Factors Affecting Participant Engagement in the Design and Implementation of Public Programs: Lessons from Cash & Counseling

A Research Issue Brief from the
National Resource Center for Participant-Directed Services

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Federal funders often require that individuals in need of services be engaged in the design and improvement of public programs, and this expectation is most recently evident in the newest acute and long-term service and support models found within the Affordable Care Act. The following research issue brief summarizes the findings of a three state in-depth study on participant engagement practices within Cash & Counseling programs. The programs examined were diverse in length of existence, enrollment size, populations served, and engagement practices. According to this research, multiple factors influence the perceptions of state employees, advocates, and program participants pertaining to the meaningfulness of engagement and its related outcomes. Various person, process, and environmental factors influence outcomes, whether they be positive (e.g., improved program design, knowledge, and advocacy) or negative (e.g., unsuccessful, time intensive, and conflict-ridden). While focusing on the experiences of Cash & Counseling states, this research provides a strong foundation for understanding and implementing meaningful and effective engagement practices in the design and improvement of a broad range of public programs and policies.

Background

For decades, policymakers and state employees administering public programs have been called on by their peers, federal funders, and advocates to involve individuals receiving services in the design and improvement of programs. While many grants, including grants funded by federal agencies (e.g., the Centers for Medicare and Medicaid Services) and private foundations (e.g., the Robert Wood Johnson Foundation) require stakeholder engagement in funded activities, states are often challenged with initiating and sustaining such activities as well as with creating approaches that are meaningful to both the state employees and the constituents engaged (Lomerson et al., 2007; Lowndes, Pratchett, & Stoker, 2001a, 2001b; Nemon, 2007; Parkinson, 2004a). The argument heard from many perspectives is that participant engagement is simply, "the right thing to do." Even so, a closer look at most programs finds engagement practices nonexistent or sporadic, despite assumptions about engagement benefits.

Cash & Counseling, a model tested vigorously in three states,[1] provides those in need of long-term supports with access to a self-directed individual budget for the purchase of supports in lieu of receiving services provided by an agency (Carlson, Dale, Foster, Brown, Phillips, & Schore, 2005). The original three states to receive Cash & Counseling grants as well as the subsequent twelve replication states were all required to engage stakeholders as they designed their programs. While some were successful, many more faced roadblocks (McGaffigan, 2011). A review of the literature provides very little insight as to the benefits of engagement, not to mention the ingredients to make it work (McGaffigan, 2011).

This issue brief is a product of the National Resource Center for Participant-Directed Services (NRCPDS). The mission of the NRCPDS is to infuse participant-directed options into all home and community-based services by providing national leadership, technical assistance, training, education and research to improve the lives of people of all ages with disabilities. This research issue brief summarizes the results of an in-depth

[1] Original three states were Arkansas, Florida, and New Jersey. Twelve expansion states included Alabama, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia.

research study (McGaffigan, 2011) on participant engagement in the design and improvement of Cash & Counseling programs. It is intended to provide policymakers, program funders, advocates, and program participants with insights into the challenges faced and subsequent outcomes when developing and sustaining meaningful participant engagement practices. This research not only provides insights beneficial to Cash & Counseling programs, but findings also have broader implications for policymakers creating and improving a wide range of programs and for stakeholder groups seeking a seat at the policy table. Since this issue brief is intended to be concise and provide concrete recommendations based on the research conducted, those interested in learning more are urged to review the research methodology and findings in their entirety at http://scholarworks.umb.edu/doctoral_dissertations/55.

Research Methods

The research study examined three major areas as they relate to participant engagement within Cash & Counseling programs: 1) how, if at all, were program participants involved in the design and improvement of programs, 2) what were the factors that influenced engagement, and 3) what were the perceived outcomes of engagement from the state employee, advocate, and program participants' perspectives? A review of the literature found that the minimal research conducted prior to this study focused primarily on isolated engagement methods (e.g., the use of surveys, local forums, and committees) and mostly the perspectives of state employees implementing efforts (McGaffigan, 2011). Unlike previous research, this study utilized a two-phased, multi-method qualitative approach to examine a diverse array of engagement practices as well as the perceptions of state employees, advocates, and program participants pertaining to such practices.

