NCI-IDD NATIONAL CORE INDICATORS PEOPLE DRIVEN DATA

How person-centered practices are related to better outcomes for people with intellectual and developmental disabilities: The critical role of case managers

NCI recently published a peer-reviewed article on the effects of person-centered planning and practices on the health and well-being of adults with intellectual and developmental disabilities. This brief summarizes the report, with emphasis on the critical role of case managers. To read the full report, click here.

Abstract

Background: Person-centered practices (PCP) are considered a best practice for developing person-centered service plans. PCP in service planning are driven by service users':

- Individual preferences
- Needs
- Priorities

US policies require state systems to adopt PCP. These policies apply to any home and community-based service setting. However, there is not enough research on how PCP impact outcomes for service users. This study aims to address this gap. This will be done by studying the relationship between PCP and outcomes for adults with intellectual and developmental disabilities (I/DD) who use state-funded services.

Methods: Data for this study comes from the 2018-19 National Core Indicators® In-Person Survey (NCI). The NCI links survey responses with state records. This study includes a sample of 22,000 adults with I/DD getting services from 37 states. We used multi-level regression to look at user experience with PCP & outcomes.
We studied 5 outcome measures:

1. Choice and control over life decisions
2. Everyday choices
3. Satisfaction with community inclusion
4. Self-reported health
5. Whether a person feels their services are helping them to have a good life

We studied 4 measures of PCP:

1. Does your case manager/service coordinator ask what you want?
2. Are you able to contact your case manager/service coordinator when you want to?
3. Were you able to choose the services that you get as part of your service plan?
4. Does your service plan include things that are important to you?

Results and Future Directions: There is a strong relationship between better outcomes and the PCP measures. In particular, participating in developing service plans was positively associated with all five outcomes. This study adds to the evidence of PCP as a best practice. This study also shows the value of linking survey data and state records to have a better picture of person-centered practices. Some of the call to action of this study are for stronger policy and training for PCP in state DD systems. This should include paid support staff as well as case managers.

Introduction

In 2014, the Centers for Medicare and Medicaid Services (CMS) released the HCBS Final Settings Rule, which outlines requirements for home and community-based services (HCBS) settings and person-centered planning (PCP). The National Quality Forum report on Person-Centered Planning and Practices defines person-centered practices as "planning, providing, and organizing services rooted in listening to what people need and want in order to more deeply connect them with their own care." A recent environmental scan of more than 300 studies examining person-centered planning found that there are still gaps in research on the impact of PCP; in particular, research on the association between PCP and person-reported outcomes and satisfaction with the planning process is needed. This study seeks to address some of the gaps by answering the following question: For people receiving state LTSS services, how is the experience of person-centered planning and practices related to self-reported outcomes such as health, well-being, community inclusion and choice-making?

Methods

This study used data from the 2018-2019 National Core Indicators® In-Person Survey, or NCI IPS. The NCI IPS links survey responses with administrative records for adults with intellectual and developmental disabilities (IDD) receiving services from their state developmental disabilities systems. The 2018-2019 sample includes over 22,000 adults with IDD from 37 states. The sample was skewed toward males (57%) and non-Hispanic Whites (73%). Slightly over one-third (38%) lived in a congregate setting and the rest lived in either their own home (17%), a relative's home (38%), or a foster/host home (8%).

This study used responses from four survey questions to evaluate whether a person had experienced person-centered planning and practices:

- Does your case manager/service coordinator ask what you want?
- Are you able to contact your case manager/service coordinator when you want to?
- Were you able to choose the services that you get as part of your service plan?
- Does your service plan include things that are important to you?

A large majority of those surveyed reported that their case manager asks them what they want (89%), that they can contact their case manager when they want (88%), and that their service plan includes things that are important to them (91%). However, just 73% reported that they were able to choose the services they get as part of their service plan.

