A Person-Centered Framework

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Contents

This document is currently a work in progress and is not intended for distribution outside of those collaborating on its development with the direction of MDHHS-BHDDA.

Chapter 1

Reason

This framework arises from a simple conviction: the intent of supports and services is to help each person flourish, to achieve a better life.

That belief is thankfully not a new one. It aligns with the person-centered planning policy(**?**) published by the Michigan Department of Health and Human Services' *Behavioral Health and Developmental Disabilities Administration* (MDHHS-BHDDA), which begins by stating that:

> *The purpose of the community mental health system is to support adults and children… to live successfully in their communities — achieving community inclusion and participation, independence, and productivity [and to] to identify and achieve their personal goals.*

The framework defined below is an attempt to apply these longstanding and fundamental values in a way that allows for consistent definitions, implementation, and evaluation.

Each person has the ability to choose a better future, to chart a course toward it and strive to reach it: person-centered planning provides a platform to enable this process. In order for services to effectively support a person in this process, they must be provided within the context of a person's goals. Orienting a broad and complex system to keep the person as its central focus requires a consistent, overarching framework. MDHHS-BHDDA is working to support this person-centered orientation with the following strategy:

Goal: To develop a common body of knowledge for person-centered planning, mapped to relevant policies and research, which will inform a shared curriculum and measurement framework to support improved quality of life for each person.

Chapter 2

Person-Centered Planning (...Doing, Checking, Acting)

Person Centered Planning upholds the truth about healthcare; while healthcare continues to focus on treating groups and classes of diagnoses, change is ultimately driven by the individual person. This is the profound insight of *person-centered planning* (PCP), which has long been the cornerstone of Michigan policy related to behavioral health services and supports.[1]

While putting forward specific definitions of person-centered planning and its parts will be a focus of later sections of this document, it is worth noting at the outset that our goal is to adopt a broader scope for person-centered planning than is often seen in practice[2]. This is because, despite the central position of PCP to policy regarding Medicaid supports and services in Michigan, its practice has often been relegated to the planning meeting itself and the preparation for that meeting: ensuring inclusion of family and friends, personal involvement, etc. While the act of developing a plan remains a cornerstone of the process, it is only one step needed to truly achieve one's goals.[3]

In this document, the phrase *person-centered planning* is used broadly, to encompass not only the initial planning process but also its implementation, monitoring, and refinement. The extension of this definition beyond the PCP meeting and document into a framework which directs all services and supports is already recognized within state policy[4], which indicates that:

[1] See **?**.

[2] Even though this broader definition does conform to existing policy and guidance

[3] Part of the focus on the meeting is due to the auditing focus on the plan document: an instance of *what is measured, is addressed*. This should serve as an abiding reminder during the implementation of the framework defined here, that there are unintended consequences to measurement.

[4] See **?**, p. 1

Table 2.1: Paradigms related to PCP

Paradigm	Tells us	Relates to	Answers
QoL	Why?	Vision for a better life	What areas of life do I want to focus on?
COM-B	What?	Turning vision into plan	How will I start to address my goal?
PDCA	How?	Making my plan work	How is the plan working? How to change?

> *through PCP, a person is engaged in decision-making, problem solving, monitoring progress, and making needed adjustments to goals and supports and services provided in a timely manner.*

The table below suggests how existing paradigms can be used to augment these policy requirements and be incorporated into our framework. Here we makes use of paradigms for Quality of Life (QoL), behavior change (*Capability-Opportunity-Motivation-Behavior*, or COM-B), and continual improvement (*Plan-Do-Check-Act*, or PDCA):

2.1 Vision for a Better Life

Priorities and choices vary from person to person, yet many dimensions of what makes a good life are broadly agreed upon across people and cultures[5]: *choice, relationships, access to needed resources, physical and emotional well-being…* these are some of the dimensions which we collectively refer to as quality of life.

People usually seek services and supports because they see a gap between their current situation and a better life. Person-centered planning encourages a person to cast a vision for their lives and to identify gaps between their hopes and their current situation. In order to ensure a comprehensive approach, it is valuable to prompt consideration across all QoL domains in identifying goals.

2.2 Turning Vision into Plan

Once a person has set a vision for a better life and identified gaps between where they are and where they want to go, a map needs to be drawn. This map draws potential routes to connect a person from where they are to where they want to be.

The COM-B model for behavioral change, an acronym for *Capability-Opportunity-Motivation-Behavior* provides a way to map out these routes. It helps to conceptualize the facilitators and barriers to changing one's life. Note that the goals addressed are not limited to "challenging behaviors" or related to

[5]For more detail, see the quality of life definitions in the measurement discussions section.

medical issues (*e.g. weight loss, or quitting smoking*). The behavior addressed could be as simple as any broad goal related to quality of life.

Visualized in the graphic below:[6]

For instance, a person may have a goal to enrich the relationship with his/her parents. The person's *capability* to enrich that relationship may be strained by previous trauma, difficulty communicating, or other challenges. Perhaps they would benefit from trauma-focused therapy or simply some coaching and modelling of how to engage in difficult conversations. If the person's parents live across town, but he/she does not have access to reliable transportation, then there is also the need to create *opportunity* to reach that goal. This might entail gettig a bus pass, finding other transportation and additionally setting up access to phone calls or other communication platforms (e.g. FaceTime or Skype). In this case, the person's motivation is already present. In some other cases, such as nutrition or smoking cessation, there is often an need for *motivation*al assistance as well.

In the example above, one is thinking through *Capacity*, *Opportunity*, and *Motivation* in order to generate ideas about how to achieve a prioritized goal. The ideas which are generated (e.g. coaching on difficult conversations, getting a bus pass, etc.) are akin to what have typically been called *objectives* in person-centered planning. These are the steps that a person wants to pursue in order meet a broader *goal* to improve quality-of-life.

Note that objectives or supports identified above are not the only ones which could possibly get a person to their goal. It may actually be the case that writing hand-written notes would be more helpful in getting this particular person to establish a closer relationship with their parents. This is why a particular set of objectives should be viewed as a personal experiment in improving one's life. The objectives form a hypothesis, where one is saying that doing a set of activities will facilitate the achievement of a goal. There is no reason to think that a person's first hypothesis will be correct, or even that the hypotheses of loved ones or experts must be correct.

This is where iteration and the improvement cycle come in…

2.3 Making My Plan Work

The *Plan-Do-Check-Act* (PDCA) cycle is a simple model for implementing a change and checking to see if it is working.[7] The *QoL* and *COM-B* frameworks discussed above provide a way to identify goals and design individualized strategies to meet those goals: they fall into the *Plan* phase of the PDCA cycle.

[6] Source of image: **?**

[7] While there are various other rubrics related to learning and improvement, PDCA has been selected here because of its use of 'planning' language, its simplicity, and its familiarity among behavioral healthcare providers and funders.