In the first research phase, state employees overseeing the existing 15 Cash & Counseling programs[2] were surveyed to answer preliminary questions pertaining to their programs and participant engagement strategies. Eleven of the 15 states participated in the survey. From these 11 states, 3 states with varying levels of engagement practices (labeled as low, moderate, or high engagement programs based on the results of the survey) were chosen to participate in phase two of this research. In-depth analysis was then conducted at the state and program level, including semi-structured interviews with program employees, advocates, and program participants as well as a review of materials and in one case, direct observation. During the interviews, comparison programs with extensive engagement practices emerged in two of the three states, providing additional data on the factors of engagement and their outcomes. Given the sensitivity of the topic, each state and those interviewed remained confidential throughout the data collection and reporting process, and subsequently, are not named within this issue brief.

Research Findings

Existing Engagement Methods and Foci within Cash & Counseling Programs

The web-based survey (n=11 of 15 states) provided an informative inventory of Cash & Counseling programs' engagement methods. Seven of the 11 states engage program participants, and the majority of those who responded pointed to a mix of engagement practices. The most popular method was the use of public forums, with 6 of the 7 states reporting use of such venues. Second to forums in popularity were advocate meetings, advisory meetings, and individual interviews, with 5 states reporting the use of various combinations of such methods. Other methods less frequently reported included topic specific committees, surveys, and focus groups.

[2] In some states, there is more than one Cash & Counseling program. For the purposes of the survey, each state had one survey respondent complete the survey to represent all Cash & Counseling programs in their state.

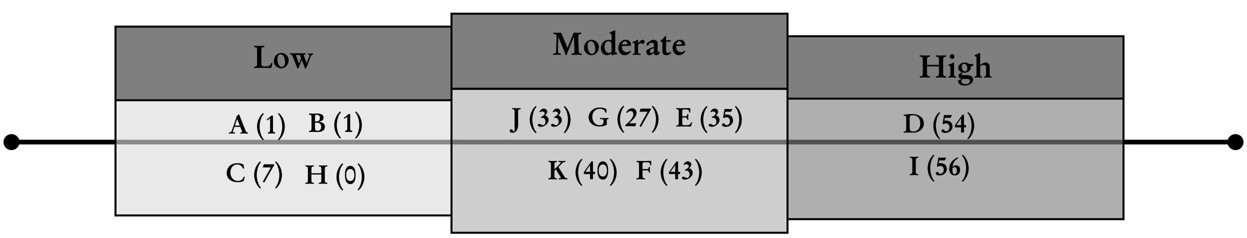
Six of the respondents reportedly engage program participants in the review of their own services and supports (e.g., the use of satisfaction surveys) while an additional mix of 6 respondents engage program participants in the design and/or improvement of program policies and procedures.

Existing Engagement Practices within Cash & Counseling Programs (Summary of Web-Based Survey Findings)	
12 of the 15 states responded (80 percent) 1 of the 12 refused to participate (n=11) 7 (63.6%) currently engage participants in the design or improvement of their programs	
Who?	Participants, caregivers, and advocates (various ages and disabilities)
How?	Public forums, advocacy meetings, advisory groups, committees, and individual interviews
What?	Feedback on services received; developing policies, procedures, tools, forms, and outreach methods
Why?	The participant's voice is valuable; be responsive to participants' needs and preferences; leads to creative thinking
Why Not?	Limited financial resources and time; can't find people interested; not needed at this time

Five of the respondents reported engagement of program participants in the design and/or improvement of program tools and forms, and 4 reported engagement in the design and/or improvement of outreach methods. Other, less frequent foci for engagement include the design or surveys, trainings, peer support, and larger systems change efforts. While the inventory provided the first glimpse into engagement practices across the Cash & Counseling programs, the self-reported data provided very little insight into the depth of such engagement, outcomes, and factors to success, all of which were further examined in phase two of the research.

