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CPIGs Fly: Consumer Involvement within the Massachusetts Real Choice and Independence Plus Grants

Final Report

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Executive Summary

As part of the New Freedom Initiative, the Centers for Medicare and Medicaid Services (CMS) released a series of Real Choice Systems Change grants, beginning in 2001. Massachusetts was among the first states to receive a Real Choice grant. The grant was awarded to the Center for Health Policy and Research (CHPR) at the University of Massachusetts Medical School in September 2001. CHPR was administering the grant on behalf of the Executive Office of Health and Human Services and the Executive Office of Elder Affairs who were co-directors.

A central component of the Real Choice grants was an expectation by CMS that states actively engage people with disabilities in all phases of the grant implementation. CMS required that grantees establish a “consumer advisory committee” as part of this involvement.

The purpose of this report is to review the history and effectiveness of the consumer involvement strategy used within the Massachusetts Real Choice and Independence Plus grants from the consumer, state partner, and grant staff perspectives. We hope to inform future consumer involvement methods in grant activities and other policy decision-making activities with this report. This report will also identify lessons learned and create recommendations to strengthen consumer involvement in future grant activities. It is hoped that this report will be useful to consumers, state partners, and grant staff in Massachusetts and across the nation; especially those who are challenged by effective methods to meaningful consumer involvement in the redesign of long-term services and support systems.

Methods

A CHPR employee not associated with grant activities conducted qualitative interviews with members of the Consumer Planning and Implementation Group (CPIG), grant staff and state partners. Questions were intentionally kept open ended, and participants were encouraged to respond to the questions via e-mail or over the telephone. 60% of participants responded.

Key Findings

- Consumers, state partners, and grant staff were willing to speak openly and honestly about their feelings regarding consumer involvement in the Real Choice and Independence Plus grants.
- Members of each group agreed that the January 2003 forum that led to the formation of the CPIG was tense. However the tension was necessary to create the changes that lead to “meaningful” consumer involvement.

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- Overall, consumers were pleased with the cross-disability and cross-age representation on the CPIG, but recognized that they had a lot to learn about others' disabilities. Additionally, most felt that the CPIG came to represent all persons with disabilities and elders in need of home and community-based supports.
- CPIG members, grant staff, and state partners were in agreement that creating cross-disability policy was more favorable than continuing the tradition of "siloes policy." Policies that reach across disability and age were seen to maximize scarce resources and allow for power in numbers.
- Reasonable accommodations provided by CHPR were not sufficient for some participants to fully participate at the first few CPIG meetings. However, grant staff soon became experts at securing accessible meeting space, providing accessible transportation, and ensuring that documents were available in alternative formats. After the first year of the grant, consumers were very pleased with the way grant staff handled accommodations.
- Grant staff recognized the importance of facilitating meetings, and providing reasonable accommodations. However, at times they felt that their role as facilitator put them in an awkward position as a "middleman" between consumers and state partners. Grant staff also expressed concern that consumers became over-reliant on them for certain accommodations such as making arrangements for transportation.
- For all parties involved, sustainability was a major challenge. This included sustainability of the CPIG, and sustainability of the pilot that the CPIG's work informed. Everyone felt a great sense of accomplishment when decisions about sustainability of the pilot project were agreed upon.
- Consumers, grant staff, and state partners agreed that one of the key lessons learned in the CPIG model was to get consumers involved as early as possible, and to ensure that this involvement was "meaningful." Additionally, consumers mentioned the disconnect between the priorities of policymaking and research and their "real-life" needs, and the value of learning about state policy as other lessons learned.
- Consumers were split when asked about the CPIG model's implications for future policy. Some consumers felt that the model would have a positive impact while others felt that the model would have no impact. However, when asked to think more broadly about implications for future policy, consumers and grants staff were able to reflect on how far they had come, and the difference that was made by the CPIG.
- Even when the groups disagreed, the process made them more aware of the other side of the argument and more aware of others feelings. Although

participants had differing views about the impact that the CPIG model could have on future policy, the fact that they were able to look back and see that progress had been made, in spite of what seemed to be insurmountable odds, is a sign of success.

