NCAPPS

Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Definitions and Principles

Prepared by the Human Services Research Institute as part of NCAPPS technical assistance

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Introduction

To guide the technical assistance provided as part of the National Center on Advancing Person-Centered Practices and Systems (NCAPPS), the Human Services Research Institute prepared a national overview of person-centered principles across aging and disability systems, including mental health systems. This document was prepared to support one State's effort to create a cross-system definition of person-centered practice. Using the common principles of person-centered thinking, planning, and practice summarized below, along with a review of State-level standards for person-centered practices, the State drafted a definition of person-centered practice to be used across its State systems of aging and disability.

This document is the first in a series of environmental scans to support NCAPPS technical assistance; it may serve as a useful tool for other States, Tribes, and Territories that are seeking to develop local definitions of person-centered thinking, planning, and/or practice based on nationally recognized principles. Forthcoming documents include a scan of person-centered approaches and a scan of indicators (or measures) of person-centered thinking, planning, and practice.

This scan specifically focuses on criteria and definitions of person-centered thinking, planning, and practice within human service systems and organizations. To perform the scan, we reviewed articles, policy statements, regulations, and websites of national aging, disability, and mental health organizations. The review of literature focused on articles, reports, websites, and other documents that were frequently cited and that were written by leading experts in these fields.

The scan identified several common themes, including choice and self-determination, community acceptance and inclusion, and access to services. Review of Federal laws and policies focused on guidance regarding choice, community, and access to services.

The main principles of person-centered practices that emerged from the review can be summarized as follows:

- **Focus on the person**. The person is at the center of the planning process. The person's desires should be heard, honored, valued and reflected in the services received. People who are important in the person's life should be part of the planning process.
- **Choice and self-determination**. People should make choices (with support if needed and wanted) about services and supports as well as decisions regarding their own health, well-being and life goals.
- **Community inclusion**. People must have full access to the community and be treated with dignity and respect.
- **Availability of services and supports**. People should have access to an array of individualized services that meet their particular needs.

There were other key issues that emerged in the review. Although they don't necessarily define person-centeredness, they are important characteristics of a person-centered system.

- **Information**. Information should be provided in a clear and meaningful way in order for people to understand options and make informed decisions.
- **Coordinated supports**. A few resources discuss the need for providers to work together to deliver services, and the importance of having cohesion and continuity with supports.
- **Positive expectations.** This theme comes mainly from the mental health field and stems from the belief that recovery can be a reality. In other fields, the assumption that improvement and growth are possible is important for person-centered practices.

The resources presented here are organized first by **primary population focus**, starting with those that focus on more than one population, followed by those that focus on aging, those that focus on intellectual and developmental disability (IDD), and those that focus on mental health. Within these subsections, resources are listed **alphabetically by author**.

Environmental Scan

Resources with Multiple Populations of Focus

No Wrong Door: Person- and Family-Centered Practices in Long-Term Services and Supports

AARP | 2017

"Individualization is at the heart of person- and family-centered practice. It represents a radical shift from simply providing someone with a list of services. Strategies such as partnering with families to listen to values and preferences, discussing pros and cons of various options, and following up with people to make sure information was helpful are some promising ways that States are implementing this individualized support."

Additional criteria: "Person- and family-centered practice requires an interactive process directed by individuals and family members to support decision making about LTSS. An individual trained in person- and family-centered practices and support options facilitates the development of a plan that accounts for a person's and family's strengths, preferences, needs, and values."

Source:
http://www.longtermscorecard.org/~/media/Microsite/Files/2017/AARP_PromisingPrac_NoWrongDoor.pdf

ACL Mission Statement

Administration for Community Living | 2014

The Administration for Community Living (ACL) believes that every person has the right to make choices and control the decisions in their lives. This right to self-determination includes decisions about where to live, decisions about work, and all the other daily decisions most adults make without a second thought. Older adults and people with disabilities are unique individuals, and the help they may need is unique as well. These programs focus on helping ensure that the preferences and the needs of older adults and people with disabilities are at the center of the system of services and supports that enable them to live the lives they want to live.

Source: https://acl.gov/programs/consumer-control

Person Centered Thinking, Planning, and Practice: The Federal Policy Context

Administration for Community Living | 2016

Person-centered practice is the alignment of service resources that give people access to the full benefits of community living and help them achieve individual goals.

Source:

http://www.nasuad.org/sites/nasuad/files/Shawn%20AIRS%20policy%20overview%2020160516.pdf

Centers for Medicare and Medicaid Services | 2014

The Medicaid Home and Community-Based Services Final Rule - CFR 42 §441.301(c)(1) and CFR 42 §441.301(c)(2) – defines requirements for person-centered planning for people living in HCBS settings under 1915(c) waivers and 1915(i) State Plan authorities.

