she be missed?

**Questions about individualized supports**

- How have the person's interests been identified?
- How do you know what social roles the person would like to perform?
- What opportunities have been provided?
- What supports does the person need to develop or maintain social roles?
- Have those supports been provided?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

## 17. People choose where and with whom they live

### Questions about this outcome for the person

- Who decided where and with whom the person would live?
- What options and experiences did the person have in order to make choices?
- If the person did not choose, why not?

### Questions about individualized supports

- How do you learn about the person's preferences for type of living situation?
- How do you present options to the person so he or she can make informed choices?
- Is the person living where and with whom he or she wishes? If not, what is the barrier?
- What are you doing to overcome this barrier?
- What organizational practices, values, and activities support the person to maintain or achieve this outcome?

## 18. People choose where they work

### Questions about this outcome for the person

- How was it decided where the person would work?
- What options/experiences did the person have?
- Who made the decision about where the person works? If it wasn't the person, why not?
- Is the current work situation satisfactory to the person? If not, what is being done?
- How are the person's concerns addressed if there is not a good match?
- How does the person's current job relate to his or her preferences, skills, and interests?

### Questions about individualized supports

- How do you learn about the person's preferences for work?
- How do you present options to the person so he or she can make informed choices?
- Is the person working where he or she wishes? If not, what is the barrier?
- What are you doing to overcome the barrier?
- How do you learn about the person's job satisfaction?
- What organizational practices, values, and activities support the person to maintain or achieve this outcome?

## 19. People choose services

### Questions about this outcome for the person

- What services does the person use?
- What services were identified as beneficial by the person?
- What options for services were presented to the person?

### Questions about individualized supports

- How do you determine the services desired by the person?
- How were options for services and providers presented to the person?
- How were the person's preferences considered when presenting options?
- If the person has limited ability to make decisions or limited experience in decision-making, what do you do?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

**20. People choose personal goals****Questions about this outcome for the person**

- What are the person's goals?
- What leads you to think that?
- How is the person working toward the attainment of personal goals?

**Questions about individualized supports**

- How have you explored hopes, dreams, and desires for the future with the person?
- What are you doing to support the person?
- Why did you select this action?
- How do you learn if the supports/activities are effective?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

**21. People realize personal goals****Questions about this outcome for the person**

- What personal goals has the person achieved?
- If any were not achieved, what is the reason?

**Questions about individualized supports**

- How do you know if the person accomplished something personally significant?
- What did you do to assist the person to experience personal success?
- What barriers to goal attainment does the person face?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

**PHOTOCOPY THIS WORKSHEET OR DOWNLOAD: [www.c-q-l.org/POM](http://www.c-q-l.org/POM)**

**PERSON'S INITIALS:**

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**NOTES**

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**FOLLOW-UP**

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**DECISION**

**Personal Outcome:**

**Individualized Support:**

# PERSONAL OUTCOME MEASURES®

Measuring Outcomes



## EVALUATING THE INFORMATION

The *Personal Outcome Measures*<sup>®</sup> are designed to help determine whether outcomes are present for people. Once information has been collected, the next step in the learning process is to evaluate the status of the person's outcomes. Decision-making requires that we ask: Is the outcome present for the person?

For each person, information gathering is used to provide the person's definition of the outcome. Based on this personal definition and the assessment of the person's current life experiences, a decision is reached regarding the presence of each of the *Personal Outcome Measures*<sup>®</sup>. This step provides critical information in the process of planning supports and services for people.

A second evaluation of the information addresses an individualized organizational support: Are there individualized supports in place that facilitate this outcome?

This question is asked about the individualized supports and services that the organization has provided to enable the person to reach and/or maintain the outcome. This step helps to identify the current supports, their effectiveness and the changes needed to support the person to achieve the outcome.

## MEASURING PERSONAL OUTCOMES

Measuring outcomes is different from collecting information. In the process of discovering personal outcomes, you can use the suggested questions for the person. During your meeting with the person, the person's interests and priorities guide the process.

