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IT'S NOT SO SIMPLE:  
UNDERSTANDING PARTICIPANT INVOLVEMENT IN THE DESIGN,  
IMPLEMENTATION, AND IMPROVEMENT OF  
CASH & COUNSELING PROGRAMS

A Dissertation Presented

by

ERIN MCGAFFIGAN

Submitted to the Office of Graduate Studies,  
University of Massachusetts Boston,  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

December 2011

Public Policy Ph.D. Program

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## ABSTRACT

# IT'S NOT SO SIMPLE: UNDERSTANDING PARTICIPANT INVOLVEMENT IN THE DESIGN, IMPLEMENTATION AND IMPROVEMENT OF CASH & COUNSELING PROGRAMS

December 2011

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Directed by Professor Donna Haig Friedman

For more than three decades, the United States federal government and the states have worked to restructure the long-term care system to be more community based and responsive to personal preferences. Some argue that those who seek such services should be actively engaged in their design (Morris, 2008; Priester, Hewitt, & Kane, 2006). While many who design and implement home and community-based services may believe that participant engagement could be beneficial, most plans move forward with little to no

provision for such engagement. The existing literature provides very little insight into the implications of such decisions.

The Cash & Counseling model is one community-based option being implemented in states as a result of a growing demand for personal choice and control in long-term services and supports. Through this model, individuals receive control over a budget allotment in lieu of agency-provided personal care. They are able to hire friends, family, and neighbors as workers as well as to purchase goods and services to assist them to live as independently as possible in the community. As with other community-based programs, the extent of participant engagement varies within Cash & Counseling programs, and there is little understanding of the methods adopted, the outcomes produced, or the factors influencing success.

This study utilized a multi-method qualitative approach to examine participant engagement strategies found within Cash & Counseling programs. Through a web-based survey of program administrators, key informant interviews with national experts, and in-depth semi-structured interviews with state staff, advocates, and program participants within three states, an understanding of existing engagement methods, influencing factors, and perceived outcomes has emerged. This research indicates that there are a multitude of interdependent factors influencing engagement that are specific to the processes utilized, persons involved, and environments within which the engagement takes place. Results of this study are useful to policymakers as they make decisions to fund, design, and improve Cash & Counseling programs, and to program participants and

advocates who seek a role at the policy table. Findings may also provide valuable insights to other public policy domains for which stakeholder engagement is of interest.

## DEDICATION

This work is dedicated to my husband, Dan, and my two boys, Patrick and Liam. If not for your patience and unconditional love, this work would not have been possible. I am forever grateful to have all three of you in my life. This work is also dedicated to all of the women in my life, physically and spiritually, for believing in me and paving my way. It is your influence that has pushed me to believe that having everything is, indeed, possible.



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## CHAPTER 1

### INTRODUCTION

Substantial advocacy within disability and aging movements and the landmark 1999 *L.C. vs. Olmstead* Supreme Court decision have led to the deinstitutionalization of elders and people with disabilities and the expansion of publicly funded home and community-based services and supports (Morris, 2008; National Council on Disability, 2003; Research Triangle Institute, September, 2009). As people with disabilities live longer and the aging baby boomer generation retires, there is a need for innovative ways to provide community-based, long-term supports. There is growing expectation that such models be individualized, flexible, and address the worker shortage faced by those who require long-term services and supports (Johnson, Toohey, & Wiener, 2007). There is also an expectation from some funders that stakeholders, including program participants, be involved in the actual program design and improvement process (Bergman, Ludlum, O'Connor, Starr, & Ficker Terrill, 2002; Lomerson, McGaffigan, O'Connor, & Wamback, 2007; National Association of State Units on Aging, 2008; Research Triangle Institute, 2008; Priester, Hewitt, & Kane, 2006).

### *Goals of the Study*

The purpose of this research study was to understand the strategies used, and the impact of, participant<sup>1</sup> involvement in the design, implementation, and improvement of public policy (more specifically, the Cash & Counseling model). It is critical to understand why some state staff choose to implement participant involvement strategies (and in these circumstances, what such practices look like) and why some did not. Benefits and challenges of participant involvement strategies in light of these factors were also examined.

Many individuals believe that participant engagement is just simply “the right thing to do.” This research is intended to move beyond a moral argument for participant involvement by supporting decision makers to make informed, evidence-based decisions as they consider if, when, and how to engage participants in the design, implementation, and improvement of their programs. Results of this study are intended to inform federal and state staff, program funders, community advocates, and program participants of the person, process, and environment-based factors that influence the use of participant involvement strategies as well as the outcomes that can result.

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<sup>1</sup> This term will be used throughout this paper to describe those who receive publicly funded long-term home and community-based services. This term includes individuals with diverse disabilities (e.g. physical, developmental, mental health) as well as elders. Although it is assumed that “participants” are currently receiving publicly funded services, there may be a group of such individuals who are included in this term who may not be receiving services currently, but may very well in the future. Sometimes, participants heavily rely on the support of loved ones to assist them in their daily lives, and because of this, such caregivers may also at times be included when this term is used. While the term, “participant” will be used most often for this study, other terms such as “stakeholder,” “consumer,” and “service users” are often used to describe the same group of individuals.

### *The Cash & Counseling Model*

Cash & Counseling is one unique community-based service delivery model that is intended to address the growing worker shortage and the rigidity of personal care services provided by agencies to elders and people with disabilities (Dale, Brown, Phillips, & Carlson, 2005). Cash & Counseling, a model tested vigorously in three states and expanded to twelve additional states,<sup>2</sup> 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 model is intended to increase access to home and community-based supports and decrease utilization of facility care by allowing people more choice and control over who they receive

**Figure 1: Cash & Counseling Design Elements**

**Cash & Counseling Design Elements**  
(NRCPS, 2009)

- ❖ Informed Decision-Making
- ❖ Surrogate Option
- ❖ Person-Centered Planning and Assessment Process
- ❖ Transparent and Equitable Individual Budgeting Process
- ❖ Methods to Address Potential Conflicts of Interest
- ❖ Participant Involvement in Program Design and Implementation
- ❖ Consultant Services
- ❖ Financial Management Services
- ❖ Quality Management System

support from as well as how and when such care is provided (see Figure 1 for a list of Cash & Counseling design elements). A thorough randomized study of the model conducted in the three original states has documented the model's success in increasing access to community-based supports, increasing participants' satisfaction and quality of life, decreasing hospitalization, and decreasing nursing home utilization while

---

<sup>2</sup> 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.

demonstrating no increase in fraud and abuse of public services (Carlson, Dale, Foster, Brown, Phillips, & Schore, 2005).

Individual budgets utilized by Cash & Counseling participants are based on functional need or past utilization of care and are used by participants to hire workers (often friends, family, and neighbors) and/or purchase goods and services (e.g., home and vehicle modifications, washer machines, microwaves, or transportation) that allow them to live as independently as possible in the community. To administer their budget, individuals receive support from a consultant who provides guidance on program rules and training related to managing a budget and overseeing workers. They also receive financial management services to address legal and tax responsibilities associated with hiring workers as well as to provide assistance and monitoring in the area of purchasing goods and services.

Cash & Counseling is most often implemented as a Medicaid model,<sup>3</sup> requiring specific design features to receive federal funding. Even so, there is some room for variability in implementation methods at the state level, such as decisions pertaining to target population, size of individual budgets and allowances and decisions about who one can hire and what they can purchase. The National Program Office, administered by the Boston College Graduate School of Social Work, assisted the three original states and 12 expansion states to develop their programs via grant funding from the Robert Wood Johnson Foundation and the United States Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Although the funding for

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<sup>3</sup> More recently, this model has been expanded within states to serve elders and veterans utilizing non-Medicaid funds.

these states is exhausted, a relationship among existing Cash & Counseling states and what is now referred to as the National Resource Center for Participant-Directed Services (NRCPDS, previously the National Program Office) continues to exist. Additional states also seek assistance from the NRCPDS as they implement new Cash & Counseling models through new funding sources, such as the Older Americans Act and the Department of Veterans Affairs (Administration on Aging, 2009).

### *Participant Engagement*

With the need to develop innovative service delivery options to support the growing aging and disability population living in community settings, there has been a push at the federal level (with some pressure at the state and local level) to involve users of services in the design and implementation of models (Bergman, Ludlum, O'Connor, Starr, & Ficker Terrill, 2002; Lomerson, McGaffigan, O'Connor, & Wamback, 2007; National Association of State Units on Aging, 2008; Research Triangle Institute, 2008; Priester, Hewitt, & Kane, 2006). The target for this engagement is mostly individuals who receive publicly funded services and their family members. As a result, those targeted for engagement tend to be low income and most often experience barriers to community participation.

Often, state staff<sup>4</sup> are sandwiched between grassroots disability advocates and federal funders who pressure them to involve program participants in the design of policies and programs. The underlying premise for this involvement is that it is simply, “the right thing to do” given that users of services have direct experiences that should

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<sup>4</sup> The term “state staff” will be used throughout this paper to describe those who are responsible for the design and implementation of state programs that provide home and community-based services to elders and/or individuals with diverse disabilities.

influence how their services are designed. State staff involve program participants to varying degrees with varying outcomes. Some state staff point to anecdotal stories of how involving participants yields positive results while others point to limited time, resources, and a lack of “know how” to make participant engagement work. While the Cash & Counseling states have been encouraged to involve stakeholders in the design of their programs, there is little documentation of states’ efforts to do so, or of the impact of such actions on program design or outcome. For example, prior to developing the model in the three original Cash & Counseling states, focus groups were held with potential participants to determine their interest in a budget model and the supports they would need to participate (Simon-Rusinowitz, Marks, Loughlin, Desmond, Mahoney, Zacharias, Squillace, & Allison, 2002; Zacharias, 2000). During the evaluation phase, interviews and focus groups were also utilized to understand the experiences of participants, their loved ones, workers, and consultants (Simon-Rusinowitz, Loughlin, & Mahoney, 2006). Beyond these attempts, there has not been a systematic review of involvement strategies deployed by state staff developing or improving their Cash & Counseling programs. Further examination of involvement methods and associated outcomes is warranted to allow state staff to make informed decisions pertaining to involvement practices.

## CHAPTER 2

### PARTICIPANT ENGAGEMENT PHILOSOPHICAL UNDERPINNINGS, RESEARCH, AND FACTORS

Involving participants in the design and improvement of publicly funded social services is not a new concept. For instance, the United States federally funded poverty programs of the 1960s included a federal mandate to involve those most impacted in the design of models and services (Nemon, 2007). The United Kingdom adopted similar consultation methods to address the public's distrust of government's use of public health dollars at the local level (Harrison & Mort, 1998; Lowndes, Pratchett, & Stoker, 2001a; Parkinson, 2004b). Recent literature points to an increased interest on behalf of funders and program administrators in involving recipients of services intimately in the design and evaluation of programs (Ross, Donovan, Brearley, Victor, Cottee, Crowther, & Clark, 2005). Some authors attribute this increased interest to changes of norms within society, calling for services to be more transparent and to more accurately reflect the needs of individuals served (Carrick, Mitchell, & Lloyd, 2001).

With the passing of the 1990 Americans with Disabilities Act and the 1999 ruling of the L.C. and E.W. v. Olmstead Supreme Court Decision, the rights of individuals with disabilities and elders to receive publicly funded services in community settings rather

than facility settings has been powerfully recognized (Morris, 2008; National Council on Disability, 2003). Since then, some attention has been devoted to ensuring that participants of publicly funded home and community-based services and supports have a role in the design of these programs. For example, in 2001, the federally funded “New Freedom Initiative” provided billions of dollars over a period of seven years to states interested in enhancing their community-based services (Research Triangle Institute, 2009). A stipulation of this initiative was the involvement of stakeholders (including participants) in the implementation of the grants. While this requirement may exist, research and anecdotal stories point to barriers policymakers and researchers face attempting to involve hard-to-reach populations in their work (Cook & Klein, 2005; Siebenaler, Tornatore, O’Keeffe, 2002). It has become clear that attempting to involve people of low income who also face functional barriers to community living offers challenges to meaningful engagement.

State staff and program administrators, working actively to address the need for more home and community-based service options for elders and people with disabilities, have responded differently to pressures to engage participants of services in the design, implementation, and improvement of programs (Research Triangle Institute, 2008). Many state staff, successful in creating roles for participants and their advocates in the design of programs, have reported such involvement to be directly beneficial to their work (Lomerson, O’Connor, McGaffigan, & Wamback, 2007; Priester, Hewitt, & Kane, 2006). Even so, other state staff are not implementing participant involvement methods. While state staff often recognize participant involvement as “the right thing to do,” many blame



a lack of resources and staffing for failure to involve participants (Siebenaler, Tornatore, & O’Keeffe, 2002).

Despite the value placed on participant involvement practices, minimal effort has been made to understand the implications of engagement. Very little research critiques participant involvement methods and their outcomes (Arnstein, 1969; Barnes, 1999; Bens, 1994; Nemon, 2007; Lowndes, Pratchett, & Stoker, 2001a; Parkinson, 2004a). The information that does exist is often anecdotal in nature (Dewar, 2005). Within the original Cash & Counseling Demonstration and Evaluation, research methods (e.g., interviews and focus groups with participants) were utilized to understand people’s preferences regarding the individual budget option, outreach methods, and implementation challenges, but participant involvement in the design of their state programs was not a focus of the research. (Simon-Rusinowitz, Marks, Loughlin, Desmond, Mahoney, Zacharias, Squillace, & Allison, 2002; Zacharias, 2000). Insufficient data may be a factor in states’ reluctance to create systematic strategies for participant involvement in program design, implementation, and improvement of home- and community-based services.

Is involving program participants simply “the right thing to do” or is there an evidence-based reason for such practices? Many take a moral stance, asserting the importance of including the program participants’ perspective in the design of community-based programs. Across the country, pockets of activity exist, but there is very little literature regarding methods and impact (Carrick, Mitchell, & Lloyd, 2001; Dewar, 2005; Wykes, 2003). Within existing participant involvement practices, there is wide variation in methods, scope of involvement strategies, and factors influencing

involvement (Lowndes, Pratchett, & Stoker, 2001a; Lowndes, Pratchett, & Stoker, 2001b; Nemon, 2007; Parkinson, 2004a).

When perceptions of involvement strategies are examined, it is typically state staff (not participants) who are the source with results showing diverging opinions and minimal understanding of the context in which perceptions are formed (Lowndes, Pratchett, & Stoker, 2001a; Lowndes, Pratchett, & Stoker, 2001b). Critical analysis of involvement methods, contextual factors that influence outcomes, and perceptions of diverse stakeholders are neglected within the research (Lowndes, Pratchett, & Stoker, 2001b; Parkinson, 2004a). Recognition of the complex environment in which participant involvement takes place and the link between the environment, methods used, and ultimate outcomes is required to confirm or challenge the existing assumptions surrounding this topic. Such analysis may lead to the creation of effective involvement strategies that move beyond apathetic or paternalistic practices (Lowndes, Pratchett, & Stoker, 2001b).

### *Defining Engagement*

Before further exploration of concepts associated with the involvement of participants in the design, implementation, and improvement of home and community-based programs, a brief discussion of terminology and definition is warranted. It seems appropriate to start with a simple and broad definition of “participation,” such as the one provided by Parry, Moyser, & Day (1992): the “public involvement in the processes of formulation, passage, and implementation of public policies” (Parry et al., 1992 cited in Lowndes, Pratchett, & Stoker, 2001a, p. 16). While this may be a common and neutral

approach to defining participant involvement, Arnstein (1969) provides a definition that acknowledges power differentials may exist. According to Arnstein (1969):

...citizen participation is a categorical term for citizen power. It is a redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future. It is a strategy by which the have-nots join in determining how information is shared, goals and policies are set, tax resources are allocated, programs are operated, and benefits like contracts and patronage are parceled out. In short, it is the means by which they can induce significant social reform which enables them to share in the benefits of the affluent society.

Unlike the definition presented by Parry et al. (1992), Arnstein's definition recognizes a political and economic context in which participant involvement takes place. She acknowledges the power differential that exists between those who have the power to involve others and those who may be engaged. In her work, Arnstein also highlights the many approaches to involvement as well as the many points in time at which participants may be involved. For example, individuals may be involved in broader-based activities such as goal setting or more defined activities once goals are identified, such as operations. Arnstein (1969) points to engagement as a means to address significant political and social disparities, even hinting that addressing these social inequalities may not be possible without the direct involvement of those who face the inequality. Her

definition of participation provides a window into what may be a much more complex and contextually driven reality for participant involvement than is typically understood.

### *Philosophical Underpinnings*

There is a debate within the literature, more specifically literature built on economic, sociological, and philosophical tenets, pertaining to our rights as individuals (Somers & Roberts, 2008). From the most traditional viewpoint, we as free thinking, rational beings enter into a contract with others (via the government) to maintain our basic rights associated with security and property while the market is intended to meet the majority of our other needs (Nozick, 1974). Others describe a more extensive role for government. John Rawls' "liberty principle" recognizes the importance of equal opportunity for all and the need for government to ensure a basic level of fairness through the work of socially constructed institutions (Rawls, 1971). Discrimination based on age, gender, race, disability, etc. threaten not only the ability of the market to be truly competitive, but also the opportunity for individuals to be productive members of society.

Civic engagement, a process through which citizens are involved in influencing the design or improvement of government practices and the allocation of public resources, recognizes the role of citizens in addressing government inefficiencies (Harrison & Mort, 1998). Citizens, as experts in their own right, are engaged based on the assumption that professionals do not always make decisions that are in the best interest of society given their distance from the challenges common people face (Harrison & Mort, 1998).

The dwindling interest of citizens in the workings and effectiveness of democracy has led to a call for “democratic renewal” to transform citizens’ perceptions pertaining to the transparency and effectiveness of government practices with the goal of increasing their involvement and ultimately improving the system (Lowndes, Pratchett, & Stoker, 2001a). The civic engagement literature recognizes the rights and responsibilities held by citizens in order to make democracy work. There is an assumption within this framework that we as citizens have equal access to civic life, and therefore, the same opportunities to engage in democratic practices and public policy decisions.

Citizenship requires the ability to be “makers and creators” as well as members of the worlds in which [we] live (Ranson et al., 1995 cited in Barnes, 1999, p. 82). The ability of all citizens to “act” is often not questioned even though some individuals face significant barriers to participating in the democratic processes affecting their lives, creating a “second class” citizenship of sorts (Barnes, 1999). For instance, a community may exclude from civic activities many who are low income or have functional limitations given the barriers such individuals face. The women’s movement, the Civil Rights movement, and the anti-poverty movement are examples of organized reactions to the second-class citizenship and the social and attitudinal barriers faced by many individuals seeking to be engaged in their government and society (Barnes, 1999; Nemon, 2007).

Individuals who require publicly funded long-term services and supports, by definition, fit into one of these groups challenged by second-class citizenship. Lipsky (2010) recognizes that those who seek publicly funded services most often do so as a last

resort given the power dynamic that exists between “street level bureaucracies” and the people they serve. Lipsky (2010) argues that while street level bureaucrats (those who have direct communication with clients) have little to lose when clients are dissatisfied, this is far from the case for those who rely on such services. Given this, those in need of publicly funded services monitor their own behavior with the goal of not putting their access at risk.

The Independent Living movement, building from the struggles within the Civil Rights movement of the 1960s, came to life when Ed Roberts and his peers fought for integration at the University of California, Berkley (Shapiro, 1994). As individuals in wheelchairs, these early advocates fought to be recognized as citizens who have a right to live where they choose, be educated, and be gainfully employed (Shapiro, 1994). But the old stereotypes, including such concepts as “Gerry’s Kids,” continue to perpetuate the paternalistic and poverty-sustaining public policies that “serve” people with disabilities (Shapiro, 1994). A culture around disability was formed in an effort to survive and combat stereotypes and oppression. Since the advent of the Independent Living movement, other disability groups (e.g., those representing individuals who are deaf, have intellectual or mental health disabilities, and elders with functional limitations) have led similar fights to resist disability-specific stereotypes and barriers that limit their rights as citizens (Shapiro, 1994).

The impact of a second-class citizenship on participants’ involvement in the design, implementation, and improvement of home and community-based services and supports is not well understood. Physical barriers (e.g., inaccessible transportation and

buildings) and economic barriers (e.g., money for travel and the ability to miss work) exist. As well, public perceptions pertaining to individuals' desires and abilities to participate exist and may even create barriers to involvement. The label of "consumer" or "client" and the dependency associated may bear more weight than any citizenship status (and its associated rights and responsibilities) (Lipsky, 2010; Barnes, 1999). Barnes (1999) calls for a reprioritization of labels, acknowledging people who access public services as citizens rather than consumers. As citizens, such individuals have the right to "make" and "create" the very services they access (Barnes, 1999, p. 84). Lipsky (2010) agrees and notes that "client involvement in governance of service agencies will help to insure that clients contribute to the way street-level bureaucrats define their roles" (p.196). The engagement of these citizens through "participatory democracy" provides an opportunity that will not only create more responsive public policy, but also gives voice to a group of constituents often voiceless within the democratic process (Harrison & Mort, 1998).

#### *Relationship between Engagement Factors and Outcomes*

Involving participants in the design, implementation, and improvement of home and community-based services and supports may on the surface seem a straightforward process: A state staff person or program administrator sees the benefit of seeking input or advice from participants and therefore gets it. In reality, numerous variables may exist. A complex set of factors associated with personal attributes, the environment, and the process chosen may ultimately impact participant involvement decisions.

### *Understanding Person-Driven Factors*

*State staff designing and implementing services and supports.* The literature emphasizes various personal traits of state staff that seem to influence whether or not such individuals partake in participant involvement and the outcomes associated with such efforts. One's values may very well play a role in one's own personal leadership style, communication style, and the assumptions one brings to the engagement process. One of the most influential factors is obvious: the state person's receptivity to participant involvement (Nemon, 2007). Authors describe this influential factor as state staff willingness to be open and nurturing of an involvement process that includes a safe environment for questioning leadership (Barnes, 1999; Bens, 1994). Reluctance of those in power to willingly share their power can be damaging to participant involvement opportunities (Arnstein, 1969; Bens, 1994). The underlying theme appears to be that state staff who are comfortable with sharing power, who are transparent in their communications, and who believe participants can play a key role in shaping public policy are most likely to partake in participant involvement and be satisfied with its outcomes (Arnstein, 1969; Barnes, 1999; Bens, 1994; Nemon, 2007).

Lipsky takes a more complex view, recognizing person-driven factors in light of environment-driven factors. According to this author, the mere organization of bureaucracies put state staff in the position of control, ultimately influencing their perceptions pertaining to the role of program participants. State staff who have direct interaction with those in need of services demonstrate their control daily, making personal judgments about who is eligible for services, the extent of those services, and the boundaries of appropriate participant behavior (Lipsky, 2010). When this is the case,



it can create an internal conflict for some state staff who are cognizant of our society's expectation that citizens have a "right to equal and responsive services." (Lipsky, 2010, p. 63).

*Program participants accessing services and supports.* Lipsky (2010) recognizes those who utilize services as unique individuals with unique characteristics and life experiences who are "transformed into clients" and then assumed to fit "standardized definitions...[and] specific bureaucratic slots" once they need services (p. 59). Those who are dependent on services are forced to use behaviors that are beneficial to the system, being at the mercy of the "priorities and preferences" of state staff and the specifics of his/her job description (Lipsky, 2010, p. 59).

While the literature on participants' values and characteristics pertaining to engagement is limited, the literature does recognize that the participant perceptions of the willingness of state staff to take part in involvement practices influences their own interest in such activities. Participants who feel as though state staff are not invested in involvement practices are more likely to mistrust officials' motives and related outcomes, and become less interested in being involved themselves (Arnstein, 1969; Goss, 1999 and Sergeant and Steele, 1998 & 1999 cited in Lowndes, Pratchett, & Stoker, 2001b). Survey research conducted by Lowndes, Pratchett, and Stoker (2001a) validates participants' distrust since only one-third of the public officials surveyed said that participants' involvement actually changed an intended decision.

Participants' desire to be involved also seems to be influenced by participants' perceptions about the end result. Most often, people tend to participate in efforts they feel

passionate about or that they feel have direct impact on their own lives (Lowndes, Pratchett, & Stoker, 2001b). The age old question of “what is in it for me?” seems to be a factor in participants’ decisions to be involved in public policy deliberations. If participants feel as though their involvement will lead to benefits such as increased skills and knowledge, a system changed for the better, and/or increased esteem and sense of identity, they will be more likely to participate (Lowndes, Pratchett, & Stoker, 2001b). Concerns about token involvement and feelings that professionals are limiting opportunity rather than creating it may lead to less involvement (Lomerson, O’Connor, McGaffigan, & Wamback, 2007). Even with these characteristics in mind, Lowndes, Pratchett, and Stoker (2001b) recognize that some individuals just tend to gravitate toward community involvement more than others.

*Assumptions pertaining to representation.* The literature identifies representation as a factor in involvement methods (Nemon, 2007; Parkinson, 2004a). State staff often have a powerful role in determining who should be invited to the engagement table. Their own personal experiences with program participants can influence who they choose, and they often choose to engage individuals based on who they feel would be most successful in the role (Lipksy, 2010). Some argue for the involvement of advocates over “real” participants citing participants’ lack of systems knowledge and competing personal priorities as barriers to meaningful involvement (Hogg & Williamson, 2001). Ironically, once participants become more informed about policy systems through their involvement, their knowledge is then evidenced by some as the reason why they can no longer adequately represent the view of “lay people” (Harrison & Mort, 1998).

Some state staff avoid involving advocates, referring to such individuals as the “usual suspects” given their reoccurring involvement, inside knowledge, and political stake in the decisions being made (Harrison & Mort, 1998; Parkinson, 2004b). Lipsky (2010) actually believes that public officials do what they can to minimize the success of organized groups given their potential to be powerful and demanding. Parkinson (2004a) describes a mistrust of interest groups among state staff, but argues that when state staff demand the involvement of those who are less informed, they are withholding the opportunity for participants to be informed decision makers.

Parkinson (2004b) describes why both arguments for representation are weak. He refers to two types of representation and factors to their success: principal agent and descriptive representation. Advocates seeking a role in public policy as representatives of a constituency group often fail to recognize the essential principal agent characteristics: the requirement to be formally appointed and held accountable by their constituents (Parkinson, 2004b). That being said, “real” participants tend not to meet the expectations of descriptive representation: the ability to reflect the rainbow of characteristics found within the larger constituency group (Parkinson, 2004b). Even more challenging, real participants often have no chain of communication or accountability back to the larger group of constituents, making their potential to be representative weak at best. Lipsky (2010) actually argues that bureaucracies are organized in a manner that isolates individuals from their peers, making a chain of communication or accountability close to impossible. Individuals who do not formally represent anyone can only represent themselves, possibly making the involvement process ineffective (Hogg & Williamson,

2001). Because of this, Parkinson (2004b) argues that the strongest representation has characteristics that are principal agent and descriptive in nature: they are appointed by a constituency group (of which they hold similar characteristics) and are held accountable for their actions performed on behalf of the group.

Along with the division between participants and professional advocates, a “them” and “us” dynamic between professionals and lay persons also exists and is argued as artificial by some (Hogg & Williamson, 2001). Grouping state staff into one group of “professionals” and “lay persons” into another group of nonprofessionals fails to recognize that both groups are heterogeneous and include people with a wide range of experience, knowledge, values, and skills (Hogg & Williamson, 2001). Labeling individuals as one or the other can have lasting impact. Terms such as “ordinary” and “lay” as well as “consumers” signify inexperience or disempowered individuals, thus these terms potentially have an impact on just how meaningfully such people are involved (Hogg & Williamson, 2001; Parkinson, 2004b).

#### *Understanding Process-Driven Factors*

In addition to person-dependent and environment-dependent factors, literature points to process-dependent factors and varying interpretations based on state staff experiences (Lowndes, Pratchett, & Stoker, 2001a). State staff who have little experience involving stakeholders may view some of the most established and consistently used approaches as innovative while others with more experience may see the same practices as a traditional business practices (Lowndes, Pratchett, & Stoker, 2001a). Involvement methods include a collection of specific involvement traits, such as those associated with

the frequency of involvement, focus of involvement, level of access to information, level of interaction with others, and decision-making strategies. These characteristics, described in more detail below, are exhibited with wide variation and are interrelated to form various participant involvement strategies. The focus on traits rather than pre-defined strategies (e.g., advisory groups, interviews, and task forces) is intentional since approaches can be defined differently from one group to the next with no understanding of the underlying characteristics. Even so, examples of commonly used strategies associated with specific characteristics are provided.

*Frequency of involvement.* When reviewing various approaches described in the literature and witnessed in the field, it is evident that the frequency with which the participant is involved is one characteristic trait that differs from one strategy to the next. Some methods include participants at only one point in time. In such cases, those involved are responding to a topic from a personal perspective rather than from knowledge of the system as a whole. It would appear that the knowledge tapped from the participant, for the most part, is based on personal experience rather than systems knowledge. An example would be the use of satisfaction surveys or focus groups to garner participants' thoughts on a particular service or program. The data collected from this one event is used to better understand an existing service, program, or policy or even to lead to the creation of new services or policies. The intention of this strategy is to seek information from those who are not aware of the intimate workings of a service, program, or policy.

On the other side of the spectrum, are methods that seek involvement of the same participants on multiple occasions. One example would be the use of an advisory committee or a task force. In this case, frequency of involvement is intended to have the opposite effect: to allow for informed individuals who can use a combination of their own experiences and systems knowledge to provide guidance on a particular topic. It may be assumed that the more a person is involved, the more knowledge about the system he or she gains. This may potentially alter the content of the input they provide.

*Focus of interaction and choice of methods.* When participants are sought for involvement, those seeking their involvement often have a preconceived notion of the type of information they seek, which very well may inform their approach. For instance, a state staff person who is interested in strengthening outreach for a particular program may choose to engage a focus group representative of the targeted population, rather than conduct a large number of interviews with people they have already had a problem finding. A state staff person seeking guidance on the type of services to offer under a new program may seek ideas from a well established stakeholder group familiar with the intricacies of the policy decision. This approach would be intended to lead to decisions based on historical policy knowledge and access to data, rather than based on personal interests.

A second consideration is the unit targeted for change, whether it is at the individual, program, or policy level (Lowndes, Pratchett, & Stoker, 2001a). For example, individual participants may be requested to inform the delivery of a specific service they receive. This may include the use of a survey to assess the individual's satisfaction with

his or her home delivered meals. While this may lead to an improvement at the individual level, it may lead to programmatic improvements as well. Individuals or groups may also be requested to comment on the barriers associated with existing procedures or programs. For example, individuals may be asked to participate in a focus group to discuss barriers utilizing transportation services. The goal would be to improve transportation at the program level, not just one individual's services. On the macro level, participants may be requested to comment on a specific issue or general policy impacting the lives of many individuals. One example may be the use of a public forum to identify barriers or develop ideas for addressing the institutional bias in Medicaid. While specific examples of involvement practices intended to lead to change at the individual, programmatic, or policy level are easy to identify, it is less clear if state staff are choosing the most effective strategies to meet their desired outcomes. Also, other than survey results pointing to youths' interest in receiving stipends for their involvement (Lowndes, Pratchett, and Stoker, 2001b), very little research exists on the use of accommodations (e.g., interpreter services, payment for travel, access to personal assistance services, etc.) to support individuals to be involved.

*Access to information.* Harrison & Mort (1998) categorize involvement methods based on the level of information participants have access to prior to their input. Some methods are intended to seek untainted insight from those involved. Because of this, no additional information on the topic of interest is provided beyond the knowledge resulting from the participant's personal experiences. Other methods are intended to inform the

participant, providing technical reports, data, or other types of information to assist individuals to play an informed role complemented by their own personal experiences.

*Deliberative and nondeliberative methods of involvement.* When reviewing the various involvement methods that exist, it becomes clear that some approaches involve participants one-on-one, while others include group interaction. Harrison & Mort (1998) make a distinction between nondeliberative methods, methods in which individuals provide their thoughts without discussion with others and deliberative methods, methods in which individuals are able to discuss the topic prior to their input or recommendations. Deliberative methods (such as those often associated with the use of advisory boards and task forces) are discussed extensively within the civic engagement literature, recognizing the role of every day citizens in critically examining public policy activities or intentions (Economist, 1998). Deliberative democracy is identified as a pivotal piece of creating a workable democracy, providing citizens with the opportunity to be informed and involved to “generate broad and inclusive discourse about important questions of public interest” (Cook & Jacobs, 2002 cited in Hudson, 2006, p.52). As described previously, some state staff value the input received by “real” participants through individual interactions untainted by systems knowledge or politics, such as the input received via one-on-one interviews or surveys (Harrison & Mort, 1998; Hogg & Williamson, 2001).

*Involvement in decision-making.* The extent to which participants are engaged in decision-making as part of their involvement appears to be noteworthy. Literature recognizes that the participants’ level of involvement in decision-making can be placed on a continuum, from not involved at all to driving the entire process (Arnstein, 1969).



Before diving deeper, it is important to understand the styles of decision-making that typically exist within United States government, which serve as a backdrop for how participants are involved.

Bens (1994) highlights three types of decision-making: closed decision-making, front end decision-making, and non decision-making. Closed decision-making, labeled as “back room” decision-making by Bens (1994), is a process in which officials make decisions involving select influential powerful leaders. This model often leads to frustration since those most affected stakeholders are informed of decisions only after the decisions have been made (Bens, 1994). At the other extreme, front end decision-making is a “transparent” and “meaningful” process in which stakeholders are involved up front and throughout the process (Bens, 1994). Non decision-making is an insightful recognition by Bens (1994) that not making a decision is often in fact a tactical decision in order to avoid making decisions that could be displeasing to some. Bens’ (1994) modes of decision-making indirectly imply a role (or lack there of) for participants. For instance, back room decision-making devalues the role of participants (as well as other stakeholders) as active decision-makers, assuming that the required expertise is held by a few influential individuals already involved. Front end decision-making, while not explicitly communicated, seems to support an active role for participants, given the emphasis that decisions and the decision-making process itself should be open to criticism.

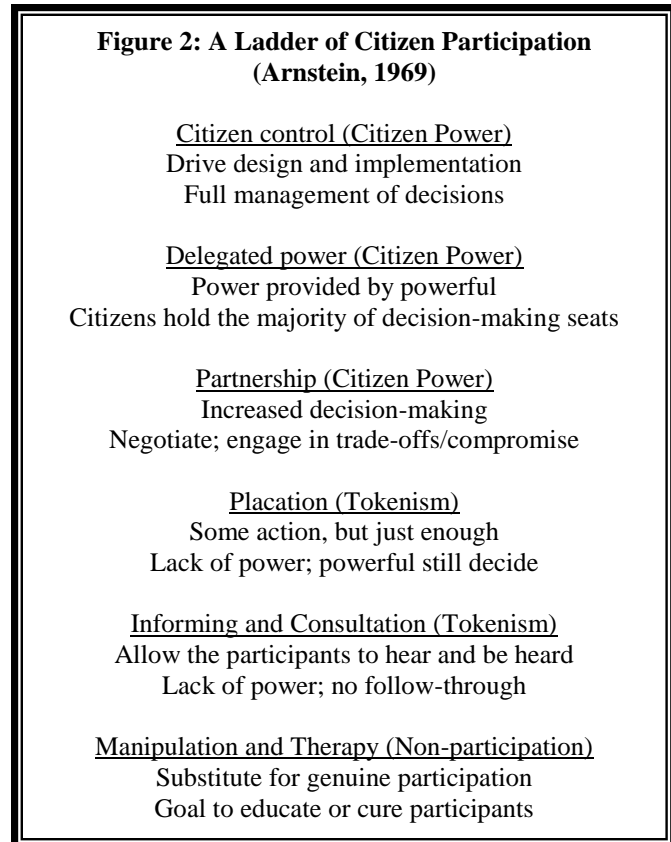
Federal funders of the urban renewal and antipoverty programs of the 1960s called for inclusion of citizens in decisions pertaining to how publicly funded resources

were utilized (Nemon, 2007). Program State staff at the state and local levels applied different techniques to meet this mandate, some more successful than others. Lipsky (2010) reflects on these efforts and the importance of examining the processes utilized as when determining success. According to Lipsky, “More often than not, the experiments of the 1960s inappropriately discredited citizen participation by providing control over programs lacking financial viability or by narrowly circumscribing the scope or powers of client or citizen boards” (2010, p. 196). Arnstein (1969) describes the common use of “rubber stamp” advisory committees and boards to meet this mandate. Although the intention was for participants to provide insight, in actuality, the author describes a paternalistic process that was created to meet the needs of officials. Arnstein describes this as non-participation, a model that aids the powerful rather than the powerless (Arnstein, 1969).

Arnstein (1969) describes the varying degree of citizens’ involvement in such programs utilizing her “Ladder of Citizen Participation” (see Figure 2). Each of Arnstein’s eight rungs of the ladder depict a different degree of citizens’ involvement in public policy, with the lowest rungs representing non-existent or even detrimental involvement mechanisms and the highest rungs representing empowering, or even citizen-driven practices. When describing the ladder metaphor, Arnstein recognizes that it is an oversimplification to assume that “power holders” and the “have nots” are homogenous groups, and in fact, assumes each is inclusive of varying experiences, interests, and intentions (Arnstein, 1969, p. 3). Arnstein (1969) is also cognizant that the

symbolism is missing an important variable: how one moves up and down the ladder of participation, a topic that is central to this research project.