An Overview of the Three States Chosen for In-Depth Analysis

In preparation for the in-depth analysis of engagement practices, each state that completed the web-based survey was given a letter (A through K) to maintain confidentiality. The survey results were tabulated for a total score based on all of the answers provided, with "0" equating to no engagement and "70" equating to the most extensive engagement practices.[3] Upon tabulation, states were placed into one of three categories relative to their peers: low, moderate, or high engagment. As seen in the chart below, 4 states scored between a "0" and "7" and were categorized as "low" engagment states; 5 states scored between a "27" and "43," placing them in the "moderate" engagement category; and 2 states, placed in the "high" catetgory, received a "54" and "56"respectively. Three states[4] participated in the in-depth analysis: State B (low), State K (moderate), and State D (high).



When conducting the in-depth research in State B and State K (low and moderate engagement programs respectively), a comparison program was identified in each state. Within State B, Initiative B-1 (the Cash &

[3] The survey tool was the first of its kind, and as a result had not been previously validated. The results of the survey were validated by the in-depth research conducted within the five programs (the Cash & Counseling programs plus two comparison programs) during phase two of this research.

[4] The three states chosen for the in-depth analysis were chosen based on their ability to represent the diversity of programs that exist across the nation, included diversity in geographic location, enrollment size, and populations served.

Counseling Program) had no formal mechanisms for engaging participants in program design and improvement. A separate personal assistance program, Initiative B-2 (later calculated as a "high" engagement program), was required by statute to utilize an Advisory Council to inform overall design and improvement as well as day-to-day operations. The differences in engagement within these two programs (administered by the same state agency) were well recognized by a Cash & Counseling program leader who stated:

> the best way that I can describe [our lack of engagement] to you is in comparison to another program we have… they have a Consumer Advisory [Council] and that [Council] actually has voting privileges; they vote on things and how they want their program to go. The State has final discretion, but [the Consumer Advisory Council is] heavily involved; they have committees that actually help to write the regulations for the program.

Initiative K-1's (the Cash & Counseling program classified as moderate) engagement efforts focused on program expansion, program improvements, and peer training while an initiative within the same state agency (Initiative K-2, later classified as a moderate to high engagement program) extensively involved stakeholders in the design of a controversial new funding protocol. One advocate described the difference between the two engagement models when s/he stated:

> There was definitely stakeholder involvement in [Initiative K-1]. It was a little smaller scale and a little less formal than what I just went through with [Initiative K-2]. That's why I'm kind of raving about [Initiative K-2] because every "i" was dotted and every "t" was crossed.

Before further explanation of the factors that set these programs apart, it is important to describe State D, the program labeled high engagement as a result of the survey. State D included program participants in both the design and improvement of a broad array of programs, including Cash & Counseling. A multi-stakeholder workgroup assisted in the design of the Cash & Counseling program, and once complete, State D relied on its existing Quality Council[5] to improve its program. According to a state employee working closely with the Council:

> It's just part of the recipe. It's the way it is… we're very participant-oriented. I really can't see it being any other way. It's just the way it's been, and it just makes sense… I don't think we could do what we do if we didn't have stakeholder involvement.

While the existence of engagement practices varied tremendously across the three states, employees from State D did not appear to understand how program design and improvement could effectively occur without engagement. Research conducted during phase two provides great insights into the factors that make engagement practices so different, not only from one state to the next, but from one program (within the same state agency) to the other.

Personal, Process, and Environmental Factors Influencing Engagement

A total of 23 semi-structured interviews conducted with state employees, advocates, and program participants were included in this analysis, allowing for a multi-perspective data collection approach that

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[5] Terminology used to describe various engagement mechanisms have been modified slightly to protect confidentiality.

spanned five programs within three states. This, along with a review of materials and direct observation of a two-day Council meeting conducted in State D, confirms that the existence of engagement practices and their subsequent outcomes are influenced by a large range of characteristics grouped into three major buckets: person, process, and environmental-driven factors.