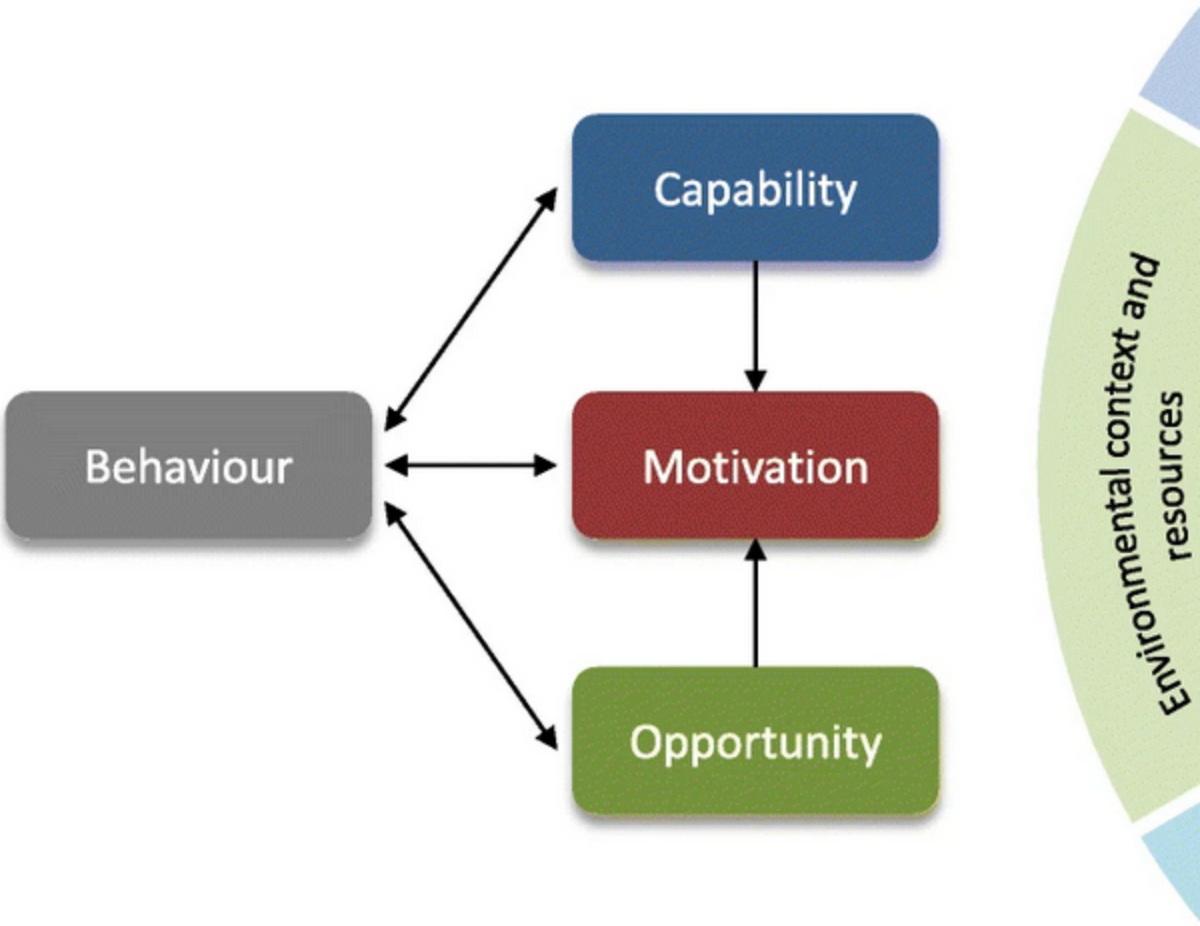


Figure 2.1: The COM-B Model

Table 2.2: Alignment of PDCA and PCP

Factor	Plan	Do	Check	Act
Questions	What is your life like?	What are you working on?	Is life better?	What next?
	What do you want to pursue?	How are supports provided?		How to improve
	What supports do you need?			
Activities	Identify QoL	Work on plan	Check QoL	Revise plan
	Assess needs	Coordinate services	Reassess needs	(Repeat cycle)
	Develop plan			
Quality area	Structure	Process	Outcome	(Re)structure

As the intent of supports and services is to improve personal quality of life, practitioners can view the PCP process as similar to the PDCA cycle, which involves many elements of the broader scope of PCP referred to above. Versions of the PDCA cycle have already been successfully incorporated into the supports and treatment planning process for people with varying conditions and needs, from intellectual and developmental disabilities, to mental illness, to physical health concerns.

If we want to understand whether a person's plan is supporting his/her goals, it is necessary to have a strategy to measure improvement in the person's desired areas of focus. Such measurement-based approaches have been gaining traction in their use across populations and been implemented in a manner which is valued by people receiving services.[8]

Framing the intent of supports and services as improving personal quality of life through planning creates a natural bridge to using well-tested quality improvement processes at the individual level. Rather than assuming that an objective will lead to the desired goal as it is initially written, this approach allows for trying out different approaches and revising them to find what works, in the spirit of continuous quality improevment.

The table below illustrates the relationship between the PDCA process and a fuller definition of the PCP process:

Note that, while the questions above can be tied to various data-points[9], it is most important that they should be conversational: founded upon an ongoing process of personal striving for improvement.

[8] **?** notes "an increased emphasis on… conducting outcome evaluation… to assess the degree to which personal goals, positive changes, or benefits have been achieved" in IDD planning.

[9] See the section on measurement for examples of how this might be accomplished.