*General findings on approaches.* There is a significant gap in the literature regarding participants' perceptions of participant engagement strategies. Through a survey of participants conducted by Lowndes, Pratchett, and Stoker (2001b), public meetings were identified as the most common involvement approach, although they were poorly rated as a method of seeking meaningful input given the perception that public officials had already made up their minds.



Questionnaires were recognized as a viable option, but involvement methods that involved face-to-face contact were more appreciated. Youth who were surveyed emphasized the importance of financial compensation for involvement, intimate settings for in-depth discussions, as well as the provision of adequate information for meaningful involvement (Lowndes, Pratchett, & Stoker, 2001b).

Henderson (2003) recognizes key process factors to making participant involvement work: relationship building, open communication, and an effective feedback

loop to ensure clear communication regarding how input will be used. Henderson also emphasizes the need for a collaborative approach over a “them and us” approach. Henderson’s ingredients are reminiscent of Bens (1994) “open system” and the use of “front-end” decision-making which requires user-friendly information sharing to allow for a transparent and accountable process from the very beginning (p. 34). Some also highlight the importance of training as well as opportunities to apply the policy directly as agents for change (Nemon, 2007).

#### *Understanding Environment-Driven Factors*

*System’s readiness.* While it is recognized that person-dependent factors described above can have a direct impact on the environment in which participant involvement takes place, additional environmental factors require attention. Lipsky (2010) recognizes that bureaucracies are not well prepared, based on their own design, to easily engage service recipients in program creation and improvement efforts. This is because service recipients are taught by bureaucracy to be compliant at the individual level, which then at the collective level creates an environment that “cues clients concerning [the] behavioral expectations” (Lipsky, 2010, p. 57). Lipsky (2010) actually recognizes the potential for success of “voucher” programs (e.g., participant direction) given they are built to work within the competitive market, but sees such models as being unsuccessful for as long as providers continue to have the power over service design and access while those in need of services face limited access to information.

Bens (1994) describes environments that are conducive to participant involvement as well as those that are not. Bens describes three stages government may pass through:

stage one (a closed system), stage two (an uncertain system), and stage three (an open system). The author describes a closed system as one with limited political diversity, weak or insecure leadership, and a secretive bureaucracy (Bens, 1994, p.33). The back room decision-making associated with this environment may very well discourage participant involvement since leaders are not interested in sharing power nor is there is political pressure or information flow that forces the involvement of stakeholders. The uncertain system within the second stage is framed by Bens has having slightly more political diversity and slightly more collaborative leadership than found in the previous stage. Even so, it appears that non-decision-making would be more likely within this environment given the desire to please many in order to maintain control. Participant engagement may be argued to exist in this stage but most likely would have limited influence given the desire to minimize decisions that make waves. It may be assumed that an open system would be the most likely environment to encourage participant involvement given its transparent and collaborative characteristics, encouraging public access to information for the sake of seeking high quality decisions.

*Trust and its linkage to a topic's significance.* Trust appears to be an additional environmental factor associated with participant involvement. Trust can be examined through multiple lenses, but at minimum includes the lenses held by State staff and those engaged. Trust may very well be linked to the perceptions and assumptions described earlier. Bens (1994) also links trust to an important environmental characteristic: the seriousness of the public policy topic at hand. Bens (1994) discusses the “trust” gap: the seriousness of a public policy issue and its direct influence on the ability (or lack there of)

for State staff and participants to develop trust. The more serious the issue is perceived to be, the more difficult it is for those involved to trust one another.

### *Perceived Outcomes of Participant Engagement*

The literature points to many intended and perceived outcomes pertaining to the use of participant involvement strategies within public policy. Some see participant involvement as both a means and an end to allow for good public policy making while others seem to focus on one or the other (Barnes, 1999; Nemon, 2007). Positive and negative outcomes for the participant, the State staff person, and the larger system or society are found within the literature. What appears to be lacking is a connection between participant involvement factors (such as those described above) and their associated outcomes (Nemon, 2007). For instance, an outcome may be described within the literature with little attention provided to the values and environment for which the engagement existed. While recognizing this limitation, the literature does provide a foundation for understanding the various outcomes that are the result of involvement. The purpose of this study will be to link participant involvement outcomes, both those found within the literature and those still unknown, to various personal attributes, environments, and processes.

*Participant outcomes.* Positive outcomes for participants, while fewer in quantity than what is found for state staff and the larger system, can have a deep and lasting impact on both individuals and their larger constituency group. Involvement can increase participants' knowledge of the system and its complexity, potentially leading to increased advocacy and better services (Barnes, 1999; Lowndes, Pratchett, & Stoker, 2001b;

Parkinson, 2004a). Also, the opportunity to work directly with state staff allows participants to test their assumptions pertaining to the intentions of state staff (Barnes, 1999; Lomerson, O'Connor, McGaffigan, & Wamback, 2007).

Many of the perceived benefits and challenges associated with participant involvement actually effect participants as a group in addition to individuals. For instance, participant involvement provides the opportunity to empower a group typically assumed to offer little to society, transforming their label from consumers of services to experts (Arnstein, 1969; Barnes, 1999). That being said, knowing that some people tend to enjoy joining groups and others do not, involvement strategies tend to engage small group of participants, leading some to be overstretched and reactive rather than innovative (Barnes, 1999). Also, participant involvement can lead to the creation of true partnerships among those who are assumed to be powerful and those assumed powerless, providing advocates an opportunity to have a lasting impact on the system (Barnes, 1999).

*State staff and system outcomes.* The literature emphasizes that participant involvement can lead to more informed state staff and better decisions (Arnstein, 1969; Barnes, 1999; Bens, 1994; Lowndes, Pratchett, & Stoker, 2001a). Parkinson (2004a) notes that state staff often involve participants for the following reasons: to demonstrate a respect for public accountability of public resources and/or to improve how services are implemented. One research study that compared two local communities' planning strategies, one eliciting citizen involvement from the beginning in the development of a planning and visionary process and one that was driven from a purely professional

standpoint, found the former to cost less while leading to an action-oriented product with larger buy-in where the latter did not (Bens, 1994). In the example provided by Bens (1994), one rural county that did not involve citizens upfront and reluctantly involved them in a public forum process costs the county \$175,000 and led to a vision that neither the government nor the public was ready to support. This was compared to a rural county that involved citizens early on as facilitators of the process, ensuring they were well-informed and key in the identification of issues and solutions, which led to a vision that was strongly supported and cost \$75,000 (Bens, 1994).

Participant involvement, just by nature of the process, requires State staff to examine their approach since they are required to present their concepts, methods, and intended results to others (Parkinson, 2004a). The literature also points to involvement methods as an opportunity for state staff to address highly sensitive topics in a transparent manner, minimizing public assumptions about political influences (Parkinson, 2004a). Even so, some state staff emphasize the downsides of participant involvement. For one, some state staff fear that involvement leads to unfair expectations given legislative and fiscal restrictions. Also, there is concern that participant involvement removes the decision-making responsibility from those originally empowered by the community to make decisions and puts such decisions in the hands of unelected individuals (Lowndes, Pratchett, & Stoker, 2001a). Figure 3 below outlines the literature findings for positive and negative outcomes associated with participant involvement activities.



**Figure 3: Summary of the Literature: Perceived Outcomes Associated with Participant Involvement**  
 (Arnstein, 1969; Barnes, 1999; Bens, 1994; Hogg & Williamson, 2001; Lomerson, O'Connor, McGaffigan, & Wamback, 2007; Lowndes, Pratchett, & Stoker, 2001a)

Perceived Participant Outcomes	Perceived Policymaker/System Outcomes
<p>Positive</p> <ul style="list-style-type: none"> <li>❖ Can make policy that better meets the needs of participants</li> <li>❖ Involves individuals typically oppressed and provides such individuals a voice</li> <li>❖ Provides the opportunity to test assumptions pertaining to State staff' intentions</li> </ul> <p>Negative</p> <ul style="list-style-type: none"> <li>❖ Once involvement increases, participant interest in public policy efforts can decrease</li> <li>❖ Involved too much can stretch resources, lead to less meaningful involvement, and lead to being reactive to State staff' agendas rather than creating own</li> <li>❖ Potential to be labeled and only involved when it works for State staff</li> <li>❖ If seen as knowing too much, may be labeled as an advocate rather than a "real" participant</li> <li>❖ If seen as knowing too little, may be seen as representing individual interests rather than interests of the community</li> <li>❖ Established relationship with State staff may lead to a dependency on public funding and a compromise of mission</li> <li>❖ May not lead to a difference in decision-making</li> <li>❖ If not successful, can lead to assumptions about the benefits of participant involvement</li> </ul>	<p>Positive</p> <ul style="list-style-type: none"> <li>❖ Provides the opportunity to test assumptions pertaining to good public policy</li> <li>❖ Can supplement existing skills and assets</li> <li>❖ Can become more informed, which can lead to better decision-making</li> <li>❖ Efficient use of public funds</li> <li>❖ Increased legitimacy and accountability</li> <li>❖ Increased/higher quality product</li> </ul> <p>Negative</p> <ul style="list-style-type: none"> <li>❖ Can lead to participants' unrealistic expectations in an environment with legal and financial boundaries</li> <li>❖ Can provide participants with decision-making authority that may undermine the authority of elected officials</li> <li>❖ Public policy can be influenced in a direction better for a few rather than larger society</li> <li>❖ Can slow down the decision-making process, especially problematic when a swift process required</li> <li>❖ Can cost more and increase burden to make decisions with little to no benefit</li> </ul>

## CHAPTER 3

### ANALYTIC FRAMEWORK, RESEARCH METHODOLOGY, AND ASSUMPTIONS

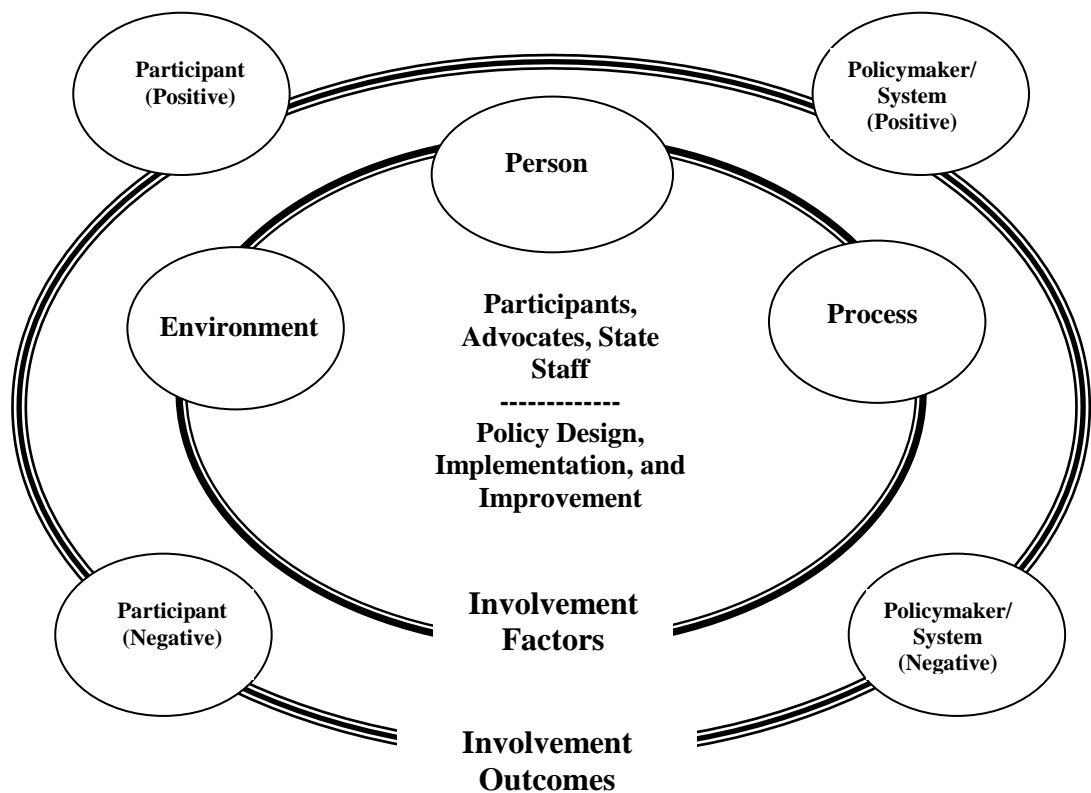
#### *A Conceptual Framework for Understanding Engagement Factors and Outcomes*

A review of the literature has led to the identification of some factors relevant to participant involvement strategies as well as some perceived outcomes. There appear to be multiple factors and variance within factors that may influence involvement outcomes, leading analysis of this subject to be extremely complex. For instance, the leadership style of state staff, participants' access to accessible information, and receptivity of both state staff and participants may all have influential dimensions that need to be accounted for within analysis. Further research in this area warrants a conceptual framework that recognizes the potential for multiple factors to influence engagement as cited within the literature. Doing so provides a starting point from which to examine engagement comprehensively and from multiple angles.

The review of literature has led to the categorization of engagement factors into three separate groups: person, environment, and process-driven factors. Participant involvement can take place in one of the three phases: design, implementation, and/ or improvement. The conceptual framework seen in Figure 4 provides a visual depiction of the factors to engagement and the phases in which engagement may occur. The inner

circle recognizes the key stakeholders who are involved in and/or impacted by participant engagement efforts. This conceptual framework assumes a complex system of variables in which participant involvement takes place, with various combinations of factors that are linked to positive or negative outcomes for participants and state staff. Utilizing this conceptual framework, this research provided insight into the factors of engagement as well as the relationship of participant involvement factors to engagement outcomes.

**Figure 4: Conceptual Framework:  
Participant Engagement in Program Design, Implementation, or Improvement**



#### *Existing Research and its Influence on Research Methods Utilized*

*The gap between research and practice.* Over time, government has played varying roles in addressing socio-economic inequities within our society. One can point to decades of social policy development intended to address inequities with very little

evidence pertaining to the effectiveness of the intervention (Glasgow, 2006; Glasgow & Emmons, 2007; Grosse, Teutsch, & Haddix, 2007). Regardless, government funds continue to be invested in interventions only later to be labeled as inaccessible, underutilized or even wasteful.

A substantial amount of new literature has been devoted to the topic of the great divide between pure research and practice (Glasgow, 2006; Glasgow & Emmons, 2007; Grosse, Teutsch, & Haddix, 2007). Findings indicate the gap is linked to the fact that many research studies do not take into account practice-based needs and challenges. Some of these needs and challenges include the shortage of resources (time, staffing, and funding) as well as diversity in settings in which policy exists and their complex characteristics (Grosse, Teutsch, & Haddix, 2007). What seems most significant is the difference in priorities among researchers and practitioners with researchers focusing on methods to isolate causes in controlled settings and practitioners addressing unique circumstances in unpredictable environments (Glasgow & Emmons, 2007).

In an attempt to try to minimize the gap between researchers and practitioners, the literature recommends a prioritization of research that is more applicable to the needs of practitioners. This includes an emphasis on context and an examination of the effectiveness of complex implementation practices with multiple systems variables (Glasgow & Emmons, 2007). To be responsive to the unknown complexities that may exist, this research includes a combination of pre-specified and emergent approaches, allowing for the initial research methods to be modified based on the data that is presented (Krathwohl & Smith, 2005; Lincoln & Guba, 1985).

*Research strategies for examining participant involvement.* Researchers' examinations of participant involvement methods, for the most part, have been descriptive in nature and have merely described methods and outcomes with little focus on the relationship between the two (Parkinson, 2004a; Stewart, 1995; 1996; 1997 & LGA/LGMB 1998 cited in Lowndes, Pratchett, & Stoker, 2001a; New Economics Foundation, 1999). The literature has led to the identification of promising practices, but with only anecdotal evidence to support such determinations (Stewart, 1995; 1996; 1997 & LGA/LGMB 1998 cited in Lowndes, Pratchett, & Stoker, 2001a; New Economics Foundation, 1999). Whether or not qualitative or quantitative methods are utilized, to determine the effectiveness of participant involvement practices, researchers need to examine the impact such efforts have on outcomes while also examining the complex nuances of involvement that vary from one situation to the next.

Lowndes, et al. (2001a) implemented a research methodology that included a combination of survey methods and in-depth interviews which ultimately led to quantitative data complemented by case studies. This research model resulted in data on the range of methods utilized by local government authorities within the United Kingdom as well as data on the personal perceptions and interests of both state staff and participants. Clear differences in viewpoints of these two stakeholder groups surfaced with the use of this methodology. More specifically, the survey addressed topics such as the range of involvement methods used in each of the surveyed areas, stakeholders' perspectives on involvement efforts, involvement factors, as well as benefits and

challenges with involvement. This was complemented by the creation of case studies on eleven local authorities based on data from in-depth interviews.

The researchers recognized potential weaknesses associated with their survey approach. For one, the information was only as good as those who were providing the answers. The state staff who completed the survey and/or participated in an interview may not have been well-informed or deeply involved in the methods utilized in their jurisdiction. Another potential challenge was the researchers' use of ordinal rankings within their survey, requesting respondents to rank ideas and beliefs that were presented to them. This may have led to weak results since some important ideas or beliefs may have been missing from the data. The topics presented were complex, possibly leading some to have difficulty ranking them. Also, given the political sensitivity associated with participant involvement, those surveyed or interviewed may have responded in a way that was politically palatable to the organization or agency they represent, leading to a rosy or over critical recollection of events that transpired. While Lowndes, et al.'s (2001a) overall methodology was replicated within this research study, less emphasis was made on the collection of data through surveys with far more reliance on semi-structured, in-depth interviews. The intention is to allow for factors to surface through the data collection process itself. Also, the states chosen for this research have remained confidential, providing those involved with the freedom to discuss topics that they may not otherwise discuss due to political sensitivity, addressing a challenge faced by Lowndes et al. (2001a) while conducted their research.

Lowndes, et al. (2001a) utilized focus groups to collect data on participants' views of involvement methods utilized. The data from these focus groups were also used to test the reliability and validity of the survey and to provide rich data for the case studies. The researchers recruited subgroups for four separate focus groups: participants from local initiatives, individuals from local organizations, youth, and randomly selected citizens. The intention for reaching out to these groups was to ensure representation of those who are already involved and those who are not, those with content expertise and those with less technical knowledge, as well as those who are typically underrepresented in involvement efforts. The researchers described the focus group methodology as a beneficial approach to seeking in-depth understanding of participants' perceptions and experiences related to their involvement with government. This research builds on Lowndes, et al's. (2001a) approach by calling on a national network of program participants in a focus group style to confirm and/or expand on the findings. This was an important component of the research process since it was far easier to identify state staff for interviews than it was program participants, especially in states where engagement was minimal to non-existent.

Parkinson (2004a) utilized an unstructured interview data collection strategy to understand the deliberative democracy practices implemented as a result of healthcare reform within the United Kingdom. The researcher intentionally conducted unstructured interviews to minimize the potential for the researchers own bias, terminology, and perceptions to influence the data. The researcher also intended to use this approach to assist in the identification of "mismatches" between typical labels of practices and actual

practices that take place. While this methodology may lead to challenges with generalization, the researcher was confident that the patterns of behavior noted were not unique (Parkinson, 2004b). This approach seems to have merit and informed the interview process implemented for this research study given the topic's political sensitivity and the variances that can occur in engagement methods from one program to the next.

To understand involvement methods utilized by Community Action Agencies, Nemon (2007) also utilized in-depth interviews with key informants (both by phone and in-person) to understand the success of anti-poverty programs as well as their participant-involvement practices. While a review of organizations' reports and records supplemented interviews, interviews were only conducted with policy and agency staff, leaving the perceptions of actual participants missing (Nemon, 2007). It is arguable that this missing perspective provides a loss of opportunity to test the reliability of data collected. This study, informed by Nemon (2007), included the participant lens while also reviewing materials to supplement the data collected.

### *Research Questions*

This research was intended to examine participant engagement practices within Cash & Counseling programs. The literature points to various participant involvement factors as well as perceived negative and positive involvement outcomes. What was unclear was the extent to which involvement factors, such as those associated with the person, the environment, and processes utilized, influenced outcomes. The purpose of this research study was to understand the many factors that may influence participant



involvement outcomes. While this research study was conducted within existing Cash & Counseling programs, it appears to have much broader public policy implications as recognized by the literature. To examine this topic, the following research questions were identified:

1. How, if at all, do state staff involve participants in the process of design, implementation, and improvement of their Cash & Counseling programs?
2. What are the contributing forces for state staff engagement (or not) in participant involvement strategies within their Cash & Counseling programs?
3. What are the perceptions of state staff, advocates, and participants as to how, if at all, participant involvement factors lead to positive and/or negative outcomes?

Collaboration with the NRCPPDS (previously, the Cash & Counseling National Program Office) and consenting state staff from existing state-run Cash & Counseling programs have provided access to the data required to answer the research questions listed above. Please see Figure 5 for a visual map of how the research questions connect to the study's purpose, conceptual framework, and methods.

#### *Connecting Research Questions to Research Methods*

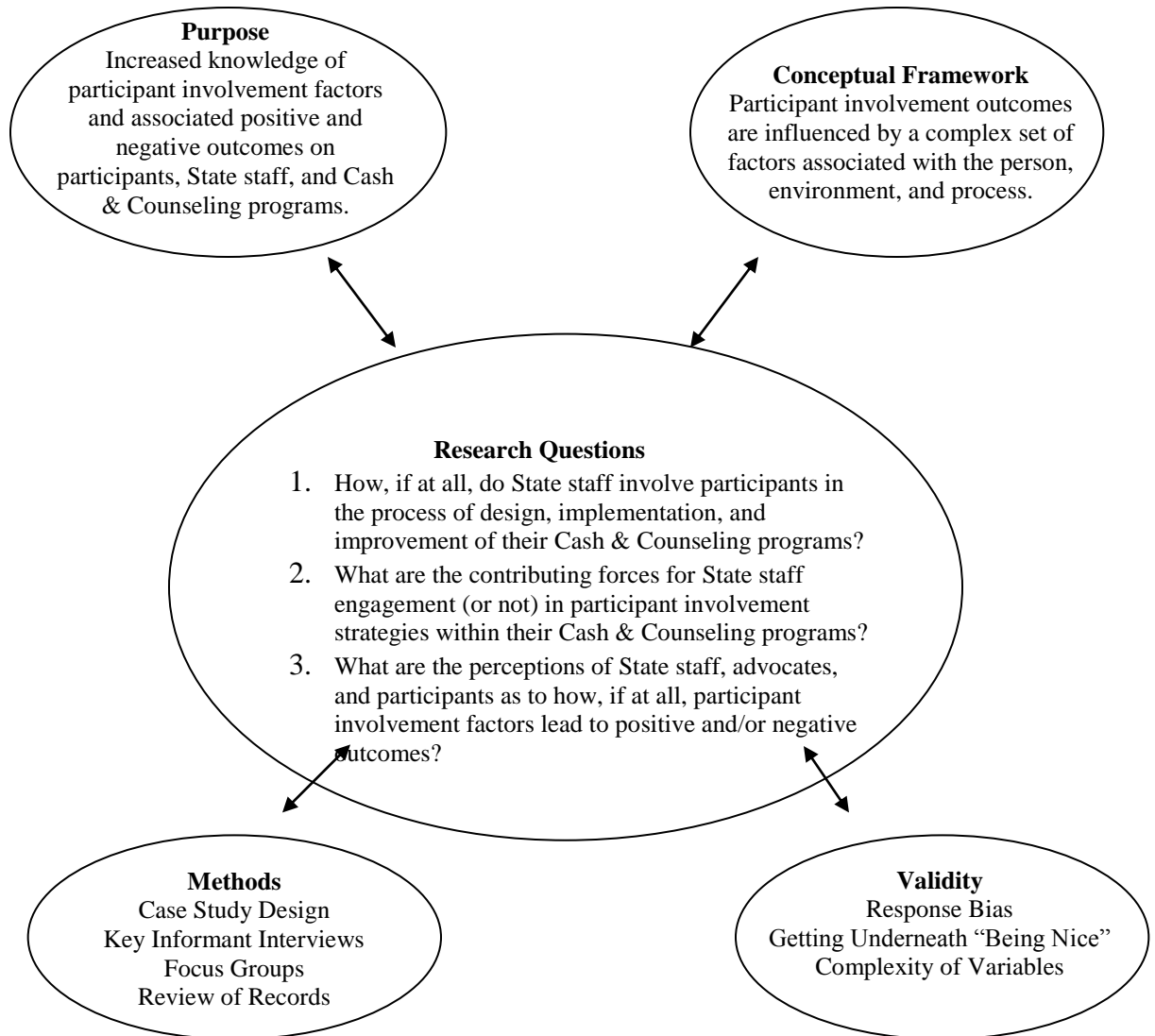
A preliminary understanding of the first research question (how state staff involve participants in the design, implementation, and improvement of the Cash & Counseling programs) was sought through analysis of a web-based survey on states' engagement processes. The survey results informed a typology of involvement and the ranking of states as "low," "moderate," and "high" engagement, which then led to the identification

of states for more in-depth analysis. The participant involvement typology formed is intended to support the measurement of engagement not only in this research, but future studies as well.

Data collected from the interviews was intended to identify and explain the contributing factors to participant engagement within Cash & Counseling programs (research question two). Key informant interviews conducted early in this research informed the questions posed during the semi-structured interviews with Cash & Counseling state staff, participants, and advocates. This process assumed that some state staff within the Cash & Counseling programs may feel compelled to provide socially acceptable answers, thus limiting the depth of their data. The key informant interviews provided an understanding of the difficult topics and paved the way for more fruitful conversation through refined interview protocols.

To understand the perceptions as to how, if at all, participant involvement strategies led to positive and/or negative outcomes (question three), data from interviews with state staff, participants, and advocates were analyzed. Questions were posed during the interviews pertaining to perceived outcomes, both positive and negative. In addition, a review of program records, media coverage, and pertinent legislation was intended to lead to tangible examples of how participant involvement may have influenced the Cash & Counseling program or vice versa. The connection of data collection methods to research questions, as described above, is visually depicted below in Table 1.

**Figure 5: Participant Involvement in Cash & Counseling Program Design**  
(utilizing model from Maxwell, 1996)



**Table 1: Connecting Research Questions to Research Methods**

	Web-Based Surveys	Participant Interviews	State Staff Interviews	Advocacy Leaders Interviews	Review Records	Legislative Changes	Media Coverage
Research Question 1	√	√	√		√		
Research Question 2		√	√	√			
Research Question 3		√	√	√	√	√	√

*Research Assumptions*

There are many assumptions regarding participant involvement methods as well as their influence on policy design, implementation, and improvement. These assumptions are held by some researchers and also by state staff, funders, participants, advocates, and other stakeholders. These assumptions, among others, can impact research practices as well as whether or not involvement mechanisms are adopted and how they are implemented. Below is a review of some of these assumptions, all of which were examined more closely as a part of this research design.

*Program participants and professionals value different things.* The recent push to include participants in program design is based on an assumption of dissimilar values among participants and professionals (Dewar, 2005). Even so, grounded theory paints a different picture: when state staff and participants work collaboratively for the common good of a new program, values are often not so far apart (Lomerson, O'Connor, McGaffigan, & Wamback, March 2007).

*Involvement of participants leads to better programs.* This is an assumption of many state staff who implement participant involvement strategies. It is built on the belief

that those with direct service experience have insight to share with state staff, which will ultimately lead to stronger programs (Priester, Hewitt, & Kane, 2006). While on the surface this assumption may seem justifiable, there is limited research that exists pertaining to this topic and further examination is required.

*State staff are the experts in policy design.* There are assumptions, sometimes overtly recognizable and other times less so, regarding “who” has the expertise required to form policy (Carrick, Mitchell, & Lloyd, 2001; Reed, Weiner, & Cook, 2004). Our United States system of publicly funded social services is built on the assumption that those who need services and supports need professional guidance when receiving such assistance (Lipsky, 2005). Medical professionals, social workers, researchers, and public policy professionals drive the design of programs, assuming that this process leads to the creation of cost-effective services. A more recent thrust from grant funders, legislators, and advocates has led many to challenge this assumption, noting that expertise not only sits with academically trained experts in policy and research, but also with those who have personal experiences receiving services. The assumption that “lay” people will make a difference in the research and policy process is one that often goes unchallenged due to its moral underpinnings and, because of this, may lead to practices that are not evidence-based (Dewar, 2005).

*Elders and people with disabilities are too sick to participate.* A “second class” citizenship status for elders and people with disabilities has led to the assumption that such individuals are too sick or face too many barriers to be involved in policy design, implementation, and improvement. Given that the target populations, by definition, face

economic, medical, physical, cognitive, communication, and other barriers that make participation in society difficult, it is easy to understand why state staff argue that such factors make involvement too difficult. On the other side of the spectrum, arguments from advocates highlight the need for participant involvement because of these realities, arguing that involving those directly impacted is the only way to ensure the creation of meaningful services.

*Involving participants' advocates is enough.* “Who” should be involved in policy design, implementation, and improvement is often debated. As noted above, the barriers faced by participants may create challenges to their involvement. This reality, along with a continued paternalistic approach to serving elders and people with disabilities, often leads to the assumption that advocates should represent the needs and desires of program participants. For example, organizations representing the aging, often hire professional advocates who are not necessarily reflective of the characteristics of those who are aging. Although some may recognize the need to involve advocates, others may feel that advocates' involvement should not replace the voice of program participants.

*Participant involvement is the use of one particular approach.* Although many do not argue the moral goodness associated with participant involvement, simplistic assumptions regarding what “involvement” means seem to exist. Some assume meaningful involvement occurs when participants are involved in each stage of policy development. Others define involvement much more narrowly as the participation in pre-determined structures or practices, such as advisory groups, interviews, and/or focus

groups. A more comprehensive understanding of available approaches and their uses is warranted.

### *Study Sampling Strategy*

A purposeful sampling strategy was utilized to study the participant involvement practices of existing Cash & Counseling programs. This project included two sampling phases: 1) the entire 15 Cash & Counseling programs (assuming consent acquired) and 2) three of the 15 Cash & Counseling programs. In the first phase, consenting state staff overseeing existing 15 Cash & Counseling programs were surveyed to answer preliminary questions about their programs and participant involvement strategies (to the extent they exist). Eleven of the 15 states participated in the survey. A review of the data collected during the first phase led to the identification of three states with Cash & Counseling programs to participate in phase two of the data collection.

States chosen for phase two were intended to represent the diversity that exists among Cash & Counseling programs and involvement practices. The sample was intended to include Cash & Counseling programs that vary in length of existence, population(s) served, and geographic density since all of these traits may be linked to the person-driven, process-driven, and environment-driven factors. Involving Cash & Counseling programs that have diverse involvement practices (as identified through the web-based survey) was intended to allow for the examination of involvement across a continuum, ultimately leading to the strengthening of a typology that can be utilized to fill the existing gap in research on participant involvement outcomes. Snow ball sampling was utilized in each state to identify additional state staff, advocates, and program

participants who could inform this research topic. This emergent method not only led to additional interviews, but also the examination of a comparison initiative within two of the three states.

### *Data Collection Strategies*

Multiple data collection strategies were implemented in recognition of the complex variables, internal and external influences, as well as the diverse perspectives that exist pertaining to the use of participant involvement strategies. Data collection took place in two phases, as described in more detail below.

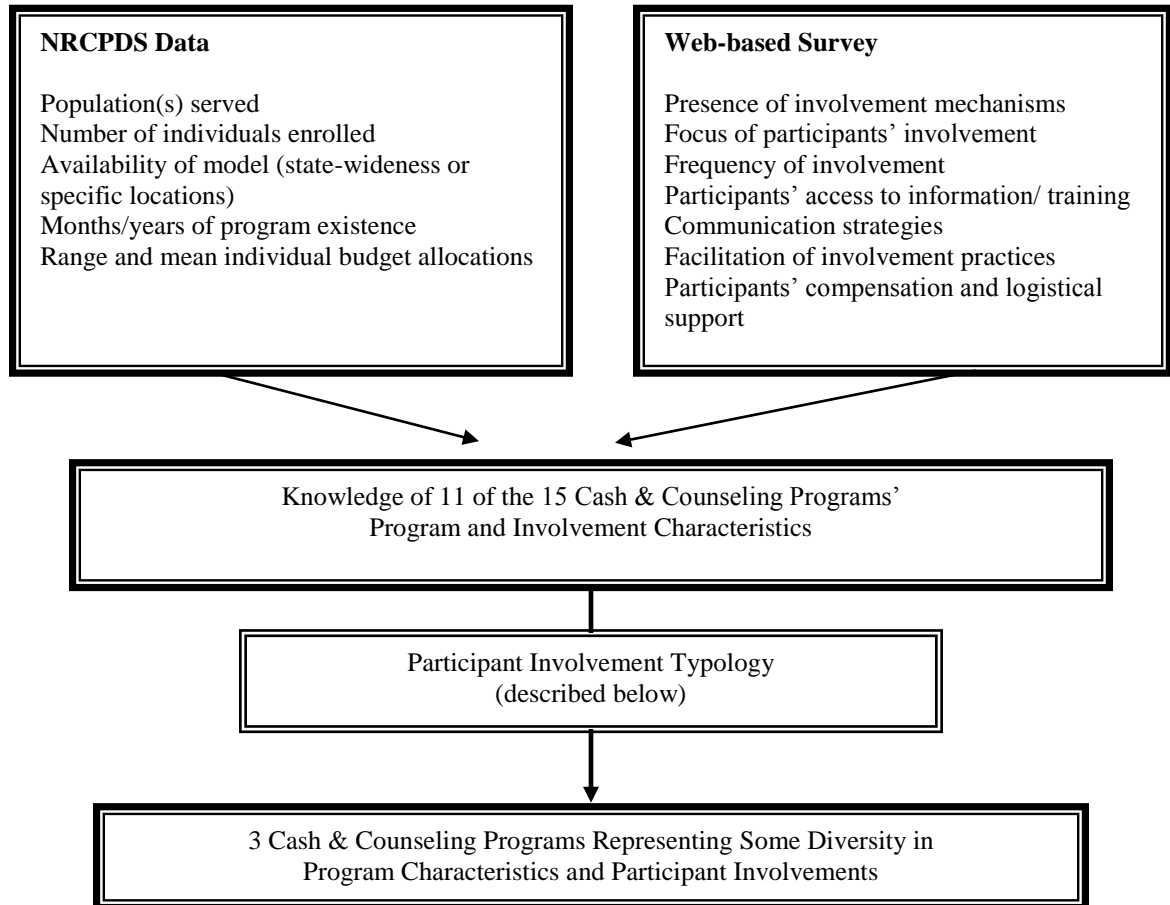
*Phase one: Surveys of models' characteristics and involvement practices.* In phase one of this study, basic program characteristics and participant involvement practices within the Cash & Counseling states was examined. This was accomplished utilizing two approaches. For one, data collected from the NRCPPS provided information on basic program characteristics of the state-run Cash & Counseling programs. These data were combined with data from a web-based survey of program administrators (n=11) regarding their existing (or non-existing) participant involvement strategies. The web-based survey was built on the factors identified during the literature review and pre-tested with individuals who have state policymaking experience. The researcher contacted each of the Cash & Counseling states prior to the release of the survey to request that the individual most informed of the state's engagement practices complete the survey. For a review of the web-based survey, please see Appendix A.

The review of data provided by the NRCPPS and the web-based survey provided the researcher with comprehensive information on 11 of the 15 Cash & Counseling



programs, allowing for up to three states to be chosen to participate in further analysis pertaining to their involvement factors and outcomes. Figure 6 below provides a flow chart depicting how data collected during phase one led to the identification of the phase two sample.

**Figure 6: Data Collection Phase One**



Building on the literature, a typology representative of participant involvement characteristics (as seen below in Figure 7) was utilized to categorize programs into three involvement groups prior to the identification of the phase two sample: low engagement, moderate engagement, and high engagement. The phase two sample was intended to, at

minimum, include states that sit on each end of the spectrum of this involvement continuum. General program characteristics noted earlier, such as the length of the program's existence, population(s) served, and the state's geographic density was taken into consideration when choosing the three states since such traits may influence participant engagement practices.

Since this categorization was performed in the first phase of analysis and was the first time this typology was used, an opportunity to examine its validity was provided as the researcher examined three states in more depth during the second phase of research. Factors identified through the literature review that are not examined during phase one of data collection were studied during phase two. Also, all factors that were examined during phase one were examined in greater depth during phase two. Modifications to the typology were then made based on the research findings, making the tool useful for future research studies on participant engagement practices and outcomes.