Background

In June 1999, the Supreme Court issued a ruling in a case known as the “Olmstead Decision,” in which they reinforced the responsibility of public entities to offer programs and services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Following this ruling, in February 2001 President Bush announced the New Freedom initiative, a federal initiative designed to intensify activities among federal and state agencies to enhance opportunities for people with disabilities to live in the community. As part of the New Freedom Initiative, the Centers for Medicare and Medicaid Services (CMS) released a series of Real Choice Systems Change grants, beginning in 2001. Massachusetts was among the first states to receive a Real Choice grant. The grant was awarded to the Center for Health Policy and Research (CHPR) at the University of Massachusetts Medical School in September 2001. CHPR administered the grant on behalf of the Executive Office of Health and Human Services and the Executive Office of Elder Affairs who were co-directors.

A central component of the Real Choice grants was an expectation by CMS that states actively engage people with disabilities in all phases of the grant implementation. CMS required that grantees establish a “consumer advisory committee” as part of this involvement.

Like many states, Massachusetts took a while to start the grant activities. The key state agencies involved in the grant did not reach consensus to enable CHPR to establish the consumer committee until early in 2003, over a year-and-a-half after the grant funds had been awarded. During that initial grant period, people with disabilities and advocates became frustrated and angry about the lack of meaningful consumer involvement. A low point was reached in January of 2003 when the first public meeting of the grant was held. Consumers and disability advocates voiced their dissatisfaction with the lack of involvement and pressed for the establishment of the consumer committee, indicating that they would advocate the return of the funds if meaningful consumer involvement was not established. From that point forward, a cautious partnership between consumers, state partners and the CHPR grant staff began to evolve.

The work of this collaboration did not always progress smoothly, and many setbacks were experienced by all parties. However, as the end of the grant drew near, key stakeholders began to look back and realize that significant progress had been made. In order to document lessons learned both for policy makers and other stakeholders within Massachusetts and for other states, CHPR conducted the study described below.

Purpose

The purpose of this report is to review the history and effectiveness of the consumer involvement strategy used within the Massachusetts Real Choice and Independence Plus grants from the consumer, state partner, and grant staff perspectives. We hope to inform future consumer involvement methods in grant activities and other policy decision-making activities with this report. In addition to history and effectiveness, this report will also identify lessons learned and create recommendations to strengthen consumer involvement in future grant activities. It is hoped that this report will be useful to consumers, state partners, and grant staff in Massachusetts as well as across the nation. We hope that the report will be especially helpful to those who are challenged in their efforts to implement effective methods to meaningful consumer involvement in the redesign of long-term services and support systems.

Methods

During the final year of the Real Choice and Independence Plus grants, consumers and state partners recognized the growth of consumer involvement strategies in the Commonwealth due to the work of the Real Choice Grant. Because of this, these partners requested that the University of Massachusetts Medical School's Center for Health Policy and Research (CHPR) document the methods used and lessons learned to share with others. CHPR grant staff worked with representatives from the Consumer Planning and Implementation Group (CPIG) to develop standard questions to ask consumer and state partners as well as grant staff. These questions were then provided to the CHPR Research Design and Methods Unit for methodological review. This process resulted in the refinement of a limited number of open ended questions for consumers, state partners, and grant staff, tailored to their experiences related to consumer involvement and the CPIG (Please see Appendix A for the list of questions). Approval for this project was obtained from the University of Massachusetts Medical School Committee for the Protection of Human Subjects.

A CHPR employee not associated with grant activities conducted the interviews. All 35 potential participants were contacted via e-mail (and/or hard copy through mail). They were provided a brief introduction to the project, a fact sheet which served as a passive consent form, and a copy of the list of questions (for those who chose to participate by providing written answers). Participants were asked to respond to the questions via e-mail or traditional mail, but were also given the opportunity to complete the questions over the telephone with the same CHPR employee. Participants received a follow-up e-mail after a two-week interval and reminder phone calls encouraging their participation. Every effort was made to provide reasonable accommodations for participation. Qualitative data were collected from members of the CPIG, the Nominating Committee, grant staff, and state partners. Prior to public release, participants had the opportunity to review a draft version of this report and edit their quotations, if necessary. At the end of

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the interview, participants were informed that a documentary was being prepared to accompany the report, and they were encouraged to contact CHPR if they were interested in participating.