Person-driven factors, built on a foundation of personal values and experiences, are the characteristics of state employees and program participants that can influence whether or not engagement occurs and its subsequent outcomes. There were common themes that surfaced throughout the research. For instance, state employees who were successful at engaging participants and other stakeholders were consistently described (across the state, advocate, and participant interviews) as strong communicators with a great deal of respect for participants and a high level of comfort with conflict. Program participants identified as effectively engaged during state, advocate, and participant interviews were valued for being well-informed (both of program practices and the larger policy context), strong communicators, and strong advocates (with often a caveat that they were also reasonable with their demands). These characteristics identified through the research, in addition to others, are described in more detail in both Box 1 and Box 2.

Box 1: State Employee Characteristics for Meaningful and Effective Engagement

- ✓ Strong and transparent communicators
- ✓ Clearly demonstrate respect for participants
- ✓ Able to pro-actively and constructively address conflict
- ✓ Emphasizes teamwork and de-emphasizes personal control
- ✓ Comfort and/or personal experience with disability

Box 2: Program Participant Characteristics for Meaningful and Effective Engagement

- ✓ Well-informed of program goals and related policies
- ✓ Strong communicators
- ✓ Strong advocates, yet reasonable and ready to partner
- ✓ Confident
- ✓ Able to devote time and effort

When turning to "how" program participants are engaged, the method (e.g., use of an advisory group, task force, forums, etc.) appeared less important than the actual decisions made pertaining to how such strategies would be implemented (e.g., process-driven factors). For instance, decisions pertaining to the extent to which program participants and other stakeholders are informed of program policies and practices as a pre-requisite to involvement, the frequency of meetings, and facilitation approaches were some of the factors influencing the meaningfulness of engagement and their ultimate outcomes. States with engagement practices found to be most meaningful, productive, and lasting were those that were intentional in the sharing of information while also scheduling meetings that were timely and influential. Also, such states were intentional in their facilitation practices, creating collaborative approaches that included participants in leadership roles and/or utilizing expert independent facilitators to support the process. Programs with the most extensive and well-recognized engagement practices also implemented transparent decision making processes. While those interviewed across the state, advocate, and participant lenses frequently recognized that the State was ultimately responsible for decisions, people believed that the input mattered, was heard, and was clearly used. Box 3 provides additional insights pertaining to process factors identified through this research.

Box 3: Process Factors Influencing Meaningful and Effective Engagement

- ✓ Clear purpose for participants' involvement, moving beyond influencing individual services to influencing program design, implementation, and improvement
- ✓ A mix of stakeholders engaged, with an emphasis on those actually receiving services and community advocates
- ✓ A match between meeting frequency and the windows of opportunity for influencing program policy
- ✓ Access provided to real time and accessible information to inform input received
- ✓ Clear and standardized approaches for identifying and addressing the accessibility needs of engaged participants
- ✓ Transparent communication protocols that support timely updates, discussions, and divergent opinions
- ✓ Deliberative facilitation strategies that include a partnering role for participants
- ✓ Transparent decision-making strategies that strive for consensus building
- ✓ Devotion of staff time and resources to make engagement successful

Environment-driven factors also play a role in the depth of engagement and subsequent outcomes. For instance, the transparency in government demanded by key public and executive-level officials played an important role in some of the high engagement programs. Also, the extent to which program managers and other state leaders wanted to see change in what they deemed was a "broken system" was also a driving factor. Often times, the expectations for involvement from external advocates and providers played a key role as well. While at least one program implemented extensive engagement practices with no additional resources when compared to its sister program, many pointed to the availability of financial and/or staffing resources as helpful in creating an environment supportive of engagement. The environmental factors most recognized throughout this research are represented in Box 4.