**Figure 7: Participant Involvement Typology**

Participant Involvement Typology Informing the Identification of Three States for Phase Two Research				
	Continuum			
	0	1		5
<b>Focus of Involvement</b>	None ↓	Individual	←→	Policy or System
<b>Frequency of Involvement</b>		Once	←→	Multiple Occasions
<b>Access to Information and Training</b>		Uninformed	←→	Informed
<b>Communication Strategies</b>		No Follow-up Controlled	←→	Feedback loop Transparent
<b>Facilitation of Involvement Practices</b>		Non-deliberative Controlled	←→	Deliberative Participant-driven
<b>Involvement in Decision- making</b>		“Closed” Decision-making	←→	“Front end”/ Open Decision-making
<b>Compensation and Logistical Support</b>		None	←→	Compensation Time & Supports

*Phase two: In-depth analysis in three states.* Phase two data collection allowed for the refining of interview protocols and the subsequent in-depth analysis of participant involvement factors and perceived outcomes. The phase two data collection methods, as described in more detail below and depicted in Figure 8, included unstructured interviews with key informants, semi-structured interviews with state staff, advocates, and program participants, and a review of materials pertinent to the engagement processes studied. Focus groups with program participants were also considered, but were not feasible given participants’ lack of availability and being widely dispersed geographically. To inform data collection methods (more specifically, the questions asked during semi-structured interviews), confidential interviews were held with key informants who were nationally recognized participant direction experts.

Unstructured interviews with national experts. Three unstructured interviews were conducted early in phase two with national experts who had program design and/or research experience in the area of participant direction. Given the sensitivity of the topic at hand and the tendency for state staff to provide socially acceptable answers to questions pertaining to their participant involvement practices, it was important to strive for a safe environment in which state staff could communicate their experiences and concerns. The key informant interviews led to insights into how to create this safe environment and how to present questions to yield the most accurate and detailed data.

Semi-structured interviews with state staff. Once three states were chosen to participate in the in-depth research, interviews with state staff were conducted. Interviews were intended to explore the existing environment, involvement strategies (or lack of), engagement factors, and state staffs' perceptions pertaining to engagement outcomes. The interviews were semi-structured, allowing for specific topics to be addressed (e.g., thoughts pertaining to engagement outcomes and representation) while also allowing engagement factors to naturally surface. Given the sensitivity of the topics discussed, it was important for the interviewer to develop a trusting rapport with the interviewees. To develop a safe environment for discussion, the interviewees were not only informed that their involvement would be confidential, but also were informed that the data would be analyzed and reported out in the aggregate form.

Semi-structured interviews with participants involved in advisory capacities. Program administrators from the Cash & Counseling programs that agreed to participate in the phase two research were requested to identify program participants involved in

advisory capacities for semi-structured interviews conducted by the researcher. In programs where there was little to no engagement, program administrators were requested to identify individuals who have provided informal guidance or who may be interested in such a role. As with the State staff interviews, it was understood that the topics discussed during these interviews were sensitive. In order to allow for an environment supportive of open discussion, the researcher discussed the confidential nature of the research and assured those interviewed that the data would be analyzed and reported in the aggregate form.

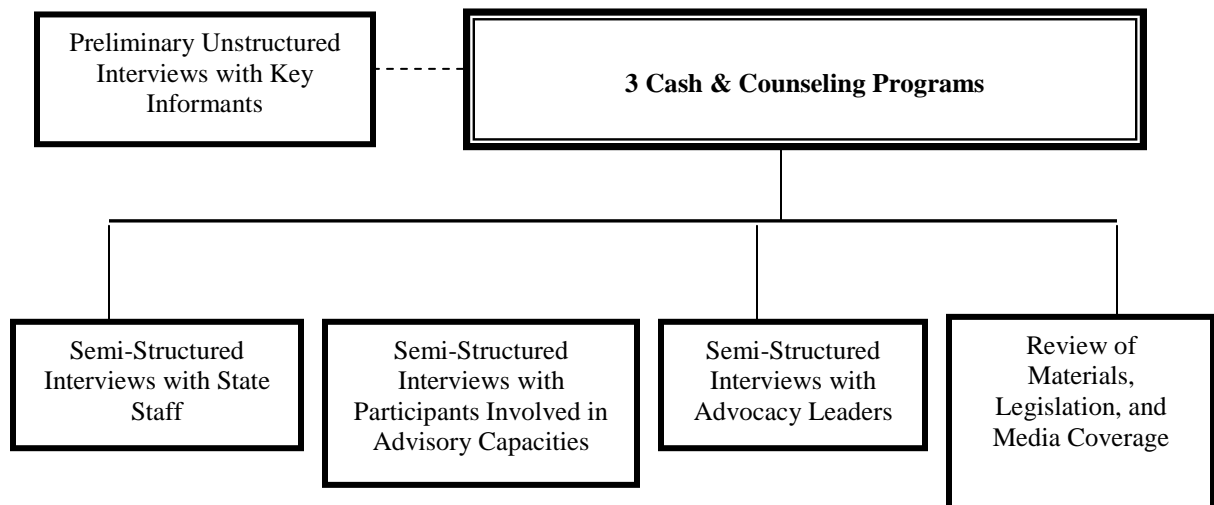
Semi-structured interviews with advocacy leaders. In addition to interviews with Cash & Counseling state staff and program participants, interviews with advocacy leaders also took place. As with program participants, state staff participating in this research were requested to identify advocacy leaders who were knowledgeable of the Cash & Counseling program and/or engaged in the program design or improvement efforts. The purpose of these interviews was to gain insight into the State's Cash & Counseling program from stakeholders who are not intimately involved with the every day practices of the program. Advocacy leaders provided indication of the general awareness and perceptions pertaining to the model, and many had insights into the historical development of the model and the role (if any) participants and advocates played in improving and sustaining the model.

Review of materials associated with participant involvement activities and outcomes. While semi-structured interviews provided significant data on participant involvement strategies and their perceived impact, a review of materials associated with

the programs' administration and participant involvement activities was intended to provide insight into practices, specific strategies, and outcomes that may be otherwise forgotten or minimized. This included meeting notes documenting efforts associated with advisory groups, committees, and public forums; deliverables resulting from engagement activities; existing participant direction or participant engagement legislation; and participant direction or participant engagement media coverage. Upon the completion of interviews, interviewees were requested to share materials that would provide a more in-depth understanding of the engagement activities explored during the interview.

Direct observation of an in-person advisory meeting. While not part of the original research design, a semi-emergent research methodology allowed for the opportunity to observe a two day, in-person advisory committee meeting within one of the three states. The original intention was not to include direct observation in the research methodology given the number of programs involved in the analysis, their geographic diversity, and the need to understand the involvement over a period of time rather than a snapshot of time. Even so, the timing of interviews in one state made the observation of an advisory group meeting feasible. As a result, data from this observation were included in the analysis.

**Figure 8: Phase Two Data Collection**



### *Validity Considerations*

It was imperative that potential validity pitfalls and strategies to minimize validity threats be examined prior to conducting this research. Through this process, the following potential threats to validity were identified: researcher bias, response bias, the need to get beyond being nice, and the complexity of variables. Each of these, and methods to minimize threats, are discussed in more detail below.

*Researcher bias.* The researcher has participated in the design and implementation of engagement practices, and as a result, has developed an interest in the topic of engagement based on personal experiences. The researcher's experiences have led to the formulation of personal perceptions pertaining to the benefits and challenges of engagement. Even so, the researcher has been intrigued by the variances in engagement practices utilized across programs, and as a result, is interested in understanding why these variances occur and sharing these findings with those who are seeking to improve engagement practices. The researcher has implemented research methods to minimize

this risk of researcher bias. For instance, the researcher included multiple sources (e.g., the state staff, advocate, and participant lenses) and multiple data collection strategies (web-based survey, unstructured and semi-structured interviews, review of materials, and direct observation) in an attempt to seek a well-balanced understanding of this topic. Also, the researcher developed in-depth case studies with quotations from each perspective within each state to provide a well-documented trail of how the overall findings were formed.

*Response bias.* State staff who participate in the study, given their role in the implementation of the Cash & Counseling model, may be biased in their interpretation pertaining to the success of the model and the impact of participant involvement strategies. Also, participants who rely a great deal on the program for their daily living needs may be overly positive about the strategies used within their state and the results of the program itself. To address the potential for this bias, triangulation of sources and methods was again required. This includes interviews with advocacy leaders not directly impacted by the program and the review of program documents, media coverage, and pertinent legislation rather than relying solely on interviews.

*Getting underneath “being nice.”* It is also important to recognize the culture that surrounds participant involvement as it relates to the development of community-based programs. More specifically, given the self-directed model itself, there is a common belief among state staff that participant involvement is the ‘right thing to do.’ This can influence how a state staff person responds to the questions posed, leading one to believe that the state staff include participants more than he or she actually does. To address this



issue, the researcher needed to pinpoint concrete practices that existed and evidence of their impact on the model. Also, key informant interviews provided insight into the importance of maintaining the confidentiality of states involved, allowing for the interviews to produce the strongest data possible.

*Complexity of variables.* A final validity concern was the complexity of participant involvement variables and the relationship among variables. It is difficult to understand all of the variables. Even so, there is an obligation to try to understand the complexities that surround participant involvement. Qualitative methods were chosen in recognition of these complexities and the desire to know important intricacies.

Unstructured and semi-structured interviews provided the opportunity to dive deep into the complexities, and the semi-emergent research methodology allowed the researcher to follow new topics and opportunities for data collection as they arose.

#### *Ethical Considerations*

There were a few ethical points to be considered when this research was conducted. For one, state staff and program participants could fear the impact their sharing of experiences could have on them as individuals. State staff could fear that their sharing of thoughts and experiences could be negatively perceived by colleagues and stakeholders. Program participants could fear that their sharing of concerns could lead to a change in how they were served within the program. Although both outcomes were highly unlikely given the research methods utilized, confidentiality protocols and the right to refuse involvement were in place and well-communicated to research participants.

Another ethical consideration pertained to perceptions of how the research results would be utilized. There may be an underlying assumption on behalf of program participants that by communicating engagement challenges to outside researchers, state staff will be required to implement new strategies of involvement. In reality, while the researcher will present the overall findings to State program administrators, the state staff within each of the participating states may or may not decide to implement new participant involvement strategies. To minimize the potential for this false expectation, the researcher communicated verbally and in writing the purpose of the research and the intended use of the research findings.

Finally, being a consultant employed by the NRCPPDS required ethical consideration as well. For more than a decade, the NRCPPDS at Boston College has been recognized as a leader in the design of participant direction. The NRCPPDS has provided technical assistance to multiple states and has managed the administration of grants at the national level. This has led to the NRCPPDS assuming an authoritative role at times. Given this reality, the researcher was sensitive to the purposeful separation of being a NRCPPDS consultant and being a doctoral researcher. This was done by emphasizing the methods adopted to assure confidentiality.

## CHAPTER 4

### DATA COLLECTION AND ANALYSIS

#### *Introduction*

A two-phased research process was implemented to investigate participant engagement in Cash & Counseling programs. The first phase included an inventory of engagement methods that existed across the 15 Cash & Counseling states (11 of the 15 participated in this data collection process). The results of the web-based survey led to the identification of three states for in-depth research on the factors of engagement and perceived outcomes, which was the focus of phase two of this research.

The three states chosen, based on the web-based survey findings, represented three levels of engagement: low, moderate, and high. Within phase two of this research, a total of 23 in-depth semi-structured interviews were held with state staff, advocates, and participants directly linked to five programs. In addition to three Cash & Counseling programs, two comparison initiatives with extensive engagement strategies were identified in two of the three states. Content analysis was performed on relevant materials to confirm as well as elaborate on the findings from interviews. This chapter provides further information on the data collection processes and the subsequent analysis. In addition, this chapter describes the methods utilized to address the validity threats that have been identified.

### *Web-based Survey of Cash and Counseling States*

The purpose of the survey was to collect information on states' basic participant engagement practices. In addition, a portion of the items were intended to inform the placement of each of the Cash & Counseling states onto a continuum of engagement, building on the typology developed in the conceptual phase of this project. The states' placement on a continuum was intended to support the identification of a minimum of three states for more in-depth analysis conducted in phase two of this research study. Upon completion of their survey, State administrators had the opportunity to volunteer their state for further research. Only the researcher could link surveys to specific states, including those that volunteered for phase two of the study.

Prior to the administration of the survey, the researcher attempted to contact leadership within each Cash & Counseling program to share an overview of the research project and to seek clarification on the correct individual to complete the survey. On June 23, 2010, a web link to the survey was provided to leads in each state as part of an electronic cover letter sent by the Director of the NRCPDS. This process was utilized to ensure that the program leads received information on the research study from a reliable source, that they knew that the NRCPDS was involved and valued its findings, and to communicate the confidential nature of the research methods. One follow-up email reminder was sent by the researcher on July 9, 2010, and a final email reminder was sent by the Director on July 21, 2010. The final email reminder provided a one week window for the completion of the survey before it was officially closed. Please see Appendix B for the cover letter and subsequent reminders. Prior to completing the survey, State

administrators reviewed a Frequently Asked Questions (FAQ) section and were asked to consent electronically to participation in the survey.

The web-based survey included 19 items pertinent to participant engagement practices. All of the questions were multiple choice except for three (reasons why administrators chose to engage participants, benefits to engagement, and challenges to engagement). Where appropriate, the respondent was able to choose more than one answer to the multiple choice question as well as to choose “other.” For each opportunity to choose “other” as an answer, the respondent was requested to elaborate in an open field. Please see Appendix A for a copy of the web-based survey. Upon collection of the survey results, simple descriptive statistics were compiled on the existence of engagement practices within the Cash & Counseling states and the methods used. The data collected from the open ended questions on barriers and benefits to engagement were compiled and sorted into themes.

In addition to providing general descriptive information on states’ participant involvement strategies, 11 of the 19 survey questions were coded to provide states with a participant engagement score based on their responses. These data were intended to inform the placement of each state on a continuum of participant engagement, leading to the identification of states as having low, moderate, or high engagement relative to their counterparts. The intention of this grouping was to allow for the identification of at least one state from each category for more in-depth case study analysis.

The 11 survey questions fit into seven topical areas linked directly to the literature and the participant engagement typology created as a result of the literature review. These

topical areas are: focus of involvement, representation of those involved, frequency of involvement, information provided to those involved, communication strategies, facilitation strategies, and accessibility. The researcher coded and weighted each answer to the 11 questions based on its relevance to participant engagement. For instance, if a state utilized individual interviews as its sole method of participant engagement, this received a lower weight than if they used advisory groups since the extent of which an individual provides input via an interview is limited to his or her own services rather than the system at large. If the respondent was able to choose more than one answer to a question, the weight of each answer was totaled for a final score for the question. For example, if the respondent reported that his/her state utilized interviews and focus groups, his/her total for the question would then be the sum of both scores. To see how each item was weighted, please see the coded survey in Appendix A. The table below shows how many points were available for each focus area. It is important to recognize that the validity of this survey tool, prior to this administration, had not been tested. The purpose of the subsequent coding and the scoring was to choose States for further research. The ability to conduct in-depth research in three states following the administration of this survey provides the researcher with the important first step in testing the tool's validity for measuring States' engagement practices.

**Table 2: Topical Areas, Questions, and Points**

	<b>Number of Questions</b>	<b>Range of Available Points for Area</b>
<b>Focus</b>	3	0-16 Possibility of additional points based on “other”
<b>Representation</b>	3	0-14 Possibility of additional points based on “other”
<b>Frequency</b>	1	0-2 Possibility of additional points based on “other”
<b>Information</b>	1	0-19 Possibility of additional points based on “other”
<b>Communication</b>	2	0-20 Possibility of additional points based on “other”
<b>Facilitation</b>	1	0-1
<b>Logistics</b>	1	0-8
<b>Total</b>	<b>11</b>	<b>70 points</b> Possibility of additional points based on “other”

While there were 12 states that responded to the survey, only 11 states provided data that could be used for analysis (one state refused to participate). While the survey was anonymous, those interested in participating in phase two had the option to provide their contact information. The states interested in participating in phase two demonstrated a reasonable range of difference, leading to little concern that they were markedly different (e.g., geographic density, geographic location, or poverty rates) than the fifteen states as a whole. Each one of the 11 surveys, represented by a letter in the chart below, were coded and weighted according to the process described. The range between the states is tremendous, with 0 being the lowest score and 56 being the highest. A review of the subtotals across each of the states confirms that the highest scoring states were dominant in most of the categories. This means that a “fluke” in weighting did not lead to unjustifiably high scores. While more testing is needed, this may indicate that the weighting of the survey is a meaningful way to begin to measure engagement practices within states.

**Table 3: Scores by Cash & Counseling State**

Topical Area	States										
	A	B	C	D	E	F	G	H	I	J	K
Representation (0-14)	0	0	5	<b>11</b>	7	10	2	0	<b>11</b>	8	8
Focus (0-16)	1	1	2	<b>14</b>	10	11	10	0	<b>14</b>	6	10
Frequency (0-2)	0	0	0	2	1	1	1	0	2	1	2
Information (0-9)	0	0	0	<b>6</b>	1	5	3	0	5	0	4
Communication (0-20)	0	0	0	<b>18</b>	13	13	9	0	<b>18</b>	14	12
Facilitation (0-1)	0	0	0	0	0	0	0	0	1	1	0
Logistics (0-8)	0	0	0	3	3	3	2	0	<b>5</b>	3	4
Total (0-70)	<b>1</b>	<b>1</b>	<b>7</b>	<b>54</b>	<b>35</b>	<b>43</b>	<b>27</b>	<b>0</b>	<b>56</b>	<b>33</b>	<b>40</b>

As seen in the table above, two states received the highest scores as a result of receiving the highest score in four of the seven categories. Three states scored “1” or lower and a fourth state scored “7.” The remaining five states scored in the middle of these two extremes. Based on the survey scores, states were placed into one of three categories: “low,” “moderate,” or “high” engagement states. As confirmed in the table below, the states are distributed in representation with the highest number of states (5) in the “moderate” engagement category, the second highest (4) in the “low” engagement category, and the least amount (2) in the “high” engagement category.

**Table 4: Scores on the Continuum**

Low		Moderate			High
A (1)	B (1)	J (33)	G (27)	E (35)	D (54)
C (7)	H (0)	K (40)	F (43)		I (56)

While it was assumed previously that those with minimal engagement practices may be less likely to participate in this survey, the findings indicate that “low” engagement states were well represented.



### *Key Informant Interviews*

Key informant interviews were held with three national participant direction experts that collectively possessed knowledge in the areas of program design and improvement as well as research. The purpose of the interviews was to inform the phase two methodology, more specifically the content focus areas and the interview protocols. Each informant participated in one interview that ranged from one hour to one and one half hours. The interview questions were open ended and broadly focused on the following areas: 1) the factors of participant engagement (person-driven, environment-driven, and process-driven), 2) perceived outcomes (both negative and positive), and 3) suggestions on the researcher's interview content and process when conducting the interviews within the states. The content of each of the three interviews was tape recorded, transcribed, and analyzed utilizing qualitative analysis software. The initial category set (or organizational categories) for which data were segmented was based on the conceptual framework and included participant, environment, and process-driven factors as well as perceived outcomes of engagement (Maxwell, 2005). As analysis took place, subcategories that were descriptive as well as theoretical were formed under each category (Maxwell, 2005). When subcategories developed to include a large quantity of data excerpts, the potential for additional segmenting within the data was assessed. If additional segmenting took place, the data already coded was reviewed once again to assure its appropriate coding given the expanded category set. In addition to the pre-determined categories, additional categories were also formed as a result of the data analysis (e.g., engagement phases and strategies for improving intended research

methods). Once coding was complete, the data found within each category were reviewed for linkages to other categories.

Preliminary interviews with key informants as well as the response rate to the web-based survey informed the decision to maintain confidentiality of the three States chosen for the in-depth research. Results from the key informant interviews did indicate that the political sensitivity of the research topic may very well influence people's comfort level with participation, potentially limiting the data available to comprehensively address the research questions posed. There is a belief that, given the sensitivity of the topic, that state staff will be more likely to communicate less-socially acceptable factors if they felt that they will not be judged by their peers, participants within their program, or even the NRCPDS. One informant felt that trust may be better established if interviews with state staff took place over two meetings rather than one. Other informants noted that one meeting should be sufficient if the interviews are done well. All of the informants felt that the in-depth interviews should be no more than two hours long.

The key informants recognized that the researcher's approach will weigh heavily on the strength of the data collected via the in-person interviews within the states. There was a concern that some state staff and some participants may view involvement efforts as more positive than they were or more negative than they were. The key informants provided specific suggestions on methods in which to frame questions so the researcher received the most accurate answers. The feedback on the interview protocols provided as part of the key informant interviews can be found in Appendix C.

### *In-Depth Interviews within Three States*

Upon the identification of three states for participation in this research, the researcher contacted the lead person (identified through the web-based survey) to provide a general overview of the purpose and methods for phase two of this research. Overview materials (see Appendix D) were shared at that time. Initially, the researcher approached State B, State K, and State I to participate in this research. These three States were chosen with a desire to seek diversity in the length of the programs' existence, populations served, and the geographic densities. State B and State K agreed to participate while State I did not. As a result, State D was requested to participate in an attempt to replace State I, and state staff ultimately agreed. The chart below compares the phase two states to the larger group of 15 Cash & Counseling states.

**Table 5: Phase Two States in Comparison to all 15 Cash & Counseling States**

	<b>15 Cash &amp; Counseling States</b>	<b>Phase Two States</b>
<b>Populations Served</b>	All of the programs serve elders and the majority serve adults with physical disabilities.	All serve elders <u>and</u> people with physical disabilities.
<b>Length of Program Existence</b>	Three states developed their programs during the demonstration (1998-2000) and 12 states developed their programs during the replication (2004-2009).	A mix of demonstration and replication states.
<b>Size of the Program</b>	Enrollment sizes range from less than 100 to over 3500.	Focus on larger programs.
<b>Geographic Focus</b>	The majority are statewide. While there are a few states that are heavily populated throughout and a few that are primarily rural, the majority of the programs serve both urban and rural areas.	Focus on statewide programs. Mixture of urban and rural areas.

Upon their agreement to participate, each lead within the chosen states were asked to identify state staff, community advocates, and program participants to be interviewed. On occasion, multiple requests needed to be made to identify community advocates and program participants to participate, leading to varying levels of success in this area. All

27 interviews were tape recorded upon the provision of signed consent. Table 6 provides information on the interviews conducted, broken out by State and role.

Prior to travelling to the research states, interview itineraries were developed. On multiple occasions, the

interviews conducted led to the identification of additional interviews to be conducted, some of which

**Table 6: Interviews Conducted by State**

	<b>State B (Low)</b>	<b>State K (Moderate)</b>	<b>State D (High)</b>	<b>Total</b>
<b>State Staff</b>	3	3	5	<b>11</b>
<b>Program Participants</b>	2	2	3	<b>7</b>
<b>Advocates</b>	1	3	1	<b>5</b>
<b>Total</b>	<b>6</b>	<b>8</b>	<b>9</b>	<b>23</b>

were conducted by phone once the site visit had ended. The researcher combined pre-specified research methods (e.g., identification of three states for in-depth interviews) with an emergent research design, allowing for the collection of data from comparison efforts emerging from the in-depth interviews conducted in two states. As a result, the data collected spanned a total of five programs within the three states (Lincoln & Guba, 1985).

The interviews with state staff, advocates, and program participants tended to range from forty-five minutes to one and a half hours. Interviews conducted with state staff tended to last longer than interviews with program participants since a component of the interview was providing descriptive information about the program itself. The focus of the interviews was similar to that of the key informant interviews (although more structured), with slight variation in focus depending on whether an individual was state staff, and advocate, or a program participant (protocols can be found in Appendix G.

While there was consideration of conducting focus groups with participants if such a data

collection method was needed, two factors played into not utilizing this method. For one, State staff had a difficult time identifying program participants to include in the research. This was compounded by the fact that those who were involved lived in different locations across the State, making attending an in-person focus group difficult. Instead, additional telephone interviews were held with program participants who were identified during the site visit in an attempt to increase the number of program participants interviewed.

Of the 27 interviews conducted, 23 were coded and analyzed to examine the engagement practices that exist within a total of five programs across the three states. The four interviews not analyzed were relevant to other Cash & Counseling programs in State K that were ultimately not included in this analysis when the decision was made to focus on a comparison program in State K in addition to one of the Cash & Counseling programs administered by the same state agency. Analysis was conducted utilizing qualitative software while adopting a similar approach utilized for the key informant interviews. As with the key informant interviews, the initial category set (organizational categories) for which data were segmented was based on the conceptual framework, which included the sorting of data as it related to person, process, and environmental factors to engagement as well as perceived positive and negative outcomes to engagement (Maxwell, 2005). A supplemental category, programmatic phases for which involvement occurs, was also included in this initial category set given the analysis results from the key informant interviews.

As analysis took place, subcategories were developed under each initial category. For instance, under person-driven factors, descriptive subcategories included state staff who do engage program participants, state staff who do not engage program participants, and program participants typically engaged (Maxwell, 2005). For process factors, subcategories such as communication processes, facilitation practices, and decision making strategies formed as data were analyzed. Data analysis also led to the surfacing of new categories beyond this initial list for which data were further analyzed. One example is the topic of representation. For this category, additional descriptive and theoretical

subcategories were formed, such as who is represented in engagement processes, communication feedback loops among those engaged and larger constituency groups, and challenges with representation (Maxwell, 2005).

Upon the analyzing of the data into categories and subcategories, the data within each were then analyzed once again to ensure its accurate categorization. At this time, data that were inappropriately placed were corrected and data that crossed more than one category or subcategory were copied and included in all pertinent categories. For example, an excerpt from a state staff person describing facilitation strategies would be placed in the “process” category under a facilitation subcategory. This same excerpt, which provided insight into the state staff’s desired level of control over a process was also placed into the “person” category under “desire to control.” A third review and analysis of the data was then completed as the researcher drafted report findings. If excerpts were found to be inappropriately placed or missing from a relevant category, this was addressed and taken into consideration in the overall tallying of findings.

Analysis was conducted for each state independently, leading to comprehensive and free standing findings for each. In States B and K which included comparison programs, independent subcategories were formed to differentiate practices and perceived outcomes among the two initiatives, when possible. Once one state’s analysis was complete, the researcher drafted preliminary report findings for that state then coded a subsequent state. For the analysis of cross-state findings and reporting purposes, the newly created subcategories within each state were compared with one another and common terminology and labels were then adopted as appropriate. In doing so, there was

sensitivity paid to ensuring that unique factors that presented within individual states were not lost.

#### *Review of Pertinent Materials*

At the end of each interview, the researcher provided each interviewee with an exit interview document. The document thanked the individuals for participating and requested that they share any relevant materials that could further inform the research process. The document, which can be found in Appendix F, provided potentially relevant materials. This document included an email address so that interviewees could send this information.

All of the information submitted was provided by state staff, while some program participants did reference the same documentation in their interviews as well. The researcher performed content analysis on the documents provided. Upon the completion of analysis, those data were used to supplement the interview data. For the most part, the materials that were submitted focused on the processes utilized within the three high engagement programs (State D and the two comparison programs) that were included in this research.

#### *Findings Validation*

Potential threats to validity, which were identified prior to the start of research, were addressed throughout the design and implementation of this research (Maxwell, 2005). For one, the researcher had to address basic concerns pertaining to both researcher bias and response bias in order for this research to be meaningful. The mere act of interviewing individuals about engagement practices insinuates that engagement is



important, presenting the potential for respondents to provide answers that gravitate towards what they feel the researcher wants to hear. This practice could be a significant threat to the validity of this research given the intention is not only to understand occasions where engagement exists, but also the factors influencing when it does not.

Similarly, another threat to validity is the impact the existing professional culture has on the responses of state staff participating in interviews. The professional culture from which the State staff are working is built on the values of empowerment and person-centeredness. To take it one step further, those administering participant direction programs are expected to have a certain level of buy-in and respect for participant direction philosophy, which recognizes program participants as ‘experts’ in their own lives and the best way to meet their long-term support needs. Participant direction funders and staff from federal agencies have consistently communicated their desire for participant engagement to take place, and in some cases, have required such. The point of this research is to understand why engagement practices, in many instances, are not implemented despite such expectations and professional values. Whether or not state staff buy in to the importance of engagement, they most likely understand the external pressures for engagement, which ultimately can put the accuracy of the data at risk.

To address both of these validity threats, the research implemented multiple strategies. For one, the researcher interviewed key informants with no direct stake in state efforts prior to embarking on in-depth semi-structured interviews. These individuals were not only asked what they perceived to be factors influencing engagement, but also what they feel would be effective strategies to get beyond the professionally acceptable

answers. One recommendation that resulted from these interviews was maintaining confidentiality of the states and individuals who participate in the research, and as a result, measures were put into place to do so. For example, only the researcher has access to a database that links the transcribed data to actual interviews and all the identifiable information was removed when reporting findings.

In addition, the researcher conducted three levels of response validation (or “member checking”) (Maxwell, 2005; Lincoln & Guba, 1985). First, the key informants were asked to comment on the findings report that resulted from their interview. Each person interviewed reported that the findings were reflective of the answers provided. Second, given the low number of program participants who participated in the research, the researcher presented the preliminary findings from two states and the complete findings from all three states to a small group of interested members of the National Participant Network, a network of program participants from across the country who direct their own services and participate in program design and improvement efforts within their own state.

Involving members from the National Participant Network in this member-checking process was important given that far fewer program participants took part in semi-structured interviews than state staff. This process allowed program participants beyond those who are directly linked to the phase two research states to validate the comprehensiveness of the data as well as to identify any potential data inaccuracies or gaps. The feedback received on the preliminary findings from two states pointed to no major gaps in the data. Upon the completion of the research in the third state, a similar

presentation on the cross-state findings was conducted. The comments received through this process were confirming of the data collected. As one individual who participated in the presentation reported in his/her email, “Your study was very interesting, and was a reflection of some of my past experiences. It sounded like one of the states that you survey was Georgia, but I guess other states are experiencing similar issues.” Since Georgia is not one of the 15 Cash & Counseling states, this statement does indicate that these findings have the potential for much broader implications. Another individual communicated his/her frustrations specific to the topic of representation. As this person wrote in an email shortly after the presentation:

...your comment about how participants ‘don’t talk to other people’ [resonated with me]. Well, hello, the state won’t share names of other participants in program due to privacy issues. VERY TOUGH to network with other participants, especially in rural states where you don’t see other people in person. VERY TOUGH in a population where participants aren’t particularly communicative by telephone (can’t afford) or computer (don’t know technology and can’t afford). VERY TOUGH when participants have physical or intellectual disabilities or both.

While National Participant Network members who participated in the member-checking process asked many clarifying questions and elaborated on many of the findings presented, they did not recognize any gaps or perceived inaccuracies in the data presented. The third level of member-checking took place with those who took part in in-

depth semi-structured interviews within the three states. The results of this process are described in more detail below.

Conducting research on systems and processes also creates significant challenges given the quantity and complexity of variables that can influence practices. The ability to dismantle factors and analyze them individually as well as collectively is difficult, and if not done well, can threaten validity. A strong conceptual framework informed by research provided a consistent and clear foundation from which to develop interview protocols that provided room for data collection on a broad array of variables. Doing so allowed the researcher to demonstrate replication of findings at two levels: multiple lenses (state staff, advocate, and program participant) and multiple cases (three states and five initiatives) (Miles & Huberman, 1994).

The ability to conduct interviews with additional individuals as new topics presented themselves allowed for the identification of unique circumstances within a State, providing even more depth and room for understanding of complex variables. For instance, it was not until the research was well underway that the potential for comparison initiatives in not just one, but two states was identified. Even more surprising was the existence of such comparisons in not just one, but two of the three states. Also, the member checking process described above allowed those who were interviewed to confirm or question the framing of complex variables that were discovered and presented by the researcher.

*Member checking results from semi-structured in-depth interviews.* Three in-depth case studies that explored the person, process, and environmentally driven factors

to engagement as well as perceived outcomes to engagement resulted from the multi-pronged data collection methods implemented. As described above, a process of member checking was utilized as one approach to address validity threats specifically linked to the challenges associated with measuring complex organizational processes and the factors that influence them. This process took place after final analysis was conducted, allowing those interviewed to comment on the researcher's display of initiatives' descriptive components, the engagement factors and perceived outcomes, as well as the interpretative conclusions (Miles & Huberman, 2004).

Upon the completion of each of the in-depth case studies, the researcher implemented a review process with those who participated in the research. Recognizing state staff's concerns pertaining identifiable information and the breach of confidentiality, the draft case studies were first sent to state staff from the relevant state. State staff were asked to review the case study with two important focus areas in mind: potential inaccuracies and descriptive information that could breach confidentiality. Once concerns were addressed, the case study was then sent electronically to other interviewees with the same request for focus. All individuals who received the case study were provided a window of at least two weeks to review the document. People were requested to inform the researcher if they needed more time to review the report.

The member checking response rate was the highest among state staff. At least one lead contact from each of the three states responded to the inquiry for feedback on case studies. In State B, two state staff responded. One provided minor edits (e.g., correcting where "Initiative B-1" should have actually read "Initiative B-2." A second

state staff person provided feedback on the overall content of the report. According to this individual:

I have reviewed this and I think it looks good. The reported information is consistent with my perceptions and understanding. Your writing style is excellent and the organization of the material is logical. I really have no significant comments/suggestions. Good luck!

This response provides some indication that the researcher was able to identify, analyze, and report on the complex variables to engagement, especially the complex factors that exist within a State that has two similar programs within the same State agency, one having low engagement while the other having high engagement.

The most comments that resulted from the member checking process came from State K. In addition to the requested descriptive changes to protect confidentiality, an Initiative K-2 state staff person communicated the following in an email:

From a leader stand-point....It was hard reading... you pointed to some areas for K-1 that opened my eyes some on participant engagement and K-1 lack of open engagement. As I do all reviews and Audits on the program I will use the observations as a means to incorporate where possible.

This response points to evidence that the researcher was able to conduct interviews, perform analysis, and draft subsequent findings that moved beyond the professionally driven culture of “being nice,” a well identified validity concern. It also provides insights into how this research is, in itself, a method of intervention that can ultimately influence engagement practices.

Even so, this state staff person did utilize the member checking process to communicate his/her own conclusions as to the reasons for extensive differences in engagement practices between Initiative K-1 and Initiative K-2. According to this person:

I know your paper was focused on engagement; open, closed.... elements for successful engagement practices, etc... But as a reader, no where in your paper do you incorporate the level of Risk...K-1 has a higher level of Risk compared to K-2, thus various area to mitigate and engage are weighed against the level. Just thought I would point this out for your next thesis...

This respondent believed that Initiative K-1 was a program that had to minimize risk for program participants, ultimately decreasing the feasibility of participant engagement in implementation and improvement. This was assumed to be less of an issue for Initiative K-2, which was not an actual program, but rather a planning initiative. Interestingly, there

were perceived outcomes to engagement that were recognized only by State K, and more specifically, from those involved in Initiative K-2 that shed light on the extent to which minimizing risk may actually be a desired outcome (e.g., the outcomes of stakeholder buy-in, trust, informed decisions, and creativity). One may argue, based on the research, that those from Initiative K-2 were acutely aware of the risk associated with their finance design decisions, and as a result, actually utilized engagement to build the trust required to ensure creativity and informed decisions pertaining to a topic that was of great importance to the State as well as its stakeholders. Also, Initiative B-2, being an initiative that includes program participants at the programmatic level, did provide indication that extensive engagement can occur to inform services that ultimately impact a population with long-term support needs.

State staff from State K (Initiative K-1), as part of the member checking process, also communicated the belief that engagement was less possible for Initiative K-1's improvement committee given it was time-limited. Even so, it is important to recognize that Initiative K-1 had longer-term efforts, such as their quality committee, that did not include extensive participant engagement practices. According to those interviewed, Initiative K-2 was also a short term committee.

Finally, state staff from Initiative K-1 also commented on the researcher's recognition that Initiative K-2's engagement practices were more well known than Initiative K-1's efforts. In response, state staff reported that Initiative K-2 "impacts a greater number of people." Even so, extensive engagement practices were found within Initiative B-2, a comparison program also targeting a specific population.



As part of the member checking process, a state staff person commented on his/her review of State D's case study, and this review was also positive although his/her review was incomplete. According to this individual:

I have reviewed as much of the document that I could. It appears to be very thorough and accurate. I think it is ok to submit the report as is, based on what I reviewed. I saw no inaccuracies or anything that may identify our state. I would however appreciate another opportunity to review the document before it is finalized. Thanks.

Interestingly, state staff from neither comparison initiative (Initiative B-2 and Initiative K-2) responded to the request for feedback.

### *Conclusion*

The data collection and analysis conducted as part of this research was implemented utilized a two phase approach. The first phase, which included a web-based survey of state staff leading Cash & Counseling programs and key informant interviews, was intended to inform ways in which to address threats to validity that could surface in phase two, which was in-depth case study research in three Cash & Counseling States. Recognizing that the comprehensiveness of this research was dependent on the incorporation of three lenses (the state staff, advocate, and program participant lenses), there was a significant attempt to ensure all three lenses were adequately represented in numbers.

Once it was clear that the participant lens, although important, would be weaker than the state staff lens, a constituency validation process was implemented. This process

required the presentation of preliminary data from one Cash & Counseling state to a national network of program participants who have some experience with participant engagement activities to validate the findings and to identify any major gaps in the data from the participants' lens. Once the research was complete, this same national network was presented with the complete findings and requested to confirm, once again, the validity of the research, and any concerns pertaining to the findings. This approach, in addition to a member checking process with individuals who participated in phase two in-depth semi-structured interviews, was intended to address threats to validity. It appears that these practices, along with a triangulation of methods and data collection processes, have allowed for a comprehensive research project that was able to 1) address potential response bias, 2) move beyond 'being nice' given the professional culture that surrounds participant direction and participant engagement, and 3) effectively measure complex and inter-related factors associated with organizational processes.