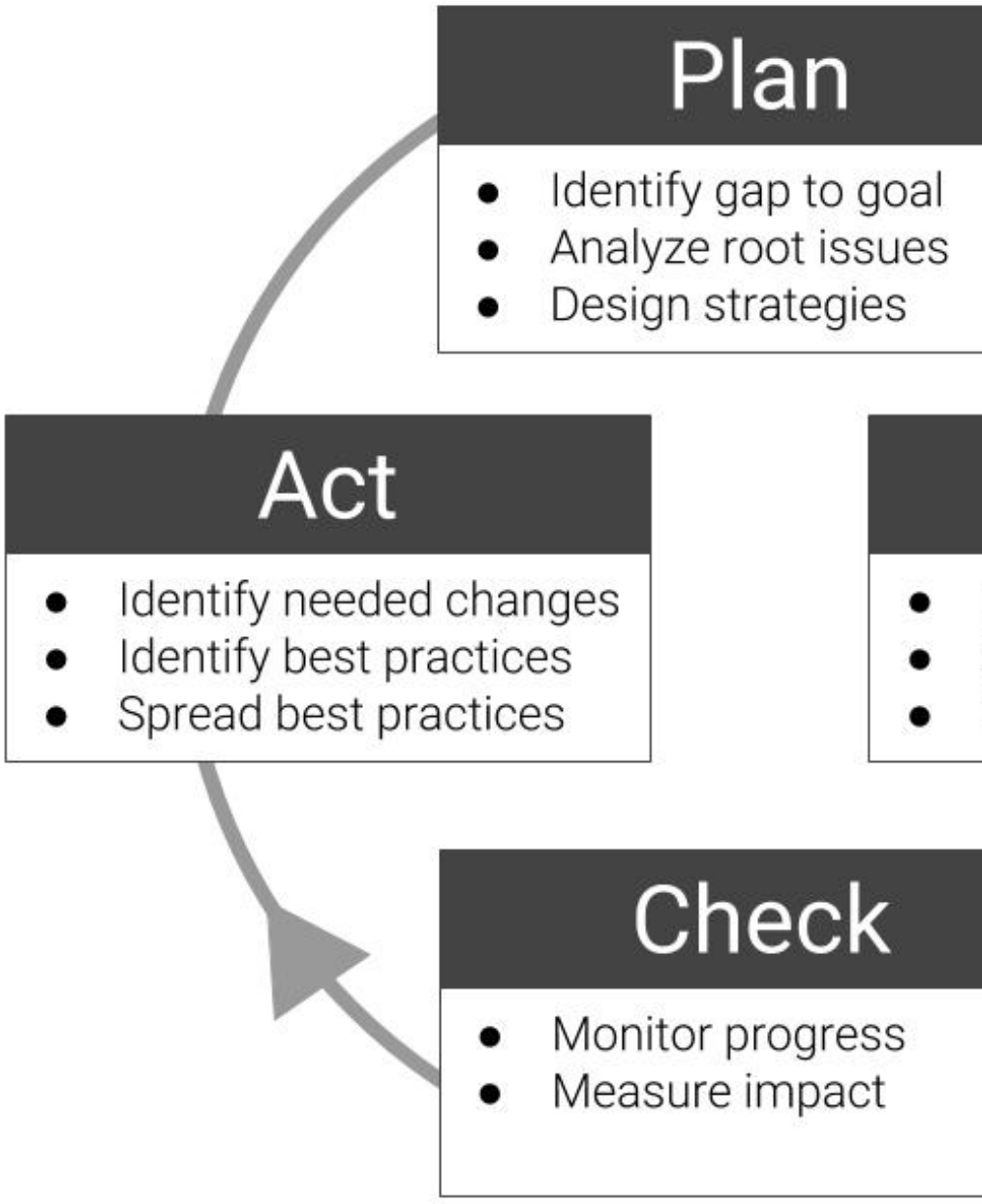


Figure 2.2: PDCA cycle applied to PCP process

Chapter 3

A Common Body of Knowledge

As a foundation for this effort, MDHHS has begun to develop a shared repository of key terms and concepts, their definitions, and how they are related to one another. This common language has the following key features:

- Relates all terminology back to the person, who drives service delivery
- Includes concepts related to the PCP process, as broadly defined above, as well as common attributes for understanding the person[1]
- Promotes consistency in implementation and training, and a platform for future development
- Allows for change; the language can be extended as new concepts are identified.[2]
- Reduces confusion across various policies with inconsistent terminology and scope

3.1 What is a Body of Knowledge?

> "If you wish to converse… define your terms."
>
> — Voltaire

Person-centered thinking and planning should never become rote, and continue to be a part of a living dialogue. Dialogue and consistent implementation require

[1] Note that the body of knowledge is not intended to classify services and supports.

[2] This approach also requires that ideas claiming to be new must differentiate themselves from existing terms and concepts.

a shared language.[3]

Our purpose here is to identify and define concepts related to person-centered planning. This is done in a way which connects core concepts to both state and federal regulations. This collection of core concepts is intended to serve as an evolving, foundational outline for a body of knowledge; encompassing person-centered thinking, planning, implementation and monitoring.[4]

3.2 Potential Uses

Potential uses of this body of knowledge include the following:

- *Policy Search*: searching of existing policies in electronic format to identify requirements related to each core concept
- *Impact of Policy Changes*: identification of relevant new federal policy requirements to allow for clear understanding of which current policies are related and complicated by the new federal policy
- *Basis of Curriculum*: serving as the foundation of a standard curriculum to train people receiving services, their families, direct-care team members, supports coordinators, case managers, clinicians, and others about the PCP process.
- *Monitoring Quality*: allowing for system-level monitoring of the quality of PCP practice, through measurements and/or the use of a best practice review model.[5]
- *Promising Practices*: use of key terms for ongoing literature review and meta-analysis of PCP-related practices in the research literature, to build a base of best practices and evidence for effectiveness.

3.3 Identifying Core Concepts

3.3.1 What makes a concept a 'core' concept?

In order to compile relevant policies and guidance related to person-centered planning, we selected and defined an initial set of core concepts related to person-centered planning. The 'source of truth' for these concepts was state-level policy in Michigan, since this is the level at which shared dialogue and consistent implementation is sought.

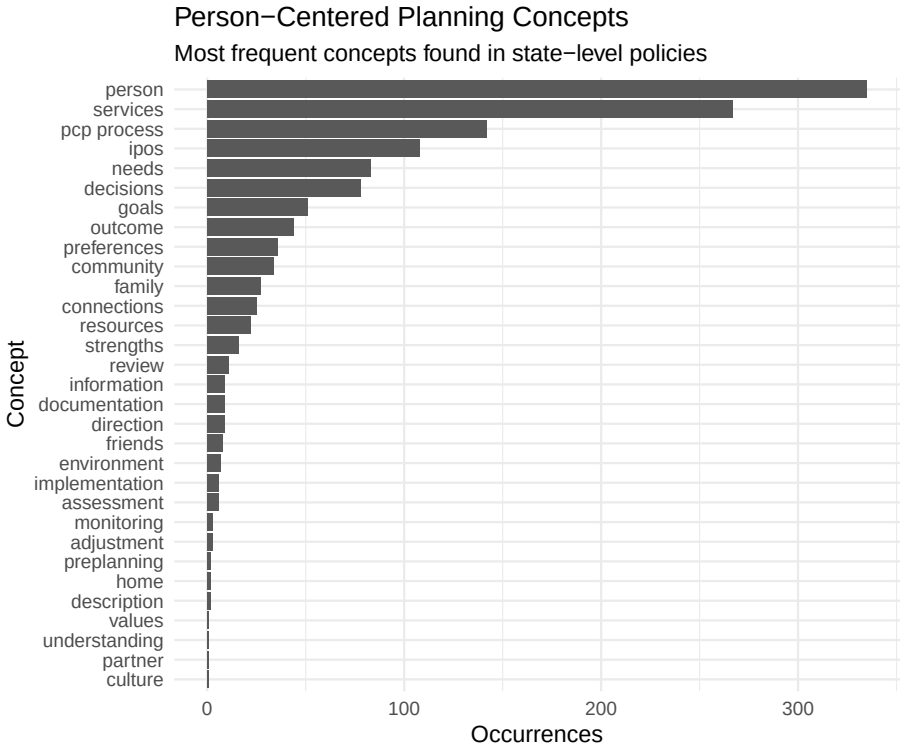
[3] According to Will Durant, this requirement is "the heart and soul of [logic], that every important term… be subjected to strictest scrutiny and definition. It is difficult, and ruthlessly tests the mind; but once done it is half of any task." **?**

[4] Please note that the current work aims at an initial proof-of-concept, and not as a process ready for automation or scaling.

[5] This could be developed similar to the MI-FAST model, which has been used to review the fidelity to evidence-based practices.

The following methods were used to develop this initial set of core concepts:

- **Manual review and annotation** of documents which define person-centered planning in the Michigan Public Behavioral Health System. These include (a) the Person-Centered Planning Policy[6], (b) the Self-Determination Policy and Practice Guideline[7], and (c) the Michigan Mental Health Code section 330.1712 Individualized written plan of services[8].
- **Identifying synonyms** For instance, the term *person* was mapped to the similar terms *person, personal, patient, individual, client, consumer, recipient, beneficiary.* This was done for all core concepts in order to identify their occurrence across multiple policies.
- **Comprehensive annotation** for the policies referenced above, to assure that the most commonly used terms and phrases were included as core concepts.



- **Purposeful Word Choice.** We select a distinct, 'master' term to refer

[6] ?
[7] ?
[8] ?