The focus is on information gathering, not on making judgments about the information. During decision-making, however, your task is to make judgments about the information according to the decision matrix for each outcome. In making these judgments, you must use the decision matrix, not intuition or feelings, to determine answers about outcomes. Objective use of the decision-making guidelines enables you to make valid and reliable decisions about people's outcomes. As with the information gathering phase, the emphasis is on each person as an individual.

Make decisions about the presence of outcomes and individualized supports one person at a time, based on that individual's priorities and personal definitions.

PERSON'S INITIALS:

OUTCOME	OUTCOME PRESENT	SUPPORTS PRESENT
<b>MY HUMAN SECURITY</b>		
1 People are safe		
2 People are free from abuse and neglect		
3 People have the best possible health		
4 People experience continuity and security		
5 People exercise rights		
6 People are treated fairly		
7 People are respected		
<b>MY COMMUNITY</b>		
8 People use their environments		
9 People live in integrated environments		
10 People interact with other members of the community		
11 People participate in the life of the community		
<b>MY RELATIONSHIPS</b>		
12 People are connected to natural support networks		
13 People have friends		
14 People have intimate relationships		
15 People decide when to share personal information		
16 People perform different social roles		
<b>MY CHOICES</b>		
17 People choose where and with whom they live		
18 People choose where they work		
19 People choose services		
<b>MY GOALS</b>		
20 People choose personal goals		
21 People realize personal goals		

## TOTAL NUMBER OF PEOPLE INTERVIEWED:

OUTCOME	TOTAL # OF OUTCOMES PRESENT	TOTAL # OF SUPPORTS PRESENT
<b>MY HUMAN SECURITY</b>		
1 People are safe		
2 People are free from abuse and neglect		
3 People have the best possible health		
4 People experience continuity and security		
5 People exercise rights		
6 People are treated fairly		
7 People are respected		
<b>MY COMMUNITY</b>		
8 People use their environments		
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# UTILIZING THE OUTCOMES DATA

## TIES TO QUALITY ENHANCEMENT

Along with conducting *Personal Outcome Measures*<sup>®</sup> interviews, gathering information about the presence of outcomes and supports, and coming to determinations on decision making, many agencies evaluate outcomes data for quality enhancement. When organizations and systems can assess the effectiveness of their initiatives based on the impact on people's lives, measuring the return on investment is possible through results-based decision making. This means that while agencies face financial constraints, they are better equipped in making sound determinations regarding specific resources, staff development, and new programs.

## IMPORTANCE OF OUTCOMES ANALYSIS

Beyond the presence of outcomes and the supports in place to help people achieve those outcomes, agencies often require additional data analysis across a variety of data elements. An organization may want to explore whether a specific type of residential setting has any implications for a person participating in the life of their community. When it comes to people exercising their rights, agencies may want to evaluate decision-making authority to understand how autonomy and independence can affect the presence of particular rights. To dive deeper into the effect of staffing changes in various homes, outcomes data involving continuity and security could be reviewed by geographical location.

The depth and detail of this level of analysis offers organizations insight into outcomes that can be effective for planning and reporting purposes. This can then be shared with board members, executive leadership, organizational staff, and other stakeholders.

## PORTAL: CQL'S DATA SYSTEM

Organizations are now using CQL's data system, named PORTAL, for the reporting, tracking, analysis, and logging of outcomes data. It is a secure, online tool to collect and evaluate your discoveries during *Personal Outcome Measures*<sup>®</sup> interviews. PORTAL integrates the information gathering questions and decision making matrix that are outlined within each indicator of this *Personal Outcome Measures*<sup>®</sup> manual. The data system aligns with this manual, which can serve as a convenient crosswalk for entering data.

While accessing PORTAL is by no means a requirement of agencies who embrace the *Personal Outcome Measures*<sup>®</sup> or use the manual, it is an accompanying component of quality enhancement that can provide lasting value to the *Personal Outcome Measures*<sup>®</sup> process.

To learn more about PORTAL, visit:

[www.c-q-l.org/PORTAL](http://www.c-q-l.org/PORTAL)



**"Personal Outcome Measures<sup>®</sup>**  
isn't something we do,

**IT'S EVERYTHING WE DO."**

*- Kim Zoeller, Ray Graham Association*





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