## CHAPTER 5

### WEB-BASED SURVEY FINDINGS

#### *Introduction*

A total of 12 states responded to the survey. The survey was sent to administrators in fifteen states, leading to a response rate 80 percent. Of the 12, one state did not agree to participate and did not complete the questionnaire. Each of the survey respondents that did complete the survey reported that they were in the “implementation phase” of their program (as opposed to a design phase). When asked whether or not their programs involve participants in the design, implementation, and/or improvement of their Cash & Counseling program, seven (63.6%) reported yes, three (27.3%) reported that they had in the past, but not currently, and 1(9.1%) reported that they did not. Those that do currently (a total of seven states), were requested to answer a set of multiple choice questions that addressed outreach, representation, facilitation, focus of involvement, involvement methods, training and information sharing, and accessibility. Findings from key areas are described in more detail below.

#### *Outreach*

States were requested to answer questions pertaining to how they identified potential individuals to participate in their engagement process as well as how they chose who participated. State respondents reported a variety of mechanisms in which to identify potential individuals, and many states used a combination of methods. All seven states

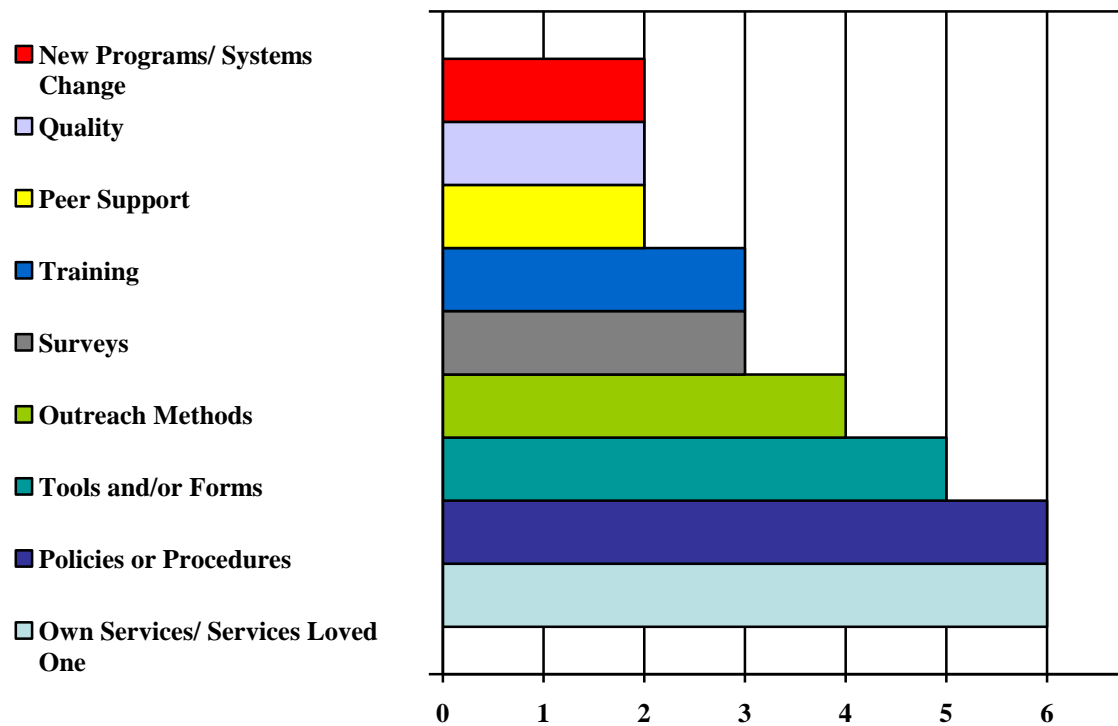
responded, and the most popular method was to request advocates to identify interested participants (five, or 71.4%). Four of the seven states (57.1%) involve those already involved in the design of other home and community based services. Financial management agencies and/or consultant entities also played a role in the identification of participants in four (57.1%) of the states. Only a minority (two, or 28.6%) sent out requests for involvement to all of their program participants. Three (42.9%) of the states requested well-known advocates to participate on behalf of participants. Other methods noted by respondents included holding stakeholder meetings (one) and tapping existing participants via customer surveys (one). For the most part, these findings point to outreach processes that are targeted rather than broad-based and open to all participants enrolled in the program.

#### *Focus of Involvement*

State respondents were requested to identify the program phases in which participants have been involved, if at all. Six of the seven states responded to this question, and all of these states reported that participants were involved in the design, implementation and improvement phases of their programs. The majority reported that participants are also involved in the evaluation stage (five, or 83.3%). The stage that states seemed to involve participants in the least was the sustainability phase (three, or 50%), although responses may have been impacted by varying definitions and assumptions pertaining to what is meant by “sustainability.” Phase two provided more of an opportunity to understand the programmatic phases in which participants are involved.

A total of five of the seven states answered a question pertaining to the facilitation of their engagement activities. Of the five, five (100%) reported that state staff facilitate the process. Respondents were also requested to share information pertaining to the topics for which participants have provided input. Six of the seven state respondents answered this question. All of the respondents reported that participants have provided input into their own services or the services of a loved one as well as into the design of policies and procedures. A total of five states (83.3%) reported that participants provided input into the design of tools and/or forms and four (66.7%) reported participants provided input on outreach methods. Other topics, such as providing input into the development of surveys and training were less popular, but used in three states (50%). Participants' involvement in providing input into peer support models and methods for monitoring quality were minimal (two states, or 33.3%). Minimal involvement methods associated with monitoring quality is surprising given most respondents' indication that participants were involved in the improvement phase of their program. Interestingly, across the states, the focus of involvement touched each end of the spectrum: input provided at the individual level, but also input that had the potential to change the program for which others would also be impacted. That being said, only two states (33.3%) moved input beyond the program to other programs or larger systems change. It is important to note that none of the respondents noted "other" focus areas for participant engagement, which may indicate the list of choices provided was comprehensive in nature.

**Figure 9: Topics of Engagement**

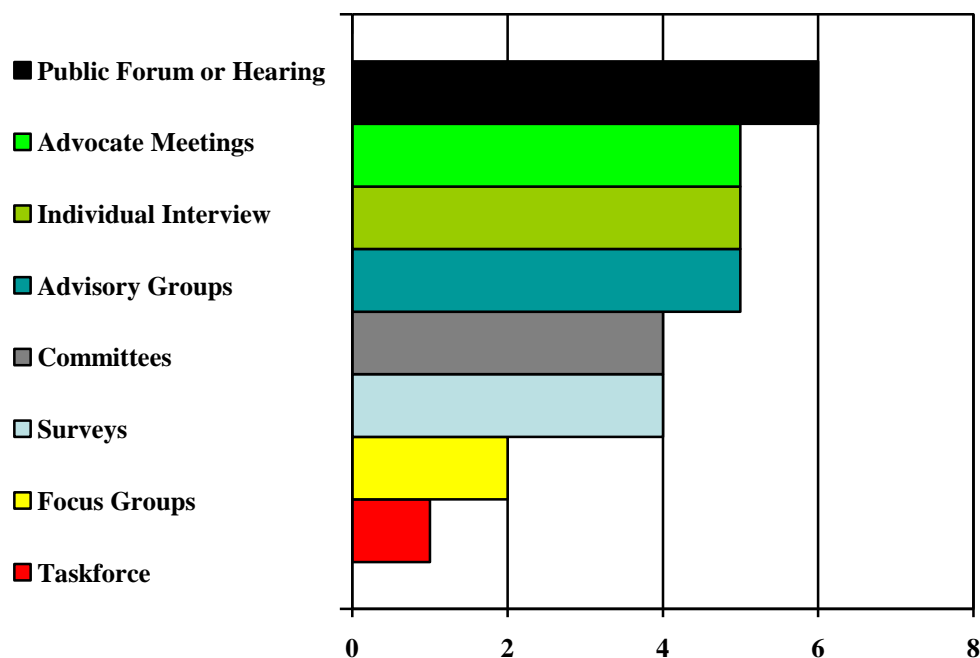


### *Involvement Methods*

Respondents were asked to share information on the methods in which they involved participants. Six of the seven respondents answered this question, and all six reported that they used public forums or hearings as involvement methods, although it is unknown whether or not this is because of an external mandate to do so. The majority of the survey respondents reported that they used individual interviews (five, or 83.3%), advisory groups (five, or 83.3%), advocate meetings (five, or 83.3%), surveys (four, or 66.7%) and/or committees (four, or 66.7%). These findings indicate that the majority of respondents utilize more than one method to involve participants, and most likely this is dependent on the topic of involvement. The method used the least was taskforces (one, or

16.7%), although it is important to note that taskforces often have similar characteristics to committees, a method that was reportedly commonly used. It appears that the majority of involvement methods have been captured in this survey given the lack of “other” strategies provided by respondents. As with the focus of topics ranging from individually-focused to program-focused, the methods follow a similar trend. This makes sense if the intention is to match the method with the topic at hand. For instance, states most likely used individual interviews and surveys to understand people’s feelings about their services or the services of a loved one. They most likely used advisory groups and committees to focus on more programmatic topics, such as policies and procedures.

**Figure 10: Involvement Methods**



In regard to frequency of involvement, six of the seven states responded, and the majority of the six respondents (five, or 83.3%) reported that they involved individual

participants on more than one occasion, either ongoing until a specific project is completed or throughout a series of projects. How states chose to communicate with participants throughout their involvement was consistent as well. Six of the seven states responded and all six utilized telephone and/or teleconferences to support communication. The majority of the states also met with individuals in person (five, or 83.3%) and communicated with participants via email (five, or 83.3%). The method least used was web conferencing (two, or 33.3%). Respondents described no other methods for communication when prompted, which most likely indicates that the list of methods provided was comprehensive in nature.

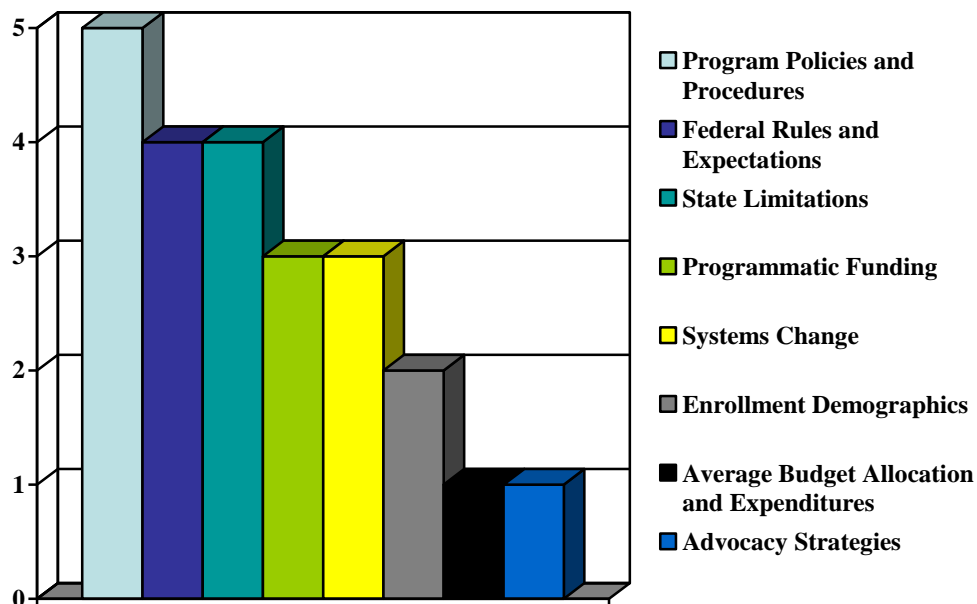
#### *Training and Information Sharing*

States were requested to answer a question pertaining to what, if any, information and/or training they provided to participants prior to their engagement. There was not one specific topic that was the focus of all states, and in general, it appeared that participants' preparation was not a focus of many states' efforts. Of the six states that responded, the majority (five, or 83.3%) provided information and/or training on the program's policies and procedures (although, this may very well be provided to all program participants who enroll). A little over half of the respondents (four, or 66.7%) provided information on federal rules and expectations, and the same number (four, or 66.7%) of the states provided information on the state's limitations. Areas least addressed by states included the average budget allocation and expenditures (one, 16.7%) and advocacy strategies (one, 16.7%). One of the respondents (16.7%) reported that they provide no information or training on the topics noted above. When reviewing these responses, it appears that the



information provided by states to prepare individuals was most likely no different than the level of information all enrollees received. Although other entities (e.g., providers and/or advocacy organizations) may be assuming responsibility for such education, it is important to understand why information sharing and training is so minimal, especially given the diversity of topics of engagement and engagement methods states are reporting. One survey respondent did report that training happens throughout the involvement process rather than upfront, an important distinction that may be the case for many of the states. Two of the states reported that they provide information and/or training on “other” topics, which were 1) access to information of their interest and 2) an overview of the process and any relevant information about the program timelines and commitment expectations.

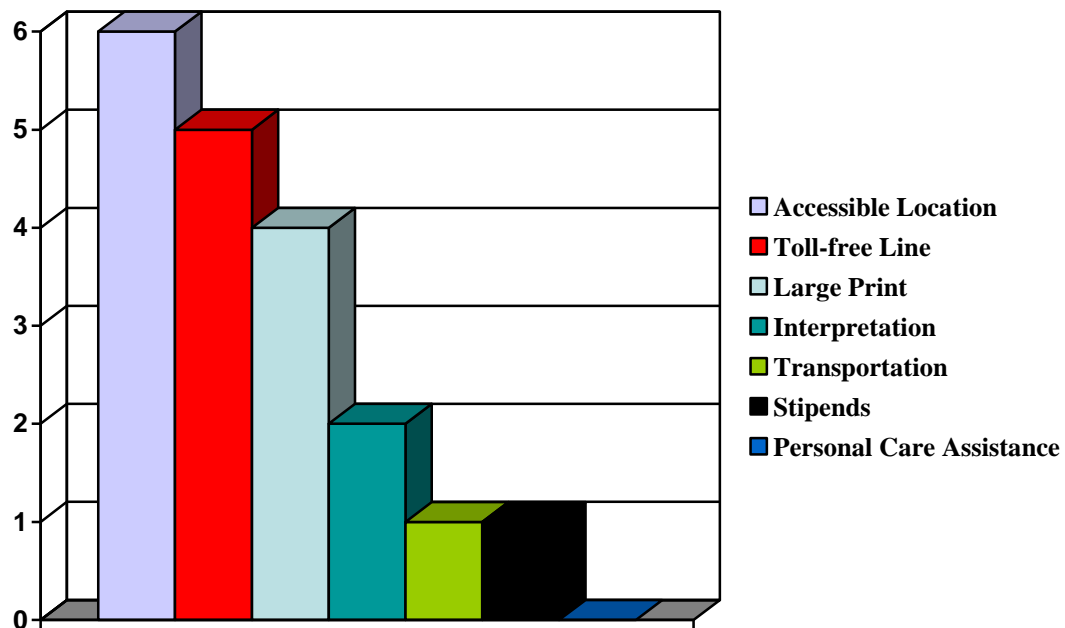
**Figure 11: Training and Information to Aid Participants in Involvement**



### *Accessibility*

States were asked to provide information pertaining to their methods for addressing the accessibility needs of participants who are engaged. Six out of the seven states responded, all of which reported that they provided an accessible location, five (83.3%) provided a toll-free line, and four (66.7%) provided large print. Methods least used to address accessibility were interpretation services (two, or 33.3%), transportation (one, or 16.7%), and stipends (one, or 16.7%). No respondents indicated that they provided personal care assistance. One respondent indicated that their ability to provide supports was dependent on supplemental grant funds.

**Figure 12: Addressing Accessibility**



### *State Staff Persons' Rationale For and Against Engagement*

While the web-based survey was primarily answered via multiple choice with the option to expand upon answers listed, there were a few sections that allowed individuals

the ability to provide open-ended responses. One such section focused on the rationale for why a state had chosen to involve participants in the design, implementation, and/or improvement of the Cash & Counseling program. Respondents were requested to list up to three reasons why their state involved participants. The survey was also intended to provide insight into why some states chose not to engage participants. Such respondents were asked to choose from a list of frequently referenced reasons and/or to describe “other” reasons for their decisions. States were able to choose as many reasons as they felt appropriate. Multiple choice with the option for “other” was intended to begin to test common assumptions as to why states are not involving participants. It is important to recognize that the different types of questions (open ended vs. multiple choice) may have played a role in the answers provided. It was important to examine reasons for and against involvement in greater depth during phase two of this research in order to validate and expand upon the survey answers provided. Also, future surveys should be modified to ensure stronger comparability between the two rationales.

Five respondents described why they did involve participants and four described why they did not. Interestingly, the reasons for involving participants appear to be more philosophically or value-driven (labeled as person-driven in the literature review) compared to reasons for not doing so, which appear to be more focused on process and environmental factors. Those who chose not to engage participants pointed to a lack of finances, time, and external expectations (e.g., it was not required or there was a lack of interest on behalf of participants). External requirements, or lack thereof, was given as a reason why and a reason why not (respectively) to engage participants. This discrepancy

is most likely due to respondents' varying interpretations and/or knowledge of the Centers for Medicare and Medicaid Services' (approves Medicaid-funded participant direction models in order for states' to receive federal matching funds) expectations in the area of stakeholder involvement.

Those who involved participants focused their reasoning on the belief that such involvement was not only supportive of the person-centered philosophy, but also a method for ensuring program responsiveness. So, in actuality, the answers are not only philosophically driven, but also process and outcome-driven. One respondent who pointed to an "other" reason for not involving participants indicated a belief that involvement is less crucial beyond the design phase. This response may be considered more process and outcome-based than its counterparts that focused on the lack of financial resources and time. Phase two of this research has provided an opportunity to examine these reasons in more detail to further understand if this distinction really exists.

#### *State Staff Persons' Perceptions of Benefits and Barriers to Engagement*

All respondents, regardless of whether they have or have not involved participants, had the opportunity to share barriers and/or benefits to engagement. Responses were open-ended, and respondents had the ability to note up to three benefits and three barriers. The majority of respondents listed both barriers and benefits, with most identifying more benefits than barriers. The benefits appear to fall into one of four categories: provides a new perspective, improves the program, increases buy-in, and increases advocacy. The barriers to engagement appear to fit into one of two categories: lack of access and interpersonal conflict. Overall, there were many more benefits

described by respondents than there were barriers. The one respondent who reported that he or she did not engage participants (currently or in the past) interestingly enough identified three benefits to engagement.

### *Conclusion*

The web-based survey was enlightening and provided an informative inventory of Cash & Counseling programs' engagement methods. Nearly half of the existing Cash & Counseling states reportedly have some type of participant engagement within their programs. While four states reported that they did not currently engage participants, one may theorize that the three states that did not respond (and the one that refused to participate) may fit this category as well. Despite clear communication pertaining to the confidential nature of the survey, concerns pertaining to how the findings would be used could have played a role in the non-participation of three states. While this cannot be confirmed, it should be considered when approaching states to participate in the more in-depth research conducted in phase two.

Seven of the Cash & Counseling states appear to be engaging diverse groups on diverse topics utilizing diverse methods. That being said, when one looks closer at the information and accommodations provided to participants to support their engagement, the meaningfulness of engagement is still unclear. The benefits and barriers to engagement shared by respondents are not surprising. The numerous benefits described by respondents are consistent with what has been heard anecdotally, but even with these documented benefits, only seven states are utilizing engagement methods and the depth of the methods are still unknown. The barriers described by some respondents began to

shed light on the dynamics of engagement that make engagement less attractive for states. Phase two allowed for a more in-depth understanding of these barriers and why in many states they seem to outweigh the benefits. Phase two also began to shed light on whether or not the states that do engage participants have more active participation than those that do not, and/or whether specific design features resulting from the engagement lead to more successful programs. The qualitative focus of phase two provided the foundation needed to link engagement processes to outcomes. That being said, further research will be required in order to meaningfully determine whether or not participant engagement leads to positive or negative outcomes at the programmatic or individual level.

## CHAPTER 6

### KEY INFORMANT FINDINGS

#### *Introduction*

Three key informant interviews were held in August of 2010 to inform the research interviews planned with state staff, participants, and advocates within the three states chosen for in-depth analysis. Individuals chosen for the key informant interviews have extensive participant direction policy and/or research expertise. Individuals were chosen to be key informants given their demonstrated interest in the area of participant engagement and their ability to talk openly about sensitive and controversial topics in this area. It is important to note that those interviewed have divergent views on engagement and the factors associated with it. The purpose of the interviews was two fold: to validate the framework for which interviews within the states was grounded and 2) to strategize methods in which to conduct interviews that would elicit accurate data on controversial and/or sensitive topics related to participant engagement within the Cash & Counseling programs. With this focus in mind, the key informant interviews intentionally were unstructured.

#### *Person-Driven Factors to Engagement*

All three key informants recognized state staff and/or administrators' personal level of motivation as a major force in influencing their decisions whether or not to

engage participants. For the most part, those who were perceived as invested in the engagement topic were perceived as more likely to engage participants. While this point seems obvious, it is clear that those who are called upon to engage participants may have varying levels of motivation for this work, which then could influence their efforts. Each of the informants, upon request, described in detail what they believed were the characteristics that lead some to be more motivated than others. Assumptions pertaining to pragmatism, efficiency, and expertise (all discussed in more detail below) were commonly referenced during these discussions.

*Pragmatism.* When discussing why some are less motivated than others when it comes to adopting participant engagement, all three of the informants reported that they felt (or that they have heard others argue) against the practicality of such practices. As one informant stated,

...just thinking about the logistics of what goes into that process, I think it's just a matter of efficiency... there's certain rules and reg[ulations] that you're going to have to... comply with to get the thing going. The people who are... in charge of designing and implementing and evaluating, had years of training and--and doing those activities, and so why would you bring into that people who aren't trained in those activities?

Engagement was recognized as time-consuming, especially “to do it well” and hard to handle when “participants may not want to do what you want to do.” Respondents pointed to the time it takes to engage individuals, including the time to educate individuals on the system so they understand the boundaries that exist when they are



providing input. Reportedly, many who are less motivated are seeking the easiest approach to meet a task they are required to perform with the least amount of “unnecessary” work required.

Interestingly, an argument of pragmatism was made on more than one occasion for why engagement should occur. For example, one informant argued that private market corporations engage their consumers to ensure a strong product. “Private corporations market test all the time; you know they bring people into give their input and that’s what you’d want. You—you don’t want to get at the other end and—and find out that you’ve made, you know, a terrible flaw for something that was—is going to be detrimental to the program. You want to catch that early in the process.”

*Expertise.* All three of the key informants discussed the assumption that state staff are typically assumed to be the expert, leaving little to no room for participants in the design and implementation of policy. One informant describes an “elitist mentality” that exists among some who do not utilize engagement methods. It’s a belief that “I know better—I know best what’s good for you.” This concept was confirmed by another informant who mentioned that some may “just think they know best and [that] the participant doesn’t have a place in designing programs...” Similarly, one informant noted that engagement may very well be appropriate, but that state staff (as the experts) should decide when and how participants should be engaged. According to one informant, “it takes them a long time to--to understand the way State and Federal government... does and does not work.” Some of the informants believe these perceptions are fed by a

professional culture embedded within the social service system, which is described in more detail below as an environmental-driven factor.

*Empathy and Personal Experiences with Disability.* Based on the key informant interviews, it can be argued that empathy may play a role in engagement decisions. It was communicated by all three informants that those who have had personal experiences with disability may be more likely to engage participants in the design of programs. According to one informant, “I think the people... that you’re going to find are people who--who are... passionate about it, I think are going to be the people who have... personal experience with it.” One key informant empathizes with people who want to have control over their lives and the potential for his/her desires to be ignored one day. “I want to have a voice. I need to have a voice. When I have a voice I feel better about things--whether everybody agrees or not.” Personal experience with disability may not be valued by some state staff. When asked to describe those who engage participants from the perspective of those who do not, key informants used terms such as “fluffy” and “naïve.” On the other hand, when asked to describe those who don’t engage from the perspective of those who do, descriptors such as “traditional thinkers” and “not good listeners” were used.

*Fear.* During the interviews, fear surfaced as a person-driven factor for why state staff may not engage participants. Fear of the unknown appears to be a potential trigger. For one, participants or advocates may ask questions that the state staff may not feel they can easily answer. According to one informant, “there is an inherent fear of not being able to legitimize and truly answer common sense questions... trying to make sense out of something that doesn’t make sense...” Also, state staff may fear that the answer they

provide will not be the answer the participant and/or advocate wants to hear, which could then lead to a negative or even confrontational response. For some, there may also be inexperience with disability leading to discomfort when a state staff person is required to communicate with a person who is unfamiliar to them in ways that are accessible to the individual with a disability. Finally, fear may also be driven by the collision of two worlds: a world of bureaucracy for which policy is resistant to change in institutional practices and systems and a world of real life experiences built on the emotion of those who face disabilities and community barriers.

*Distrust.* The key informant interviews also shed light on another potential factor of engagement: distrust. Although state staff may be confident that most people who require services use such services appropriately, there may be an inherent culture of distrust, leaving some less likely to engage. According to one informant, “I think it’s distrust... you think everybody is out to rob the system.” It appears that this factor may be less noticeable on the surface, for instance in one-on-one interactions, but instead a much deeper factor resulting from a system built to protect the appropriate use of public funds.

*Desire to meet external expectations.* One last person-driven factor discussed was the desire to be perceived as supportive of participant engagement. In a policy climate that emphasizes person-centered planning and participant-directed services, key informants pointed to a general perception that participant engagement is the right thing to do. According to one informant, “people think it--it looks good.” Whether it is funding mandates, leadership’s expectations, or advocate pressure, participant engagement is

expected by many and is assumed to lead to positive results. This factor makes research on the topic of participant engagement particularly difficult given the potential for people to gravitate to socially acceptable answers to participant engagement-related inquiries. This means that some state staff may be “going through the motions” that ultimately lead to less than meaningful methods and outcomes perceived as mediocre or even poor. When describing one such case, an informant argues, “as much as they did want to hear from parents, [they] really didn't think the parents knew what they were talking about when it came right down to it...So I think that--that did make a difference, and I think that's why the engagement ended up--you know they ended up kind of phasing it out over time because it was so uncomfortable for everybody.” External expectations were not enough to make engagement work, and instead, led to mediocre process and results.

#### *Environment-Driven Factors to Engagement*

The key informants were asked to describe the type of environments that are conducive to participant engagement as well as those that are not. By far, leaderships' expectations and the professional culture were the two most frequently cited by all three informants. In addition, all three of the key informants referenced public pressure to engage participants and fiscal feasibility as factors influencing engagement. Each of these factors is examined in more detail below.

*Leadership.* Regardless of whether or not the key informant believed in engagement, there was clear agreement among all three that leaderships' values and practices are most likely one of the most powerful environmental factors influencing participant engagement practices. Interestingly, leadership was never discussed in a

vacuum, but instead, directly linked to other factors assumed to be associated with successful engagement outcomes. For example, in examples provided to demonstrate successful engagement, there were leaders who valued the participant voice, bought into the practice of engagement, provided a vision for others to adopt, and provided access to tools and resources to make it happen.

*Professional culture of services and supports.* Assumptions of state staff pertaining to the role professional experts play in making policy design decisions surfaced as a person-driven factor to engagement. Because of this, it is no surprise that the key informants named the existing professional culture as an environmental factor that influences participant engagement efforts. Within our service culture, “they [participants] don’t have authority... you’ve got people who’ve spent two years being trained to be a manager or to be a social worker... they have a certain level of formal training, but also knowledge of the system, so there’s an imbalance there.” Another informant states, “There is an assumption that participants don’t have the education, the history experience, the ability to understand complex bureaucratic rules and regulations and things like that.”

*External pressure for engagement.* All three of the key informants pointed to external forces that encourage or require state staff to create strategies to engage participants, whether it is political leaders, advocates, or the general public. Some appear to feel that there is pressure to engage participants within participant-directed programs simply because of philosophical ideology, not because people agree it works or that it is a necessary component of systems design. In addition, there are federal mandates for the

expansion of person-centered home and community-based supports that are reportedly utilized by advocates to justify and push for engagement. According to this informant,

I think that Olmstead forced us into it and it forced it by having Olmstead Advisory Councils... it gave the disability rights organizations and participants then the ability to come to the table without saying, “I’m going to lock myself to your desk, and I want to be heard.”

*Fiscal restraints.* Budget restraints are commonly pointed to as a reason why state staff are unable to engage participants. Budget shortfalls may lead to the existence of limited staff to plan for and implement strategies for engagement in addition to limited (or nonexistent) funds to pay for the accommodations requested by participants. Surprisingly, fiscal restraints were not a major topic of discussion during the key informant interviews, and in most circumstances, surfaced as a topic by the interviewer.

The key informants did recognize the struggles of state staff to make extremely difficult decisions during budget times and how this can lead to limited engagement methods employed. Even so, the majority of the key informant discussions pointed to the prioritization processes of state staff as the leading factor rather than the actual budgets themselves. According to one informant, “I think you almost have to make the assumption that when anybody says there’s not time what they’re really saying is I’ve decided that the other things I have to do [are] more important than this.” This point is validated by another informant who says, “You can find money. We’re not talking about much money here. We’re talking about what—\$10,000 to \$20,000 a year. With the waste that we have I just—I don’t buy that.”

### *Process-Driven Factors to Engagement*

Key informants were requested to discuss actual engagement methods, including what they feel are factors related to engagement outcomes as well as methods that they perceive to have worked and/or not worked well. The importance of training and the topic of paying participants for their involvement (both described in more detail below) were two topics that surfaced across all three interviews. Interestingly, the informants devoted more attention to the focus of involvement as well as to outreach, communication, and accommodation practices rather than specific modes of involvement. That being said, some discussion about the use of advisory groups, focus groups, and public meetings did take place and analysis of these discussions is provided below. A visual depiction of the process-driven factors is also presented in Figure 13.

*Investment.* Investment in engagement processes surfaced in each interview when discussing factors that lead to engagement and positive outcomes. All three informants referenced the extensive work associated with engagement, and the time required to implement participant engagement practices successfully. At the forefront of this investment is leadership buy-in, which then directly influences the time and resources devoted to process. Also, the investment of time was specifically referenced when informants discussed the need for training for participants (and one informant actually referenced training for state staff) as well as the time required for adequate communication between state staff and participants. According to one informant, it is “definitely...more time-consuming in some ways... I think to do it well anyway, you have to at least spend some time with education and developing a relationship with participants and participants may not want to do what you want to do.” State staff are not

the only ones who need to invest as the time and burden for participants was also referenced by two of the informants. Also, the belief that engagement actually slows down the program design and implementation process did not go unrecognized.

*Engagement phases.* While it was not a topic of significant focus, each of the informants referenced the phases of program design, implementation, and improvement in their comments. One informant felt that engagement was not needed in the design stage while it is more likely needed to assist state staff to approve the program. According to this informant, “I don’t think it alters the programs... in those early, early stages.” The informant noted that there are rules and regulations which drive the creation of the program, leading to very little room for modifications. According to this informant, “the people who... are in charge of designing and implementing and evaluating, had years of training... and so why would you bring into that people who aren't trained in those activities?” Instead, the informant notes that engagement is the most needed in improving the program. “I would think [engagement] would be important for quality assurance, you know the evaluation part of it. When the end-user says... maybe this isn't working.”

Two of the three informants referenced the design phase as an especially important time to engage participants (one stating that involvement should actually be more frequent in this phase compared to others). One informant referenced a specific example for which there was “deliberate” involvement of participants, “and as a result, they were able to build a program that... [the] bureaucrats felt like [was] really going to meet needs and they did it with--with a concerted effort.” This informant also recognized

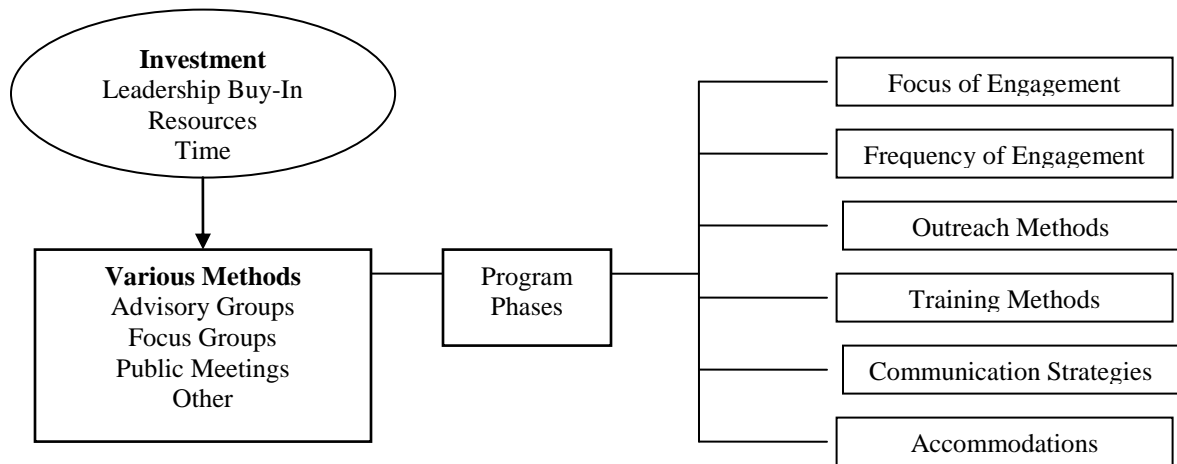


the boundaries in which programs need to be formed. “It was built...within the confines of funding sources,” creating an avenue to have difficult conversations about what is and is not allowed. This runs counter to the argument made by one informant that engagement is unnecessary in design since policies and regulations have already been decided.

*Engagement methods.* There are many different methods to engaging participants, although only three (advisory groups, focus groups, and public meetings) were referenced by the key informants. Despite prompting on the topic, actual methods for engagement received minimal attention throughout the interviews. Instead, the informants tended to focus on the characteristics that make methods more successful or least successful, such as the topics mentioned above (leadership buy-in, time, and resources).

Advisory boards or groups, as a method of engagement, were referenced by each informant. Across all three informants, the view was consistent that such groups, for the most part, are an ineffective method to engagement. In reality, it seems as though the informants were focusing on the underutilization or the misuse of advisory groups rather than the challenges with method itself. There were concerns about advisory groups being more about presentation (one informant used the term “tokenism”) rather than a method for tackling meaningful topics. There was concern that advisory groups tend to meet infrequently (one informant noted quarterly). For the most part, concerns focused on advisory groups not being actively engaged in meaningful discussions and decisions that were important to the program.

**Figure 13: Process-Driven Factors to Engagement**



*Focus of engagement.* The focus of engagement methods was referenced by each of the key informants and seemed linked to informants' view of successful outcomes. For one informant, the phase in which participants were involved was key to whether or not such involvement would be beneficial. According to this informant, "I would think [participant involvement] would be important for quality assurance, you know the evaluation part of it. But are they really necessary for the design? Isn't there enough in the research literature that says these types of programs work most effectively this way? And so you know just follow that and tweak it on the--on the other end." Open communication between state staff and participants with the ultimate goal of establishing relationships and creating better programs was seen as an important focus of engagement by at least one of the informants. The informant describes the creation of communication and engagement "pathways" to positively influence what is currently a complex system of services and supports. Training for both participants and state staff was also noted as an engagement focus to ensure that state staff understand the participants' daily life

experiences and participants understand the boundaries of the system, allowing “resources match needs and needs match resources.”

The need for establishing common ground between state staff and participants was implied in many of the conversations pertaining to engagement focus. Whether it is establishing a common language, a common vision, common goals, etc., informants pointed to the need to ensure that both groups have bought into the process and find it worthy of time. According to one informant, “my priorities aren't going to necessarily be the same as the participants, as a program person, and so therefore, sometimes I think that may lead to misperceptions on both sides of what the purpose of participant engagement is...” One informant directly linked successful outcomes to this consensus building process.

*Frequency of engagement.* Only one informant spoke specifically about frequency of engagement. This informant linked frequency directly to the phase of program development, assuming that teams developing programs should meet with the most frequency when compared to groups linked to established programs. The informant noted that new groups developing programs may meet as often as weekly or bi-weekly. It was presumed that once the program is designed, the group may be interested in meeting on a monthly basis through the program’s first year and possibly move to quarterly meetings once the program is well-established. The informant recommended that the group determine the meeting frequency and intensity based on the intended outcomes.

*Outreach methods.* Throughout the interviews, the informants emphasized that those who typically come to the engagement table on behalf of participants are most often

not truly representative of the individuals receiving services. Because of this, informants discussed the need for effective outreach methods to make engagement work well. With a belief that most participants who receive services can not easily leave their homes and/or do not have access to transportation, informants advocated for outreach to those who cannot get to the engagement table on their own. Some informants emphasized the need to go to where participants are rather than expect them to come to you. The phone (e.g., teleconferences) may not work as well as in-person contact. Because of this, the use of local town meetings and/or regional conferences was identified as one strategy for outreach for states that have geographically diverse areas. Also, mailings to all participants to share information about engagement efforts were seen as important, even if such practices did not lead to a high turnout for meetings. While he or she did not elaborate, one informant pointed to the potential of technology (e.g., webcams) as an untapped outreach resource.