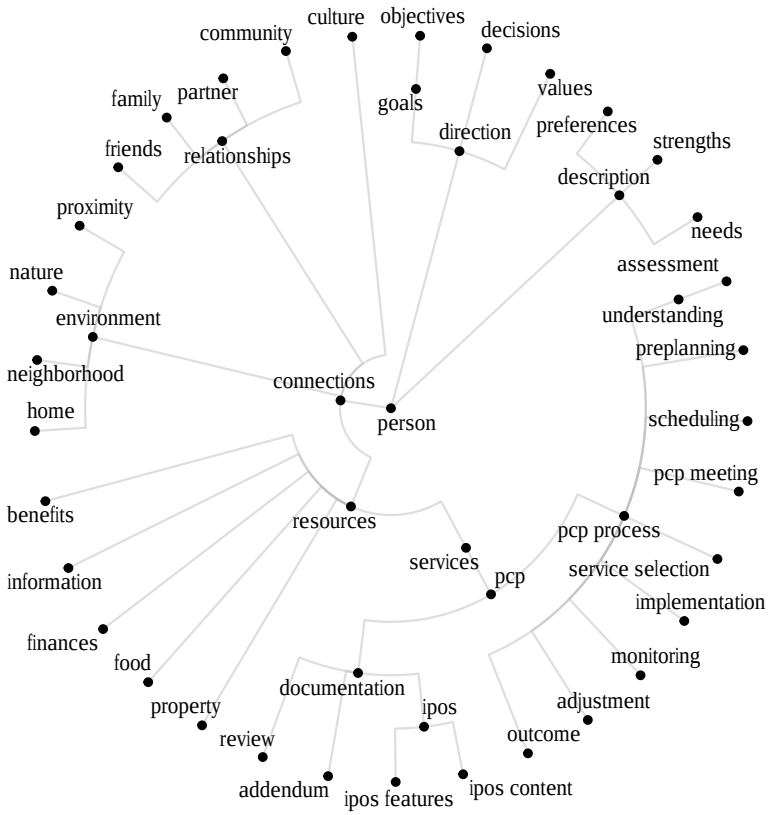
to various synonyms across documents. The selection of terms is informed by a consistent set of principles.

3.3.2 Characteristics of a Person

To honor the person in the language used, and to do so simply, we define each person as having the following features:

- **description**: a set of characteristics specific to the person, defined by that person and those who know the person well.
- **connections**: the people, places and things which make up the context of a person's life
- **direction**: what the person intends for his/her life to become, by imagining a future and making choices to move toward it

Note that these are features of being human for all of us. The intent of this framework is to describe attributes of a person which are more broadly human, and not merely focused on illness or disability. While this framework is intended for implementation with Medicaid public behavioral health recipients, the approach outlined here should apply to any reader: from legislators to clinicians, from administrators and direct-care workers.



Each element of the person-centered planning framework is shown above. Each concept is defined by its relation with other concepts, as well as having a distinct definition, as shown below.

3.4 Defining Core Concepts

Defining core concepts and terms, using policy where possible.

Table 3.1: Concept Definitions and Synonyms

Concept	Definition
description	Features which can be attributed to the person, as opposed to his/her connections, env
direction	The aspects of the person which allow him/her to imagine a future and to plan and wo
connections	The relationships which a person has to the people, places and things around them
relationships	Natural relationships which the person has with other people. Does not include econor
environment	The physical context in which the individual lives; here referring to the non-human env

Chapter 4

Comprehensive Mapping to Policy

As with any important idea, person-centered planning has been discussed and debated for decades, leaving a vast body of policy, regulations, guidance, and explanations to sift through. While the basic idea of person-centered planning is simple and commonsense, practitioners are also required to adhere to complex existing policies. With this in mind, the body of knowledge is being developed:

- Based on a broad scope of relevant state and federal policies identified by MDHHS-BHDDA.
- Using natural-language processing techniques to identify and refine core terminology from the text of the identified policies
- In a manner that allows MDHHS-BHDDA to identify whether new federal policies would align with the current implementation of PCP

4.1 Identify Scope of Policy

In collaboration with policy experts at MDHHS-BHDDA, we identified this initial set of state and federal regulations:

This set of policies and regulations can be expanded as necessary.[1] Additional work will be needed to assure that the most current version of amended policies is used, as this approach is refined.

[1]For example, using the Federal Register API to search for policies containing the phrase "person-centered" by relevant agencies.

Table 4.1: Regulations included in PCP body of knowledge.

Source	Abbreviated Title	Regulation
MI-State	Self-D	Self-Determination Policy & Practice ...
MI-State	PCP	Person-Centered Planning
MI-State	MHCode	Mental Health Code
MI-State	Mcaid-PM	Medicaid Provider Manual
MI-State	AFC-TA	Adult Foster Care Group Homes Technic...
MI-State	AFC-SC	Certification of Specialized Programs...
MI-State	AFC-Act	AFC Facility Licensing Act 218 of 1979
MI-State	AFC-12	Licensing Rules for AFC Small Group H...
Federal	Parity	Medicaid and Children's Health Insura...
Federal	No-Wrong-Door	Agency Information Collection Activit...
Federal	MU-Medicaid	Medicare Program; Hospital Inpatient ...
Federal	MU-EHR	2015 Edition Health Information Techn...
Federal	MH-BG	Mental Health Block Grants
Federal	MCMC-Rx	Medicare and Medicaid Programs; Polic...
Federal	Mcare-Adv	Agency Information Collection Activit...
Federal	Mcare-ACO-Waiver	Medicare Program; Medicare Shared Sav...
Federal	Mcare-ACO-Savings	Medicare Program; Medicare Shared Sav...
Federal	Mcaid-ManagedCare	Medicaid and Children's Health Insura...
Federal	LTC-Reform	Medicare and Medicaid Programs; Refor...
Federal	HCBS	Medicaid Program; State Plan Home and...
Federal	ELTSS	Medicaid and Children's Health Insura...
Federal	Discharge	Medicare Program; Hospital Inpatient ...
Federal	CCHBC	CCHBC Requirements
Federal	ACA-Market-	Patient Protection and Affordable Car...
Federal	ACA-Benefit	Patient Protection and Affordable Car...

4.2 Find Occurrence of Concepts in Policy

The core concepts are derived from key policy documents, as defined in the previous section, which allows for related terms to be flagged within other policy documents. One of the most challenging issues facing any attempt to give clear, consistent, and comprehensive guidance related to person-centered planning is the large, diverse, and continually evolving set of requirements and guidance.