Source:

https://www.medicaid.gov/medicaid/hcbs/downloads/final-rule-slides-01292014.pdf

Affordable Care Act

2010

The Affordable Care Act contains a number of provisions that promote person-centered approaches. These provisions include: Community first living setting; availability of services to meet individual need; person-centered services and supports based on functional need and agreed by or on behalf of individual; individual choice and control; coordinated delivery of services and supports.

Source: http://housedocs.house.gov/energycommerce/ppacacon.pdf

Americans with Disabilities Act

1990

The Americans with Disabilities Act prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. The Act requires reasonable accommodations to be made for people with disabilities.

Source: https://www.ada.gov/

What 'Patient Centered' Should Mean: Confessions of an Extremist

Berwick, Donald | 2009

"The experience (to the extent that the informed patient desires it) of transparency, individualization, recognition, respect, dignity and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care."

Source: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.28.4.w555

Person-Centered Planning and Self-Direction: HHS Issues New Guidance on Implementing Section 2402(a) of the Affordable Care Act

2014 | HHS

Person-centered planning is a process directed by the person with long-term service and support (LTSS) needs. The person-centered planning approach identifies the person's strengths, goals, preferences, needs (medical and HCBS), and desired outcomes. The role of staff, family, and other team members is to enable and assist the person to identify and access a unique mix of paid and unpaid services to meet their needs, and to provide support during planning and implementation.

Additional criteria: As a first step in implementing Section 2402(a), the Secretary issued guidance on person-centered planning and self-direction. This information will help States, agencies, providers, people with disabilities, families, and other stakeholders to encourage the development of systems and services that are person-centered and maximize self-direction. That, in turn, will empower people who receive LTSS to reach their goals and achieve a better quality of life.

Source: https://acl.gov/news-and-events/acl-blog/person-centered-planning-and-self-direction-hhs-issues-new-guidance

What Is Person-Centred Care and Why Is It Important?

Health Innovation Network, South London

"There are many different aspects of person-centred care, including: respecting people's values and putting people at the centre of care; taking into account people's preferences and expressed needs; coordinating and integrating care; working together to make sure there is good communication, information, and education; making sure people are physically comfortable and safe; emotional support; involving family and friends; making sure there is continuity between and within services; and making sure people have access to appropriate care when they need it."

Source:

https://healthinnovationnetwork.com/system/ckeditor_assets/attachments/41/what_is_person-centred_care_and_why_is_it_important.pdf

Guiding Principles for Successfully Enrolling People with Disabilities in Managed Care Plans

National Council on Disability | 2014

The provision of health care and long-term supports must be designed and delivered through a person-centered lens. Health services must be carefully synchronized with long-term supports based on a common set of goals and desired outcomes spelled out in each participant's person-centered plan. The plan must enable the person to exercise decision-making authority over activities of daily living and health maintenance functions. . . managed services and supports should be built around and linked to existing community-based disability structures, such as independent living centers, recovery learning communities, and community-based developmental disabilities and mental health agencies.

Additional criteria: Person-centered approaches are designed to (a) help an individual map out his/her life goals and identify the supports required to achieve them; (b) help an individual exert greater control over his/her life and live as independently as possible; and (c) promote social inclusion in the community.

Source: https://www.ncd.gov/publications/2013/20130315/20130315Ch3

Convention on the Rights of Persons with Disabilities (CPRD)

United Nations | 2008

"The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection toward viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society."

Additional criteria: Principles: Respect for inherent dignity/individual; non-discrimination; full and effective participation and inclusion in society; respect/acceptance as part of human diversity and humanity; equal opportunity; accessibility; equality between men and women; respect for the evolving capacities of children and respect for the right of children to preserve their identities.

Source:

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Resources Focused on Older Adults and Aging Services

Person-Centered Thinking with Older People

Bowers et al. | 2007

This is a book on person-centered thinking and planning with older people that offers some ideas to ensure they are in control of the support they receive.

Additional criteria: This resource describes eight "tools" of person-centered thinking that can be used when planning individualized support: appreciations (focus on what we like and admire about people); relationships (identifying at least one person important in the person's life); what's important to and for people; communication (particularly for people who do not use verbal communication or have limited verbal communication and/or have memory or orientation challenges); histories; wishing (person's goals); good days and bad days (recognizing and being able to support a person in good and bad days); know what is working/not working.

Source: https://www.ndti.org.uk/uploads/files/PCPOPweb3.pdf

Moving Toward Person- and Family-Centered Care

Feinberg, Lynn | 2014

"When we talk about how person- and family-centered care (PFCC) must address an individual's needs, goals, preferences, cultural traditions, family situation, and values, we realize that these are all essential pieces of the advanced illness puzzle. Looking beyond the medical and physical needs of a person, communicating with him or her and the family, and developing a plan and coordinating the services are all part of the formula for better care."