*Training methods.* All three informants emphasized that participant engagement requires training and education. One informant noted that participant training is essential since state staff typically have years of professional education and/or experience to maneuver within the complex systems they tend to work. There was some questioning as to whether any amount of training can realistically level the playing field and still be feasible to do. According to one informant, “it is time-consuming... to do it well anyway, you have to at least spend some time with education and developing a relationship with participants and participants may not want to do what you want to do.” While informants did not go extensively into training topics, the majority of the discussion in this area

focused on providing participants with the training needed to assist them to understand the participant direction program and what state staff can and can't do as a result of external mandates.

In addition, supporting participants to learn how to utilize their personal experiences to influence programs seemed important, since there was a concern that some participants will not naturally look beyond their individual service needs to comment on ways to strengthen the program as a whole. The need to cross-train was noted with great importance by one informant. According to this informant, "I think that there's a certain level of training that... we all have to have and it's on--it's on both sides... Information about living with a disability on the [state staff] side and then information about... what it's like to live in the bureaucracy." An underlying theme throughout the interviews was the investment in training required to involve participants in a meaningful way.

*Communication strategies.* Although the need for effective communication was implied in many of the discussions, only one key informant spoke specifically about the importance of well-established, purposeful communication. This informant reported that participant engagement strategies should be created by state staff, first and foremost, to listen. It was assumed that effective participant engagement strategies included transparent communication processes specifically meant to establish a common vision and goals to ensure that state staff and participants were on the same page about their intended purpose, timelines, and limitations. When done well, the informant noted that the two parties build trust and can work together to address any challenges or limitations that may exist.

*Accommodations.* Two of the key informants discussed the need for accommodations for participants who are engaged in program design and improvement. Specific accommodations noted were transportation, stipends, payment for personal care assistance, and payment for other expenses incurred as a result of the individual's participation. In regards to stipends, one informant states, "I was paid to be there. It was part of my salary... I think stipends should be automatically given to everyone who is not a paid professional [with] the ability to say no; I don't want it." In addition to these accommodations, one informant noted more unique accommodations for those who may have intellectual disabilities. This includes the ability to have smaller group meetings before, during, or after the large group meeting to ensure the participant understands the material and is able to meaningfully participate. Also, the informant noted that some individuals who have challenges communicating may also benefit from someone to assist in their communication processes (e.g., an ally or an interpreter). While the informants recognize the costs associated with accommodations, they seem to feel that the cost is manageable. The informants also referenced technology as an untapped resource that has the potential to address accommodation needs.

#### *Perceived Outcomes to Engagement*

All three key informants were asked to comment on what they feel are the positive and negative outcomes, if any, associated with the engagement of participants. It is important to note that some of the informants have direct experience with engagement while others are commenting on what they perceive to be the outcomes based on observation and/or personal perceptions. It also seems important to note that some

informants linked outcomes directly to the preconceived notions of state staff pertaining to engagement. When one informant discusses negative outcomes, the informant argues, “I think a lot of programs do it... because they’ve been told to do it and they have no understanding and no respect for what--what the outcome could be.” The time and effort devoted to participant engagement was assumed by all three key informants to have a direct impact on outcomes as well.

The key informants believe that engagement processes can increase awareness. This is not only as it relates to the program, but also of participants’ needs and the boundaries and limitations faced by state staff. Also, engagement is assumed to provide more program creditability given the participant voice is included in the design and implementation. The most negative outcomes appear to be linked to the process of engagement itself. For the most part, the informants point to typical concerns regarding the resources required, the methods used, and who is engaged (the argument of accurate representation). When reviewing these outcomes, it is important to recognize that the themes have not been weighted in regards to importance.

### *Conclusion*

The key informant interviews were conducted to provide the researcher with the first opportunity to explore the factors to engagement. The key informants were chosen based on their experiences and perceptions as they relate to participant engagement within participant direction programs. The researcher was successful in beginning to disentangle complex factors that fall within three categories: person-driven, environment-driven, and process-driven. Analysis of the informant interviews supported much of what

was found within the literature. The interviews confirmed a major theme of the literature: state staff who are comfortable with sharing power, who are transparent in their communication process, and who believe participants can play a key role public policy are most likely to partake in participant involvement and be satisfied with its outcomes (Arnstein, 1969; Barnes, 1999; Bens, 1994; Nemon, 2007). The key informant interviews also provided the opportunity to expand upon the findings in areas less touched upon within the literature and provided valuable insights into the challenges the researcher will face addressing the politically sensitive topic of engagement. Findings from the key informant interviews have supported the researcher's conceptual framework of participant engagement factors while, at the same time, allowing the researcher to refine and expand upon the factors already identified.



## CHAPTER 7

### FINDINGS FROM THREE STATES

#### *Introduction*

A multi-method, multi-site case study research design was utilized to understand how, if at all, state staff involve program participants in the design, implementation, and improvement of Cash & Counseling programs, the factors influencing engagement, and the perceived outcomes of such practices. The three states, chosen based on the findings from a web-based survey on engagement practices, represent three levels of engagement: low, moderate, and high engagement. This research not only examined the engagement practices of these three programs, but also led to the identification of two comparison initiatives with extensive engagement activities being administered alongside the low and moderate engagement Cash & Counseling programs. Given the sensitivity of the data, identifiable information from all five programs and all three states has been removed.

A total of 23 semi-structured interviews conducted with state staff, advocates, and program participants allowed for a multi-perspective data collection approach that spanned five programs, addressing an existing gap in the literature not only in the depth of perspectives, but also in the range of practices analyzed. These data, in combination

with document analysis and direct observation (within the high engagement state) led to the creation of three state in-depth case studies. The in-depth case studies were then analyzed to determine themes across the states, leading to this chapter on cross-state findings.

The research indicates that the existence of engagement practices and their subsequent outcomes are influenced by a large range of factors that fall into three categories: person, process, and environment-driven factors. These findings, which are explored in more detail below, provide evidence that participant engagement is a complex organizational topic for which the outcomes are dependent on who is responsible for programs, who they engage, the engagement processes they utilize, and the environment in which the practices take place. As a result, engagement strategies that are sensitive to these to multi-dimensional influences have the best chance of positively influencing Cash & Counseling programs. Given that this research focused on engagement influences that are not limited to Cash & Counseling programs, these findings have potential implications for home and community-based services and possibly all public programs seeking to involve program participants in the design, implementation, and/or improvement of their programs.

#### *Overview of the Three States Chosen for In-Depth Research*

*State B: A low engagement Cash & Counseling program with a comparison program.* The results of the phase one web-based survey indicated an engagement score of “1” for State B, placing the State into the “low” category on the participant engagement continuum. This finding was confirmed by the in-depth research that occurred within the

state. A total of six semi-structured interviews were conducted in State B. This included three state staff, two program participants, and one advocate. When asked directly, the State leadership overseeing the program confirmed that the Cash & Counseling program does not utilize any participant engagement activities. According to an advocate who was interviewed during the site visit, the lack of engagement is not

*Within State B, Initiative B-1 (Cash & Counseling Program) has no formal mechanisms for engaging participants in program design and improvement. A separate personal assistance program, Initiative B-2, is required by statute to utilize an Advisory Council to inform overall design and improvement as well as day-to-day operations.*

limited to the state's Cash & Counseling program. This advocate reported, "I don't really know [if] [participant engagement has] really... happened yet in [State B] to the extent that I would think that it should from a true advocate standpoint."

The existing Cash & Counseling program (referred from here on as Initiative B-1) serves people with diverse disabilities, including people who are elder, people with physical disabilities, and people with developmental disabilities. There are over 1,000 individuals served by this program. One full-time program administrator is allocated to the program. This person is responsible for overseeing the overall implementation of the program, including enrollment of members, the training of consultants and other contracted staff, the review of assessments, the approval of spending plans, and the approval of spending plan modifications. The state administrator also oversees the work of the contracted entities responsible for implementing the consultant and financial management services. In addition, this person is supervised by an executive leader within the state agency and receives intermittent support from two staff persons who provide some assistance with reviewing and approving spending plans.

As noted above, the interviews conducted confirmed that there are no engagement efforts in place within

Initiative B-1. When asked if he or she was involved in the design, implementation, or improvement of the Cash & Counseling

Table 7: Interviews Conducted in State B (“Low” Engagement State)		
3	State Staff	Leadership oversight for both Initiative B-1 and B-2, State administrator for Initiative B-1, and State administrator for Initiative B-1
1	Advocate	Executive Director of a advocacy program for people with disabilities
2	Program Participants	Receiving services from either Initiative B-1, Initiative B-2, or both programs

program, a program participant reports, “No; but I’d be happy to help with it if anybody asked me.” Even so, the participant was able to identify ways in which he or she informally provided input into the program (such as through informal conversations with state staff by phone or email). Despite the lack of engagement practices occurring within Initiative B-1, the State Agency leadership who oversees the program appears to have well established relationships with disability advocates. Also, some mechanisms for engagement were previously attempted early on in implementation, but they were not extensive or long-term.

Reportedly, Initiative B-1 does not have an Advisory Council since the requirements for the program are already clearly determined by the Centers for Medicare and Medicaid Services. Initiative B-1 does hold bi-monthly open forums by teleconference that are hosted by a contracted agency. The purpose of these teleconferences is to provide program participants with an opportunity to ask questions and to voice their concerns. As little as eight and as many as seventeen program participants have attended the bi-monthly teleconferences at one time, and the program

participants differ from forum to forum. These forums are not recognized by state staff as a method in which to systematically seek program participants' involvement in program improvement efforts.

During interviews with State leadership from the Cash & Counseling program, direct comparisons to the engagement practices of a second initiative within State B were made. According to one state staff person from the Cash & Counseling program:

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 they're heavily involved; they have committees that actually help to write the regulations for the program."

This second program (referred from here on as Initiative B-2) was included as a comparison program for this research. Initiative B-2 has been in existence for over twenty years, is funded by State and local funds, and serves less than one thousand people. Those who access the program are adults with physical disabilities who are considered "active" in their community (e.g., working, attending school, or volunteering). While this "active" requirement may mean that many of those utilizing services through Initiative B-2 have fewer barriers to community engagement than those served through Initiative B-1, almost 20 percent of those served by Initiative B-2 are on Medicaid and are receiving services through Initiative B-1 as well. While the program has participant direction elements, it is currently in the process of transitioning from a model that is mostly implemented

utilizing traditional personal care agencies to a more participant-directed model utilizing individual budgets.

As with Initiative B-1, there are limited state staff dedicated to Initiative B-2. For this program, there is one State administrator who is responsible for assuring the program is administered appropriately. Unlike Initiative B-1, Initiative B-2 is primarily administered locally. The State administrator is responsible for training those who are locally administering the program (and their professional staff) and for assuring the program policies are appropriately upheld at the local level.

An Advisory Council for Initiative B-2 is mandated by State statute and has been in existence for the length of the program. While some of those interviewed were unclear whether or not Initiative B-1 had engagement methods, all of those interviewed were aware of Initiative B-2's Advisory Council. The purpose of the Council, as determined by State statute, is to provide recommendations on how to improve the various components of the program. The Council's membership consists primarily of people who access the program's services. State funds are allocated to support the work of the Council, including travel reimbursement and payment for personal assistance.

Currently, the Council has a representative (and one alternative) from each of the State's local areas. Reportedly, the Advisory Council's membership will most likely be modified when the program is modified, although the regulations have not yet been finalized. The majority of the analysis conducted on Initiative B-2 focuses on the current make up and processes of the Council.

*State K: A moderate engagement Cash & Counseling program with a comparison program.* The findings from the phase one web-based survey indicated an engagement score of “40” for State K, placing this State into the “moderate” category on the participant engagement continuum. This score was based on the engagement practices utilized within multiple participant direction programs. The existence of multiple programs was not considered when the web-based survey was developed. Moving forward, it appears important to assess each program individually or to modify the survey tool to account for the existence of different engagement practices within multiple programs.

State K’s multiple participant direction programs serve multiple populations, including elders, people with physical disabilities, and people with intellectual disabilities. The focus of this case study is the state agency serving people with intellectual disabilities only. The reason for this focus is twofold. For one, there were an inadequate number of participants and advocates that were identified for interviews by state staff from the other programs. Second, the research that did take place led to the surfacing of a comparison initiative within the agency serving people with intellectual disabilities. While extensive analysis on the other participant direction programs in the State did not take place, it is clear that engagement efforts within these other programs are less developed than those described within this case study.

A total of eight in-depth semi-structured interviews were conducted with individuals familiar with Initiative K-1, Initiative K-2, or both efforts. Of this eight, three were state staff, three were advocates, and three were program participants. One of the

three interviews conducted with state staff actually included three people. While these three people are quoted separately within this case study, the points made during the interview were analyzed collectively as one interview. Of the three advocates interviewed, one was a self-advocate with a disability who administers his/her own organization and one was a parent of a person with a disability. Both of these advocates have direct experience accessing services from the State agency. These individuals were included under the advocacy lens given their current advocacy roles and the fact that they are not currently receiving services from a participant direction program. Of the two participants interviewed, both were formal representatives of individuals served by the agency utilizing the Cash & Counseling program (Initiative K-1). In addition to semi-structured interviews, engagement materials from Initiative K-2 were examined.

Within State K's intellectual disability agency, the existing Cash & Counseling program (referred from here on as Initiative K-1) was administered along side Initiative K-2,

*Initiative K-1 (Cash & Counseling program) engagement efforts focused on program expansion, program improvements, and peer training while Initiative K-2 engagement efforts focused on designing a controversial new financing mechanism.*

which was an initiative to design a new financing strategy<sup>5</sup> for all individuals being served by the agency. Initiative K-2 surfaced as a supplemental research site when those interviewed about Initiative K-1 made direct comparisons between the two initiatives. According to one individual interviewed:

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<sup>5</sup> The focus of this initiative was altered to protect the confidentiality of the State.



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 [it] because every “I” was dotted and every “T” was crossed.

Initiative K-1 has over 1,000 program participants. Eligible participants (and their representatives, if they choose to appoint one) of this Cash & Counseling program receive access to a budget allotment to directly hire their workers and purchase a limited amount of goods and services to assist in their independence.

Reportedly, many

Table 8: Interviews Conducted in State K (“Moderate” Engagement State)		
3	State Staff	Leadership oversight for both Initiative K-1 and K-2, State administrator (and support staff) for Initiative K-1, and State administrator for Initiative K-2
3	Advocates	Two of the three have experiences utilized Agency services, one as a parent and one as a self-advocate
2	Program Participants	Formal representatives of family members receiving services through Initiative K-1

participants hire friends and family. While many of those interviewed recognized the benefits of this program, some state staff who were interviewed were concerned that funds are not always used “appropriately.”

Initiative K-1 has both ad-hoc and long-term participant engagement practices. Even so, knowledge of the engagement practices (on behalf of internal agency leadership as well as external advocates) was minimal. One engagement method was the implementation of a committee to inform the growth of the Cash & Counseling model. The purpose of the improvement committee, which is now disbanded, was to guide an intense outreach process as well as strategies for improving the program during the

enrollment phase. The second engagement method, which is currently active, is the use of a Quality Council. This Quality Council meets quarterly to discuss customer service issues, the implementation and analysis of a quality survey, and other topical issues as they surface. In addition, some family members are involved in peer training, and some communicate their thoughts on how to improve the program through informal conversations with state staff. Overall, the majority of engagement practices appear to focus on engaging professionals, such as state staff and providers.

Running parallel to the existing participant direction program is the planning of a new system-wide financing strategy for the agency. The purpose of this initiative is to develop a new financing mechanism for those who receive State agency funding, regardless of whether or not they currently receiving traditional or participant-directed services. The intention is to create an equitable financing mechanism that allows participants to decide how all of their allocated funds are spent. They can choose traditional services, participant-directed services, or a mix of both. This initiative is intended to create opportunities for choice and control while also allowing for cost predictability. This project was attempted once before, but was reportedly unsuccessful given a lack of stakeholder buy-in and a flawed methodology. This new initiative was assumed to be controversial given the failure of the previous effort and the looming budget cuts.

A multi-method stakeholder engagement process has been a central focus for Initiative K-2. This engagement process includes the utilization of a 16-member

stakeholder group, focus groups, and local forums. When describing this project, an advocate reported:

[Initiative K-2] was very good because other times people [were] all set in what they were going to do, but this time they 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.

Unlike Initiative K-1, Initiative K-2's engagement practices were well known by those internal to the agency as well as external. The initiative was described by many as an effort to achieve buy-in on what was seen as a very important, albeit very controversial project. Even though both initiatives are being implemented by the same State agency and have a participant direction emphasis, this research found that the extent to which program participants and other stakeholders are engaged varies considerably between the two.

*State D: A high engagement State in which Cash & Counseling engagement efforts are a part of a larger program.* The results of the phase one web-based survey indicated an engagement score of "54" for State D, placing the State into the "high" category on the participant engagement continuum. A total of nine in-depth semi-structured interviews were conducted in State D. Of the nine individuals interviewed, four were state staff assuming various roles, three were program participants, one was an advocate, and one was a provider. For the majority of the analysis conducted, the provider perspective was included with the voice of the State perspective. When visiting

State D, the researcher was not only able to conduct in-depth semi-structured interviews, but also observe a two day planning meeting of the Quality Council. The Quality Council is the primary mechanism for the State agency to seek stakeholder input into the improvement of their programs. The data from the semi-structured interviews, direct observation, and a review of pertinent materials did confirm that the State agency administering the Cash & Counseling program is a “high” engagement entity.

State D’s Cash & Counseling program is part of a larger program serving elders and people with physical disabilities. There

are less than ten thousand people who receive services through this broader program, of which less than one thousand are receiving services through the Cash & Counseling program. There are two full time

*State D includes program participants in both the design and improvement of programs. A multi-stakeholder workgroup assisted in the design of the Cash & Counseling program. Once the design was complete, State D relied on its existing Quality Council to improve its program. The Quality Council assists the State to identify and implement quality projects across the existing services. As a result, the majority of the Council’s work is not specific to participant direction and is driven by the needs of traditional agencies.*

state staff who support the implementation of the Cash & Counseling program, with one being the program administrator and the other providing administrative support. The consultant and financial management services are implemented by providers, and the state staff play a major role during enrollment and provide ongoing support with problem solving.

When asked about engagement practices within State D, a person with advocacy experience reported, “there are several committees in this State dealing with a whole variety of issues that have consumer representatives, advocates, etc. on it.” This person continued by stating that “every group I’ve been involved with [has had] some

representation from consumer groups, advocates, etc...” A state staff person supported these statements when s/he reported:

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.

Individuals who were interviewed described systematic processes to ensure stakeholders are involved in the design of a variety of initiatives, not only including the current improvement of program

<b>Table 9: Interviews Conducted in State D (“High” Engagement State)</b>		
5	State Staff	Medicaid Agency, Administrator of Cash & Counseling Program, Agency leader involved in the design of the Cash & Counseling program, and Quality Improvement Manager. Includes one provider who had had experience with the design & implementation of Cash & Counseling.
3	Program Participants	Two recipients of Cash & Counseling services and one representative of a previous recipient
1	Advocate	Involved in the design of Cash & Counseling program

and services, but also the design of new grants and initiatives.

The engagement methods occurring within State D do not focus solely on the Cash & Counseling program. Instead, the Cash & Counseling program is one program impacted by the engagement strategies which are intended to improve a wide range of services and supports provided by the State agency. Previously, there were participant engagement methods implemented to specifically inform the design of participant direction within the State.

This research examines both the previous and existing engagement efforts. The majority of the research conducted in State D focused on two engagement processes: the use of a workgroup to inform the design of the Cash & Counseling program and the ongoing implementation of the Quality Council. The Quality Council, which includes topic-specific committees, addresses quality topics for the entire program, including the Cash & Counseling program.

The Quality Council meets quarterly and as part of its quarterly meetings, allocates time to a stakeholder input forum where stakeholders are invited to share their concerns or ideas with the Quality Council members. The members of the Quality Council include people representing the traditional agency model (leadership, case managers, and program participants) as well as participants from the Cash & Counseling program. One fifth of the membership is required to be past or present program participants and/or representatives receiving traditional or participant-directed services and the remaining members can be a mix of services providers, direct care workers, family members, and other advocates. There is no existing Council or advisory committee that focuses solely on the Cash & Counseling program. In addition to the work of the Quality Council and its stakeholder input forums, the State agency has also implemented various workgroups to seek input on new initiatives and grant proposals as well as held public hearings to seek input on proposed policies and implementation practices.

The research conducted in State D points to extensive engagement practices, although the direct impact of such activities on the improvement of the Cash &

Counseling program appears limited. While the Council does include program participants, the voice of the Cash & Counseling constituents is one of many on the Council, including providers and state staff. Overall, the engagement practices examined in State D provide great insight into how program participants and other stakeholders can be involved in the design and improvement of programs that span multiple programs or initiatives.

#### *Process-Driven Factors to Engagement*

A review of the process-driven factors to engagement across the three states provides clear indication of the extensive range of processes that can occur, not only from one State to another, but even within any given State. The variance in methods utilized seems to be linked to the diverse range of person and environment-driven factors that exist. For instance, a person managing a program who has a tendency to seek control over programmatic practices will likely gravitate towards less threatening engagement practices at the individual rather than program level. Also, extremely controversial topics, such as economy-driven service cuts, coupled with a leadership style and an advocacy climate, may lead some to implement open decision making processes while others more restrictive methods. It became clear that states can implement a wide variety of practices that included important decisions in many areas. These areas, which were analyzed extensively within the three states, are discussed below and described in detail in Appendix G.

*Focus of involvement.* The research provided very clear examples of engagement practices that targeted one of three areas: individual level, program level, and systems

level. Initiative B-1's engagement focused on the individual level. While there were no systematic methods to ensure engagement, the participant involvement that did occur focused on information sharing among peers. Initiative B-2's engagement was at the program level. The Advisory Council had direct involvement in improving the program. Initiative B-2 also had engagement at the systems level with some program participants advocating for program funding by providing public testimony. Within State K, Initiative K-1 involved program participants at the program level in program expansion and improvement efforts. Initiative K-2 involved program participants and other stakeholders at the systems level, utilizing a stakeholder group to inform a new finance methodology. Like Initiative B-2 and K-2, the engagement practices found in State D were at the program level and focused on program design and quality improvement efforts.

<b>Table 10: Focus of Engagement Across the Three States</b>			
	<b>Focus Level</b>	<b>Focus Phase</b>	<b>Practice</b>
<b>Initiative B-1</b> Cash & Counseling	Individual	Implementation	Separate
<b>Initiative B-2</b> Comparison Program	Program	Design, Implementation, and Improvement	Separate and Integrated
<b>Initiative K-1</b> Cash & Counseling	Program	Implementation and Improvement	Separate
<b>Initiative K-2</b> Comparison Program	System	Design	Integrated
<b>State D</b> Cash & Counseling	Program	Improvement	Integrated

The research also indicates that engagement can occur within three phases: design, implementation, and improvement. Initiative B-1, to the extent that it included program participants, included them in implementation (i.e., program participants becoming consultants as well as providing informal peer support). Within Initiative B-2,



program participants were involved in program implementation (creating and disseminating success stories as well as providing informal peer support), program improvement (Advisory Council committees on training and policy), and even program design (the Council's involvement in model redesign). Initiative K-2 participants were also involved in design, specifically design of the new financing methodology. Program participants were involved in improvement efforts for Initiative K-1 (as seen in the expansion activities and the Quality Council work) as well as in State D's quality efforts.

This research has found well-established engagement practices to be present, regardless of whether a program or policy is in a development, implementation, or improvement stage. This research also finds that well-established engagement can occur in new initiatives as well as in long-standing efforts, and that long-standing initiatives do not necessarily indicate long-standing engagement practices.

<b>Table 11: Engagement Topics Across the Three States</b>				
<b>Program Design</b>	<b>Program Implementation</b>	<b>Program Improvement</b>	<b>Systems Change &amp; Advocacy</b>	<b>Engagement Infrastructure</b>
Propose policies for a new program	Recommendations for distributions of local funding	Expansion strategies	Prepare and provide public testimony	Membership outreach
Design of consultant model and training concepts	Create marketing materials	Quality monitoring and improvement strategies	New financing mechanism	Review of membership applications
Design of financial management services model	Conduct peer mentoring and peer training	Identify training needs and create trainings		Recommending new members
Design of grievance procedures	Develop curriculum standards	Revise/ simplify forms		Development/revisions of Council's handbook
Determination of allowable goods and services	Assume role as Consultant	Strengthen communication practices		Identify and address membership's training needs
Decisions pertaining to contractors		Revise handbook		
		Test new technology		

It was also evident that engagement of program participants generally occurred with program participants utilizing either separated or integrated practices. Some programs, such as Initiative K-2 and State D, seemed to engage program participants in an integrated fashion, including them as active partners in the identification of problems as well as solutions. In each of these initiatives, program participants had access to a level of information that allowed them to collaborate with state staff and other stakeholders in the identification of problems as well as solutions. Research also shed light on processes in which program participants are provided less information and are providing advisement from the outside, but are not actively engaged in the communication and decision making efforts that exist within the program. One example would be the practices found within Initiative K-1. Initiative B-2 appeared to have a mix of practices. While program participants received extensive information and worked collaboratively with state staff, they appeared to implement an engagement model external of the state staff's own projects, working more independently than what was found in Initiative K-2 and Initiative D.

States also utilized engagement methods to tackle a wide range of topics. Program participants were involved in program design and improvement projects, such as the design of manuals, the improvement of forms, and the development of training. They were also involved in program implementation efforts, such as marketing, conducting training, providing peer support, and assuming a consultant role. Some program participants were involved on a broader level, such as in the design of a new system-wide financing mechanism and in providing advocacy support for a model. Finally, a

significant portion of engagement actually focused on the engagement process itself, including conducting outreach, screening potential new council members, and identifying training needs of those who are engaged. One State went as far as to limit the amount of time engagement practices could actually focus on the improvement of engagement infrastructure as to ensure the majority of focus was on program improvement.

*Membership.* The state staff from the five initiatives examined included a diverse array of individuals in their engagement methods. While some focused almost primarily on engaging other state staff and providers, other initiatives had formal methods to include a broader range of stakeholders, such as advocates and program participants. Some of the initiatives focused on the engagement of advocates more so than program participants while other initiatives did the exact opposite.

It is apparent that the stakeholders state staff choose to involve in engagement practices has a direct influence on meaningfulness of the engagement practices utilized. This was clear in a review of the topics covered in the quality improvement efforts found in Initiative K-1 and State D. Programs that focused on engaging mostly professional staff (e.g., State staff and providers) subsequently addressed the issues that were of most interest to these groups, potentially abandoning topics of most importance to program participants. Even if topics of interest to program participants were addressed, they appeared to be addressed through the lens of the professionals being engaged, possibly missing the nuances that would be identified by those with direct experiences. For instance, although worker training was a topic of importance identified by Quality Council members from State D, the provider majority and the inclusion of program

participants with less participant direction program design knowledge led to training decisions that are more commonly implemented in traditional programs than participant direction programs.

When program participants were engaged, there was often conflicting beliefs as to whether those engaged were representing themselves or a larger group of constituents. While the latter was the intention among state staff in most circumstances, most often, there were no clearly communicated expectations in this area or methods for ensuring that individuals were able to adequately represent others. In fact, there appeared to be conflicting desires among state staff who wanted “real” participants as opposed to advocates, but wanting them to have extensive knowledge and be able to think beyond their own personal needs and interests. Given the significance of this topic within the research, it is examined in greater detail below as a process-driven factor.

It seems important that state staff, when considering membership for their engagement efforts, think not only about the ratio of program participants to other stakeholders (e.g., professional advocates, providers, and state staff), but also about the impact program participants’ knowledge and experience with engagement will play in their ability to effectively participate. The research indicates that not all program participants will have a comprehensive knowledge of the philosophy behind participant direction, and therefore, may make recommendations that go against the basic tenets of the model. This seemed especially true when examining the engagement efforts found in Initiative K-1 and State D. While diversity in viewpoints and values are important, it appears equally important to ensure that those who are engaged receive proper training

on the program model and their role in representing a larger constituency group (if that is desired).

*Meeting frequency.* For most formalized mechanisms of engagement, involvement occurred at pre-determined frequencies, most often quarterly. In some circumstances, there were committees that were meeting more frequently than quarterly and sharing their progress during the quarterly meetings. Often, state staff played a role in the committees' work, ensuring that there was integration of efforts between those engaged and the efforts of state staff. Initiative K-2, a systems design project, did not have a pre-determined frequency of stakeholder meetings. Instead, this initiative hosted meetings at a frequency that was determined by the work being conducted and based on the timing of key decisions.

Regardless of whether or not the meeting frequency is pre-determined or as needed, the research indicates that what is most important is that the meeting frequency is aligned with the key decisions being made, providing ample time for stakeholders to inform the decision as well as participate in the discussion pertaining to implications of decisions. Given this finding, the frequency of meetings does provide some indication as to whether program participants are actively engaged in the identification of problems and the creation of solutions or if they are more passively engaged with no direct link to the problems and solutions identified.

*Access to information.* There was tremendous variance in the extent to which program participants involved in engagement methods were informed and the type of information they received. When engagement took place, there was often a baseline of

information provided to those who were engaged. This included a meeting agenda, meeting notes, and key documents related to decisions that were being made. The most meaningful engagement practices, such as those found in Initiative B-2, K-2 and State D, included program participants receiving critical materials for decision making in advance (usually one to two weeks) to allow for their active involvement in decision making. For instance, to support decision making within Initiative K-2, State staff provided stakeholders with access to white papers, PowerPoint presentations, and guest speakers prior to their involvement in technical discussions. In State D, stakeholders received quality data reports and the State staff person reviewed sections of the reports during the meeting prior to discussions about critical quality priorities. In more than one State, there was a handbook for those engaged that provided information on the purpose of the group and their role as members.

Most State staff discussed the importance of program participants being well-informed when they are engaged. More specifically, state staff and others interviewed discussed the importance of program participants being knowledgeable about the programs and systems they are intended to be influencing. This shed light on the need for state staff to play an active role in the sharing of information that is important to program participants' success in engagement activities.

*Communication strategies.* Communication strategies also varied considerably among the five initiatives. Some of the initiatives had controlled communication practices that were most often one-way. For instance, Initiative B-1's bi-monthly forum was a place for program participants to communicate their issues and challenges. Most often,

state staff utilized the majority of the time to clarify misinformation rather than allow for a dialogue on program barriers and possible solutions.

In Initiative K-2, communication was two-way with meetings providing a means for two-way conversations regarding controversial topics. Also, communication with constituents beyond the stakeholder group was intentionally transparent with meeting materials posted on the state agency's website. It appears that the most meaningful engagement includes transparent communication practices that take place within an environment that encourages constructive conflict pertaining to controversial topics. This research indicates that such communication requires the involvement of state staff and program participants who are comfortable with some level of conflict, a level of trust among those involved, and a strong facilitator.

*Facilitation strategies.* There were three major ways in which facilitation of engagement methods took place. In some instances, such as Initiative B-1 and Initiative K-2, facilitation was conducted by state staff. In Initiative B-2 and Initiative K-2, this was not the case. Initiative B-2's Quality Council had its own by-laws that charged the Council's leadership with facilitation responsibility. State K chose an independent facilitator for Initiative K-2 given the controversial nature of the financial mechanism topic and the desire for the State to remain an independent and active participant in the discussions. State D took a collaborative approach with the Committee Chair and State staff working together to facilitate meetings.

Analysis of facilitation strategies finds that it is not necessarily who facilitates, but the facilitation methods utilized that are most influential. Initiative B-2's Quality

Council's handbook provides some insight into important facilitation qualities. For instance, a section of the handbook indicated the importance of strong communication and effective problem solving, which seems to be possible regardless of whether or not state staff, program participants, or both are facilitating. Even so, findings from Initiative K-1 indicate that facilitation practices controlled solely by state staff, especially by state staff who have less tolerance of conflict and a desire for control, may be more likely to be non-deliberative and controlled in their facilitation practices. Methods that are independent or collaborative in nature, such as those found in Initiative K-2 and State D, support an open dialogue and collaborative decision making.

*Decision-making practices.* When reviewing the five initiatives within the three states, it became clear that decision making can occur internally or externally of engagement. Within Initiative B-1 and Initiative K-1, all program decisions were made by State staff independent of any engagement practices that did or did not exist. Within Initiative B-2, Initiative K-2, and State D, there were consensus building and/or negotiation practices utilized to make programmatic decisions within established working groups that were created for stakeholder engagement purposes. The importance of buy-in from state agency leadership on decisions made was well recognized in Initiative B-2, Initiative K-2, and State D. As seen in Initiative K-2 and State D, it appears beneficial to have State agency leadership well-informed and supportive of the existing engagement practices to avoid complications in the area of decision making. In State D, state agency leadership staff were actually active participants in many of the Council meetings.



Research also points to the importance of those who are engaged ensuring similar buy-in from the constituents they represent, although the existence of such practices were minimal. One example was the communication model created within Initiative B-2. Within this model, there are local Councils that are represented on the statewide Council. Also, state staff from Initiative K-2 strived for transparent and open communication practices with the broader constituency groups represented through the posting of materials and meeting progress on the state agency's website.

*Accommodations.* Surprisingly, only one initiative had well-established practices for providing accommodations to program participants who were active on committees. The Council handbook from Initiative B-2 communicated the requirements for accommodations. According to this handbook, program participants must have access to alternative formats and reimbursement for travel expenses. In addition, Council members are required to ensure accessible information is provided to allow for informed decision making within the Council. Initiative B-2 also had a budget line item that was allocated specifically to the Council's accommodations, which is not true for any other initiative. State staff from other initiatives did recognize the need for accommodations, but they tended to have no formal methods for identifying or addressing accommodation needs.

While some state staff from State D felt that engagement was successful even without such accommodations, some state staff recognized that, at minimum, the provision of accommodations and even stipends has symbolic meaning (i.e., your presence and time is as important as professionals). Despite the belief that engagement was successful even without accommodations, the majority of those engaged in State D

are providers who were reimbursed by their respective agencies. State staff from State D did discuss the benefits of accommodations that were provided when grant funds were allocated to such activities.

*Time and resources.* State staff often point to a lack of time and resources as a reason why engagement does not take place. This research indicates that a lack of time and resources, itself, is not a primary influencer of whether or not engagement exists. For instance, the most extensive engagement practices were found in Initiative B-2, conducted by one state staff person who held primary responsibility for the entire program. While the administrative design of the programs varied considerably, making it difficult to compare administrative resources among them, the number of state employees dedicated to Initiative K-1 dwarfed all of the other initiatives, yet the engagement practices were less extensive than three of the other four initiatives examined.

The research actually indicated that those who engage program participants did so with the intention of actually boosting productivity given their limited time and resources. In State B, those from Initiative B-1 who were not engaging program participants were well aware of the productivity that came from engagement practices utilized in Initiative B-2 (e.g., the creation of needed products and decisions being made pertaining to complex program policies faced by both programs). It was also clear from the analysis conducted that engagement can occur even when resources are not budgeted for such practices. In State D, engagement practices were implemented with no resources beyond State staff investing some of their professional time to the process. The ability for this State staff person to integrate the Council and its work into his/her own work

responsibilities and productiveness appeared to make the time required for engagement activities less overwhelming. The same appeared true for the state staff person administering Initiative B-2.

*A comparison of web-based survey findings and in-depth research findings.* The process factors that were analyzed in great depth (e.g., focus of engagement, membership, frequency of meetings, access to information, etc.) were driven by the literature as well as the key informant interviews conducted as part of this research. The summary of the findings from each state were compiled into chart form (see Appendix G), allowing for each process factor for each of the five programs to be depicted independently. Based on these individual measurements, each program received a total score for their engagement based on their process factors alone. Given that the research conducted in State B and State K led to the analysis of comparison programs, the chart also includes these initiatives as well (labeled as B-2 and K-2).

The state scores that resulted from the web-based survey findings and the more in-depth charts that were developed as a result of the phase two research showed consistent findings. For instance, State B was labeled a “low” engagement state as a result of receiving the score of “1” on the web-based survey. The in-depth research confirmed the Cash & Counseling program was a “low” engagement program. State K received a score of “40” on the web-based survey, leading to the state being labeled as a “moderate” engagement state. A review of the continuum chart also finds State K to be a “moderate” engagement program. Even so, the in-depth research conducted in the state points to a score of “40” as being high. This high score seems to be influenced by the

inclusion of more than one participant direction program in the measurement (e.g., the state getting points for the multiple methods of engagement that span the programs). Finally, State D received a score of “54” as a result of the web-based survey; the in-depth research affirmed this programs’ high engagement rank.

The in-depth chart (see Appendix G) includes information on process-driven factors that were not integral to the web-based survey, specifically “decision-making strategies” and “time and resources.” These two concepts were not included in the survey given the difficulty in measuring them through this method. Clarity of these factors emerged through the case study research. Beyond these two, no additional process factors surfaced as a result of the in-depth research. Even so, there was some slight modification to terminology used to label each of the factors that resulted from the phase two research. For instance, “Representation” was changed to “Membership” and “Logistics” was changed to “Accommodations.”