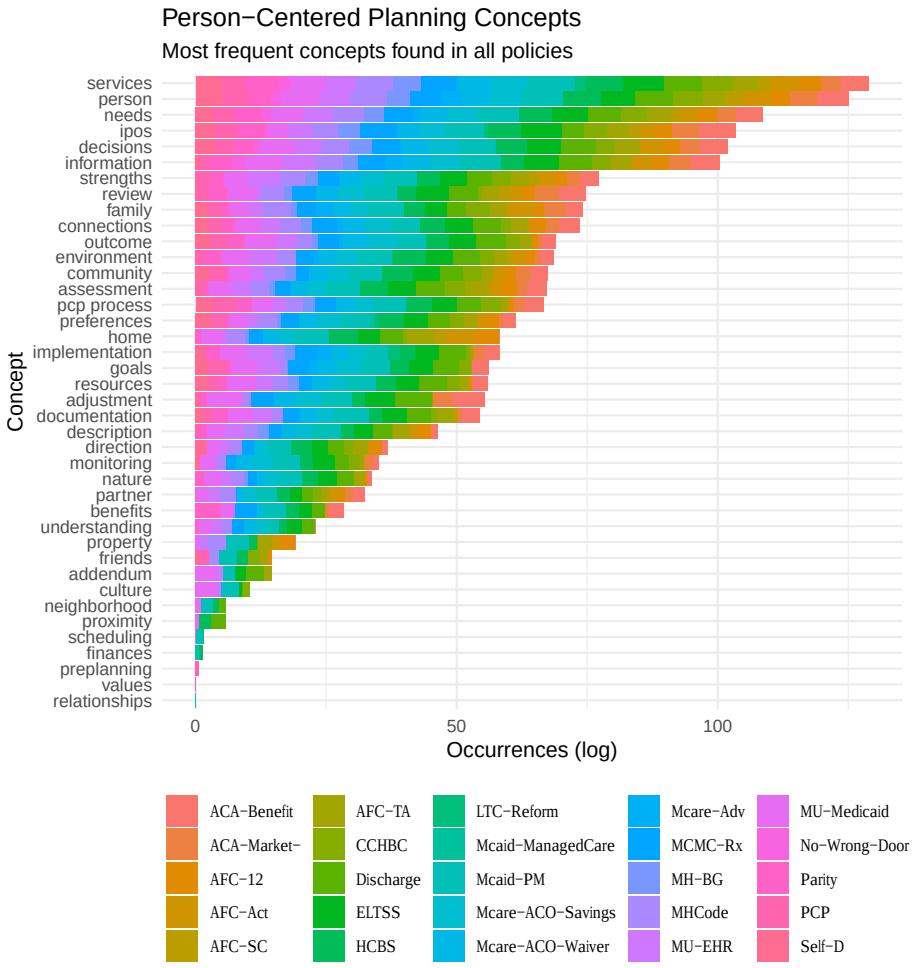
The previous section outlined the process for deriving key concepts from state-level policies and guidelines. The next step is to identify these concepts when they occur within a much larger set of federal policies. This will allow for policy specialists to:

- suggest necessary refinements to the body of knowledge
- identify relevant requirements which were previously unknown
- identify potential discrepancies between policies which address a similar concept

To do this, this analysis maps policy words and phrases with their corresponding concepts. As new policies are identified for inclusion, new synonyms for core concepts will need to be identified if new terms are introduced to refer to existing concepts.

The plot below shows the number of occurrences[2] of core concepts across the entire corpus of policies identified above. While the frequency of occurrence does not speak to the importance of one concept in relationship to others, it point out the number of uses of the concept in different contexts, underlining the challenge in harmonizing divergent policy language.

[2] using log scale to show the less frequently used terms



An example may be helpful in understanding what goes into the chart above. For instance, the concept of *assessment* shown in the chart above occurs 1835 times across 22 separate policy documents.[3]

The table below shows a sample of the text from some of the policies where this concept is flagged:

[3]The specific policies including this concept are: ACA-Benefit, ACA-Market-, AFC-12, AFC-Act, AFC-SC, AFC-TA, CCHBC, Discharge, ELTSS, HCBS, Mcaid-PM, Mcare-ACO-Savings, Mcare-ACO-Waiver, Mcare-Adv, MCMC-Rx, MH-BG, MHCode, MU-EHR, MU-Medicaid, No-Wrong-Door, Parity, PCP

doc_id	text
AFC-TA	Resident admission criteria ; resident assessment plan ; emergency admission ; resident care agreement
AFC-TA	(d) " Assessment plan " means a written statement which is prepared in cooperation with a responsil
AFC-TA	Assist with the completion of a written assessment plan at the time of admission and review with the l
AFC-TA	[ ] (j) " Health care appraisal " means a licensed physician 's , licensed physician 's assistant 's , or re
AFC-TA	// STATE OF MICHIGAN Department of Licensing and Regulatory Affairs of ADULT FOSTER CAI
AFC-TA	(c) Be capable of assuring program planning , development , and implementation of services to reside
AFC-TA	The consultant is to determine that the licensee has a training methodology in place that assures that
AFC-TA	This can be accomplished by TB testing , x - ray , screening , an assessment or physical exam complet
AFC-TA	The home health aide can not be counted when determining the adequacy of on duty direct care staff
AFC-TA	A licensee shall have sufficient direct care staff on duty at all times for the supervision , personal care
AFC-TA	For purposes of this rule " Sufficient direct care staff " is defined to mean the number of staff necessary
AFC-TA	Resident assessment plans g .
AFC-TA	Resident admission criteria ; resident assessment plan ; emergency admission ; resident care agreement
AFC-TA	// STATE OF MICHIGAN Department of Licensing and Regulatory Affairs of ADULT FOSTER CAI
AFC-TA	A licensee shall not accept or retain a resident for care unless and until the licensee has completed a w
HCBS	This commenter urged CMS to ensure that individuals have assessments of need to ensure they are no
HCBS	Sections (c) , (i) and (k) of the Act all require that individuals have an individual assessment of n
HCBS	While we understand that there may be circumstances in which an individual 's needs require a differe
HCBS	One commenter supports the regulation , but believes the rule should go further and require living uni
HCBS	This review will also include assessment of how the settings allow for full integration into the broader c
HCBS	States are responsible for determining the provider qualifications of the entities who will conduct the a
HCBS	The regulation already specifies the involvement of an individual 's representative in the evaluation of
HCBS	Several commenters asked how frequently the assessment must be made if the condition causing the m
HCBS	We also state in the rule that reviews and any needed revision of the independent assessment and the
HCBS	While (i) ( ) (F) (i) requires that the independent assessment include an objective evaluation of ar
HCBS	This suggestion is already captured in . (a) ( ) where the regulation requires the assessment to " ... i
HCBS	As stated in section III.N .. of the preamble to the proposed rule , FFP is available for evaluation and
HCBS	If the individual is found not eligible for the State plan HCBS benefit , the state may claim the evalua
HCBS	Some commenters requested clarification regarding level of need , as defined by the state and provider
HCBS	One commenter indicated that if states establish needs - based criteria for each specific service that an
MHCode	() " Incapacitated " means that an individual , as a result of the use of alcohol or other drugs , is unco
MHCode	(d) Submit to the members of the house and senate standing committees and appropriation subcomm
MHCode	The record shall contain at a minimum a written assessment and IPOS for the patient , a statement of
MHCode	(c) Sample assessments of families receiving family support subsidy payments including adequacy of s
MHCode	The office shall do all of the following : (a) Assess the mental health needs of multicultural populatio
MHCode	(b) Identification , assessment , and diagnosis to determine the specific needs of the recipient and to
MHCode	(h) Screening and assessment procedures .
MHCode	Sec . () The board of a CMH services program shall do all of the following : (a) Annually conduct a
MHCode	It is the responsibility of the CMH services program to involve the public and private providers of men
MHCode	The needs assessment shall include information gathered from all appropriate sources , including CMH
MHCode	(b) Annually review and submit to the department a needs assessment report , annual plan , and req
MHCode	The standard format and documentation of the needs assessment , annual plan , and request for new f
MHCode	(c) In the case of a county CMH agency , obtain approval of its needs assessment , annual plan and b
MHCode	In the case of a CMH organization , provide a copy of its needs assessment , annual plan , request for
MHCode	In the case of a CMH authority , provide a copy of its needs assessment , annual plan , and request for

Chapter 5

Informed by (and Informing) Research

Some activities related to person-centered planning are addressed in existing research.[1] In these instances, our goal would be to connect-the-dots between research and practice by making this knowledge available. In order to remain aligned with national efforts[2] in this area, initial steps would include:

- mapping of person-centered planning concepts to researched interventions
- literature review and meta-analyses of PCP-related practices, to build a base of best practices and evidence for effectiveness
- identification of gaps in existing research knowledge related to PCP

[1] For instance, *goals and planning*, *feedback and monitoring*, and similar activities defined by the Behaviour Change Intervention Ontology (BCIO) have related research available.