Box 4: Environmental Factors Influencing Meaningful and Effective Engagement

- ✓ Government climate that encourages transparency and collaborative decision making
- ✓ A desire for change from those within government and external stakeholders
- ✓ A culture in which the definition of "expert" includes those with lived experience in addition to those with professional experience
- ✓ Allocation of staff and financial resources to make engagement happen

It was a mix of these person, process, and environmental factors that created the unique setting in which engagement did or did not occur, the depth of engagement, and subsequently the outcomes. For instance, in State B, the Cash & Counseling program with low engagement was being managed by a state employee who was not well connected to the community being served and had no demand for such engagement from executive leadership or external advocates, leading to informal and sporadic practices. The state employee administering the moderate engagement Cash & Counseling program in State K implemented practices as a result of the state leaderships' expectations and the expectations of others, but implemented limited practices with minimal influence given his/her own assumptions pertaining to the program participants' expertise and a belief that his/her role was paramount in ensuring the appropriate use of publicly funded services. Initiative K-2, the high engagement comparison initiative to reform how services were allocated (administered by the same agency as K-1), was considered politically tumultuous by state leaders and advocates, and as a result, executive leaders appointed a state employee with extensive engagement experience and sensitivity, implemented collaborative and transparent communication and decision making practices, and met demanding timelines with products built through consensus.

Positive Engagement Outcomes

According to this research, factors of engagement play an important role in both positive and negative outcomes described by program participants, advocates, and state employees. Examples of positive outcomes (see Box 5 for a broad list) included: improvements in program policy design (e.g., addressing the needs of hard to reach populations); an increase in knowledge (not only program participants, but state employees as well); and advocacy for new program funding and/or sustaining funds for existing programs. Less tangible outcomes that were consistently communicated during the data collection process included the empowerment of program participants as well as the building of positive relationships between state employees and program constituents.

In State B, the manager administering the low engagement Cash & Counseling program (Initiative B-1) was clearly isolated as well as overwhelmed by all of the outstanding activities that were required, including the completion of a program manual outlining policies and procedures for participants. This person pointed directly to Initiative B-2's use of a Council to assist in the development of such tools and the benefits of this assistance. The state employee overseeing Initiative B-2 also recognized the productivity and the direct role the legislatively mandated Council played in program re-design. According to this state employee, "I gave them the task. I said, 'if we're going to redo the statute we're going to need new reg[ulation]s.'" As a result, the Council members were asked to "sit down and go through the reg[ulation]s line by line and make recommendations." The effectiveness of these engagement practices seemed apparent not only in the popularity of the program, but also in the partnerships developed and its long-term sustainability. According to this state employee managing Initiative B-2:

Box 5: A Sample of Positive Outcomes of Engagement

- ✓ Improved program design
- ✓ Increased knowledge (state employees and program participants)
- ✓ Program participant empowerment
- ✓ Advocacy for funding, design, and sustainability
- ✓ Relationship building; stronger public relations
- ✓ Program participant satisfaction

> [The Council members have] communicated with us; they've gone out and done public testimony. [The Council members have] sought out facts and figures that they could use when they went to the legislature around the budget cut situation… they took an active interest in the program… [The Council members have] understood how [the program] made a difference in their lives…

This same Council assumed a leadership role in the development of public relations materials that aided in sustainability. According to the state employee overseeing Initiative B-2, "[The publication] is something that a lot of legislators look forward to seeing each year, and it has been a great tool in getting us, or at least maintaining, financial support for the program."

A state employee implementing engagement practices within the State K's Cash & Counseling program (Initiative K-1, a moderate engagement program) discussed his/her own knowledge that has evolved with the engagement of program participants. The direct influence this has over program policy is evident in the following quote:

> I definitely liked what came out of [engagement] because I took for granted, in all honesty, not knowing probably as intimate[ly] as the consultant and as well as the actual advocate and the representatives. I just made the assumption, personally, that everybody had a computer in their house or had internet access, and they don't. You know, so... I, ______ was embarrassed just to assume that everybody had computer in their house and internet access... [leading to expectations and the design of practices dependent on electronic communication].