#### *Person-Driven Factors to Engagement*

The research conducted across the three states was intended to examine person-driven characteristics of program participants who are typically engaged as well as state staff who engage program participants and state staff who tend not to engage program participants. Cross-state analysis led to the recognition of common themes across these three states regarding person-driven factors as viewed through the state staff, advocate, and program participant lenses; they are described in more detail below.

*Perceived characteristics of participants who are successfully engaged.* Cross-state analysis of process-driven factors to engagement finds strong consistency across the

three States and even across the three stakeholder lenses when examining the perceived characteristics of program participants who are successfully engaged in program design and/or improvement. Of the 23 individuals interviewed, 17 (or 74 percent) highlighted the importance of program participants being well-informed. One hundred percent of the program participants interviewed referenced the need for program participants to be well-informed while more than half of State staff and advocates did the same. There was also agreement pertaining to what program participants should be informed about with 52 percent of those interviewed discussing the importance of awareness of programs' policies and procedures. State staff felt the strongest about this with six of the 11 pointing to the need for knowledge of existing programs' policies and procedures.

Equally as important is the need for program participants to be strong communicators. State staff were the most adamant about this characteristic with nine out of the 11 state staff interviewed focusing on this trait. The majority (70 percent) of those interviewed also discussed the importance of program participants being strong advocates. Even so, within State B (the "low" engagement state) and State K (the "moderate" engagement state), there was special attention focused on the need for program participants to be reasonable within their advocacy practices. The focus on a "team-like" environment within State D also sheds light on this finding. Also discussed by two individuals interviewed in State B and State D was the need to foster leadership growth in younger advocates, recognizing that many of the advocates currently engaged are aging.

<b>Table 12: Perceived Characteristics of Participants Engaged (Collective Findings)</b>				
Points made (verbally or observed) by perspective				
	Total (23)	State Staff (11)	Advocate (5)	Participant (7)
Well-Informed*	17 (74%)	6 (55%)	4 (80%)	7 (100%)
▪ Programs and Systems	12 (52%)	6 (55%)	3 (60%)	3 (43%)
▪ Needs of Peers	4 (17%)	1 (9%)	2 (40%)	1 (14%)
▪ Being an Advocate	5 (22%)	3 (27%)	1 (20%)	1 (14%)
▪ Personal Needs	5 (22%)	1 (9%)	1 (20%)	3 (43%)
Strong Communicators	17 (74%)	9 (81%)	4 (80%)	4 (57%)
Strong Advocates**	16 (70%)	7 (64%)	4 (80%)	5 (71%)
High Self-Esteem/ Confident	10 (43%)	3 (27%)	2 (40%)	5 (71%)
Devotion of Time and Effort	7 (30%)	2 (18%)	3 (60%)	2 (29%)
Team Player	7 (30%)	4 (36%)	1 (20%)	2 (29%)
Productive	7 (30%)	4 (36%)	1 (20%)	2 (29%)
Passion for Participant Direction	6 (26%)	2 (18%)	2 (40%)	2 (29%)
Ambitious	4 (17%)	2 (18%)	0 (0%)	2 (29%)
*Percentages of subcategories under “well-informed” are the percentage of the total interviewed				
**A large portion of these individuals discussed the importance of program participants also being “reasonable”				

Some interviewees across the three states asserted that program participants who are successfully engaged have an air of confidence (43 percent), have the ability to devote time and effort to the engagement process (30 percent), are team players (30 percent), and are productive (30 percent). Five of the seven program participants interviewed either discussed or exhibited the trait of confidence. The need for program participants to be confident surfaced in only three of the 11 interviews with state staff and two of the five interviews with advocates.

*Perceived characteristics of state staff who engage program participants* There was also consistency among interviewees across the three states pertaining to perceived characteristics of state staff who effectively engage program participants. For instance, the majority (65 percent) of those interviewed viewed such individuals as strong communicators with some emphasis on the importance of state staff being strong listeners. Many of those interviewed discussed the ability of such individuals to

communicate clearly the expectations of those engaged. One hundred percent of advocates interviewed pointed to effective communication skills as critical.

Second to strong communication skills was a general respect for program participants. Of the 23 interviewed, 13 (or 57 percent) touched upon this characteristic trait as present among State staff who effectively engaged program participants. The majority of advocates (five out of seven) and the majority of participants (four out of seven) discussed this tendency for respect, while only five out of the 11 state staff did so. This provides some indication that advocates and program participants perceive some state staff as having little respect for the people served by their programs, impacting the extent of engagement practices. Interestingly, the term “movers and shakers” was used in both the moderate and high engagement state to describe the state staff who do tend to actively implement engagement activities.

While not recognized by the majority, there were additional perceived characteristics that were prominent. For one, a little less than half (48 percent) of those interviewed touched upon state staff who tend to engage program participants as being either comfortable or tolerant of conflict. The need for “thick skin” surfaced in more than one state. This was far more recognized by state staff (five of 11) and advocates (five of five) than by program participants (one of seven). A comfort level or a tolerance of conflict also impacts the selection process utilized in states where engagement does exist (e.g., state staff with less comfort with conflict seek program participants who are less aggressive). Program participants who were interviewed, being sensitive to a power dynamic associated with being dependent on state services, may be less likely to engage

in conflict (and thus less likely to recognize tolerance of conflict as a state staff characteristic trait).

An equal number of individuals emphasized a tolerance of conflict and the importance of team focus. Interestingly, it was program participants (five out of seven) who referenced this characteristic most, indicating that they are cognizant that program design and improvement is typically driven by “experts.” More than a third of interviewees emphasized the importance of state staff connection (or the desire to be connected) to the constituents they serve. The state staff interviewed (five out of 11) provided far more insights into this area than did advocates (only two of the five) and program participants (only one of the seven). This seems to indicate that having little to no direct experience or personal connections to people who require services is common.

<b>Table 13: Perceived Characteristics of State Staff who Engage Participants (Collective Findings)</b>				
Points made (verbally or observed) by perspective				
	Total (23)	State Staff (11)	Advocate (5)	Participant (7)
Strong Communicators*	15 (65%)	6 (55%)	5 (100%)	4 (57%)
Respect for Program Participants	13 (57%)	5 (45%)	4 (80%)	4 (57%)
Comfort with Conflict**	11 (48%)	5 (45%)	5 (100%)	1 (14%)
Emphasis on Teamwork	11 (48%)	4 (36%)	2 (40%)	5 (71%)
Connected to Constituents***	8 (35%)	5 (45%)	2 (40%)	1 (14%)
Desire to Improve	7 (30%)	4 (36%)	1 (20%)	2 (29%)
Disability Sensitivity	6 (26%)	3 (27%)	2 (40%)	1 (14%)
Investment	5 (22%)	1 (9%)	3 (60%)	1 (14%)
Intelligence and Knowledge	5 (22%)	2 (18%)	2 (40%)	1 (14%)
Desire to be Productive	5 (22%)	2 (18%)	1 (20%)	2 (29%)
Education or Field Experience	4 (17%)	3 (27%)	0 (0%)	1 (14%)
Compassion	4 (17%)	1 (9%)	2 (40%)	1 (14%)
Strong Facilitators	4 (17%)	1 (9%)	2 (40%)	1 (14%)
Adaptable	3 (13%)	2 (18%)	0 (0%)	1 (14%)
*A portion of these individuals focused on the importance of being “strong listeners”				
**A portion of these individuals have a “tolerance” for conflict				
***A portion of these individuals actually discussed “a desire to be connected”				



Overall, program participants were relatively silent on the perceived characteristics of those engaged compared to state staff and advocates who were interviewed. Program participants discussed only three of the 14 characteristics that surfaced, and because, of this, these three perceived characteristics (being strong communicators, having respect for participants, and having an emphasis on teamwork) deserve special recognition.

*Perceived characteristics of state staff less likely to engage program participants*

There were common themes that surfaced when reviewing the perceived characteristics of state staff less likely to engage program participants. Not surprisingly, given their personal experiences, program participants had the most to say about state staff who did not engage program participants. The interviews conducted with fourteen of the 23 program participants (61 percent) indicated that state staff who are less likely to engage participants tend to have a “them” and “us” mentality. Each and every advocate

<b>Table 14: Characteristics of State Staff Less Likely to Engage Participants (Collective Findings)</b>				
Points made (verbally or observed) by perspective				
	Total (23)	State Staff (11)	Advocate (5)	Participant (7)
“Them” and “Us”*	14 (61%)	6 (55%)	5 (100%)	3 (43%)
Desire to Control**	14 (61%)	6 (55%)	4 (80%)	4 (57%)
Conflict Avoidance	12 (52%)	6 (55%)	4 (80%)	2 (29%)
Lack of Disability Awareness***	9 (39%)	4 (36%)	2 (40%)	3 (43%)
Reactive rather than Proactive	6 (26%)	3 (27%)	1 (20%)	2 (29%)
Not a Decision Maker	4 (17%)	3 (27%)	(0%)	1 (14%)
Defensiveness	2 (9%)	1 (9%)	1 (20%)	0 (0%)
*This includes “assumptions pertaining to expertise”				
**This includes “controlled communicators” and “not open to change”				
***This includes “disconnected”				

interviewed (five out of the five) believed that state staff who do not engage program participants come from a “them” and “us” mentality while the majority of state staff (six

out of the 11) did as well. While some state staff described their perceptions of colleagues, others actually demonstrated this “them” and “us” approach in their interviews. Only three of the seven program participants highlighted this characteristic, which is not surprising since program participants engaged would be less likely to experience this characteristic directly.

A desire to control was also perceived as a common characteristic among state staff who tend not to engage program participants. Of the 23 interviewed, 14 (61 percent) referenced this topic. Some of those who discussed this topic specifically described a desire among state staff to control communication, while others spoke much more broadly about controlling tendencies. Out of all of the perceived characteristics identified, the desire to control was recognized most by program participants as a barrier to meaningful engagement.

Twelve of those interviewed (52 percent) discussed the tendency for some state staff to avoid conflict, and as a result, avoid engagement. Six of the 11 state staff believed this was the case. This was not surprising since a tolerance for conflict was seen as a characteristic of those who do engage program participants. This indicates that conflict is sometimes present when participant engagement occurs.

#### *Environment-Driven Factors to Engagement*

The literature points to environmental factors to engagement in addition to the process-driven and person-driven factors already discussed. Bens (1994) describes government systems that are ‘open’ as well as systems that are ‘closed.’ Open systems, given their tendency for transparent communication and collaborative decision making

strategies, provide a culture conducive to participant engagement practices (Bens, 1994). On the other hand, a “closed” system, characterized by its insecure leadership, “back door” decision making, and secretive communication practices provides obvious barriers to participant engagement (Bens, 1994). The research conducted within the three states provided an opportunity to understand environmental factors that can influence engagement practices.

A closer look at the state agencies’ leadership, decision making practices, and communication strategies across the three states indicates that the simple classification of a system as “open” or “closed” is too simplistic. In fact, the leadership, decision making, and communication practices can vary among programs housed within one state agency, regardless of whether or not the state agency’s leadership appears to be generally “open” or “closed” in practice. In State B, the leadership, decision making, and communication styles of middle management seemed to have more impact on the implementation of engagement practices than the style of the executive leadership, which was shared across the two programs. The manager administering Initiative B-1 exhibited more closed practices while the manager administering Initiative B-2 more open practices. This may be due to a combination of factors, including expectations of senior leadership when recruiting, program mandates, and/or personal characteristics.

For State K, the styles of middle managers also seemed to play an important role. Even so, the open style of executive leadership did appear to factor into controversial, high impact projects such as Initiative K-2. For this Initiative, the state agency’s leadership personally appointed a manager who shared a similar open leadership style,

decision making practices, and communication strategies given the desire to gain stakeholders' buy-in for controversial changes. Even so, the executive leadership's open government approach failed to permeate the walls of the more established and less controversial Cash & Counseling program (Initiative K-1). Within State D, it seems as though the leadership, decision making, and communication style of executive leadership and middle management were in sync, allowing for the consistency in values to influence the overall use of active engagement methods, both in the design of new initiatives and the improvement of existing programs.

Research conducted within the three states highlighted additional environmental factors that can influence engagement beyond the government climate described by Bens (1994). These factors, which are presented in the Appendix G, indicate that multiple environmental factors may exist, along with gradation within the factors that ultimately influence the extent to which engagement takes place. For instance, a desire for change among state staff and leadership was clearly recognized as an environmental factor among the initiatives that have extensive engagement and less evident among those with less engagement. For example, state staff at all levels within State D, from program managers to Executive leadership, routinely communicated that there "was always room for improvement." Also, Initiative K-2 was created based on the notion that change had to occur in order for the state agency to survive.

Initiatives with extensive engagement also responded to external pressures, such as funding mandates, vocal providers, and/or advocates demanding involvement.

Initiative B-2's engagement efforts were a direct result of an external mandate to do so

set by state statute while Initiative B-1 was reportedly not engaging program participants because the Federal government had already clearly set the expectations for program policy and design. While Initiative K-1 had very little external pressure for engagement in programmatic change, Initiative K-2 was intended to include extensive engagement practices given the failure of the previous non-participatory approach.

A bureaucratic culture that recognizes paid professionals as the only experts intended to influence decision making also appears to be an environmental factor that influences engagement. State staff perceptions pertaining to expertise, collectively, can not only influence whether or not engagement practices are implemented, but also the extent to which the engagement informs programmatic design and policy decisions. It is apparent, based on this research, that a professionally-focused culture can surround individual programs and not an entire state agency. As seen within Initiative K-1, engagement practices were implemented, but a culture that emphasized professional expertise led to the engagement of mostly professionals and the implementation of closed-decision making practices that occurred outside of the engagement efforts. In comparison, professionals who implemented Initiative K-2 created an atmosphere that clearly recognized recipients of services, family members, advocates, and providers as individuals with their own expertise. This culture infused all aspects of the engagement process, including the level of information shared as well as the facilitation and decision making strategies implemented.

Resource limitations, while touched upon as a process-driven factor (see “Time and Resources”), deserve additional attention as it relates to the environment. While it

may be common for some state staff to point to a lack of funding as a reason for non-engagement, it was actually a motivating factor for engagement within Initiative K-2. In this initiative, engagement practices were intended to allow the State agency to make difficult policy decisions pertaining to budget restrictions while at the same time attaining stakeholder buy-in for these decisions. This inclusive approach was actually perceived by some State staff as a potential way to avoid unnecessary costs associated with hearings for appeals, such as those that occurred previously as a result of a similar policy decision that was implemented with far less stakeholder buy-in.

#### *Perceived Positive Outcomes of Engagement*

This research examined the perceived outcomes to engagement, both positive and negative in all three states. Five perceived positive outcomes were recognized. These were 1) better program design and/or improvement; 2) an increase in knowledge among those involved; 3) participant empowerment; 4) advocacy for funding for program design and/or program sustainability; and 5) the building of positive relationships.

All five of these perceived outcomes were recognized across the three stakeholder groups: State staff, advocates, and program participants. Better program design and/or improvement was the only outcome referenced by all of the program participants interviewed. This outcome was also well recognized by state staff (9 or 81 percent) and advocates (4 or 80 percent). The only other outcome that the majority of program participants (5 or 71 percent) noted was an increase in knowledge. Ten of the eleven (or 91 percent) state staff also recognized the outcome of increased knowledge. When

speaking of this topic, the majority of those interviewed actually focused on an increase in knowledge among state staff rather than program participants.

Of state staff, advocate, and program participant interviews, it is evident that state staff were most aware of the positive outcomes from engagement. This was true across the three states. When examining the five perceived outcomes identified within all three states, eight of 11 state staff interviewed identified each of these outcomes.

<b>Table 15: Perceived Positive Outcomes to Engagement (Collective Findings)</b>				
	Total (23)	State Staff (11)	Advocate (5)	Participant (7)
Recognized in All Three States				
Program Design and/or Improvement	20 (87%)	9 (81%)	4 (80%)	7 (100%)
Knowledge*	19 (83%)	10 (91%)	4 (80%)	5 (71%)
Participant Empowerment	15 (65%)	9 (81%)	3 (60%)	3 (43%)
Advocacy for Funding, Design, Sustainability	14 (61%)	9 (81%)	3 (60%)	2 (29%)
Relationship Building, Stronger Public Relations	13 (57%)	8 (73%)	2 (40%)	3 (43%)
Recognized in Two of Three States				
Satisfaction (State D & State K)	14 (61%)	8 (73%)	2 (40%)	4 (57%)
Efficiency or Productivity (State B & State K)	9 (39%)	6 (55%)	2 (40%)	1 (14%)
Recognized in One State				
Stakeholder Buy-In (State K)	7 (30%)	3 (27%)	2 (40%)	2 (29%)
Trust (State K)	6 (26%)	2 (18%)	3 (60%)	1 (14%)
Informed Decisions (State K)	5 (22%)	3 (27%)	2 (40%)	0 (0%)
Creativity (State K)	4 (17%)	3 (27%)	1 (20%)	0 (0%)
*Most references made to an increase in knowledge for State staff, second was program participants. Others who benefit from an increase in knowledge also include providers and advocates.				

There were four perceived outcomes that emerged through the research conducted in State K that were not recognized in the other two states. It may be no surprise given the nature of Initiative K-2 that the benefits of stakeholder buy-in, an increase in trust, more informed decisions, and an increase in creativity were all recognized as positive outcomes associated with engagement. Advocates within State K were vocal when it came to these perceived positive outcomes of engagement compared to other advocates, indicating that advocates involved in Initiative K-2 have been happy with the process, which was trust building. Even though this outcome surfaced only within State K, three of the five (or 60 percent) of all advocates interviewed identified it.

#### *Perceived Negative Outcomes of Engagement*

The research also highlights negative outcomes to engagement. Overall, there were eight perceived outcomes that surfaced from the data. There were three that were identified across the three states: 1) having no impact or being unsuccessful; 2) the use of time and resources; and 3) frustration and/or conflict. Ten (or 91 percent) of the State staff recognized the time and resources required, eight (or 73 percent) recognized that engagement can have no impact or be unsuccessful, and seven (or 64 percent) referenced frustration or conflict. Three (or 60 percent) of advocates discussed the potential for no impact or a lack of success and an equal number discussed frustration and/or conflict.



Five (or 71 percent) of program participants discussed a lack of impact or success and four (or 57 percent) discussed frustration and/or conflict.

There were two perceived outcomes that were recognized in two of the three states: 1) some stakeholders are left out of the engagement process (referenced by six or 26 percent of those interviewed), and two, the potential for retribution against program participants who participate (referenced by five or 22 percent of those interviewed). Interviewees who discussed retribution referenced this topic theoretically and were not able to identify any specific examples of such practices taking place. Regardless, those who were interviewed did seem to feel that the potential for such was, in itself, a deterrent of engagement for some program participants. Looking across the three stakeholder groups, it is clear that advocates worry about retribution and its potential

<b>Table 16: Perceived Negative Outcomes to Engagement (Collective Findings)</b>				
	Total (23)	State Staff (11)	Advocate (5)	Participant (7)
<b>Recognized in All Three States</b>				
Sometimes Can Have No Impact or be Unsuccessful	16 (70%)	8 (73%)	3 (60%)	5 (71%)
Time and Resources	15 (65%)	10 (91%)	2 (40%)	3 (43%)
Frustration and Conflict	14 (61%)	7 (64%)	3 (60%)	4 (57%)
<b>Recognized in Two of Three States</b>				
Some are Left Out (State B and State D)	6 (26%)	2 (18%)	2 (40%)	2 (29%)
Potential Retribution* (State B and State D)	5 (22%)	2 (18%)	2 (40%)	1 (14%)
<b>Recognized in One State</b>				
Distrust (State K)	5 (22%)	2 (18%)	1 (20%)	2 (29%)
Lack of Buy-In (State K)	5 (22%)	2 (18%)	1 (20%)	2 (29%)
Potential to Harm the Program* (State B)	3 (13%)	2 (18%)	0 (0%)	1 (14%)
*While this topic was referenced, no concrete examples were provided.				

more than state staff and program participants.

While only recognized within one of the three states, there are three other potential negative outcomes that are worthy of attention given the extent to which they were discussed in their individual states. For instance, the potential for distrust and a lack of stakeholder buy-in surfaced in State K. Also, the potential for engagement to actually harm a program surfaced in State B, although the points made were purely hypothetical.

#### *Understanding the Outcomes by Type*

With further analysis of the perceived positive outcomes, it is clear that they can be grouped into three different clusters: process, intermediate, and programmatic outcomes. Process outcomes, such as an increase in knowledge, participant empowerment, and trust, are the immediate outcomes of engagement. Process outcomes lead to intermediate outcomes, that is, direct changes in practice. These are outcomes for which the process outcomes lead to a direct change in a practice. For instance, increased knowledge, empowerment, and trust can lead to a change in buy-in, informed decisions, and an increase in advocacy for a program. From these intermediate outcomes come substantive programmatic changes. These are the outcomes that are the easiest to measure, such as satisfaction, program improvements, and efficiency in efforts. This categorization of outcomes, which is presented below in Figure 14, not only provides a glimpse into the multi-level influence engagement can have, but also the relationship between the various outcomes.

The relationship between process, intermediate, and programmatic outcomes was clearly described by some of those interviewed. When an advocate was asked whether or

not s/he thought engagement worked, s/he stated “I think it does” and then continued by stating:

I think the more people that have been educated and brought into--have their input brought into it, it impresses policy makers with grassroots involvement especially if it's their constituents. And they hear things...you know, [the] pro and con about an issue from their constituents. And people are willing to go through a change if they feel they've had some say or some input. They're more willing to compromise.

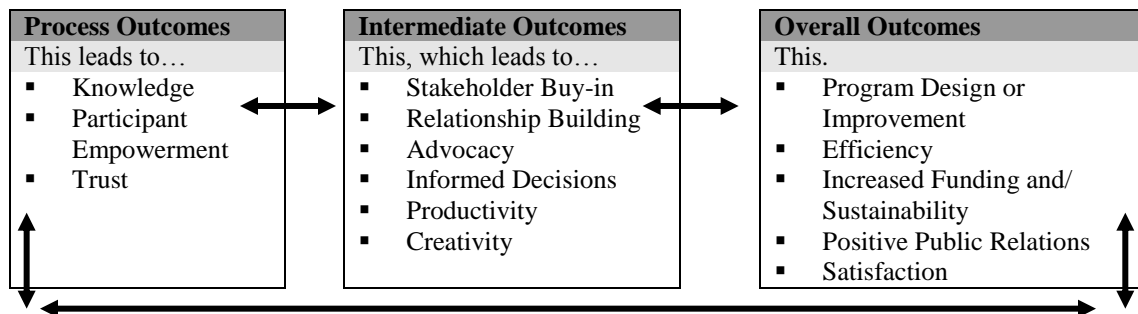
Within this one statement, the advocate recognized that engagement leads to increased knowledge which leads to informed decisions and stakeholder buy-in.

Also, a state staff person noted the linkage between becoming informed and program improvements: “having a good seasoned participant [engaged], they can tell us... why are you guys doing it this way? What is the reason? ... We then turn around and ask why are we doing it that way? And--and if it's not validated, we try to remove that obstacle so it can be a better program.”

Similarly to what was seen with positive outcomes, negative outcomes also appear to fall into three distinct categories as well. As seen in Figure 14, engagement practices, such as the dedication of too much time and resources and some stakeholders being left out of the process, appear to lead to intermediate outcomes, such as frustration and a lack of buy-in. These intermediate outcomes then lead to programmatic outcomes

**Figure 14: Understanding Perceived Positive Outcomes**

A review by type



that can be perceived as negative, such as engagement practices having a lack of impact.

As an additional example, the way an engagement process is facilitated can lead to distrust and conflict, which then leads to initiatives being implemented poorly or not at all. In Initiative K-1, decision making occurred outside of the engagement process and communication among State staff and program participants was controlled and limited.

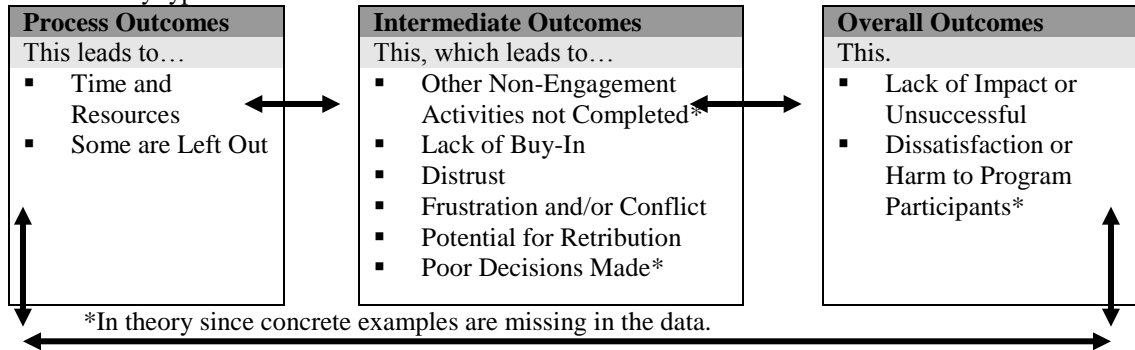
One person reflected on the implications of such practices when s/he stated:

When we were choosing a [financial management service agency] one time, it was recommended...that we choose a [specific strategy] by the participants and... the family members, [we, as stakeholders] had recommended which one [we] really felt would be doing a good job, and

of course, that was not the one that was hired. And, that was probably one of the most horrific things that happened to our program.

**Figure 15: Understanding Perceived Negative Outcomes**

A review by type



### *The Topic of Trust*

The development of trust among state staff, advocates, and program participants appears to be an important factor of engagement. For one, the research provides some insight into how individuals' previous experiences with engagement, negative or positive, can influence the level of trust they bring to the engagement process. As one participant with previous engagement experience communicated, "Does 'engage' mean we have meetings and we have surveys and we talk and we try to figure things out, but then really nothing happens? I think that's going through the motions of engagement." The extent to which there is transparency in communication and decision making processes also appears to influence whether or not trust develops. According to one state staff person from Initiative K-2:

I think that has been really a key to our success is to not only ask [members of the Stakeholder Group] what they want, but [to] truly listen to it and try to respond, and that has come up over and over- that [they]

know that things [they] say aren't just forgotten--that they're followed up on. And if we can't follow-up on them, we try to explain to them why.

[For instance,] it might be something that we delay to later in the project. I think that's really helped us have trust.

Bens (1994) discussed his theory of a “trust gap” which ultimately means that the more serious the issue is perceived to be, the more difficult it is for those involved to trust one another. State K, more specifically Initiative K-2 and the design of a new finance methodology, provides a concrete example of a controversial and very important topic to a diverse range of stakeholders. Distrust was initially present and the controversial nature of the topic did influence stakeholders' desire to be involved in the deliberations. Even so, this research indicates that there are other factors that influence the existence of distrust as well as the eventual development of trust.

Many of those who were interviewed in state K pointed to previous design efforts that were not inclusive and poorly informed program decisions that resulted. According to those interviewed, it was actually the lack of previous engagement practices and the subsequent outcome that created distrust. This example illustrates that person driven factors (e.g., the beliefs and assumptions of state staff that influenced their lack of engagement practices previously) and process factors (e.g., the lack of engagement beyond a limited number of group meetings with closed decision making) that ultimately created a problem with trust.

## *Conclusion*

Research conducted in three states on the engagement practices found in five programs indicate a wide range of person, process, and environment-driven factors that influence the nature of engagement and its subsequent outcomes. While these factors can be examined individually, the multitude of factors and their interdependence make the topic of participant engagement extremely complex. A state staff person from Initiative K-2 sheds light on this complexity when s/he reflected on why some state staff don't engage program participants:

...timeframes don't always permit it. One is, I think, respect; I think some people come in with a—"you will do what I say because I'm in charge"... people just not knowing these tools... and I'm lucky that I have had a lot of experience with participant involvement that I have learned how to structure decision making... knowing how to set the right tone with people, how to set expectations; I mean I think it's just--there's an art to it... and, I think it is challenging. And, I think just cultures don't always permit. I don't know; I think there's just 1,000 different reasons why... it's complicated.

Research findings point to states engaging program participants during various phases, including the conceptualization of policy as well as the design, implementation, evaluation, and/or improvement of a program. Decisions pertaining to when and how program participants and other stakeholders are engaged is determined by person, process, and environmental factors rather than actual evidence of outcomes. Overall, it appears that engagement is used when the stakes are the highest, when people expect

productivity to come from it, and when those involved (internally and externally) demand it. The extent to which program participants demand involvement may be influenced by many factors, including their own assumptions pertaining to what they have to offer. For instance, to be eligible for services through Initiative B-2, program participants were required to be active through volunteer or employment, which may very well have created a sense of entitlement to engagement activities.

The in-depth research conducted in the three states not only confirmed the findings from the web-based survey and key informant interviews conducted in the first phase of this research, but also elaborated on the person, process, and environment-driven factors to engagement as well as the perceived outcomes associated with these factors. The conceptual framework for participant engagement, which has been modified to reflect this enhanced knowledge, can be found in Appendix J. This research provides a foundation for effective engagement practices as well as more in-depth analysis of the relationship between engagement factors and outcomes. The results of this research, as well as subsequent research on outcomes, should allow for evidence-based decision making in the area of participant engagement, ultimately informing the better design, implementation, and improvement of Cash & Counseling programs as well as broader home and community-based initiatives across the country.



## CHAPTER 8

### REPRESENTATION

#### *Introduction*

This research highlights the importance of understanding the role representation plays within engagement practices. Representation, as examined here, refers to the individuals who are chosen and/or volunteer to be included in engagement practices to represent the participant voice. More specifically, differences in representation practices across engagement efforts are found to surround two distinct areas: who and how individuals are selected to represent others. The topic of representation was one that was addressed directly within the interviews given the attention it received in both the literature and the key informant interviews. Research findings align closely with the work of Parkinson (2004b) who highlights the importance of two types of representation: principal agent (being formally appointed and held accountable by constituents) and descriptive (representing the characteristics of the larger group). This research indicates that representation practices and their associated outcomes are linked to person, process, and environment-related factors, and therefore this cross-cutting theme warrants its own chapter.

Most of the individuals interviewed, regardless of their lens, discussed the importance of participants being representative of a larger group of program constituents. Even so, it was often unclear whether or not this expectation was communicated to those who were being engaged and how this process actually occurred. Occasionally, practices for creating representative participation were formal, but for the most part practices were informal or even non-existent. The topic of representation, more specifically how participants were selected as well as representation goals, challenges, and solutions are described in more detail below. Appendix J provides a visual depiction of the representation practices that occur within the five initiatives examined.

### *Representation Selection*

State B, an initiative with low engagement (Initiative B-1) as well as an initiative with high engagement (Initiative B-2), was examined as part of this research. For the few times in which participants were engaged in B-1's programmatic efforts, the participants who were engaged were selected by State staff. Within Initiative B-2, there was a formal process for the selection of Council members, which included an application process as well as the submission of a resume and two letters of recommendation. Applicants were vetted by a Membership Committee and were then formally appointed by the State agency leadership.

Within State K, the two initiatives seemed to utilize different representation selection approaches as well. Within Initiative K-1 (a low engagement initiative), participants who took part in engagement efforts were primarily selected by State staff or provider staff (who were asked if they knew of individuals who may be interested in

participating in engagement activities). Program participants who were selected seemed less connected to formalized advocacy groups compared to those engaged in Initiative K-2.

Initiative K-2 (a high engagement initiative) utilized a combination of methods to select participants. For instance, some participants were nominated by advocacy organizations and others were selected by State staff given their reputation as a leader within the community. When reviewing both efforts, it appears that the Initiative K-1, which had less engagement, utilized informal methods for seeking participants and leaned on professional staff to make the decision pertaining who was best for engagement. Initiative K-2, with more extensive engagement, utilized a more systematic approach to the selection of participants, which included a combination of recruitment practices. According to a State staff from Initiative K-2, “we really tried to get the whole broad spectrum of people... we have a whole bunch of different ways.” A similar comparison can be made in State B where Initiative B-2 also utilized a systematic and formal process for the selection of program participants when compared to the practices found in both Initiative B-1 and Initiative K-1.

Within State D, which was considered a high engagement state, the outreach process included multiple approaches, much like what was found in Initiative K-2. In State D, a Membership Committee led outreach to new members, conducting blanket outreach to program participants as well as requesting that provider organizations and other community groups solicit members. As part of its charge, the Membership Committee paid specific attention to underrepresented geographic locations and voices.

The selection process was also systematic and formal, much like what existed in Initiative B-2. There too is an application process. In State D, the applications are vetted through a Membership Committee and the Council approves or disapproves the recommendations provided (the State agency leadership also has an opportunity to weigh-in as well).

Multiple methods for outreach may ensure that diverse view points are present in the engagement process. For example, one advocate felt that some people who are selected tend to be heavily focused on the needs of one population rather than representing the needs of a larger constituency group. When describing one participant who was selected for previous engagement efforts, this advocate stated, “she has a daughter with profound disabilities and she’s very focused on the rights of those people with those kinds of profound disabilities. So her glasses are pretty focused in a certain area... a bunch of other people will agree with her because they’re wearing those same glasses for that particular problem.”

#### *Representation Expectations*

Both participants and state staff were clear throughout the interviews that, for the most part, they believed that participants who are engaged in program design and implementation should represent a larger constituency. According to one state staff from State K, “if you’re going to ask an unrepresentative person... you’re not going to get very good information.” This person continued by stating, “being on an advisory board, no matter who you are, calls for you to be aware of the views and thoughts of other people and the experiences of other people when you participate.”

This viewpoint was consistent across state staff in all three states and was also clearly communicated by most advocates and participants. For instance, a program participant from State K reported that “What...hasn’t been successful [is] when people [are] only there for their own personal gain... the contribution they had was purely personal and had nothing to do with what the committee was trying to accomplish.” Interestingly, most people were able to articulate their viewpoint in regards to representation, but were less successful in sharing how this goal was met. An advocate from State B reports that “they [often] believe that they know more--they know what’s going on elsewhere; they’ve had these conversations, and they may have, but they seem to say that they can speak for others, but it’s not clear if they really are speaking for others or just speaking for themselves.”

In initiatives where the engagement was far less extensive, most of the representation practices were either informal or non-existent. There were mostly informal methods for representation found within Initiative K-1, with some participants having no process for being informed beyond their own personal experiences. When one participant was asked how she represents others, s/he stated:

[I] try to look at it as a whole, so if... I’m commenting on a particular process or commenting on a particular aspect of this program, I try to make it not a personal thing, you know, not to hit on a personal experience I may have had with it, but look at it how the average person that’s out there...

Another participant from State K described how s/he represented others, which is an example of informal representation practices. This person stated, “I guess networking, because families, we have different list serves and you just get to know each other over the years, too. You might go to some of the same events.” S/he continued this point by stating, “everything is pretty informal because we’re busy living our lives working, taking care of our children...”

An attempt to seek formal representation was found within Initiative K-2. State staff invited participants to the table who were well respected within their community. They also requested that advocacy and provider organizations nominate participants to partake in their activities. Given the state staffs’ concern for stakeholder buy-in for this controversial initiative, state staff wanted to make sure that those engaged were communicating with their constituents. One state staff person was asked if s/he worried about whether or not those that are at the table are taking the time to communicate with constituents, s/he replied:

Not too much, just because I have heard... about the process... I know that [Stakeholder Group member] is talking to their [constituents’ leadership] because occasionally I’ll see [the leader] and s/he will mention something to me. And, I know that the [one particular organization] is doing something because somebody else has told me they’ve posted things on the website... I’ve been a part of some of those broader feedback loops if that makes sense.... And also we’re seeing these people show up at legislative hearings to advocate for this program... not the people

necessarily on our stakeholders group, but other people--part of their organization, so clearly some word is getting out somewhere.

Even in this initiative that had extensive engagement efforts and a reliance on representative communication to make the project succeed, there was no formal process for ensuring that those who were representing others were, in fact, doing so. Instead, the State staff utilized their own means of communication (e.g., website and local hearings) to ensure that constituents were informed of the progress being made.

### *Representation Challenges*

When reviewing the representation practices found within the three states, some specific challenges to representation were identified. As discussed above, people's views on the importance of participants representing a larger constituency were not often aligned with the participant outreach and selection practices. Even if state staff had representation expectations, they were often not well communicated to the participants engaged. Also, participants who were engaged often wore multiple hats (e.g., participant, advocate, paid professional), which could make who the person is representing even more confusing. The participant community may not be a cohesive group, leading to a significant challenge for participants who are attempting to represent the larger constituency group. Finally, a lack of resources dedicated to peer support infrastructure and the development of a formal communication feedback loop make it impossible for many participants to meet existing representation expectations. Each of these representation challenges, gleaned from the data, is described in further detail below.

*Participant selection methods do not always match the intended goal.* As noted above, for the most part, it appears that state staff want individuals that they engage to represent a larger constituency group. Most participants interviewed also felt that it was their role was to represent a larger voice. What is clear based on the research conducted on Initiative K-1 is that state staff may not always select participants who are in the best position to represent others, and in fact, may select participants who are not well connected to their peers. As seen in Initiative K-2, when the stakes are considered high and the agency is seeking buy-in for controversial ideas, staff may approach the selection of participants much more strategically with higher expectations pertaining to constituency communication (combined with State efforts to support such communication).