[2] NQF's Person-Centered Planning and Practice Project, references '*a research agenda to advance and promote person-centered planning in LTSS*'

Chapter 6

Shared Training Curriculum

To translate this information into action, various audiences need to be trained in person-centered practice, using the foundational concepts identified and defined above. Work in developing these trainings includes:

- Identification of key audiences
- Evaluation of potential training modalities based on key features
- Developing a standard base curriculum as well as specialty topics for specific audiences

Chapter 7

Person-Centered Measurement Framework

If the entire system of services and supports is intended to be person-centered, its performance should be measured within a framework that also person-centered. Many existing quality measures and data collection systems were not developed with this in mind. Thus, it will be important to develop a larger framework within which existing measures can be situated. This allows the system to retain the quality measurement work that has been completed, while filling gaps that may lead to inconsistency and poor quality.

The measurement framework outlined here attempts to align with and fulfill the promise of current definitions of person-centered planning, as well as with existing and evolving standards in the fields of behavioral health and developmental disability services. Far from contradicting these standards, it attempts to provide a broader, person-centered context for the development of the system as a whole.

Ongoing work in this area would include:

- Developing a person-centered measurement framework
- Conducting an inventory of available data assets at a state wide level
- Classifying existing measurement and data collection efforts (e.g. HEDIS, BH-TEDS, etc.) within the context of this framework
- Gap analysis of current datasets and development of a plan to address measurement gaps.

7.1 What do we mean by 'a better life'?

People have been asking themselves what it means to live a good life for thousands of years,[1] and it is among the most crucial questions for each of us to answer. For the purpose of this measurement framework, we will refer to the characteristics that make up a good life as *quality of life*, or QOL for short, relying primarily on contemporary research to arrive at a common and usable definition.

7.1.1 What makes a good definition?

If we are going to try to define quality of life, it is important that our definition gets a few things right:[2]

1. *Multiple dimensions.* A good life can only be described using multiple dimensions. These are influenced by personal factors, environmental factors, and the interaction between those factors.
2. *Broad enough for everyone.* We should each want to apply the definition to our own lives. The basic characteristics of a good life are the same for all people, regardless of culture, gender, disability, etc.
3. *Both subjective and objective.* People have different priorities. While a definition can point to objective facts related to QoL, it must include the point-of-view of the person who is living their life from day to day. Each dimension of a QoL model may have both objectively and subjectively defined indicators.

Taken together, the criteria listed above seek to balance the abstract with the specific and to arrive at a definition which is well-rounded while also being understandable.

7.1.2 What makes a better life?

Keeping our key requirements in mind, we can draw from the broad reservoir of studies on QoL to find frameworks which are multi-dimensional[3], cross-culturally relevant,[4] and which provide both subjective and objective indicators.

Below is a potential model listing essential dimensions of QoL:

[1] The philosopher Aristotle defined the highest good of human life as happiness, or flourishing (*eudaimonia*). cf. *Nicomachean Ethics*

[2] These considerations are drawn from Cummins, R. (2005). Moving from the quality of life concept to a theory. JIDR, 49(10), 699-706.

[3] See systematic review of HRQoL recommending addition of individual and environmental characteristics: Bakas, T., et al. (2012).

[4] See Schalock, R., et al. (2005)..

Table 7.1: QoL Dimensions

Area	Dimension	Example Indicators
Independence	Personal development	Education status, personal skills, ADLs, IADLs
	Self-determination	Choices, autonomy, personal control, goals
Social participation	Interpersonal relations	Social networks, activities, relationships
	Social inclusion	Community integration, participation, roles
	Rights	Human (respect/dignity, equality), Legal
Well-being	Emotional well-being	Safety, positive experiences, self-concept, stress
	Physical well-being	Health, nutrition, recreation/physical exertion
	Material well-being	Financial status, employment, housing, possessions

Please note that the framework listed above is one of many potential models, each of which contains many of the same basic dimensions, and many were developed with populations having specific conditions. Some other broad-based models for review include:

- The World Health Organization Quality of Life (WHOQOL) domains.
- The Eurostat QoL indicators show an example of QoL domains applied for entire countries alongside financial indicators such as gross domestic product (GDP).
- Healthy People 2020 has selected a subset of measures for monitoring health-related QoL and well-being in the United States. See their Foundation Health Measure Report: Health-Related QoL and Well-Being.

7.2 Benefits of a QoL Perspective

7.2.1 What other frameworks exist?

One might well ask: *Is quality of life the only potential framework that we could use to measure improvement?* The answer is *No*, so it is worth discussing other options and briefly reviewing the attributes of each. Other options include:

- *Symptom reduction*: Measurement of reduction in symptoms related to specific diagnosable conditions. Symptom scales such as the PHQ-9, GAD-7 and other tools have commonly been used to measure the impact of treatments on specific conditions, but they are more challenging to use for people with multiple co-occuring conditions (MCC).
- *Improving functional status*: Most currently used assessment tools address functional status, measuring the impact of various conditions on broader life areas in terms of their impact on functional ability. These are broader than symptom scales, and can detect the impact of various symptoms on a particular functional domain.

- *Health-related quality of life (HRQoL)*: HRQoL addresses a subset of QoL domains which are related to perceived physical and mental health. These models typically exclude non-medical areas such as education or rights, focusing on physical domains like 'mobility'.

7.2.2 Why is a quality of life framework better than others?

A QoL approach has the following benefits over the approaches mentioned above:

Strengths-based: A QoL approach asks people what they want their lives to be and encourages them to work toward that vision. Rather than focusing on needs or deficits, it aspires to use a person's strengths to improve his or her life.[5]

Inclusive: Instruments and measures from each of the other areas can be used as a part of the QoL framework, since it is broad enough to include each of these areas, and they each contribute to it. A QoL approach does not neglect the value of functional gains or symptom reduction, but values these as contributors to overall quality of life. For instance, if a person experiences an alleviation of their depressive symptoms using the PHQ-9, this would be seen as contributing toward the individual's QoL in the area of 'Emotional Well-being'.

Contextual: An approach which focuses on only a portion of an individual's life, such as mobility or anxiety symptoms, is likely to miss out on the bigger picture. It may also inadvertently create siloes among the individuals supporting the person. For instance, more recent evaluations have criticized the HRQoL approach as failing to "sufficient emphasis on mental and social domains…that are essential to people."[6] The broader focus on QoL which is proposed here is aligned with our evolving understanding of several areas, each of which stresses the critical relationship between each of us and our communities and surroundings:

- *Social Determinants of Health* (SDoH): A vast and growing body of research indicates that the places and conditions in which we live are intrinsically tied to the quality of our lives and the likelihood of achieving positive outcomes from the supports and services we receive.
- *Trauma-Informed Care*: More and more models for service provision, informed by research and by the lived experience of trauma survivors, are founded on the recognition that adverse events in our relationships and in our lived environment can have a profound and lifelong impact on our lives.[7]

[5] See the MDHHS PCP Policy value that "The PCP approach identifies the person's strengths, goals, choices… and desired outcomes." (p. 4)

[6] Read Pietersma, S., et al. (2013) regarding domains of quality of life.