To explore whether people had positive person-reported outcomes of health, well-being, community inclusion and choice-making, we used five outcome measures. Three of the outcome measures are scales, where responses to questions on similar topics are summed together and scored on a scale of 0 to 1. The scales are:

A) Life Decisions scale
- *Who chose (or picked) the place where you live?*
- *Did you choose (or pick) the people you live with (or did you choose to live by yourself)?*
- *Do you choose (or pick) your staff?*
- *Who chose (or picked) the place you work?*
- *Who chose (or picked) your day program or workshop?*

B) Everyday Choices scale
- *Do you choose what you buy with your spending money?*
- *Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?*
- *Who decides how you spend your free time (when you are not working/in school/at a day program)?*

C) Satisfaction with Community Inclusion scale
- *Think about how often you went out [see list of topics below] in the past month. Would you like to go out for entertainment more, less or the same amount as now?*

Shopping	*For entertainment*
Out to a restaurant or a coffee shop	*To a religious service or spiritual practice*

- *Do you want to be a part of more groups in your community?*

The mean scores for the outcome measure scales are: 0.65 for the Life Decisions scale, 0.88 for the Everyday Choices scale, and 0.60 for the Satisfaction with Community Inclusion scale. This means that the average person reports making decisions on approximately 3 of the 5 areas of the life decisions scale and at least 2 out of 3 areas of everyday choices scale. For satisfaction with community inclusion, the average person reports satisfaction with approximately 3 out of the 5 areas of the scale. The remaining two outcome measures are single item measures, asking people to report if their services are helping them to live a good life and how they rate their overall health. A large majority of those surveyed reported that the services and supports they receive help them live a good life (92%), while 67% reported their overall health as very good or excellent.

Results

For each of the five person-reported outcome measures, we examined the associations with experiences of person-centered planning using multivariate regressions. In other words, we looked at whether the experience of person-centered planning and practices was associated with better outcomes. These analyses allowed us to control for the effects of demographic and service characteristics, such as age, gender, residential setting, etc. For the scaled outcome measures, the graphs below display the percent change in expected scale score for those who reported the experience of person-centered planning compared to those who do not. In other words, each dumbbell in the graphs displays the change in expected outcome status when person-centered practices are present. For the single item outcome measures, the graphs show the odds ratio, or the likelihood, of reporting the outcome among those who experience person-centered practices compared to those who do not.

Figure 1: Percent change in expected Life Decisions Scale score with self-report of person-centered practices.

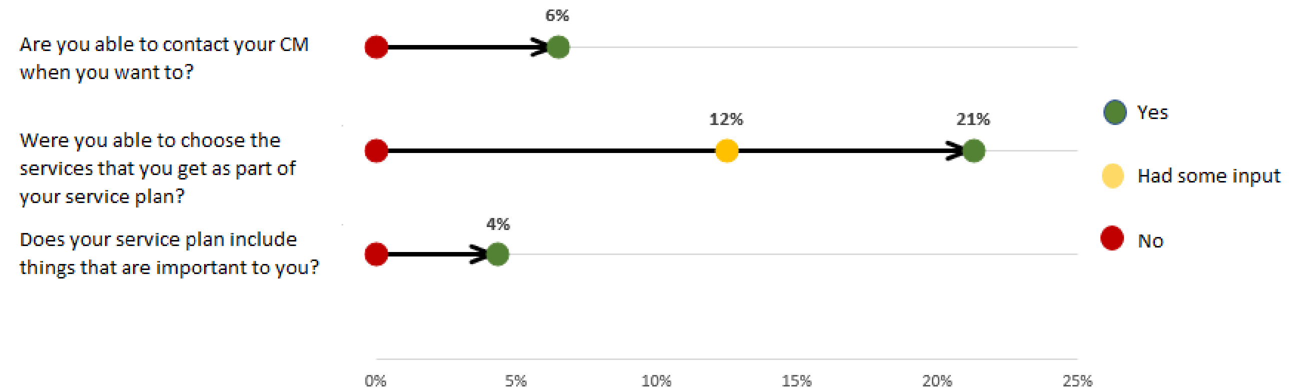


Figure 1 shows the associations between the Life Decisions Scale score and various person-centered practices variables. Controlling for all other variables, whether a person chose the services that they get as part of their service plan, there is change in expected scores both for those who report they made the choice (21% increase) and those who report they had some (but not total) choice (12%).Being able to contact your case manager when you want to and having a service plan that includes things that are important to the user is associated with a 6% and 4% change, respectively, in expected score on the Life Decisions Scale.

Figure 2: Percent change in expected Everyday Choices Scale score with self-report of person-centered practices.