While engagement practices were extensive in State D, the selection process led to a Council in which the majority of members were provider agencies. The Council was intended to oversee traditional and participant directed services and those who represented the participant direction viewpoint were in the minority. Also, some of the program participants representing the participant direction voice on the Council appeared to have less knowledge of the philosophical underpinnings and basic tenets of participant direction. The result, on occasion, has been the selection of topics and the identification of solutions and products that are provider-centric. One example is the mandating of training for all workers, regardless of whether or not they are agency-based or participant-directed. A second was the creation of a brochure that focused mostly on the



availability of traditional services, providing very little information on the participant direction option.

*Expectations may not be well communicated or understood.* Despite the fact that the majority of those interviewed communicated the need for participants to represent a larger constituency, it does not seem as though participants consistently receive a clear message pertaining to this expectation nor are they always trained on approaches to do so. One program participant from State K reported that some program participants “may not even understand what [is] the purpose of the Advisory Committee” never mind ensuring communication with broader constituents.

An advocate from State B, who has extensive experience working with the state on disability issues, is unclear how to make representation work well. This person stated:

Somehow there has to be a way to develop a strength within the service participants’ system so that the leadership of those folks can be informed of what’s really going on, so that they’re not just putting forth their own agenda, but they’re also putting for the information from others as well.

And I don’t know how to do that. I’ve not figured that out.

A participant from State B, during his/her interview, made it clear that s/he felt that s/he was representing a larger group, but there were no clear expectations from the State as to his/her representation practices. When asked about how s/he represented others, this participant pointed to his/her ability to reflect on personal experiences as well as the garnering of information through informal conversations and ongoing personal relationships with peers.

An advocate from State K recognized the important role those engaged play in ensuring the larger public is informed of what is taking place within a smaller group.

Although, s/he actually pointed to the role of the State in ensuring this happens.

According to this advocate:

I was one of 14 people, you know, which isn't that many people. So they also had to keep updating [others] through newsletters, through local workshops... to get their ideas about what we were coming up with to make sure they felt comfortable. Anything new was brought back to... the smaller group...

It is clear that some advocacy organizations see it as their role to train participants to assume a representative position, and in fact, allocated training resources for this very job.

That being said, such resources do not seem to exist broadly within the three states.

*Participants may wear many hats.* Many of the participants who were interviewed mentioned that they wore “many hats.” They referenced hats beyond their participant or participant representative role, including wearing the hat of an advocate, an academic, or a professional within the disability service arena. While not often referenced as an issue by those interviewed (and in most cases, it was referenced positively), it is possible that the wearing of many hats can make it unclear which voice participants are providing at any particular time. It can also leave those not wearing multiple hats feeling insecure or isolated. According to a participant in State B, “I think I’m really the only one [who is] just a consumer on that Council. Everybody else works for [this organization] or works

for [that organization] or is involved with State programs like that, so I guess they have some input and some experience which always helps.”

*Internal conflict within the represented community.* When interviewing participants and advocates, there was some reference of a power dynamic within the constituency community that can impede adequate representation. One advocate from State K noted times in which s/he had seen constituents disagree on policy approaches, sending mixed messages to state staff, even leading some state staff to abandon engagement processes. As one advocate puts it, “some people just didn't want to have any of it [a bill] if we couldn't have it all. And at one point, one of the Senators who was running the bill just pretty much refused to talk to anybody because [they] were off the wall. So, then you have personalities that take away the credibility of the group and that's rough.”

A participant from State K referenced a “disability hierarchy” where some felt that their disability was more significant than another. S/he stated:

I'd say that's one of the ugliest traits I've ever seen is when there's a disability hierarchy. I don't know how else to describe it. When they feel that their disability is better than that disability... I may have created this group or I may have created this list serve, but you know it's only for these people.

This was confirmed by an advocate from State K when s/he said, “some people say we eat our own young because we don't get along.” A similar point was made by an

advocate from State B when s/he reported, “within the disability community... there is a caste system, and I think that’s part of what is probably also going on...”

One participant from State K also referenced another source of conflict, which was when some participants become disconnected from their community as they get more and more engaged in state activities. According to this individual:

For some people, when they get involved, they actually get a little greedy... like power hungry greedy... they like [being engaged] and they want to be on more committees; so what they do is they kind of sell out. They maybe got initially involved for noble reasons to want to make things better for representatives, participants, to make the program better, whatever you know reason they initially got involved. I’ve definitely seen several who then what happens is let’s say that work of that committee is going to sunset or they find out about a different group that’s like even more powerful so then they want to go to the next level. And what happens is as I’ve seen them like climb they lose touch with what they originally got involved with, and it’s more about having this position of authority, power, prestige of being involved rather than why you’re involved in the first place....It’s like you try to talk to them but hey what’s going--and they won't--then they won't share information or they’re--you know they’ll blow you off or--and I’ve had that happen to me on and off.

An advocate from State B paints a similar picture. According to this individual, “It’s important for leadership to develop, but I’m also concerned that what happens is

leadership develops and then they kind of aren't always speaking for everyone and they're speaking for themselves and I'm concerned about that." A state staff person from State B also recognized that with the development of participant leadership, you tend to see the same people at the engagement table over and over again. According to this state staff person, "I personally find it frustrating because what happens is the person... gets a little stale for lack of a better term. I mean, they get a little used to being the representative and you just don't get the variety of opinions that you need." Interestingly the state staff may be blamed some for this occurrence since it appears common for state staff to select program participants from a small list of individuals who are already engaged.

*Lack of resources for organization of the participant voice.* It is clear that some advocacy organizations embrace the role (and in some cases, they are legislatively mandated) of organizing and training participants so they can be meaningful players in the policy arena. Given this role, they often create organized structures that ensure participants are communicating to constituents and representing others formally. Even so, it appears that these resources are not consistently available across all populations and programs.

An advocate from State B states that some participants "say that they're leaders, but I don't know who they're leaders of... there's not really a structure within... for them to glean information from other participants to actually help them use that information to kind help them with the system forward." One participant from State K references the political power of providers and how participants can't compete with their resources. She

states, “[providers] have lobbyists and everything... they had the time and the money to make sure they were heard and they packaged their message... Whereas [participants] don’t have a voice because we’re not organized.” It is apparent that to be able to formally represent others, time and resources are required for activities, such as communication, agenda setting, and training. Representation appears difficult if a constituency group is not formally organized. This point is made clearly by one program participant in State B who felt an obligation to represent others, but at the same time stated: “I don’t know a whole heck of a lot about a lot of things.”

#### *Representation Solutions Found within the States*

The three initiatives that have extensive engagement practices (Initiative B-2, Initiative K-2, and Initiative D) all seem to have struggled with the topic of engagement. While there is consensus about the need for those on Advisory Groups to represent a larger voice, people interviewed from each of these initiatives recognized the challenges associated with this goal. There were a few practices found within each state that were geared to addressing the representation issue, which are discussed in more detail below.

Within State B, Initiative B-2 has clearly communicated representation expectations within the Council’s handbook. According to this handbook, the responsibilities of Council Members include ensuring two-way communication between the group the Council Member represents and the Council itself. Also, the Council infrastructure was re-organized in an attempt to ensure this two way communication took place. It is apparently a continued struggle. According to the state staff person who administered Initiative B-2:

we [have X local areas] and the X local representatives [are on the Council]-one consumer from each... And, the original design of it was that this person would be, sort of, the ambassador for their [local area] to the advisory group. However, it turned out that a large number of them really had no contact with other consumers in their [local area], so they really were speaking for themselves primarily or based on their own experience. And, we then instituted a requirement [at the local area] that [each local area] have an advisory group. And, we suggested that the person who sat on the statewide Advisory Council be a part of that local advisory group and come back with a broader view, a broader perspective. Did it work? To some extent; it didn't work completely... we had some [local areas] that, once again, they formed advisory groups that were window dressing and the person would go and say 'well everybody is very happy and nobody is sad and everybody thinks everything is great.'

The state staff from Initiative B-2 tried to fill in any gaps in communication that existed by supporting the documentation of statewide Council meetings while requesting that they were distributing to the local areas. The state staff person also attended some of the local advisory group meetings to share progress at the state level. In addition, the statewide Council meetings are open to the public, and members of local advisory groups are encouraged to attend as they feel it is appropriate.

State D also utilized a Council handbook to communicate representation expectations to members. It is written in this handbook that members are to serve as a

liaison between the State agency and its stakeholders. The infrastructure and formal mechanism in which to ensure this happens is not as clear in State D as it is in Initiative B-2. Within State K, state staff from Initiative K-2 also play a significant role in ensuring the appropriate communication is taken place to inform constituents of the work that is taken place in the Stakeholder Group (and vice versa). As previously noted, the state staff post meeting information and materials on their website. Also, constituents have the opportunity to post questions or comments on the website as well. In addition to the work of the Stakeholder Group, the State also hosted local forums at two critical times: before program design and after (both of which were to solicit input). There was also an attempt within Initiative K-2 to seek Stakeholder Group members who were ‘systems thinkers.’ According to state staff, “I think [members of the Stakeholder Group] do have a broader perspective than maybe is typical of a family member who is just not as knowledgeable and aware of systems and is struggling day to day...”

### *Conclusion*

The topic of representation is one of importance, not only to Parkinson (2004b) but also to those who were interviewed within the three states. It is a common belief that those who are engaged in program design, implementation, and improvement should be representing a larger voice beyond their own. Even so, there is very little evidence that indicates that state staff and program participants are implementing methods to ensure both principal agent and descriptive representation (Parkinson, 2004b). In fact, state staff are often utilizing selection processes that are informal, selecting individuals they choose to work with rather than allowing for more formal, participant-driven selection processes.



The results of such practices are often program participants with no formal connections back to the constituency group they are intended to represent. Also, those chosen for engagement are often the easiest individuals to engage (e.g., have policy awareness or experience as well as the ability to travel), most likely meaning that their descriptive characteristics are not completely consistent with that of typical home and community-based service recipients. This is compounded by some program participants and advocates wearing more than one hat and conflict within constituency communities.

It is clear that effective representation strategies require formalized and well thought out selection processes, clearly communicated expectations, and strong two-way communication among those who are engaged and those they intend to represent. Recognizing that many program participants do not communicate with one another (and even face barriers to connecting given health privacy laws), it seems critical to ensure resources are available to assist in participant organizing, more specifically to allow for training and the development of infrastructure that supports systematic representation practices among program participants.

## CHAPTER 9

### POLICY IMPLICATIONS AND OVERALL RECOMMENDATIONS

#### *Introduction*

Cash & Counseling is an evidence-based model for providing community-based long-term services and supports. Research has proven that providing program participants with increased choice and control can increase quality of care, address unmet needs, and minimize hospitalization and institutional care without increasing costs (Carlson, Dale, Foster, Brown, Phillips, & Schore, 2005). The basic philosophy of participant-direction, providing program participants with more control over their services and supports, has also been applied to traditional models of service delivery through the adoption of person-centered practices with the goal of more effectively meeting the needs of the individuals served.

Even with the recognition that participants' own experiences and self-identified needs can inform service delivery, many participant direction programs are being designed and improved without substantial participant engagement beyond what is found at the level of individual service implementation. A similar problem appears to be occurring across a wide range of home and community-based programs that are intended to be person-centered. Until now, it has been unclear why this is occurring.

An inventory of Cash & Counseling engagement efforts in 11 states, key informant interviews, and in-depth interviews in three states with state staff, advocates, and program participants has led to the identification of multiple influences on participant engagement, which fall into the three categories of person, process, and environment-driven factors. This research indicates that these factors are interrelated and influence the perceptions of stakeholders on the actual outcomes of engagement. Meaningful change in the area of participant engagement requires that policymakers consider the importance of all three influential categories of factors identified. While the policy implications are obviously intended to inform the Cash & Counseling programs, the relevance of findings to other home and community-based programs is also clear. In addition to examining policy implications, this chapter provides concrete recommendations in the areas of policy, research, and teaching that can ultimately advance knowledge and practice in the area of participant engagement.

#### *Addressing Process-Driven Factors of Engagement*

This research found that numerous process decisions need to be made when a state decides to implement engagement methods. Without an understanding of this reality, some state staff may implement certain practices (e.g., selection of representatives as well as communication and decision-making strategies) based on their preferred style, unaware of the implications of such decisions on the meaningfulness of engagement and subsequent outcomes. It is important for this research to inform state staff, program participants, and other stakeholders of the various topics for which engagement may be helpful as well as the range of ways to achieve meaningful participation. Such individuals

need to understand the factors that can influence their success. For example, state staff who decide to implement engagement practices after a program is already designed may face frustrated advocates, and state staff who engage program participants with no direct link to constituents may become disappointed in the breadth and depth of input received.

It is also clear that as state staff gain more experience with engagement and buy-in among state staff increases, engagement processes become more advanced. For instance, state staff from programs with less engagement often pointed to difficulties identifying participants interested while those with more advanced practices developed outreach committees to address such challenges. In regards to representation (e.g., whether program participants represent themselves or a larger constituency group), programs with less advanced engagement efforts appeared content with participants providing their personal view while those that were more advanced valued participants formally representing a larger constituency group. In cases of the latter, formal nomination practices and multi-pronged communication strategies were created with this goal in mind.

Pressure exists from some home and community-based service funders to ensure stakeholder engagement occurs in the design of programs, leading some state program administrators to abandon such activities for other priorities once a program is fully implemented. Even so, some policy leaders theorize that seasoned programs are more likely to have well-established engagement practices. Findings from this research do not support this theory since well-established engagement strategies were present among both short-term and long-term initiatives. This research also does not find engagement to be

linked specifically to any one program phase (design, implementation, or ongoing improvement). Instead, this research points to the implementation of engagement strategies being driven by controversial or high stakes events rather than program age or programmatic phase.

#### *Addressing Person-Driven Factors of Engagement*

The findings on characteristics of state staff who engage program participants indicate that communication barriers commonly exist among state staff, advocates, and program participants, specifically in the area of participant engagement (and possibly beyond). Good listening, respect for recipients of services, a team approach, and connectedness to constituents have emerged as important characteristics of state agency leaders who desire meaningful participant engagement.

For participant engagement, implementation, and improvement in program design to be successful, state staff will need to examine their own communication skills and strategies. This includes not only the creation of well-formulated practices for communicating participant-engagement opportunities to stakeholders (such as the development of outreach and orientation materials that describe the purpose of engagement), but also the establishment of transparent and well-planned processes for communication during the engagement process itself. For example, staff play a critical role in communicating the boundaries from which the state agency is working as well as actively listening to stakeholders pertaining to the challenges that are impeding program success.

Research indicates that a professionally driven culture still exists, even within participant direction programs. The perception that some state staff have a desire to control is especially concerning within a program environment that is intended to support participants' own control over services. According to those who were interviewed, the desire for state staff to have control can not only limit flexibility at the individual participant level, but also impact the existence of participant engagement practices at the programmatic level. Participant-directed programs, developed without the direct influence of participants themselves, create an internal conflict within a system intended to advance major paradigm shift from a professional-driven to a participant-driven model of service.

The presence of state staff who lack disability awareness, combined with their personal desire to control, can have negative implications for the creation of flexible, person-centered systems. Examples of such were clear in Initiative B-1 where information sharing was stifled as well as in Initiative K-1 where allowable purchases were restricted as a result of inaccurate assumptions. Ironically, such practices may actually increase the chance of conflict for those attempting to avoid it. As a result, it seems critical to encourage those designing and improving participant direction programs to interact with recipients of services and advocates increasing their knowledge of disability. In doing so, the chances for conflict may be greatly reduced while , at the same time, programs are improved.

### *Addressing Environment-Driven Factors of Engagement*

Research indicates that environmental factors affect engagement and need to be recognized when attempting to implement engagement efforts. While federal agencies and other program funders have mandated stakeholder engagement in many of their programs, many of those designing and/or implementing Cash & Counseling programs are not aware of these mandates. Such may be the case for other home- and community-based programs with engagement mandates as well. While it is also obvious that leadership buy-in for engagement at the state level can be crucial, this research highlights the importance of understanding the impact management has not only at the Executive level, but at the program level as well.

Even if an external mandate for stakeholder engagement exists, other internal pressures for change seem equally as important. For instance, state staff who are responsible for engagement may narrowly define “expert” to mean those with professional education and experience, and as a result, may minimize the expertise (and therefore, the engagement) of those who have developed knowledge through personal experience. It also appears that internal pressure for change may be more common when a crisis is being faced, and in such circumstances, engagement can occur even when limited financial resources are dedicated to the cause. These internal pressures alongside external pressures, such as advocates demanding engagement, indicate the important role environment can play in the extent for which engagement practices exist.

### *Policy Recommendations*

Research findings indicate that engagement factors are numerous and that a dynamic interaction among factors exists, leading outcomes to be unpredictable if all

factors are not recognizable and easily addressed. To account for this complexity, policy recommendations resulting from this research affect three groups: the National Resource Center for Participant-Directed Services, leadership from Cash & Counseling states, and personnel from federal agencies or other entities interested in funding the improvement and expansion of participant engagement strategies. Recommendations for each of these audiences are provided below.

*National Resource Center for Participant-Directed Services (NRCPPDS).* The majority of the recommendations for the NRCPPDS surface around information sharing and training. Given the person and environment-driven factors that focus on assumptions pertaining to expertise, continued efforts to support a culture shift from a professionally driven to a person-driven environment will be critical. This is not only essential for the meaningful implementation of engagement strategies, but for the effective implementation and expansion of participant direction as a model. This shift is already found within some levels of agency leadership, but it is not always found within the states' Cash & Counseling program, even if leadership of the larger state entity endorses the concept. For participant direction and participant engagement to be effective, the cultural shift needs to occur at all levels of management, including those who administer the day-to-day operations of the program.

The NRCPPDS should also adopt a leadership role in sharing these research results in an attempt to increase awareness among stakeholders (e.g., state and federal agencies, philanthropic foundations, researchers, the National Participant Network, and others) involving the perceived benefits of engagement (within and external of the Cash &



Counseling programs), potential pitfalls, as well as the complexity of factors that influence the existence and success of engagement. As part of this process, the NRCPDS should work with stakeholders to examine what these research findings mean for them and how they can utilize the findings to inform their activities.

The NRCPDS should also work closely with federal entities that support the growth of home and community-based services to examine how these research findings can inform

<b>Figure 16: Recommendations for the National Resource Center for Participant-Directed Services (including the National Participant Network)</b>	
Continue to support a shifting in paradigm by targeting management and program operations' leaders.	
Inform stakeholders of research findings through the development and distribution of journal publications, PowerPoint presentations, and short issue briefs.	
Provide guidance to federal entities on ways in which to ensure participant engagement is effectively infused into programs that they support.	
Develop tools and resources that inform state staff and other stakeholders about the factors that influence engagement as well as concrete strategies to design and implement engagement strategies.	
Provide technical assistance to state agencies and their stakeholders on how to design and implement participant engagement strategies within Cash & Counseling programs that are responsive to a diverse range of person and environment-driven factors.	
Support stakeholders to design orientation and training tools for program participants that prepare participants for meaningful engagement.	

existing practices. For example, if federal entities want to support the expansion and improvement of participant engagement strategies across a broad spectrum of home and community-based services, the NRCPDS can provide evidence-based recommendations on how to do so in the design and rating of grant proposals, through ongoing technical assistance, and through the monitoring of ongoing program operations.

Specific to Cash & Counseling and other participant direction programs, the NRCPDS should also assume a leadership role in the development of tools and resources that inform state staff and other stakeholders of the factors of engagement and perceived outcomes that surfaced as a result of this research. Recognizing that the state agencies

that administer Cash & Counseling programs have varying experiences with engagement, the NRCPPDS should also provide technical assistance to support states in their engagement efforts. Given that the research points to a diverse range of factors that influence the extent to which engagement exists, the NRCPPDS will need to consider ways to influence the creation and expansion of engagement practices even when the personal characteristics of state leadership and the state environments are not conducive to engagement.

One major finding from this research was that those who design and improve programs believe that program participants need to be well informed to be successfully engaged. Given this finding, the NRCPPDS should work collaboratively with stakeholders to support the development and distribution of a core set of elements for program participant orientation and training. This toolbox of specific elements should include general information on Cash & Counseling, and the larger home- and community-based service system; instruction on effective advocacy and communication; and advice on how to move from personal viewpoints to larger systems thinking. Existing Cash & Counseling programs, other home- and community-based programs, and advocacy groups have already addressed many of these content areas. The NRCPPDS and its partners should build on these efforts. Next steps would require the identification of the basic content elements that are important, a scan of existing resources that address these elements, and the development of a toolbox that guides the creation of orientation and training tools for program participants within individual programs. Given the ultimate purpose is to prepare program participants at the local level for their engagement,

program participants will need to be involved in the design of this toolbox, its use at the local level, and the distribution of information.

*Cash & Counseling States.* Research findings should also be extremely informative for the Cash & Counseling states. With findings in hand, Cash & Counseling leaders could reflect with their executive leaders, program staff, and day-to-day operations staff on the potential

benefits of engagement, potential pitfalls, and the wide range of factors that influence successful engagement. The NRCPPDS can be an effective partner in the sharing of PowerPoint presentations and short issue briefs to support this process.

Those with personal experiences with disability and a connection to the disability

community are often those who partake in participant engagement strategies. Given this research finding, it would be beneficial for Cash & Counseling leadership within the states to support state staff to participate in activities that actually encourage such connectedness. For instance, state staff may benefit from opportunities to shadow program participants in their daily lives and to work with local disability advocacy

**Figure 17: Recommendations for Leadership within Cash & Counseling States**

Educate executive leaders, program staff, and day-to-day operations staff on the potential benefits of engagement as well as the factors that influence successful engagement.
Support state staff to have increased opportunities to understand through direct experience the lives of those they serve (e.g., “day in the life”) and to collaborate with people who have disabilities with the intention of creating personal awareness and responsibility for engagement.
Work with program participants and advocates to ensure that the roles and responsibilities of program participants who are engaged are clear, including their role in representing a larger voice, the intended outcomes of engagement, the amount of time required for engagement, and how decisions will ultimately be made.
Provide concrete examples and promising practices of engagement methods that are considered simple and easy to implement, including ways of integrating engagement efforts into existing practices to actually increase productivity.
Train state staff on the benefits of constructive conflict, ways to proactively minimize conflict, and effective resolution strategies for conflict.
Provide concrete examples and promising practices of effective two-way communication strategies to support meaningful engagement.

agencies. Such practices can provide state staff with the opportunity to become more aware of the struggles elders and people with disabilities face on a day-to-day basis and the culture that surrounds disability.

When designing engagement practices, Cash & Counseling leadership should also examine the process-driven factors to engagement identified through this research and utilize these findings to design their own engagement strategies. Working with the NRCPDS, the leadership of Cash & Counseling programs should examine and share among their state staff and stakeholders concrete examples of engagement processes that could be adopted within their program(s). Given that the research indicates a concern among state staff that engagement is time consuming, it will be important to provide concrete examples of ways in which engagement has actually increased productivity and has benefited the program in regard to program expansion and sustainability.

Recognizing that some state staff avoid engagement to avoid conflict, it will also be important for Cash & Counseling program leadership to discuss with state staff the benefits of healthy conflict. In addition, leadership should support state staff to learn effective strategies to proactively minimize conflict as well as ensure conflict resolution. Additionally, strong communication skills and effective communication strategies are critical to the success of participant direction. Given this finding, leadership within the Cash & Counseling states should work with the NRCPDS to share concrete examples and promising practices that support the development of two-way, transparent communication strategies.

*Federal Agencies and other Grant Funders Seeking to Improve or Expand Participant Engagement in Home and Community-Based Services.* While seeking a shift in paradigm from professional-driven to person-driven practices, it is important to recognize the role assumptions pertaining to expertise play in the utilization of engagement strategies. This is true not only for participant direction programs, but the broader spectrum of home and community-based services as well. Federal agencies and other funders should consider ways to ensure that culture change occurs, opening not only a window for more person-centered practices, but also participant engagement in the design, implementation, and improvement of home and community-based programs.

Entities funding efforts to make programs more person-centered have often required that stakeholders be involved in the design and implementation of new initiatives. In some states, this requirement has been taken very seriously, leading to stakeholders being part of planning summits, taskforces, councils, etc., but in other states this is not the case. Moving forward, federal agencies (such as the Centers for Medicare and Medicaid Services and the Administration on Aging) and other grant funders should work together to ensure a strong and consistent message pertaining to their stance on participant engagement. This stance should be clearly articulated in new initiatives as well as ongoing program operations.

For example, Request for Proposals should not only include requirements for stakeholder engagement in the design of grants and ongoing implementation, but the scoring of proposals should be heavily dependent on the applicants' ability to demonstrate engagement. Also, grant proposal developers and reviewers should be aware of the

**Figure 18: Recommendations for the Federal Agencies and Other Grant Funders Seeking to Improve and/or Expand Participant Engagement**

Support paradigm shift work beyond what is needed to implement participant direction programs since a shift in assumptions pertaining to expertise is required for meaningful participant engagement in program design, implementation, and improvement.
Ensure a consistent vision and mandate for engagement across all new initiatives as well as ongoing program efforts.
Require that grant proposals and proposed grant methods include extensive engagement and ensure the design and scoring of such grants adequately reflect the perceived importance of such practices.
Require that administrative budgets include funds dedicated to supporting engagement methods and provide incentives for doing so (e.g., administrative match for engagement activities).
Share engagement benefits internally with states and with other stakeholders in a manner that is sensitive to the person, process, and environmental-driven factors of engagement. Target not only executive leadership, but program managers and those involved in the day-to-day operations of programs.
Provide training, concrete tools, examples of engagement practices, and technical assistance to support stakeholders with various levels of experience to progress in their engagement efforts.

factors to engagement that can influence effective engagement practices (e.g., assumptions pertaining to experience and existing relationships with advocates and program participants) as they design grant opportunities and score proposals. Since engagement typically ends when grant funds are depleted, it is also important to ensure that states create strategies to support sustainable engagement through inclusion of resources for this purpose in ongoing operational budgets. To support such practices, federal partners could provide administrative matching funds for engagement activities.

While a mandate for engagement did surface as an environmental factor influencing whether or not engagement existed, there are person and process-driven factors that influence the existence of engagement as well. Because of this, future

mandates will need to be linked to additional information pertaining to engagement benefits and the factors that influence success. This information, provided through technical reports, national presentations, and technical assistance, should not only be shared with state leadership, but with day-to-day program operators and other stakeholders as well.

### *Research Recommendations*

Prior to this research study, existing literature focused on state staff and other policymakers' perceptions of engagement without accounting for the processes utilized and the environments in which engagement occurred. This research addresses a gap in the literature by not only investigating state staff's perceptions of engagement, but also the perceptions of program participants and advocates. In addition, a three-state investigation led to the identification of complex factors that influence perceptions and perceived outcomes of engagement that span across person, process, and environmental characteristics.

There are additional areas for which research is still required. For instance, there is a need to continue to test and refine the web-based survey, allowing for the measurement of engagement across a diverse array of programs. When the survey was developed, the intention was to measure participant engagement within an existing Cash & Counseling program. It is evident from the piloting of the tool and subsequent research that engagement practices among participant direction programs, even within one state, can be drastically different. This requires that the survey be administered to each program individually to assure accurate and program-specific scores.

In preparation for future implementation of the web-based survey, it will also be important to closely examine the scores each state received for each individual factor (e.g., focus of involvement, frequency of meeting, access to information, etc.) and compare these scores to the findings for individual factors that resulted as part of the in-depth research. This process will assist in strengthening the validity of the web-based tool.

<b>Figure 19: Recommendations for Further Research</b>	
Disseminate findings through peer reviewed journals and national conferences.	
Continue to test and refine participant engagement web-based survey and engagement typology.	
Create and test tools that support participant engagement design, implementation, and evaluation.	
Investigate individual, program, and system outcomes while controlling for person, process, and environment factors.	
Review applicability of research findings for participatory action research methods.	

Requesting Initiative B-2 and K-2 (the comparison initiatives) to complete the web-based survey would also be beneficial to allow for a comparison of the web-based findings to the in-depth findings. Ensuring that the survey questions measure the broad intent of each factor area and then weighing each section appropriately should also increase the validity of the tool. The findings from this research could be used to inform this process and lead to further refinement of the participant engagement typology. Refining the typology will provide meaningful benchmarks for state and local programs that are attempting to develop and improve their engagement practices. Alongside these efforts, it will be important to implement process evaluations as stakeholders design tools to support the development, implementation, and improvement of engagement practices.

Current literature does not describe participant engagement outcomes as they relate to engagement factors. This research, intended to identify the factors and perceived



outcomes of engagement, was a critical springboard for future outcomes research. To be effective, any outcomes analysis will need to include methods that are sensitive to person, process, and environmental factors identified as a result of this research. An intervention study testing a model of engagement informed by findings from this research could also be a beneficial next step.

Finally, it is also important to recognize that these research findings may have direct applicability to the implementation of participatory action research methods. Although this research focused on program design and implementation, the identified factors may be insightful for those who are seeking to ensure that research is community-driven. Opportunities to complement existing conceptual frameworks on public involvement in research are evident when reviewing the literature, more particularly the work conducted by Oliver et al. (2008) and Légaré et al. (2009).

#### *Teaching Recommendations*

This research provides some suggestions from improved teaching. As mentioned in the policy section above, federal and state policy makers should be informed of the research findings and how these

findings can be applied to their own efforts and the efforts of states. In addition to this, it could

<b>Recommendations for Teaching</b>	
Educate federal and state policy makers as well as social work and public policy faculty on research findings and potential application of the research findings to their work.	
Develop course electives on participant engagement in policy direction and program management.	

be beneficial social work and public policy graduate programs to partner in the design of curricula that recognize the role that civic engagement and empowerment theory can have on policy design and program management. This coursework would examine the existing

literature on this topic, engagement philosophical underpinnings, as well as the factors to engagement that influence success.

### *Conclusion*

Participant direction is intended to include recipients of long-term services in the design of their long-term services and supports with the goal of improving their lives by creating more efficient and effective service delivery. This notion has been adopted on an even larger scale with the implementation of person-centered practices to ensure that broader home and community-based services meet the needs of the populations served. Interestingly, while these fundamental concepts are often clearly communicated at the point of service entry, their existence is less evident in the methods used to actually design, implement, and improve home and community-based programs.

Even beyond participant direction, federal policymakers are mandating engagement of program participants and other stakeholders in the design and implementation of public policy. Most recently, participant engagement expectations are visible in the 2011 Patient and Protection Affordable Care Act, not only within long-term care segments, but acute health care components as well. Despite a lack of extensive data to inform this requirement and the subsequent methods applied, the assumption is that engagement will lead to more responsive and efficient service delivery, a topic of great import given our trying economic times.

An inventory of participant engagement practices across eleven of the fifteen Cash & Counseling programs, in addition to more in-depth research conducted in three states, indicate that engagement practices vary significantly from one program to the next

and that numerous factors play into the implementation of engagement practices as well as outcomes. These findings, more specifically, the identification of factors that span across person, process, and environmental characteristics, have significant policy implications for stakeholders who want to expand and improve upon engagement practices. While the policy implications are obviously relevant to Cash & Counseling programs, it is clear that these findings can be applied to other programs as well, given the challenges with engagement that are present in a broad range of home and community-based programs.

A series of recommendations that span three focus areas, policy, research, and training, have also resulted from this research. The intention is to ensure that participant direction exists not only in service delivery, but also in the design, implementation, and improvement of participant direction programs through the use of engagement practices. For effective advancement of participant engagement in Cash & Counseling programs and beyond, it will be important that a wide range of stakeholders partake in these recommended next steps. Stakeholders include not only personnel from federal, state, and local entities funding and administering programs, but also technical assistance providers, researchers from academic institutions, community advocates, and of course, program participants.

## APPENDIX A

### WEB-BASED SURVEY OF CASH & COUNSELING PROGRAMS WITH CODING

#### *Web-based Participant Involvement Survey*

#### **Cash & Counseling Programs State Policymakers/Administrators**

#### **Coding**

##### *Focus of Involvement Questions*

**Does your program involve program participants in the design, implementation, and/or improvement of your Cash & Counseling program?**

- a. Yes (2)
- b. No (0)
- c. We have in the past, but not currently (1)

Note: Only one answer chosen

**Participants have been engaged in the following programmatic phases (check all that apply):**

- a. Design (1)
- b. Implementation (1)
- c. Evaluation (1)
- d. Improvement (1)
- e. Sustainability (1)
- f. None of the above

Note: Sum of all answers chosen

**Participant have been engaged in the following topics (check all that apply):**

- a. Provide input on their own services or the services of their loved one (1)
- b. Design of policies or procedures (1)
- c. Outreach methods (1)
- d. Design of tools and/or forms (1)
- e. Development of surveys (1)
- f. Peer support (1)
- g. Training (1)
- h. Monitoring quality (1)
- i. Creation of new programs or other policy-level systems change (1)
- j. None of the above

Note: Sum of all answers chosen

Representation Questions

**Your group(s) also includes individuals who represent (check all that apply)**

- a. State agencies (1)
- b. Consultant/ Support brokerage entities (1)
- c. Financial management service entities (1)
- d. Advocates (1)
- e. Only participants and/or caregivers (1)
- f. Other

Note: Sum of all answers chosen

**For the most part, they are facilitated by (check all that apply):**

- a. State staff (0)
- b. Other (1)

Note: Only one answer chosen

**How are individuals chosen to participate in the design, implementation, or improvement of your program? (check all that apply):**

- a. State leadership identifies those who are most appropriate (0)
- b. Participants self-select (2)
- c. Financial management service and/or consultant entities identify those who are most appropriate (0)
- d. Advocates identify those who are most appropriate (1)
- e. Other (please specify)

Note: Sum of all answers chosen

**Those chosen to participate are (check all that apply):**

- a. Individuals who require long-term supports (1)
- b. Caregivers (1)
- c. Advocates (1)
- d. Other (please specify)

Note: Sum of all answers chosen

Frequency of Involvement

**When you involve participants, they tend to be involved (check all that apply):**

- a. One time to allow involvement opportunities for others (0)
- b. Over a series of meetings until a project is complete (1)
- c. Ongoing to allow for involvement in a series of activities or projects over time (1)
- d. Other (please specify)

Note: Sum of all answers chosen

Communication

**The following participant involvement mechanism(s) have been used (check all that apply):**

- a. Individual interview (1)
- b. Survey (phone or in-person) (1)
- c. Focus group (1)
- d. Advisory group (2)
- e. Committee (2)
- f. Taskforce (2)
- g. Advocate meetings (2)
- h. Public forum or hearing (2)
- i. None of the above (0)
- j. Other (please specify)

Note: Sum of all answers chosen

**When participants are involved, we communicate with them via (check all that apply):**

- a. Telephone/ teleconference (2)
- b. In-person meetings (2)
- c. Email (1)
- d. Web conference (2)
- e. None of the above (0)
- f. Other (please specify)

Note: Sum of all answers chosen

Information/ Training

**The following information and/or training (if any) is shared with participants prior to their involvement (check all that apply):**

- a. Program policies and procedures (1)
- b. Federal rules and expectations (1)
- c. State limitations (1)
- d. Programmatic funding (1)
- e. Enrollment demographics (1)
- f. Average budget allocation and expenditures (1)
- g. Advocacy strategies (1)
- h. Systems change (1)
- i. None of the above (0)
- j. Other (please specify)

Note: Sum of all answers chosen

Accessibility

**The following resources are provided to assist in involvement (check all that apply):**

- a. Large print (1)
- b. Interpretation services (1)
- c. Accessible locations (1)
- d. Transportation (1)
- e. Toll-free call-in line (1)
- f. Personal care assistance (1)
- g. Stipends (1)
- h. We do not provide resources (0)
- i. Other (please specify)

Note: Sum of all answers chosen

## APPENDIX B

### WEB-BASED SURVEY COVER LETTER AND SUBSEQUENT REMINDERS

**June 23, 2010**

Dear Cash & Counseling Colleagues:

I would like to take this opportunity to request your participation in a very important web-based survey that should take no more than 15 minutes of your time (see the link at the bottom of this email).

This survey is the first phase of a larger dissertation research study being conducted by Erin McGaffigan, Ph.D. candidate at the University of Massachusetts, Boston. The purpose of this research is to understand the benefits and challenges associated with participant involvement in the design and implementation of programs. While this research will focus on Cash & Counseling programs, her findings have broader implications for HCBS programs across the country.

We often hear stories of the benefits of participant involvement in the design and implementation of Cash & Counseling programs, but there has been a tremendous gap in research pertaining to this topic. We hope that Ms. McGaffigan's research will provide much needed insight, more specifically a better understating of when engagement has worked well and when it has not. To be clear, this is independent research being led by the researcher. While we are eager to learn of the research findings, we are not participating in the data collection and analysis. The NRCPPDS will not have access to your answers to this survey or any other confidential data the researcher collects.

