NCAPPS

Person-Centered Planning: Choosing the Approach that Works for the Person

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Introduction

Despite consensus regarding the content and conduct of person-centered plans (such as the person-centered planning requirements in the Home and Community-Based Services Final Rule), there has been less promising practice guidance on how to tailor the duration and extent of the planning process to the needs and wishes of the person. To be truly person-centered, the content and extent of the planning process should be tailored to the person's unique life circumstances. The intent of this resource is to reinforce the importance of aligning person-centered planning approaches with the wishes and needs of the person for whom the plan is being developed, rather than adopting a one-size-fits-all approach.

History and Background

The concept of person-centered planning was first conceived in the 1980s by a small number of people working in the U.S. and Canada including John O'Brien, Connie Lyle O'Brien, Beth Mount, Jack Pearpoint, Marsha Forest, and Michael Smull. It was initially developed to facilitate the movement of people with disabilities out of remote institutions into lives in the community (Inclusive Solutions, n.d.). From the start, person-centered planning was built on the values of inclusion and choice and tied paid and unpaid supports to goals and aspirations. Person-centered plans were originally designed as an alternative to plans based on the medical model of disability that led to an emphasis on deficits and to service decisions made by an array of clinical professionals. Historically, such deficit-based plans were developed mainly for the convenience of the provider, not to support the person's goals.

Rules developed by the Centers for Medicare and Medicaid Services now require service plans to follow person-centered principles that put each person's goals, preferences and needs at the center of the planning conversation. Although person-centered planning was developed as an alternative by leaders in the disability field, it is increasingly used to organize services and supports for a wide spectrum of people needing support across a range of settings. For instance, Kim and Park (2017) highlighted the power of person-centered planning for people with dementia and Lines et al. (2015) described the positive effect of person-centered planning principles in patient-centered care. When planning puts the person at the center of the conversation, research has shown that costs are reduced and, more importantly, that lives improve (Sanderson, et al., 2006).

What Self-Advocates Say

- Tia Nelis: ". . . the person with a disability is in charge of their plan. Everyone should listen to what the person with the disability wants; they choose who supports them and who comes to the meeting;"
- Liz Weintraub: "A person-centered plan is about what the person (me) wants. . . it's also important to LISTEN to the person when doing a person-centered plan, no matter if that's hard to do;"
- Nicole LeBlanc: "I think it . . . means that having control of your life and (be) empower(ed) to tell what you want in our life;"
- James Meadours: "One that is truly inclusive of Wishes, Hopes, Dreams of people with disabilities . . . staff that think outside the box"

Person-centered planning is not one defined process, but a range or continuum of processes all underpinned by the same values base and goal – to provide supports necessary to assist people to gain agency in their lives. It should be thought of as an umbrella concept that encompasses different purposes, content, and frequency depending on the needs of the person and regulatory requirements. The overarching aim of planning for any purpose should be to reflect the person's wishes and aspirations.

Operationalizing Person-Centered Planning

Until the Home and Community-Based Services (HCBS) Final Rule in 2014, federal guidance from the Centers for Medicare and Medicaid Services regarding planning for HCBS waiver recipients was limited to specific waiver assurances including ensuring that they address assessed needs and health and welfare risks, include the person's goals and preferences, are updated when needs change, afford choice among services and providers, and include the opportunity to self-direct.

Since the release of the HCBS Final Rule, CMS has required that all people receiving HCBS services and supports must have a person-centered plan that meets criteria including that the plan be written in plain language, include people chosen by the person, is driven by the person, and reflects cultural considerations (see list of requirements in the Appendix).

However, the HCBS Final Rule does not include specific guidance related to the extensiveness of the plan and its alignment with a person's circumstances and need/preferences for support. While it is true that states providing HCBS waiver services are obligated to conduct person-centered plans for people receiving services and supports in ways that align with the process and plan standards set forth in the HCBS Final Rule, there is little guidance regarding how to tailor the wide-ranging aspects and components of person-centered planning to the immediate context of the person for whom the plan is being developed.