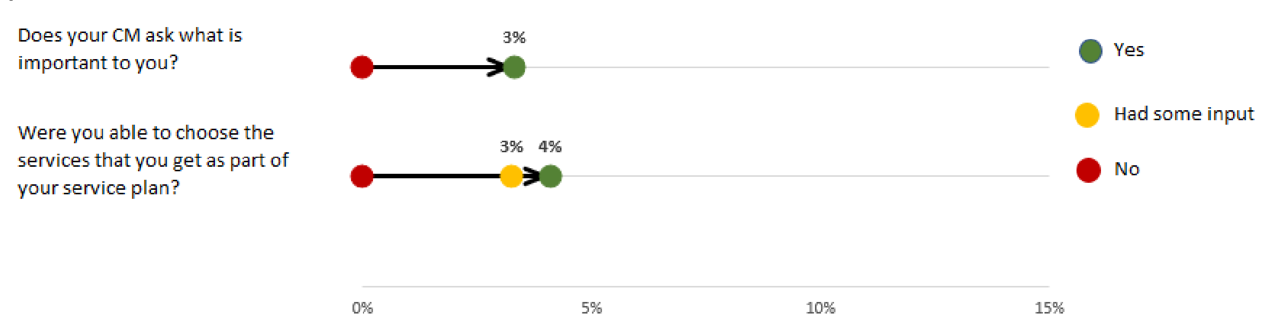


Figure 2 shows the associations between the Everyday Choices Scale score and various person-centered practices variables. Controlling for all other variables, having a case manager ask what is important to a user is associated with a 3% change in expected score, and being able to choose the services that they get is associated with a 3% and 4% change in expected score for those who had some choice and those who made the choice themselves, respectively.

Figure 3: Percent change in expected Satisfaction with Community Inclusion Scale score with self-report of person-centered practices.

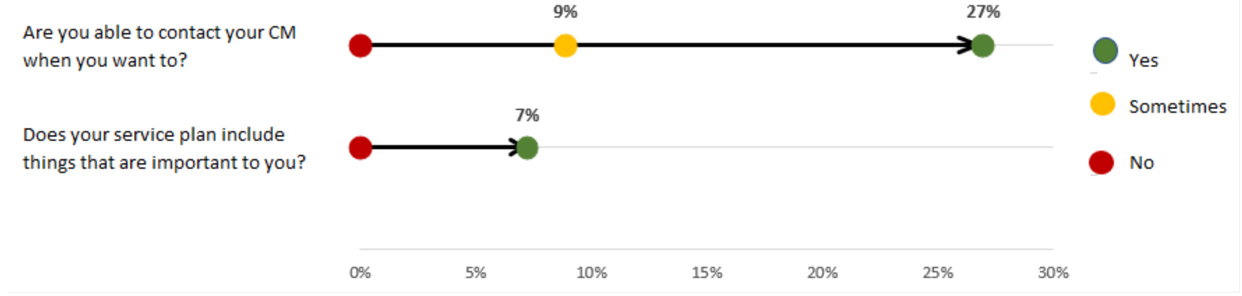


Figure 3 shows the associations between the Satisfaction with Community Inclusion Scale score and various person-centered practices variables. Controlling for all other variables, being able to contact the case manager when the user wants to is associated with a 27% increase in the expected scale score. There is also an association with only sometimes being able to contact the case manager, with a 9% change in expected scale score compared to those who cannot contact their case manager. Further, having a service plan that includes what is important to the user is associated with a 7% change in expected scale score.

Figure 4: Change in odds that services help person life a good life with self-report of person-centered practices.[1]