Although survey questions were slightly different for each group, the questions were focused on the following topic areas:

- Background that led to the creation of the Consumer Planning and Implementation Group (CPIG)
- Strengths of the consumer involvement approach
- Challenges to progress
- Lessons learned
- Implications for future policy

21 of 35 participants (60%) responded to the survey. 13 participants were members of the CPIG, one participant was a member of the Nominating Committee (who is not a member the CPIG), three participants were grant staff, and four participants were state partners. Of those who responded, nine were members of the ten-member Collaborative Team (five CPIG members and four state partners). Five participants responded in writing to the survey, 15 participants completed the survey over the phone. One participant chose to complete the survey over the phone while providing additional comments in writing. During the telephone conversations, the interviewer asked the respondents all questions, in the order listed. However, respondents were free to revisit any questions to add additional information. Respondents were free to refuse any question. The interviewer captured responses in the form of directly quoted phrases, paraphrases, and overall mood and tone of the interview. Quotations used in this report were taken directly from the telephone or written interviews, and from the uncut version of the accompanying documentary, "When CPIGs Fly."

This report will cover the following areas from the consumer, grant staff and state partners' perspectives:

- The events that led to the beginning of the CPIG
- CHPR's role in reasonable accommodations and facilitation of CPIG meetings
- Cross-disability, as a major strength of the entire process— through representation on the CPIG, representation by the CPIG, and reasons for creating policy that cuts across-disability and age
- Other strengths of the process
- Challenges and barriers to progress
- Lessons learned
- Implications for future policy

Real Choice Forum: Beginning of the CPIG

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As part of the 2001 Massachusetts Real Choice Systems Change grant, the Real Choice Consumer Planning and Implementation Group (RCCPIG) was created to represent consumers with various disabilities, ages, ethnicities, geographic locations. The group included self advocates, community advocates and some providers who were also considered consumer advocates. The RCCPIG was developed after a Real Choice public forum in January 2003, at which time the disability community voiced concern that they had not been consulted or “meaningfully involved” in the development of policy for people with disabilities, including the development of the Real Choice Systems Change grant activities. The RCCPIG later became the consumer involvement mechanism for the Independence Plus grant at which time they renamed the group CPIG. To avoid confusion, the group will be referred to as the CPIG throughout this report.

CPIG members referred to the January 2003 public forum as the “Real Choice Revolt,” and were quick to acknowledge that emotions and tempers were running high that day. Grant staff organized the meeting with the intention of introducing the five grant areas to consumers, and eliciting feedback. As a group, consumers were upset that they had not been “meaningfully” involved in the planning of the grant activities. For several participants, the aim was “to completely disrupt the proceedings” of the forum. The night before the meeting, several consumer advocates gathered together, asking the question, “Why don't we see if we can do something right out of the gate?” according to one consumer. A note was passed around the room amongst consumers during the day of the forum. One member of the grant staff caught a glimpse of the note, which simply said the battle cry of the disability rights movement: “nothing about us without us.”

At that point during the meeting consumers halted the proceedings, and segregated themselves from grant staff and state partners, to determine their next steps. Tensions were so high that the state partners nearly left the meeting. Upon their return to the room, the consumers and disability advocates refused to discuss the five grant areas defined through the grant proposal until a meaningful mechanism for consumer involvement was formed. Disability advocates at the forum felt strongly that the grant staff and state partners should not be defining how consumers should be involved. They felt that decision should be left to consumers.

“What consumers thought about consumer involvement [needed to be] part of the picture.”

“And that was the cry, “nothing about us, without us” and we said this can't continue. [We said] You're in violation of the requirements of the grant, and we're not going to allow it to continue. So, it was stopped. We had a break. We went out in the hallway and were followed by a phalanx of state bureaucrats and academics—UMass people.”

Advocates felt that their implicit understanding of disability needed to be recognized and utilized.

"[Some participants] may [have not known] policy and intention and state agencies, but we do know what people with disabilities need."