In this section, we outline different contexts and approaches to person-centered planning and highlight the importance of specifying the purpose and extensiveness of planning activities based on a person's circumstances and preferences.

Range of Planning Formats

Significant Life Event Planning

Over the past several decades since person-centered planning was first introduced, several formats have been developed to provide tools and a structure for the process such as PATH, MAPS, Personal Futures Planning, Essential Lifestyle Planning, and Charting the LifeCourse. Each of these approaches anticipates the need to respond to a significant life event such as transition from school to adulthood, retirement, movement into employment or supported housing, and other major life changes (see NCAPPS, Person-

Centered Thinking, Planning, and Practice: A National Environmental Scan of Foundational Resources and Approaches). Each entails a comprehensive process that involves the person with a disability and others in their life in a wide-ranging conversation about goals, potential obstacles, community supports, growth milestones and anticipated changes over time.

This form of planning requires supporting people to explore their options, understanding their long-term aspirations, linking paid and non-paid supports to those aspirations, and thinking about the trajectory of their lives. This type of planning does not always get into the details of how services are to be delivered on a day-to-day basis but instead tackles bigger issues like where and with whom to live or work, and how to make the transition happen smoothly. It also can be done by the person or a member of their circle of support, through private facilitators, or public support coordinators.

Ongoing and/or Periodic Person-Centered Service Planning

A more routine form of person-centered planning for people receiving HCBS occurs at least yearly as required by CMS. Some states may require more frequent person-centered plans depending on the population. Periodic person-centered service planning is convened by a case manager or coordinator, or public human services agency to review the allocation of public resources, assess progress, determine whether the service and support mix continues to meet the person's needs, initiate or update a specific service, or respond to a change in the person's life. This service planning process should have continuity with prior services planned and delivered and should, to be person-centered, be driven by the person receiving services, with acknowledgment for service system dynamics and specific provider experiences and availability. Person-centered service planning should reflect the ongoing incorporation of learning by all members of the person's circle. The anticipated duration of existing service plan goals and objectives should also inform the frequency of plan updates.

The format, content, and frequency of this form of planning is usually dictated by regulatory or policy guidance from a public agency (see Croft, et al., 2020). Person-centered service plans cover the provision of paid supports but should also take into consideration the availability of unpaid supports and personal strengths. Yearly person-centered service plans should also provide any specific services and supports linked to a person's long-term goals (e.g., those identified in a plan developed in response to significant life events as described in the section above).

Aligning the Plan with the Individual Circumstances

Because of the comprehensive nature of significant life event planning and the amount of time, attention and introspection required, plans for significant life events by definition should not occur on a set schedule (e.g., every year) but rather at important junctures in the person's life. This form of planning is at one end of a continuum, and routine yearly person-centered service planning is at the other end. To ensure plans are person-centered, the trick is to determine when some of the more in-depth planning elements should be infused into a plan and under what circumstances. People's lives rarely shift on a set schedule determined by a human service agency, necessitating flexibility and fluidity in both the planning and oversight processes to ensure that the system's demands don't undermine the person-centeredness of the planning.

Determining the point on that continuum should depend on the immediacy of needs, changes in the person's situation and/or aspirations, and the nature of the planning process favored by the person. For instance, if a person is receiving only a few hours of support a week to meet their needs, and if their goals and support needs are unlikely to change over time, their plan should be brief and to the point.

One of the important requirements for the plan is that the person knows how to signal that their needs have changed. If the change is equivalent to a major life transition, the person and their circle of support including the service coordinator may agree that a significant life event planning approach may be necessary. The bottom line is that the content and duration of the planning process should be person-centered in that it takes into account the unique context surrounding the person. The challenge going forward is to ensure that the person-centered plan neither overwhelms nor underserves the beneficiary of the plan.