Additional criteria: Describes components of PFCC as: respect and dignity for the older person and family; recognition of the whole person; assessing and addressing the individual's and the family caregivers' information, care and support needs, and their experience of care; promotion of communication, shared decision-making, and empowerment; emphasis on coordination and collaboration across care settings.

Source: https://doi.org/10.1093/ppar/pru027

Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review

Kogan, Wilber & Mosqueda | 2016

"Much of the literature highlights the importance of incorporating an individual's preferences, values, beliefs, and family or fictive kin into the decision-making process related to daily life and care in clinical practice and in social service settings. These principles, which are central to PCC, have recently been highlighted in US policy in general and in Accountable Care Organizations and Patient-Centered Medical Homes specifically."

Source: https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.13873

Resources Focused on Intellectual and Developmental Disability (IDD)

Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs

Administration for Community Living | 2014

Person-centered planning is a process directed by the person with LTSS needs. . . PCP should also include family members, legal guardians, friends, caregivers. . . PCP should involve the individuals receiving services and supports to the maximum extent possible, even if the person has a legal representative. The PCP approach identifies the person's strengths, goals, preferences, needs (medical and HCBS), and desired outcomes. The role of agency workers (e.g., options counselors, support brokers, social workers and others) in the PCP process is to enable and assist people to identify and access a unique mix of paid and unpaid services to meet their needs, and provide support during planning. The person's goals and preferences in areas such as recreation, transportation, friendships, therapies, home, employment, family relationships, and treatments are part of a written plan that is consistent with the person's needs and desires.

Source: https://acl.gov/sites/default/files/programs/2017-03/2402-a-Guidance.pdf

NASDDDS -- Guiding Principle and PCP Definition

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

”Person-Centered Practices are ways of planning, providing, and organizing services rooted in listening to what people want and helping them live in their communities based on their choices. Inherent in person-centered practices is the emphasis on transforming the options available to the person, rather than on 'fixing' or changing the person. State services systems must consciously organize their rules and procedures to enable person-centered practices to flourish.”

Additional criteria: The association's goal is to promote and assist states in developing effective, efficient service delivery systems that furnish high-quality services and supports to people with lifelong developmental disabilities. State service systems should be based on the principle that people with developmental disabilities have a right to: be treated with respect and dignity; be independent and make individual choices; participate in family, community, and work life; have opportunities to maximize their full potential; and receive outcome-based services and supports.

Sources:

- https://www.nasddds.org/about-nasddds
- https://www.nasddds.org/resource-library/general-information-on-administering-state-programs/family-living/person-centered-practices

The Origins of Person-Centered Planning

O’Brien & O’Brien | 2000

“We understand person-centered planning as a systematic way to generate an actionable understanding of a person with a developmental disability as a contributing community member.”

Additional criteria: Describes attributes of PCP as: increasing choice, avoiding depersonalizing labels and difference-making procedures, honoring the voices of the person and those who know the person best, building relationships, individualizing supports based on high expectations, and demanding that agencies adopt new forms of services.

Source:

https://www.nasddds.org/uploads/documents/The_Origins_of_Person_Centered_Planning_Obrien_and_Obrien.pdf

TASH Mission/Vision

TASH

"TASH is an international leader in disability advocacy. TASH advocates for human rights and inclusion for people with significant disabilities and support needs—those most vulnerable to segregation, abuse, neglect, and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The inclusive practices TASH validates through research have been shown to improve outcomes for all people."

Source: https://tash.org/

Conceptualizing Supports and the Support Needs of People With Intellectual Disability

Thompson et al. | 2009

"A hallmark of PCP is that the focus is on the individual's dreams, personal preferences, and interests. The primary purpose of a PCP process is to find out what is important to a person, and it is essential that discussions are not constrained by available services or by perceived barriers such as fiscal restrictions or limitations in a person's skills (O'Brien & O'Brien, 2002)."

Additional criteria: Describes five components of planning supports: identify desired life experiences and goals; determine the pattern and intensity of support needs; develop the individualized plan; monitor progress; evaluate.

Source: http://www.kshalem.org.il/uploads/pdf/article_4811_1375202913.pdf

Resources Focused on Mental Health

Recovery and person-centredness in mental health services: Roots of the concepts and implications for practice

Hummelvoll, Karlsson, & Borg | 2015

"Within mental health care, person-centeredness involves conveying a holistic approach and respect for the individual and their unique experiences and needs (Gask and Coventry, 2012; Morgan and Yoder, 2012)."