"Respect that individuals with disabilities can control their lives... [they've been] doing programs for themselves for years and should have been expected to come to the table with experience."

"Total frustration with the same old same old."

According to consumers interviewed who were at the forum, without the "revolt" the grant activities would have been similar to those in the past-- little consumer input, let alone involvement in the decisions made about the utilization of state funds for persons with disabilities.

"This whole process was the result of a meeting and was a 'revolt' by the consumers who were upset that UMass had already had money for a year and did not speak to or convey to the consumers what they were going to do with it."

"CHPR expected to present this stuff to us, and for us to say 'oh, great.'"

The forum was a difficult and emotional experience for the grant staff, as well. Although one grant staff member had reason to believe that some consumers present would be upset, grant staff as a whole were not prepared for the complete disruption that would occur at the meeting.

"We thought we would leave the meeting with people's ideas on each of the five project areas and seek their involvement in those areas."

However, this was not to be. Grant staff were aware of the disability advocates' anger, and recognized that it ran deeper than just this particular CMS grant.

"There was anger in their voices [at the forum]. I could tell this grant was more than just a grant from CMS. Instead it was symbolic of all the grants that came before, all the services cut, all the plans not implemented and historical lack of involvement of real consumers in the development of policy that affected their lives. I knew we were going to have to pay for this history."

The remaining time at the forum was used to discuss involvement strategies and to provide names for a consumer Nominating Committee. The role of the Nominating Committee was to collect nominations and choose diverse representation for the CPIG.

“Yeah, we went along with it, we formed a group. We nominated ourselves... we nominated ourselves and we took charge. We held retreats. We cost [CHPR] money we told them not to come to these meetings, they weren’t welcome in the beginning until we got our proverbial act together.”

The CPIG requested that grant staff not attend their first few meetings to allow them time to form as a group and to educate one another. They used this time to decide as a group what they felt the aims of the grant should be. They argued that the state and CHPR had already had their time to work on the grant, and that consumers needed time to formulate their own ideas as the other entities had done. CHPR agreed not to attend the first few meetings, and admittedly this was a challenging time for grant staff.

"The consumers at times felt the need to meet without state or university representatives, and it became important in establishing trust that the state/university representatives honor these requests."

"Although it was tiring and emotionally draining, I tried my hardest to allow nature to take its course. I hoped that allowing the CPIG the time it needed (even when it meant meeting without grant staff on the grant’s dime) would only build trust. I had to be okay with not knowing everything... with trying not to control everything."

After these initial meetings, grant staff then met with consumers to discuss ideas for the grant. These ideas included keeping the original Assessment project and abandoning all other proposed projects. The request was for the remaining funds to be used to pilot a Cash and Counseling model, already shown to be effective at the national level. This proposed model would be an opportunity to test the feasibility of Cash and Counseling in the state of Massachusetts, and identify issues that would affect implementation at the local level.

In June 2003, the entire CPIG met with the grant staff and state partners to discuss the future of the grant. This was a turning point in Massachusetts consumer involvement and policy designed for people with disabilities. The state agency representatives agreed to move forward with the project prioritized by the CPIG, and from this larger meeting among consumers and state partners, a Collaborative Team of decision-makers was formed.

The Collaborative Team consisted of five state partners and five consumer representatives, and was the decision-making body for Real Choice grant (and eventually the Independence Plus grant). All five consumers on the Collaborative Team sat on the CPIG and were chosen by the CPIG to represent the larger group.

According to consumers, the Collaborative Team was formed, because:

"We needed a decision-making body that would deal with conflict between consumer views and state means [and] because we wanted to talk with the state directly," and also:

"Because consumers really insisted on some decision-making power."

According to a state partner who was part of the Collaborative Team: "It made sense to have a small group steer the project." This would minimize the time and resources that would otherwise be lost if the larger group was convened for all decision-making.

The Collaborative Team began to meet monthly to provide direction on the Real Choice pilot as well as other grant activities. The CPIG eventually moved to a quarterly meeting schedule while providing input through the Collaborative Team's consumer partners and receiving updates from the Collaborative Team members. The consumer involvement process that evolved from the CPIG and its synergy with the Collaborative Team ensured that consumers were involved in the decision-making aspects of the grant activities.