Other Important Considerations

There are some key additional considerations to ensure that the person-centered planning process results in outcomes that are consistent with the person's goal and needs. The first is monitoring to ensure that the planning process is appropriate to the scope and complexity of needs and that the supports in the plan in fact align with the person's needs. Further, are the supports as envisioned available? Can they be implemented as anticipated? Will they lead to desired results?

Second, regardless of the planning process employed, many people cannot "lead" their plan unless they are supported to lead. This means that the person-centered planning process in many instances should start before the actual plan is discussed to make sure that the person understands their role, the issues they want discussed, any boundaries they want to uphold, and what their hoped-for outcomes are.

Third, aspirations in the person-centered plan should not just be exhortations but should be linked to supports and services that are likely to result in success. Those who support people during the planning process should be wary of making commitments that have very little chance of being honored given the support and service mix proposed.

Promising Practices

The person-centered planning process must include people chosen by the person. Therefore, plans should document exactly who is part of the person's inner circle and the roles they play in the person's life.

In order to "right size" the planning process based on individual needs and preferences, there are some promising practices that case managers and other supporters might consider. The goal would be to allow the person to influence how extensive the process will be. Further, the process should relieve the person from having to "tell their story" over and over.

Some potential approaches include:

- Pre-populating information from the initial assessment into the person-centered plan template in order to avoid going over the same ground during each planning session.

- Reviewing the current planning and eligibility process to determine those threshold questions that are important to determine eligibility for services, the level of services and supports the person needs, and the content of the Person-Centered Support Plan. These questions may cover a range of domains such as activities of daily living, memory and cognition, and challenging behavior. As part of the foundational questions, people should be offered the opportunity to self-direct and to seek employment.
- If people are interested and willing to provide more personal information, developing a set of questions including such issues as volunteering, training, preferences for support for activities of daily living (e.g., bathing, dressing, eating), interest in becoming a self-advocate, and how to help your caregiver.
- Creating a module for people who choose to share their "personal story."
- Working with the person in anticipation of the planning process in order to ensure that they understand what information will be shared and whether they want to volunteer to share any additional personal information.

This tiered approach should generate the information necessary to create a person-centered plan as well as a framework that allows people to pick and choose the information they choose to share.

Conclusion

There are several steps that public managers, self-advocates, advocates, and others can take to ensure that the plan fits the needs of the person:

- State regulations and guidelines should emphasize the elements that should be part of any plan but also lay out the options for duration, frequency, and content, etc. along the continuum of planning formats.
- Plan facilitator training should provide a discussion of the criteria to be applied in each circumstance prior to arriving at a planning format including consultation with the person.
- Feedback from people who use plans – including and especially people with disabilities and other support needs – should be gathered to understand what is working and what is not working in the planning process and identify areas for improving the relevance and appropriateness of plans.
- Plan review processes should include assurances that plans are in fact tailored to the particular context of the person and that the plan supports realistic expectations and desired outcomes.
- People should be supported to lead their own plans with access to information, assistance, and guidance before the planning event.

This discussion is premised on the assumption that there is no one-size-fits-all approach to person-centered planning. It is also critical to regard all planning as perpetually moving forward in time and being updated and revised. No new plan should occur in isolation from prior efforts nor should elements of time limit the revising of goals or changing strategies per the person's wishes. Though all plans should be governed by the values of choice, inclusion, and empowerment, they should reflect the specific circumstances of the person. If the plan is no more than a check-in, then the process – and the plan – can be brief. At the other end of the spectrum, if the person has or is about to experience a significant life event (a new stage of life, a traumatic event, a complex health challenge), then the process should be as comprehensive as necessary to address the person's needs and priorities. Further, the extent and content of the plan should reflect the desires of the person. It should consider the person's comfort level with repeated self-disclosures and tolerance with the duration of the planning event.

Appendix

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About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS) to help States, Tribes, and Territories implement person-centered practices. It is administered by the Human Services Research Institute (HSRI).

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