[7] For a recent review of these models, see: Purtle, J. (2018). Trauma, Violence, & Abuse.

- *Supports Paradigm*: A model, prevalent in the IDD supports system, that views a person's functioning as the match between their individual capacity and the environment in which they are expected to live and work.[8] In this model, supports are viewed as a way to supplement the persons strengths and to help match those to the person's environment.

[8]See Thompson, et al. (2009) on conceptualizing support needs.

Chapter 8

Appendix

8.1 Alignment with of Measures with Existing Requirements

8.1.1 Alignment with Federal Medicaid Requirements

8.1.2 Alignment with Provider Requirements

Feasible for Implementation: Multiple pragmatic trials have demonstrated that the use of symptom scales are both feasible to implement on a large scale[1] and acceptable to people receiving services.[2]

Provider Accreditation: New standards for Joint Commission accreditation (effective 2018)[3] require that an organization (a) "uses a standardized tool or instrument to monitor individuals progress in achieving… goals", (b) "gathers and analyzes data generated through standardized monitoring, and results used to inform goals and objectives of individual's plan", and (c) "evaluates outcomes of… services… by aggregating and analyzing data collected through the standardized monitoring effort."

Diagnostic Practice: The most recent diagnostic manual (DSM-5) includes assessment measures which were "developed to be administered at the initial patient interview and to monitor treatment progress."

[1] See the large scale implementations cited in Fortney, J. C., et al. (2016). A tipping point for measurement-based care. Psychiatric Services, 68(2), 179-188..

[2] Dowrick, C., et al. (2009) report that the use of instruments increase confidence in providers' accuracy and management.

[3] See Joint Commission *Standard CTS.03.01.09*, sections *EP1-3*.

8.2 Framework for Measurement

8.2.1 Scope

A conceptual framework as comprehensive as the one we are proposing runs the risk of becoming overwhelmingly complex and unwieldy to implement. So, before diving into any details, we want to begin by sketching out a simple way to think about the scope of the framework required to systematically measure person-centered planning and its impact of quality of life. Having a definition of scope can help us answer questions such as:

- What types of data are included, and what types of measures?
- How will we know when the framework is fully implemented?
- Does this fit with other work that we are doing?

We can define the scope of the framework using three-dimensions (*depth, breadth, and height*) as defined below:

Depth (a.k.a. *Zoom*): Does the framework allow for understanding at various levels of 'resolution', from the most immediate (i.e. *the individual person*) to the aggregate (i.e. *the population*) and other levels inbetween (e.g. *the organization, team, etc.*)?

Breadth (a.k.a. *Population*): Can the framework apply to all people who are planning to improve their lives with the help of services and supports?[4]

Height (a.k.a. *Steps*): Does the framework allow for understanding of each of the steps in the person-centered PDCA process discussed above?

If we think about the framework as a cube made of these three dimensions, then developing the measurement framework can begin by making certain that data is collected:

- at each step of the person-centered PDCA process (*height*)
- for people across all populations (*breadth*)
- which can be aggregated at various levels of the system (*depth*)

So, speaking *very* broadly, if our cube has data elements/measures at each intersection of the three dimensions, then it allows for at least a basic understanding of people's needs, planning, and services as these contribute to improved lives. In reality, there will always be additional data that can be collected and novel

[4] I.e., to all 'populations' around which systems have been developed (*SMI, SED, IDD, SUD, etc.*). Since different data exists for each group, evaluating alignment is key.