In State K (Initiative K-2), it was the economic crisis and the risk of drastic cuts that sparked the advocates' desire to invest in collaboration with state policy and program leaders, ultimately making the process meaningful and productive. According to one advocate:

> I think that basically most of us have felt that what has been coming down the pike for us has been managed care and we saw [Initiative K-2] as... I'll just be very honest, a last ditch chance to provide an avenue that might be other than managed care... there needed to be a project that would have accountability and predictability and that this model would be it and therefore we were all very, very highly vested in it. Like I say... it was a real coming together, probably the best that I've seen of any project that I've ever been part of.

This same advocate recognized the person-driven factors when describing the state employees engaged in the process when s/he stated:

> [Initiative K-2] was very good because other times people [were] all set in what they were going to do, but this time [the state employees] wanted our input... they did not want to make the wrong [decision]... they had people around the table that deal with people with disabilities... they were covering all their bases... they wanted to do a good job.

Negative Engagement Outcomes

Research also highlighted times in which engagement had less than successful outcomes (see Box 6). For instance, some described engagement efforts that had little or no impact (e.g., a project was initiated, but not completed or recommendations were provided, but not influential), required too much time and resources, and/or led to an increase in frustration and conflict between state employees and stakeholders. Those interviewed consistently pointed to person, process, or environmental factors that were influencing outcomes. In State K, an advocate described person-driven factors that stood in the way of successful engagement. According to this individual:

> If [participants] don't understand the process, [they can] get impatient if they have to go through some of the basic governmental processes... some people just didn't want to have any of [the change proposed] if [they] couldn't have it all. And, at one point, one of the Senators... pretty much refused to talk to anybody because [they] were 'off the wall."

An advocate from State B discussed an engagement process for which the communication and decision making practices were unclear, leading ultimately to frustration, future distrust, and assumed little to no impact. According to this person, the process:

> included 40 to 50 people, some folks with disabilities, provider agencies, the universities, disability [advocates]—[and we met in] five hour meetings, told [the State] what we thought, and then they basically wrote... a plan and presented it to us and didn't ask for our opinion... it was pretty much reams upon reams of paper of what they're already doing...

Box 6: A Sample of Negative Outcomes of Engagement

- ✓ Can Have No Impact or be Unsuccessful
- ✓ Requires Significant Time and Resources
- ✓ Leads to Frustration and Conflict

State D provided a clear example of when process factors, more specifically practices for choosing who is involved, can influence engagement outcomes. The Quality Council was intended to oversee all of the programs, including agency and participant-directed services. As a result, those representing the participant direction viewpoint were in the minority on the Quality Council. Also, some of the program participants representing the participant direction voice on the Council had minimal knowledge pertaining to the philosophical underpinnings and basic tenets of participant direction. One result was the selection of topics and the identification of solutions and products that were provider-centric. For instance, the Quality Council decided to mandate training for all workers, regardless of whether or not they were agency or participant-directed (an approach that is highly debated and often in conflict with participant direction philosophy). Also, the Quality Council informed the development of a brochure outlining existing services, ultimately focusing on agency services and providing very little information on the participant direction option.

Conclusion

This two-phase, multi-method research study examined engagement practices existing within Cash & Counseling programs. In-depth analysis within three states led to the identification of person, process, and environmental factors that influence engagement practices and subsequent outcomes. While some of the factors may be more malleable than others, our research indicates that careful planning of engagement practices can lead to highly valued results for not only state employees, but for programs and participants as well. Informed by this research, state employees can be aware of the role their personal values and experiences can play in the determination of engagement processes and related outcomes, and similarly, the impact of the values and experiences of others who are engaged. Stakeholder engagement is a complex topic that requires significant awareness of self and environment as well as intentional decision making pertaining to process. The end result can be streamlined program design, satisfied stakeholders, and sustained programs (to name a few). Given conflicting priorities and budget constraints, participant direction experts and funders should guide and support states in their creation of meaningful, effective, and efficient participant (and broader stakeholder) engagement strategies as they design and improve their programs.

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