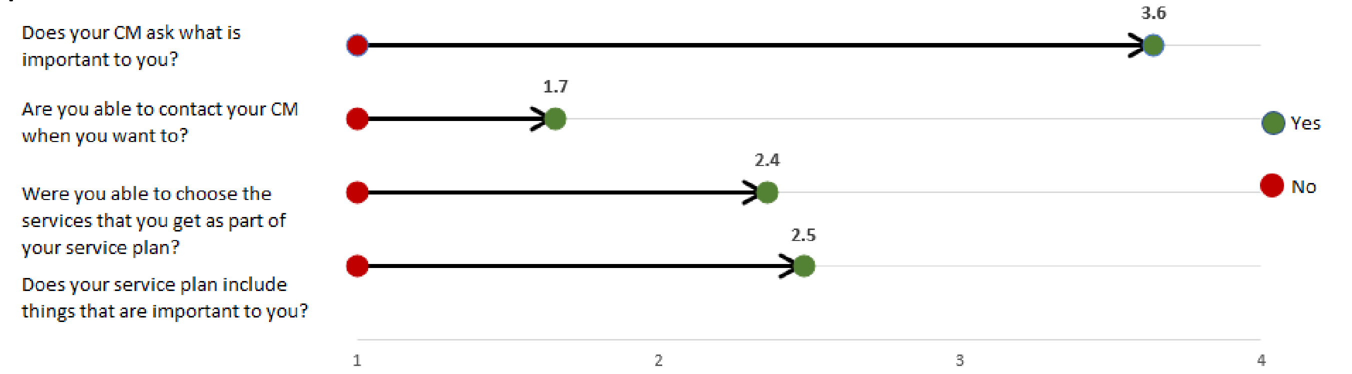


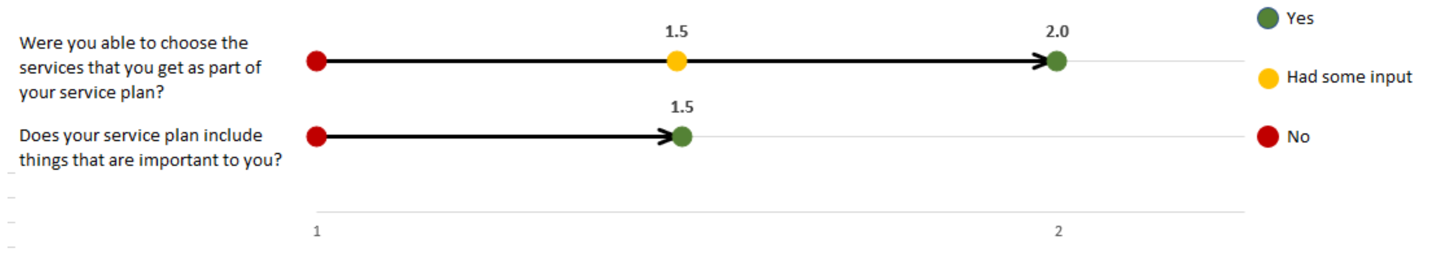
Figure 4 shows the associations between a person reporting their services help them to live a good life and various person-centered practices variables. Controlling for all other variables, the likelihood that a person reports their services help them to live a good life is 3.6 times higher among those who report that their case manager asks what is important to them, compared to those whose case manager does not ask that. Likewise, the likelihood of reporting services help a person life a good life is 1.7 times higher among those who are able to contact their case manager when they want to, 2.4 times higher among those who were able to choose what services they get as part of their plan, and 2.5 times higher among those whose service plan includes things that are important to them.

Figure 5 shows the associations between a person reporting their health as very good or excellent and various person-centered practices variables. Controlling for all other variables, the likelihood that a person reports their

[1] For the question of "were you able to choose the services you get as part of your services plan," the "some input" response option has an odds ratio of 1.0, the same as the reference category of "no" so is not displayed.

health as very good or excellent is 2 times higher among those who report that they were able to choose the service they receive as part of their service plan, compared to those who were not. Even those who had *some* input into their service planning process have 1.5 times higher odds of reporting their health as excellent or very good compared to those who do not get to choose their services. Lastly, those who report that their service plan includes the things that are important to them have 1.5 times higher odds of reporting their health as excellent or very good.

Figure 5: Change in odds of very good or excellent health with self-report of person-centered practices.



Conclusion

Taken together, these results provide strong evidence that experiencing person-centered planning and practices is consistently associated with better outcomes. Even more surprising was that even when service users did not personally participate in the planning meetings, there was still an association between the case manager asking users what is important to them and better outcomes for users.

There is a spectrum of person-centered practices, and this research suggests that even the smallest of steps towards person-centered planning, such as asking people what is important to them, is still associated with better outcomes. If you go further along that spectrum and ensure that services users make their plans, there is an even stronger association with better outcomes. This research has several implications. First, while many trainings for case manager do include information on person-centered planning, person-centered thinking and practices in person-centered plan development is not always implemented. Enhanced training and assessment of the implementation of person-centered practices in case management should be supported. Second, meaningful person-centered planning is a resource intensive effort, and this has implications for case load size for case managers. Put simply, if case managers have too many users to support with person-centered planning and practices, there can be negative impacts on the likelihood of implementing person-centered practices and consequently, a potential negative impact on outcomes of those receiving services.