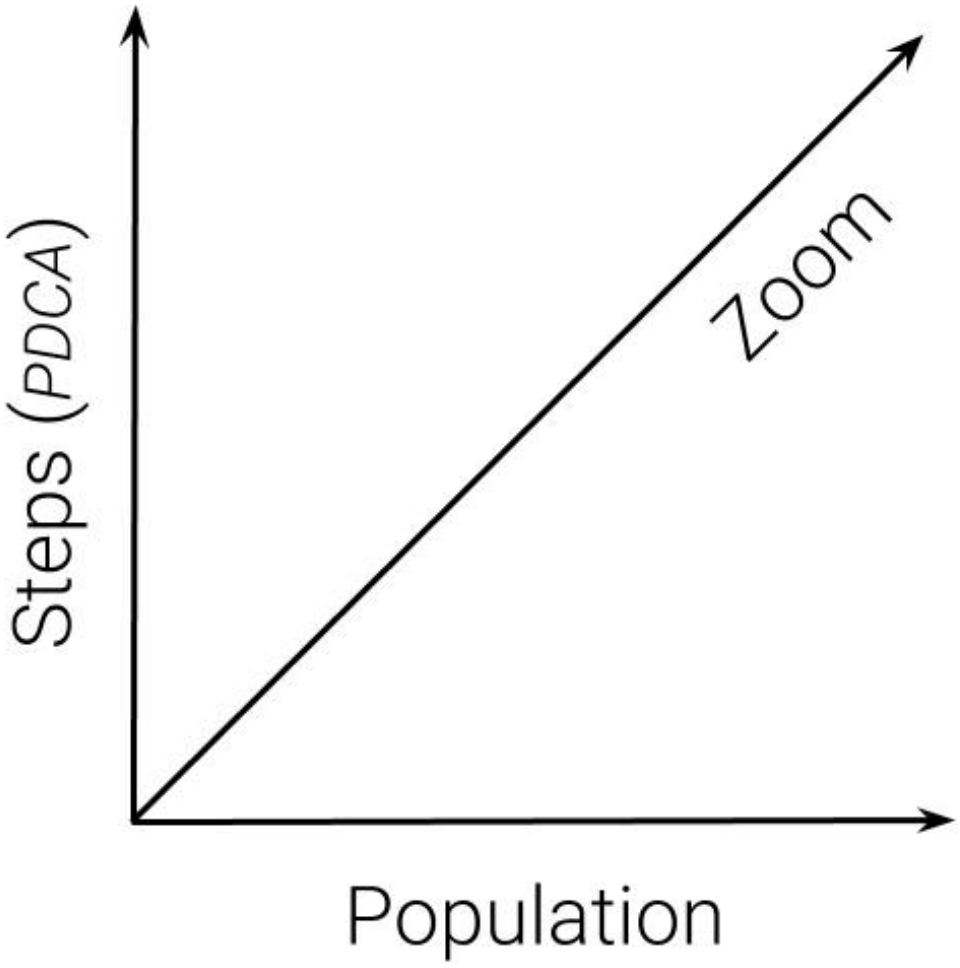


Figure 8.1: Scope of framework

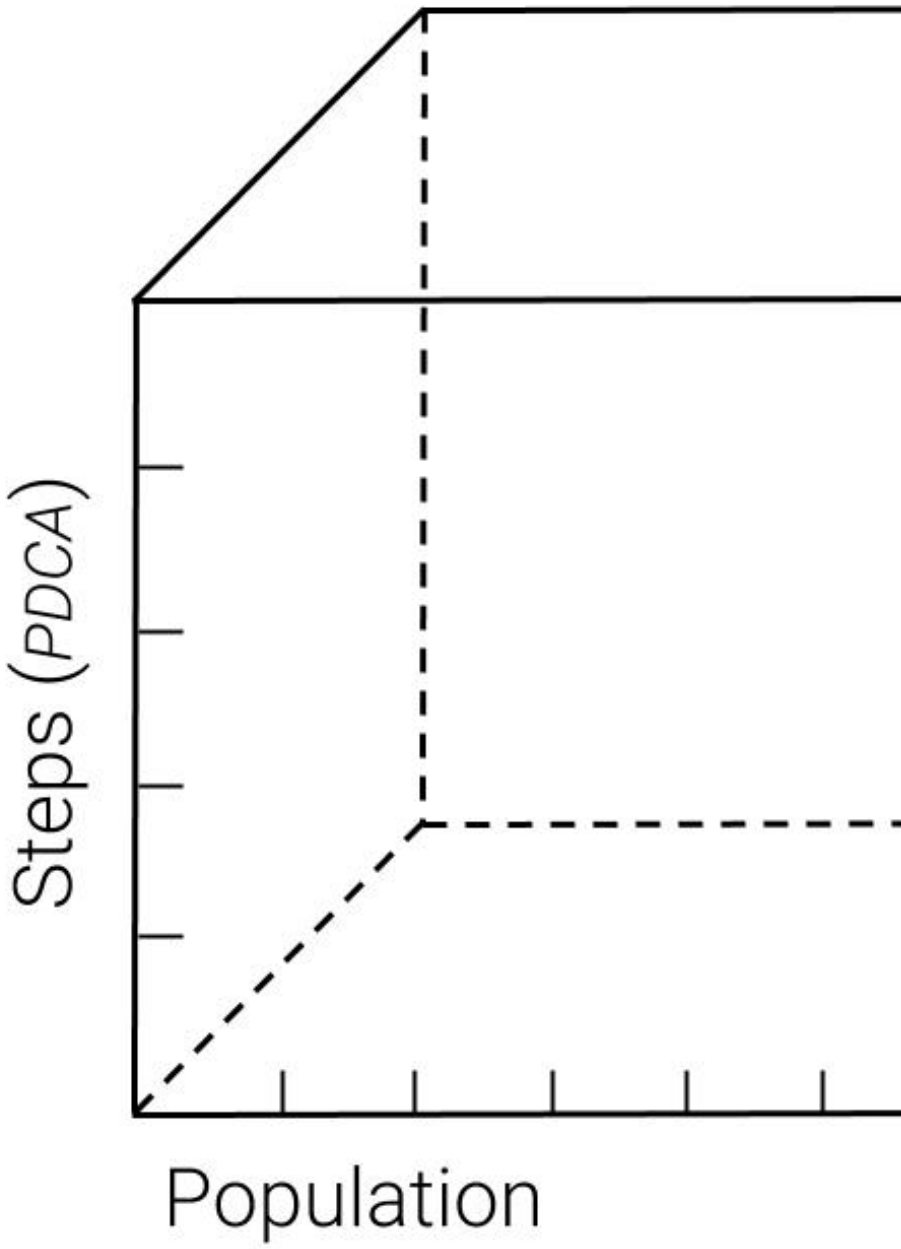


Figure 8.2: If it was a cube...

Table 8.1: Sample: Need Assessment and Related QoL Dimensions

Dimension	SIS Subscale	CAFAS Subscale	LOCUS Dimension	GAIN Item
Personal development	Health & Safety	School/Work		
	Protection/Advocacy	Thinking		
	Behavioral Support			
Self-determination	Protection/Advocacy		Engagement	
Interpersonal relations	Social Activities	Home		
Social inclusion	Community Living	Community		Living Situation
	Social Activities			Environment
Rights	Protection/Advocacy			Legal
	Health & Safety			
Emotional well-being	Behavioral Support	Moods/Emotions	Risk of Harm	Emotional health
	Health & Safety	Behavior		
Physical well-being	Medical Support	Self-Harm	Co-Morbidity	Physical health
	Health & Safety		Risk of Harm	Disease prevention
Material well-being	Employment	Material Needs		Vocational

ways of combining that data, just as there continue to be additional books and songs written describing the human experience.

The next sections define each of the dimensions listed above, and how they relate to one another, in greater detail. Based on these details, it will be possible to begin a practical gap analysis to assess how closely the system's current data assets match the scope of the framework. Please note that this paper does not develop or identify specific measures, except as illustrations of how individual data elements or metrics *might* fit into the overall framework.

8.2.2 Steps

8.2.2.1 Plan

Understand Quality of Life.

Understand Needs Related to QoL. The table below identifies example variables from required assessments which relate to the QoL domains outlined above.[5] While this is not an exhaustive mapping, it shows how the assessment of personal needs (*from the "Plan" step of PDCA*) relate to quality of life domains across multiple populations.

As mentioned above, the table above is intended to illustrate how assessments

[5]Assessments included are the *Supports Intensity Scale (SIS)*, the *Child and Adolescent Functional Assessment Scale (CAFAS)*, the *Level of Care Utilization System (LOCUS)*, and the *Global Appraisal of Individual Needs (GAIN)*

of need can be tied to QoL domains, but is not comprehensive.[6] The actual mapping will need to be done at the level of specific questions, as opposed to subscales which are not as likely to fit neatly within a single QoL domain. Note that instruments which contain a larger number of items (such as the SIS) are likely to have greater coverage of QoL domains than instruments with a smaller number of items (such as the LOCUS).

8.2.2.2 Do

8.2.2.3 Check

When are measures taken?

What types of measures relate to what parts of the PCP process?

8.2.2.4 Act

8.2.2.5 PCP-based Episodes

Improvement takes time, both in our personal lives and in our collective work as organizations and systems. Various frameworks have been developed to help evaluate improvement over time, many of which rely on the concept of "episodes": periods of time which characterized by specific events or attributes. For instance…

- an admission to treatment is used to define an episode in the *Substance Abuse and Mental Health Services Administration* (SAMHSA) *Treatment Episode Data Set* (TEDS)
- the course of a particular illness is used to define an episode in the *National Quality Forum*'s Patient-Focused Episodes of Care

Neither of the approaches above is optimal for understanding the effectiveness of the implementation of a person-centered plan. The admission-based approach will create longer episodes for long-term services and supports which do not correspond to revisions of the person-centerd plan and the effect of those revisions on quality of life. The illness-based approach will be overly reductive for people with multiple, concurrent conditions, lifelong conditions, or whose social and environmental conditions have a strong adverse impact on their quality of life.

If the person-centered planning (and doing, checking, acting) process is to be the primary catalyst for improvement of life using Medicaid supports and services, then that process should be used to define episodes for improvement. The

[6] For the SIS instrument, this table relied on the mapping described in Van Loon, J., et al. (2010). *Assessing individual support needs to enhance personal outcomes.* Exceptionality, 18(4), 193-202.

broader 'episode' of the PCP process would correspond to the period of time during which the person is receiving services, while also marking the interval between the plan and its next subsequent revision. If person-centered planning is expected to be creative, collaborative, and dynamic, then different 'visions and revisions' of the plan will be longer or shorter. For instance, if a person develops a plan but soon realizes that it is not helping them to achieve the life goals they intended to, then the plan would be revised and the PCP cycle would be relatively short.

8.2.3 Zoom

8.2.4 Population