To get the most comprehensive understanding of this topic, one survey needs to be completed by every state. Please complete the survey even if you do not have involvement methods. If you have more than one program in your state, please contact Erin (781-944-1853) to confirm who should complete the survey. Please know that your involvement in this survey is extremely important, regardless of how "weak" or "strong" you may think your state is in this area. As a follow up, the researcher will identify a few states for more in-depth analysis. If your state is chosen, we hope you strongly consider this opportunity to inform not only the literature, but the work of our Center and the work of your colleagues.



Please feel free to contact me if you have any questions. You can access the survey by following this link: <https://www.surveymonkey.com/s/CashandCounselingengagement>

Peace,  
Kevin

Kevin J. Mahoney, PhD  
Director, Center for Participant-Directed Services  
Phone: 617-552-4039  
Fax: 617-552-1975  
[www.participantdirection.org](http://www.participantdirection.org)

**July 9, 2010**

Greetings!

I would like to thank everyone who has taken a moment to complete the survey mentioned in Kevin's email below. We have a 50 percent response rate so far. In order to have complete findings, it will be important to have a 100 percent response rate. I know some of you have been on vacation. I am hoping that once you are back at your desk, you will take 15 minutes to complete the survey at <https://www.surveymonkey.com/s/CashandCounselingengagement>

FYI- this is a short web-based survey associated with participant engagement. This is not the participant direction inventory currently being conducted. If you have questions, please do not hesitate to contact me at 781-944-1853.

Thank you again to those who have already responded. I will share the findings as soon as they are complete!

Erin McGaffigan

**July 21, 2010**

Dear Cash & Counseling Colleagues:

Thank you to all who have completed the web-based survey on participant engagement (referenced below). I have been informed that this survey will be closed as of Thursday, July 29. If you have not had a chance to complete this survey, we hope you can take a

moment to do so. If you have any questions, please do not hesitate to contact Erin McGaffigan at 781-944-1853 or [ebmcgaffigan@verizon.net](mailto:ebmcgaffigan@verizon.net)<<mailto:ebmcgaffigan@verizon.net>>.

Peace,  
Kevin

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## APPENDIX C

### FEEDBACK ON INTERVIEW PROTOCOLS FROM KEY INFORMANTS

#### **Framing of Questions**

The key informants recognized that the researcher's approach will weigh heavily on the strength of the data collected via the in-person interviews within the states. There is a concern that some state staff and some participants may view involvement efforts as more positive than they were or more negative than they were. The key informants provided specific suggestions on methods in which to frame questions so the researcher receives the most accurate answers. These included:

- Make sure people understand the purpose of the research and how it will ultimately benefit them. Be clear up front that the intention is not to make judgments about methods, factors, and outcomes, but just to understand them better.
- Don't preface questions by recognizing reasons why people are not engaged (e.g., recognize the difficult budget climate) as this can be leading. Even so, there may be times where it is appropriate to share what you have learned so far and ask people to validate and/or add to the discussion.
- Allow the person being interviewed to disassociate from their state if that makes it easier for him or her to discuss the topic. For instance, what do they see versus what they are specifically doing as individuals.

Key informants provided helpful suggestions on how to focus the interviews. Most of the suggestions surrounded the desire to clearly understand the specific engagement methods, factors, and outcomes while trying to avoid “cookie cutter” or overly simplistic answers. Their suggestions, which were adopted, are listed below.

- Make sure the questions are simple while at the same time avoiding jargon.
- Don’t just ask people to list methods of engagement, but ask people to describe engagement methods in great detail to ensure a clear picture of the extent of engagement and methods utilized.
- Inquire about the challenges within the program since this may provide insight as to how those challenges are being addressed and whether or not program outcomes are possibly linked to participant engagement.
- Make sure reasons why people do and do not engage participants are specifically addressed. Try to clearly understand why people choose to invest in engagement, what they feel is the value added, if any.
- Understand if the phase of program design influences people’s assumptions about the importance of engagement.
- Understand the longevity of those being interviewed (e.g., is the person being interviewed someone who was part of the design, or is he or she newer?)
- Explore differences among population groups; does disability culture play a role?
- Understand people’s belief about payment of participants and its linkages, if any, to engagement results.
  - Understand people’s weighting of outcomes, if such weighting exists.

## APPENDIX D

### ■ RESEARCH OVERVIEW MATERIALS

■

### **Cash & Counseling Research Opportunity Participant Engagement in Program Design and Implementation**

#### A Brief Overview

#### WHO?

- Cash & Counseling Policymakers and Administrators
- Community Advocates
- Program Participants Involved in Advisory Groups, Committees, and Taskforces

#### WHY?

- If you have involved program participants in program design (or if you are a participant or advocate who has been involved), this is your chance to share your lessons learned to help others.
- If you have not had the chance to involve program participants in program design, this is your chance to share your experiences, too!

#### HOW?

- If you are a policymaker or a community advocate, we would like to interview you for no more than 1½ hours to hear your thoughts on involving program participants in [Cash & Counseling]’s program design
- If you are a program participant involved in an advisory group, committee, or taskforce, we would like to meet you to hear your thoughts on this subject. You may be asked to participate in a 1½ hour focus group, a 1½ hour interview, or both.
- While payment is not available, we will work with you to identify a time and a place most accessible and convenient to you. We will also do our best to meet any of your accommodation requests.
- All interviews and focus groups will be strictly confidential. While benefits and risks to participation are considered minimal, we will discuss any issues and concerns you may have before you decide to participate.
- All participation is voluntary. You may decide at any time not to participate without penalty.

**Call Erin McGaffigan for more information:**

ebmcgaffigan@verizon.net

781-944-1853

## **Participant Engagement in Cash & Counseling Semi-Structured Interview Topics**

Ideal working environment

Role within the program

Existing challenges within the program

Methods of engaging participants, if any

Overview of existing advisory groups/ committees, if any

Who is involved? Who do they represent, if anyone?

Why do you involve participants/representatives?

Important characteristics of those you involve?

Expectations and desired outcomes pertaining to involvement

What makes engagement work and not work

Methods for dealing with conflict and difficult topics

How you make involvement successful

Others' perceptions of involvement

Benefits of engagement, if any

Consequences of engagement, if any

Thoughts on accommodations

Thoughts on phases of program design and engagement

Thoughts on specific disability groups and engagement

## APPENDIX E

### INTERVIEW PROTOCOLS

#### **Semi-Structured Interview Questions**

Program Participants

Involved in Cash & Counseling Programs in an Advisory Capacity

1. Please describe your role in the \_\_\_\_\_ program. Can you give examples of ways in which you were involved? (design, implementation, and/or improvement phases).
  - a. What did/does this process look like?
  - b. How often have you been involved?
  - c. What were the topics of your involvement?
  - d. How did you communicate with policymakers? With other participants?
  - e. Who facilitated the process?
2. Do you represent yourself, a larger group, other? Please explain.
3. Why do you participate?
4. What type of information, if any, did you receive in preparation for your involvement? During your involvement?
5. What would you like to see come out of your involvement?
6. What do you feel are the important pieces to making your involvement (and the involvement of other participants) work?
7. What are the characteristics of policymakers who have made involvement work well? Are there other characteristics that you feel are important?
  - a. Are there specific characteristics that make involvement challenging?
8. What are important characteristics of program participants who are successfully involved?
  - a. What characteristics make involvement less successful?

9. At times when involvement has appeared to work well, what did it look like? What was happening?
10. At times when involvement appeared to not work as well, why? What was contributing to this?
11. What have been the outcomes/benefits for you... the program... the larger system?
12. What have been the consequences for you ... the program.. the larger system?
13. When challenging topics have come up, how have they been addressed?
  - a. How were/are decisions made?
14. Did you run into any barriers to involvement? What type of support, if any, did you receive to make your involvement easier? If so, what were they?
15. What have been the benefits of being involved, if any?
  - a. For you
  - b. For policymakers
  - c. For the program
  - d. For the larger system
  - e. Other
16. What are the consequences of being involved, if any?
  - a. For you
  - b. For policymakers
  - c. For the program
  - d. For the larger system
  - e. Other



## Semi-Structured Interview Questions

### Community Advocates

4. Is participant engagement happening in your state/program? If so, what does it look like?
  - How are participants involved?
  - What stage are participants most often involved?
  - What topics do they tend to be involved in?
5. Tell me about the policymakers who are engaging/ not engaging participants: Do they make participant engagement work/not work? Why or why not?
  - Leadership style
  - Communication style
  - Decision-making style
  - Focus of involvement
  - Accommodations
  - Other
6. Tell me about the participants who are engaged: Are they up for the task? Why or why not?
  - Knowledge of the system
  - Disability focus
  - Connection to constituency group
  - Personal style
  - Barriers faced
7. Is participant engagement working? Why or why not?
8. What do believe have been the benefits of engaging participants, if any?
  - For participants
  - For policymakers
  - For advocates
  - For the program
  - For the larger system
  - Other
9. What do you believe have been the consequences of engaging participants, if any?
  - For participants
  - For policymakers
  - For advocates
  - For the program
  - For the larger system
  - Other

## Semi-Structured Interview Questions

### Policymakers

#### Introductions.

#### Communicate purpose of the research.

#### Policymakers employing engagement methods

2. In general (not necessarily in the area of participant involvement):

- A. What is your ideal day?
- B. A challenging day?
- C. Name a difficult decision you have had to make and discuss how you made this decision?

Interviewer Box  
(content addressed):

- ☐ communication style
- ☐ leadership style
- ☐ decision making
- ☐ controversial topics

3. Please describe your role in the \_\_\_\_\_ program.
- a. How long have you been in your position?
  - b. How long have you been with the program?

4. What do you feel have been the top challenges within your program?
- a. How are you addressing them?
  - b. What has been the outcomes?

5. Can you give examples of ways in which you have involved program participants? (design, implementation, and/or improvement phases).

- a. What did/does this process look like?
- b. How often were participants involved?
- c. What were the topics?
- d. How did you communicate with participants?
- e. Who facilitated the process?

Interviewer Box  
(content addressed):

- ☐ design
- ☐ implementation
- ☐ improvement

6. If you have a committee or advisory group:

Tell me about your last meeting.

- a. When was the last meeting? How often do they meet?
- b. What was on the agenda? How was the agenda formed?
- c. Who was the chairperson or facilitator?
- d. What took place at the meeting?
- e. Who was at the meeting?
- f. How many people attended the meeting?
- g. Were you happy with attendance? Why or why not?
- h. Where did the meeting attendees come from?
- i. What was your role? The role of others?
- j. Outcomes?
- k. Challenges?
- l. Benefits?

7. Do you have any other methods of engaging participants?
  - a. Purpose?
  - b. What the process looks like?
  - c. Outcomes?
  - d. Challenges?
  - e. Benefits?
8. Who do you tend to involve?
  - a. Who do they represent, if anyone?
  - b. What are their characteristics?
9. Why do you involve participants?
10. Why do you think others don't involve participants?
11. What are important characteristics of those you involve?
12. What do you expect of those you involve?
13. What do you feel are the important components to making involvement work?
14. What do/did you hope would come out of involving participants?
15. What do you do when you are dealing with topics that are divisive or extremely controversial?
16. How do you make involvement successful?
17. What does your boss (or executive leadership) think about engagement?
18. Any benefits of involving participants, if any?
  - a. For participants
  - b. For you
  - c. For the program
  - d. For the larger system
19. Any consequences of involving participants, if any?
  - a. For participants
  - b. For you
  - c. For the program
  - d. For the larger system
20. Do you provide accommodations?
  - a. If so, what are they?

- b. Do you think this is important?
  - c. Challenges?
  - d. Benefits
  - e. Do you pay participants?
  - f. Stipends
    - i. Consultants
    - ii. Thoughts on the impact of this process
21. Thoughts on participant engagement specific to programmatic phases?
- a. Most important phases, if any?
  - b. Challenges associated with phases?
22. Thoughts on participant engagement specific to disability populations?
- a. Challenges faced
  - b. Solutions
  - c. Benefits

Policymakers not employing engagement methods

1. In general (not necessarily in the area of participant involvement):
  - A. What is your ideal day?
  - B. A challenging day?
  - C. Name a difficult decision you have had to make and discuss how you made this decision?

Interviewer Box  
(content addressed):

- ☐ communication style
- ☐ leadership style
- ☐ decision making
- ☐ controversial topics

2. Please describe your role in the \_\_\_\_\_ program.
3. What do you feel are your top challenges within your program right now?
4. Can you give examples of previous ways in which you have involved program participants, if any? (design, implementation, and/or improvement phases).
  - A. What did/does this process look like?
  - B. How often were participants involved?
  - C. What were the topics of their involvement?
  - D. How did you communicate with participants?
  - E. Who facilitated the process?

Interviewer Box  
(content addressed):

- ☐ design
- ☐ implementation
- ☐ improvement

5. Do you think there is a role for participants in design, implementation, or improvement of programs? If so,
  - a. Who would you involve?
  - b. What would their role be?
  - c. What would involvement look like?
  - d. How often would they be involved?
  - e. What would be good topics for involvement?
  - f. What would facilitation look like?
6. If you have had experience with involvement, what made it work?  
What made it not work?
7. What do you do when you are dealing with topics that are divisive or extremely controversial?
8. What does your boss (or executive leadership) think about engagement?
9. What are the benefits of involving participants, if any?
  - a) For participants
  - b) For you
  - c) For the program
  - d) For the larger system

23. What are the consequences of involving participants, if any?
- a. For participants
  - b. For you
  - c. For the program
  - d. For the larger system

## APPENDIX F

### EXIT INTERVIEW DOCUMENT

#### **Thank You for Joining Us in this Participant Engagement Research Project!**

Thank you again for participating in this research opportunity. Your involvement is helping to generate knowledge pertaining to participant engagement in program design and implementation!

The last phase of data collection for this research project includes the review of documents related to participant engagement activities.

#### **Do you have any of the following documents you can share?**

- ☐ Meeting summaries or notes from Advisory Groups, Committees, Taskforces, Public Hearings, or other engagement activities
- ☐ Products/reports or other documents that describe any outcomes, tools, products that are the result of participant engagement activities
- ☐ Legislation (proposed or passed) that is linked to person-centered planning, participant direction, stakeholder involvement, etc.
- ☐ Media (articles, websites, radio, television, etc.) pertinent to person-centered planning, participant direction, stakeholder involvement, etc.
- ☐ Any other documents you feel may be helpful?


If you are unable to provide these materials during our visit, please feel free to forward them to Erin McGaffigan at [ebmcgaffigan@verizon.net](mailto:ebmcgaffigan@verizon.net). A fax number and/or mailing address is available upon request.

## APPENDIX G

### PROCESS FACTORS CHART



Participant Engagement Continuum A Review of Process Factors Across the Five Initiatives			
	Low	Moderate	High
Focus of Involvement	Individual Services	Program Improvements	New Policy or Systems Design
	<p>Within Initiative B-1, bi-monthly teleconferences allowed state staff to inform program participants of program policies and practices. Within Initiative B-2, a statutorily mandated Advisory Council is intended to ensure program participants inform the overall design and day-to-day operations of the program. The Advisory Council includes four committees: membership, training, budget, and legislative. Advisory Council members have been involved in the redesign of the program, creation of program tools, program training, budget decisions, and program advocacy.</p> <p>Initiative K-1 engagement efforts have focused on program expansion and improvement. Focus has been on effective ways to expand the program as well as the development of internal controls to improve the program. Most often, state staff are identifying areas of concern and developing materials, subsequently asking stakeholders to provide comment. Participants take a leadership role in peer training activities, but not directly integrated into program improvement efforts. Initiative K-2 focuses on creating a new method for allocating service funds, which was previously attempted and unsuccessful. Engagement included topics such as finance methodology, assessment, service coordination, and quality design.</p> <p>Within State D, a group of stakeholders (providers, advocates, and members) were involved in the design of the Cash &amp; Counseling program. Once the program was created, the group was disbanded. The Cash &amp; Counseling program was then adopted by the existing waiver Quality Council. Quality Council assists to identify, prioritize, and implement a quality work plan. State develops workgroups as new grants/initiatives are being developed. Focus of the meeting observed included Chair and Vice Chair elections, work plan development, prioritization, and activities for upcoming year, and training from the fraud and abuse division.</p>		
Membership	Mostly State and Providers	Mix of Stakeholders	Mostly those with Personal Stake
	<p>Initiative B-1's bi-monthly forums (not intended for program advisement) have different program participants attend each month (may range from 8-17 participants during each call). B-1 leadership developed a strong relationship with community advocates and providers and engaged them as needed. Seventy-five percent of Initiative B-2's Advisory Council members are required to be program participants. Interested individuals are required to complete an application as well as submit a resume and letters of recommendation. The Membership Committee recommends new members who are formally appointed by the agency's Commissioner. Approximately 25-60 people attend each Advisory Council meeting. The general public is also invited to</p>		

<b>Participant Engagement Continuum</b> A Review of Process Factors Across the Five Initiatives			
	<b>Low</b>	<b>Moderate</b>	<b>High</b>
	<p>Advisory Council meetings. In addition, every local entity administering the program is required to have its own local Advisory Council. Members of local Advisory Councils are welcomed to attend the Statewide Advisory Council meetings.</p> <p>Initiative K-1 is predominantly engaging state staff and providers. Program participants (primarily representatives) who are engaged were chosen by State staff based on previous experiences. Peer training efforts include mostly participants, but these efforts are not integrated into program improvement. Initiative K-2 is engaging a diverse group of stakeholders, of which many have a personal stake (e.g., participants). Some of the members were chosen by state staff based on previous experiences and others were nominated by advocacy groups.</p> <p>Within State D, the group of stakeholders involved in the design of Cash &amp; Counseling included a mix of stakeholders, but a significant portion of the individuals were those who had a personal stake in the program. The Quality Council guidelines require that 5 out of the 13 members be waiver participants or their legal representatives. The remaining participants are provider or advocate representatives. The Council has a Membership Committee that outreaches to new members and makes recommendations to the Committee. Committee chooses Council members with some general (and indirect) oversight from State. The majority of Council members appear to have a provider stake.</p>		
<b>Meeting Frequency</b>	One Time or Sporadic	Pre-determined Intervals	Aligned with Key Decisions
			
	<p>Initiative B-1 holds bi-monthly open teleconferences for information sharing purposes only. Initiative B-2's Advisory Council holds quarterly meetings. The Advisory Council's committees are active on hot topics during the months that the Advisory Council does not meet. The Legislative Committee was meeting monthly as it developed its suggestions for the transition from an agency to participant direction model.</p> <p>Initiative K-1's Expansion Team met 2-3 times per month for 6 months prior to being disbanded. Quality Assurance Advisory Group meets quarterly. Peer training group was meeting monthly, but is not currently active. Initiative K-2 is utilized various engagement practices, with meeting frequency intentionally aligned with key decisions. This included four 2-day in-person Stakeholder Group meetings, a series of Stakeholder Group teleconferences, focus groups, and two rounds of open forums (first round included 7 local forums and the second round included 5 local forums).</p> <p>Within State D, When planning Cash &amp; Counseling, multi-member workgroup met quarterly, while the management team (state staff and grant staff) met one to four times per month. Once the Cash &amp; Counseling program was designed and improvement was adopted by the Quality Council, meetings were quarterly. Committees of the Quality Council meet as needed in between quarterly meetings.</p>		

<b>Participant Engagement Continuum</b> A Review of Process Factors Across the Five Initiatives			
	<b>Low</b>	<b>Moderate</b>	<b>High</b>
<b>Access to Information</b>	Does Not Receive Any Information Prior to Meetings	Receives Some Information, but Not Well-Prepared	Receives Accessible Documents prior to Meetings and Other Information to Make Decisions
	← <b>B-1</b> ————— <b>K-1</b> ————— <b>K-2</b> <b>B-2</b> <b>D</b> →		
	Those who attend B-1's bi-monthly forums receive an email with the telephone number for the forum. Initiative B-2's Advisory Council has by-laws that communicate its purpose and processes, which are shared with each Council member. Specific training for members? Prior to the meetings, state staff work with Council leadership to provide an agenda, meeting minutes from the last meeting, and a packet of pertinent information for the meeting (such as information related to the committees' progress). The state staff person also provides programmatic updates and larger system updates at the Advisory Council meetings. Council members who do not attend receive meeting minutes to ensure they are informed. The state staff person also attends local meetings as needed to provide additional insights pertaining to the work of the Advisory Council and the program.		
	Those involved in Initiative K-1 receive agendas and meeting notes prior to next meeting. They also receive materials that are pertinent to the meeting topic. Those involved in Initiative K-2 receive agendas and meetings notes plus white papers, PowerPoint presentations, and access to experts to inform discussions.		
<b>Communication Strategies</b>	Within State D, materials are provided to meeting attendees a week prior to the meeting (with some sharing of last minute materials). Materials include an agenda, meeting minutes from the previous meeting, quality data reports, and products produced by the committees). Unclear how much attendees review/understand the information prior to the meeting. State staff provide a Council guidebook that clarifies purpose, roles, and procedures of the Council. State staff provide orientation for new Council members. A component of the quality work plan pertains to Quality Council development. Routine trainings occur for the Council.		
	Communication Flows One Way with Little to No Conflict	Communication Flows Two Way, but Little to No Conflict	Communication Flows Two Ways with Transparent Conflict, Resolution Strategies, and Feedback Loop
	← <b>B-1</b> ————— <b>K-1</b> ————— <b>D</b> <b>B-2</b> <b>K-2</b> →		
	Initiative B-1's bi-monthly forums provide an opportunity to hear participants' issues and challenges. State staff utilize the call to clarify misinformation. Initiative B-2's Advisory Council is intimately engaged in the ongoing efforts related to the program via Council Committees and updates from the program manager (conversations with Chair occur multiple times in one week). A statewide Advisory Council and local Advisory Councils are intended to		

<b>Participant Engagement Continuum</b> A Review of Process Factors Across the Five Initiatives			
	<b>Low</b>	<b>Moderate</b>	<b>High</b>
	<p>ensure two-way communication (local to State and vice versa) in regards to program implementation challenges and opportunities. Handbook communicates member's responsibility to "act as a two-way channel of communication between the group or institution he/she represents, and the full Council."</p> <p>Within Initiative K-1, the majority of communication is driven by state staff, and no conflict is present. Within Initiative K-2, meeting practices are intended to support controversial discussions. Conflict is present, but addressed constructively. Direct attempts to synthesize feedback received from multiple sources to aid in decision making. Information for all meetings is posted on the website.</p> <p>Within State D, state staff appear comfortable with discussing controversial topics and communicate the importance of transparent communication. State staff recognize conflict as a normal part of the engagement process (although conflict within the group is not apparent). State staff support the Council to identify priorities then works with State agency leadership to seek buy-in. Despite opportunities for stakeholders to provide insights during stakeholder input session that occurs during the Quality Council meetings, attendance is low and appears to be the result of less organized communication strategies that go beyond the Council members. Council seems genuinely interested in hearing from other providers, advocates, and participants and strengthening approaches to do so. There does not appear to be a structured approach to ensuring those involved on the Quality Council are representing the needs and interests of a larger group.</p>		
<b>Facilitation Strategies</b>	Non-Deliberative, State-Controlled Facilitation	Deliberative, State-Controlled Facilitation	Deliberative and Member-Driven Facilitation
	<p>Initiative B-1's bi-monthly forums are facilitated by a contracted entity. State staff attend the call. The intention of the forums is information sharing only. B-2's Advisory Council has by-laws that guide its work. Handbook communicates the importance of respectful communication and effective problem solving. Advisory Council has an Executive Committee, which includes a Chair, Vice Chair, and Secretary. Advisory Council meetings are facilitated by the Chair of the Council. Committee meetings are facilitated by a local administering agency staff or an Advisory Council member.</p> <p>Initiative K-1's Expansion Team and Quality Assurance Advisory Group were facilitated by state staff. Peer training efforts had an independent facilitator and a participant Chair (although these efforts were not directly integrated into the program improvement efforts). Initiative K-2 is independently facilitated. A major role of the facilitator is to support an open dialogue to inform decision making; State decides focus of meetings, but members' drive progress.</p> <p>Within State D, state staff facilitate Quality Council meetings with assistance from the Chair. State staff facilitates a process of identifying, prioritizing, and implementing quality projects. Supports synthesis of information during meeting and types up written notes from the first day of the meeting to inform the</p>		

Participant Engagement Continuum A Review of Process Factors Across the Five Initiatives			
	Low	Moderate	High
	second day's discussions. Encourages open discussion on controversial topics; seeks clarification on areas unclear. Creates an environment supportive of open communication, respectful teamwork, and partnership. Seeks methods in which to demonstrate progress and products (work plan timeline, creation of deliverables).		
<b>Decision Making Strategies</b>	Decisions Made by Others Outside of the Engagement Process	Mix of Decision Making Practices, Although Not Always Clear	Open Decision Making, Consensus Building
	<p>Within Initiative B-1, decisions are made by state staff (informed by Medicaid rules) with no formal input mechanism. Within Initiative B-2, the Advisory Council is comprised of voting members and alternates. The Advisory Council abides by by-laws. The Advisory Council makes program improvement recommendations, with specific attention focused on Committee areas. The State decides whether or not to accept the decisions. Differences of opinion are welcomed; Handbook communicates requirement for members "to assist in working out solutions."</p> <p>In Initiative K-1, recommendations were provided by the Expansion Team, but decisions are made Executive leadership outside of meetings. Within Initiative K-2, the goal is consensus building and transparent decision making. Independent facilitator implements conflict resolution, consensus building, and negotiation strategies.</p> <p>Within State D, recognize the need for a collaborative approach to decision making. Recognizes the role of Council members and State leadership in the role of decision making. Strives for partnership and collaboration in decision making. Ongoing communication pertaining to what is under the purview of the Council. Relies on voting when consensus not reached, but representation may skew voting results.</p>		
<b>Accommodations</b>	Unaware of Individual Needs and Methods to Address Them	General Practice is to be More Accessible	Clear Process for Identification of Needs and Strategies to Address them
	<p>Initiative B-1's bi-monthly forums are held by teleconference. Previous Quality Management Team included access to funds for travel expenses. Initiative B-2's Advisory Council Handbook communicates the requirement for Council members to have access to alternative formats and reimbursement for reasonable travel expenses. Council members are required to ensure accessible information is provided to allow for informed decision-making and that meeting communication is accessible to all members. Committees have access to a teleconference line.</p> <p>While neither Initiative K-1 nor Initiative K-2 had a formal process for the identification of accommodation needs, some accommodation practices were</p>		

Participant Engagement Continuum A Review of Process Factors Across the Five Initiatives			
	Low	Moderate	High
	<p>present within both initiatives. Initiative K-2 had more people with accommodation needs actively participating. Staff from Initiative K-2 recognized the importance of simplified communication to make the process more accessible.</p> <p>Within State D, no budget allocated to meeting accommodations. General awareness of accommodation needs and attempt to address them (accessible meeting location and materials provided electronically prior to the meeting), but no formal process for doing identifying and addressing accommodations. General awareness and sensitivity given people with disabilities are employed by the State agency. Given that no budget allocation for meetings, members without transportation can call in for meetings. Those on the call do not have full ability to participate in the meeting given brainstorming practices.</p>		
Time and Resources	Time and Resources not Allocated	Time and Resources Allocated as they are Needed	Time and Resources Allocated as Part of the Formal Allocation Process
	<p>← B-1 ————— K-1 ————— K-2 — D ————— B-2 →</p>		
	<p>There are no staff resources dedicated to participant engagement within Initiative B-1 (beyond attendance during bi-monthly forums). Funds are not specifically allocated for engagement practices. Within Initiative B-2, state staff play a significant role in supporting the work of the Advisory Council, including working with the Chair to prepare for the quarterly meetings, taking notes at the meetings, providing refreshments, and distributing meeting minutes. Funds are specifically allocated for engagement practices.</p> <p>Both Initiative K-1 and Initiative K-2 devoted state staff time to engagement. Given the multiple methods of engagement employed, Initiative K-2 dedicated more time. Neither initiative allocated a component of their budget to specific engagement activities</p> <p>Within State D, one full-time equivalent staff person dedicated to quality is responsible for the planning, facilitation, and follow-up pertaining to the Quality Council activities. No budget for the implementation of the meeting itself (overnight accommodations, travel reimbursement, refreshments). One two-day meeting per year. Some Council members travel up to three hours to attend (providers). Provider travel reimbursed by the provider agency</p>		
Total Score	Low	Moderate	High
	<p>←———— B-1 ————— K-1 ————— K-2 D ————— B-2 →</p>		
	<p>Based on all of the characteristics presented, Initiative B-1 is found to be low to engagement and Initiative B-2 is found to be high engagement. Based on all of the characteristics presented, Initiative K-1 is found to be low to moderate engagement and Initiative K-2 is found to be moderate to high. Based on all of the characteristics presented, the program described within State D is confirmed to be a “high” engagement state. Although, membership and accommodation practices found in State D are consistent with moderate engagement practices.</p>		

## APPENDIX H

### ENVIRONMENTAL FACTORS CHART

Environment-Driven Factors Found within the Three States			
	More Likely to Utilize Engagement Methods	Less Likely to Utilize Engagement Methods	Analysis within Three States
<b>Government Climate</b>	Open system at both the Executive and middle management levels that includes secure leadership, collaborative decision making, and transparent communication.	Closed system at both the Executive and middle management levels that includes insecure leadership, back-door decision making, and controlled communication. Closed leadership at the middle management level may lead to less effective engagement practices even if an open style exists at the Executive level.	In State B and State K, the style of middle management seemed to be a factor, regardless of whether or not Executive leadership adopted an open style to management. Within State K, the Executive leadership style and its influence on the use of engagement seemed to be a factor for the more controversial project (Initiative K-2). In State D, Executive and middle management seemed to share an open style, leading to well established engagement practices across the design and improvement phases.
<b>Internal Push for Change</b>	Executive leadership and state staff believe that there is “room for improvement” for which they may not know all the answers.	The role of state staff in being “good stewards” of public resources and this desire to protect trumps opinions of others who are not State employees.	In Initiative B-2 and State D, there was recognition by state staff that there was room for program improvements and that those outside of the State can play a role in such improvement. Initiative K-2 was created based on the premise that change is necessary and that engagement was an important part of this change. In Initiative B-1 and Initiative K-2, there was more focus on ensuring the program rules were upheld by program participants.
<b>External Push for Change</b>	Funders require engagement. Providers and/or advocates expect engagement, but are fair in their expectations.	Funders do not require engagement. There is no legal mandate to implement engagement practices. Approaches utilized by providers and advocates that are more adversarial in nature lead state staff to implement more closed practices.	State staff from Initiative B-1 perceived engagement as unnecessary since program design was set by federal agency. Initiative B-2 had long standing engagement methods that resulted from State statute. Initiative B-1 and K-1 did not appear to have extensive external push for engagement while Initiative B-2 and K-2 did. State D had extensive provider involvement in response to a strong provider community involvement and less advocacy involvement given the weaker advocacy community.
<b>Culture of Expertise</b>	State staff recognize program participants and other stakeholders as ‘experts’ in their own right and see their expertise as critical to the improvement process.	State staff recognize professionals as the experts and program participants as too sick or uninterested in participating.	State staff from Initiative B-2, K-2, and D often recognized the expertise of program participants and other stakeholders while state staff from Initiative B-1 and K-1 tended to limit the use of this label to those with professional labels.
<b>Resource Limitations</b>	See difficult budget climate as a time in which to engage stakeholders in difficult	See difficult budget climate as a time in which to make critical decisions while trying not to be biased by personal	While those who were not engaging program participants often pointed to limited time and resources as a reason, some of these same individuals (from Initiative B-1) pointed to engagement practices



Environment-Driven Factors Found within the Three States			
	More Likely to Utilize Engagement Methods	Less Likely to Utilize Engagement Methods	Analysis within Three States
	discussions. Sees engagement as a way in which to stretch existing resources by including stakeholders in the design of effective products and processes.	situations. Sees engagement as possibly taking time away from important responsibilities and required activities.	utilized by peers (Initiative B-2) as actually leading to the creation of needed products and policies. State D implements engagement practices with no allocated budget beyond state staff. Initiative K-2 was utilizing engagement to address difficult budget decisions resulting from the budget climate.

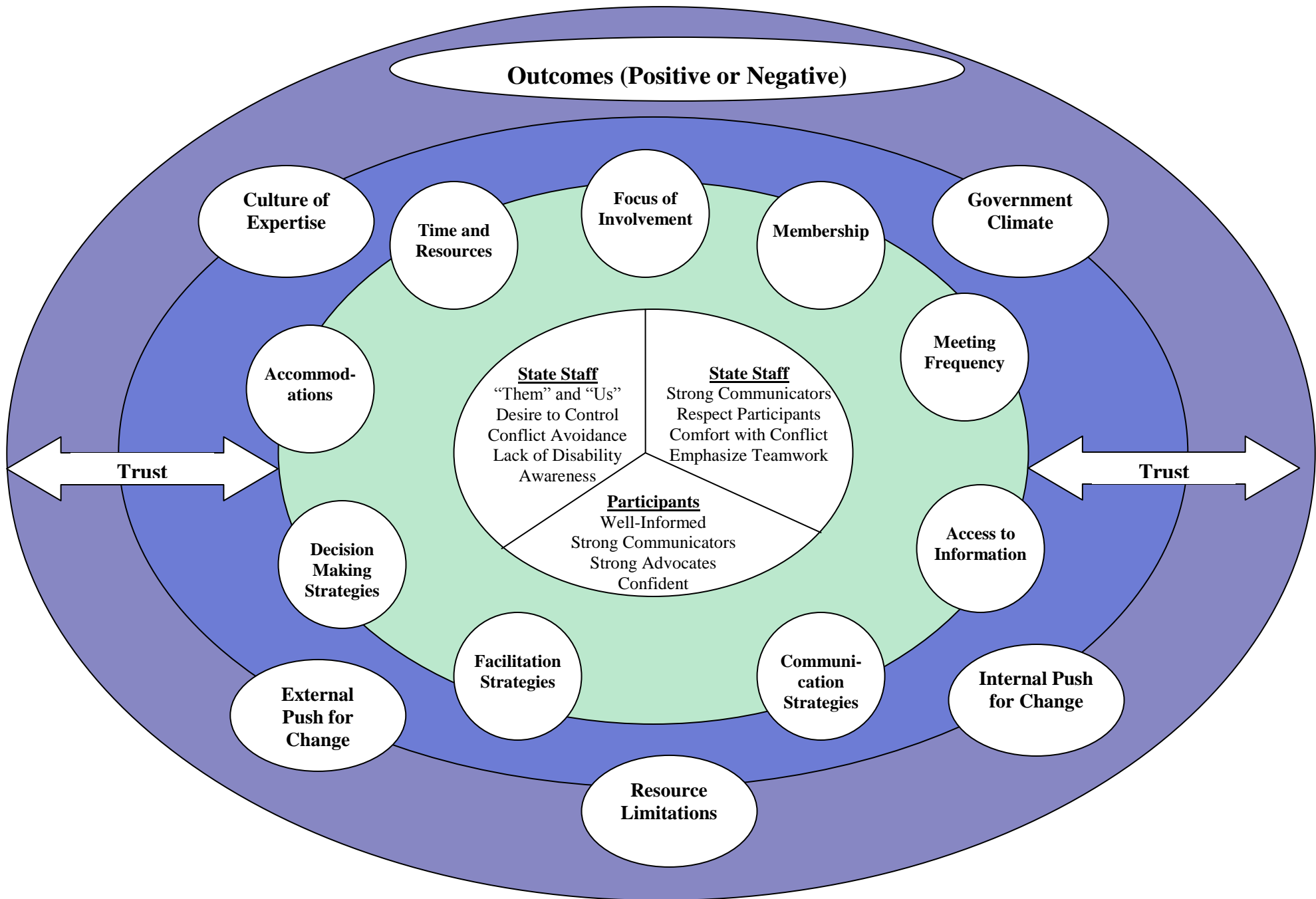
## APPENDIX I

### REPRESENTATION CHART

Representation Practices Across the Three State					
	State B: Low Engagement State		State K: Moderate Engagement State		State D: High Engagement State
	B-1 Low Engagement	B-2 High Engagement	K-1 Low/Mod. Engagement	K-2 Mod./ High Engagement	Initiative D (High Engagement)
<b>Selection of Participants</b>	Participants are selected by state staff	State and local staff seek participants with particular qualities and Council Membership application materials are available to the public via the internet. Membership Committee recommends applicants, State leadership appoints new members.	Selected by state staff and Providers	A combination of approaches, including some being selected by state staff, some nominated by organizations, and some self-selected.	Membership Committee outreaches to existing program participants and local organizations to seek Quality Council Members. Five out of the 13 members are required to be program participants. Interested individuals complete application process. New members are recommended by a Membership committee and are approved by the Quality Council.
<b>Communication Feedback Loop</b>	Mostly non-existent or informal	According to the Council Handbook, Council Members are required to ensure two-way communication between the Council and the group or organization he or she represents. State-level Council members represent local Advisory Councils. State staff play a significant role by presenting at local Advisory Council meetings and ensuring meeting notes are distributed.	Mostly non-existent or informal	Mostly formal, including the use of a public website to share progress, local forums, and articles in newsletters.	According to the Council Handbook, Members are required to serve as a liaison between the State and the stakeholders, although process for doing so seems informal and unmonitored.

## APPENDIX J

### REVISED PARTICIPANT ENGAGEMENT CONCEPTUAL FRAMEWORK



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