Additional criteria: "Person-centred care is a collaborative process between the person seeking help and the practitioner in various contexts. Morgan and Yoder (2012, p 8) conducted a concept analysis of person-centred care, and found the defining attributes of person-centred care to be: a) holistic, b) individualized, c) respectful, and d) empowering."

Source:

https://www.fons.org/Resources/Documents/Journal/Vol5Suppl/IPDJ_05(suppl)_07.pdf

MHA – Position Statement 11: In Support of Recovery-Based Systems Transformation

Mental Health America

"Mental Health America is committed to the principle that every individual with a mental health or substance use condition can enjoy recovery and wellness. Individuals must define for themselves what recovery means to them—what their personal goals are, what it means to live a fulfilling and productive life, and how to manage their condition effectively. The individual must be able to define his or her recovery free from (most) cultural judgments about what constitutes a meaningful and productive life. This is important not only for the individual's autonomy but also for the community, allowing it to grow in acceptance of people in recovery, living with behavioral health conditions. For an individual to engage in the recovery process, it is important that she or he possess hope that recovery is possible, have choices regarding community-based services and supports, have access to resources that allow for basic needs to be met such as food, clothing and housing, and have a strong community network. Such a network can include but is not limited to friends, family and faith-based organizations."

Source: https://www.mhanational.org/issues/position-statement-11-support-recovery-based-systems-transformation

Transforming Mental Health Care in America

New Freedom Commission on Mental Health | 2003

The Commissioners envisioned a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports. The Commission articulated a vision of a transformed system as one in which Americans understand that mental health is essential to overall health; mental health care is consumer and family driven; disparities in mental health services are eliminated; appropriate and early mental health screening, assessment, and referral to services occurs; excellent mental health care is delivered and research is accelerated; and technology is used to access mental health care and information.

Additional criteria: To transform the mental health service delivery system, the Commission challenged the federal government, state governments, local agencies, and public and private health care providers to: Close the 15- to 20-year gap it takes for new research findings to become part of day-to-day services for people with mental illnesses; harness the power of health information technology to improve the quality of care for people with mental illnesses, to improve access to services, and to promote sound decision-making by consumers, families, providers, administrators, and policy makers; identify better ways to work together at the federal, state, and local levels to leverage human and economic resources and put them to their best use for children, adults, and older adults living with—or at risk for—mental disorders; expand access to quality mental health care that serves the needs of racial and ethnic minorities and people in rural areas; promote quality employment opportunities for people with mental illnesses.

Source:
https://govinfo.library.unt.edu/mentalhealthcommission/reports/reports.htm

PROMISE Global

2016

"First, and arguably most important, is the philosophy of person centered care planning (PCCP). PCCP can only grow out of a culture that fully embraces recovery, self-determination, and community inclusion: believing that people can, and do, recover. Believing that people can, and should, have choice in the decisions that impact their treatment and their lives. And believing that a meaningful life in the community is a fundamental right and NOT something that must first be earned through acts of compliance or demonstration of "clinical stability"—these beliefs are the bedrock in which person centered care planning is rooted." Note: This is one of four elements of centered care planning: Philosophy, Process, Plan and Purpose.

Source: http://promise.global/2016_04_29_pccp_02_philosophy.pdf

Implementation of Person-Centered Care and Planning: How Philosophy Can Inform Practice

Tondora et al. | 2005

"Person-centered planning (PCP) has increasingly been recognized as one promising tool in the process of transforming the current system and restoring certain elementary freedoms (e.g., self-determination, community inclusion, etc.) to American citizens with psychiatric diagnoses and the loved ones who support them (Institute of Medicine, 2001). . . The practice of PCP can only grow out of a culture that fully embraces the principles embodied in these types of changes. As such, for the remainder of this paper, we assume as the foundation for the practices we describe a system which reflects this major paradigm shift toward recovery-oriented, person-centered care."

Additional criteria: While the "package" of strategies will look different across systems and individuals, select practices that exemplify person-centered principles include those which: make continuous use of strengths-based assessment strategies; adhere to person-centered principles in the process of building person-centered plans; recognize the range of interventions and contributors to the planning and care process; value community inclusion as a commonly identified and desired outcome; support the "dignity of risk" and the "right to fail" (Deegan, 1996); demonstrate a commitment to both outcomes and process evaluation.

Source:
https://www.hsri.org/files/uploads/publications/ImplementationOfPersonCenteredCareandPlanning.pdf

About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services to help States, Tribes, and Territories to implement person-centered practices. It is administered by the Human Services Research Institute (HSRI) and overseen by a group of national experts with lived experience (people with personal, first-hand experience of using long-term services and supports).

NCAPPS partners with a host of national associations to deliver knowledgeable and targeted technical assistance.

You can find us at https://ncapps.acl.gov

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