CHPR as Facilitator and Coordinator of Accommodations

The CHPR grant staff provided staff support to the CPIG and facilitated Collaborative Team meetings. They also served as meeting planners. Grant staff's responsibilities in this role were multi-faceted and included finding accessible space, arranging transportation, providing refreshments, recording meeting notes, and ensuring that participants had the reasonable accommodations that they needed in order to fully participate in meetings.

Consumers

The members of the CPIG reportedly had different accessibility needs to ensure full participation in their meetings. Reasonable accommodations provided by grant staff at the first few meetings of the CPIG were not acceptable to some participants. It took time for CHPR to learn about the various accessibility needs of CPIG members, and several CPIG members admitted to treating grant staff harshly where accommodations were concerned:

"[the CPIG] put them [CHPR] through the paces at the first meeting.... it was a real ringer process."

"[CHPR] took hits early on about not having materials in an accessible format."

One participant described having to "bum a ride for the first two meetings" until CHPR was able to streamline transportation for participants.

This being said, the struggles with accommodations were short-lived and CHPR soon became adept at providing consumers with what they needed:

"As a participant with blindness, I congratulate CHPR on making sincere and regular efforts to provide electronic and hard copy documentation in accessible formats. Staff were receptive to member recommendations, member needs, persevering in procurement of materials, support services, and generally interested in feedback."

"Once we instructed them, they did it with no prodding."

Meetings were described as "fully accessible" by several CPIG members. Coordination of transportation was described as "amazing" by several participants. The streamlining and timely approach to accessibility was indicative of CHPR understanding what accessibility means, and how it often means different things to different people. One CPIG member mentioned that there was "never a drop-off" in grant staff's willingness to understand accommodations.

In addition to providing accommodations, CHPR served as a facilitator for Collaborative Team meetings and provided staff support (such as meeting notes) for both the CPIG and the Collaborative Team. CHPR was described as an "honest broker between consumers and state partners." And as "coming from a middle ground perspective, by virtue of being academics," and as "not having an axe to grind."

Grant Staff

Although grant staff's intentions were well-meaning in the beginning regarding accessibility, consumers quickly let them know that what they were providing was inadequate. At the first few meetings of the CPIG, reasonable accommodations were often improvised. For example, grant staff, unaware of the need for an integrated sound system, improvised by using a karaoke machine with a microphone so that those participants with speech difficulty or hearing impairments could fully participate. With short notice they did this in good faith, not realizing that many consumers would be upset by their actions.

From their perspective, grant staff recognized that there was much room for improvement at the beginning for providing reasonable accommodations to CPIG members. The first few meetings were held in free or low-cost locations. It became clear that these spaces did not provide the accommodations that participants needed, including microphones to ensure that everyone could be heard. Additionally, some initial meetings were almost cancelled because of the lack of an ASL interpreter.

Over time, the grant staff gained a much better understanding of what participants needed and the multiple steps that were required to secure accommodations:

"I was unaware then of how the term 'accessibility' meant so many different things to different people. Once all individuals' accessibility needs were met and grant staff was aware of those needs, meetings became much more effective. For example, the height of the tables needed to be just right so individuals who use wheelchairs could get the chairs under the table, the luncheon buffet could not have risers ... different fonts for documents, Braille copies of all documents for those who are visually impaired, interpreters for those who are hearing impaired, arranging transportation for members--I could go on and on!"

Grant staff quickly learned that "going the extra mile" for accommodations resulted in more productive meetings. Transportation was a specific accommodation that required a great deal of the upfront work and expense, but once put in place, yielded great results.

"We probably ended up spending more money than necessary to assure that we used reliable transportation companies... if we tried to cram many people into one [taxi], they often got to the meeting frustrated and tired from so many stops... if we used a cheaper transportation company, they would often show up late (or not at all) and staff would be on the phone constantly trying to track someone down."

Grant staff was praised by both consumers and state partners for their willingness to work proactively to ensure appropriate accommodations at all CPIG meetings. However, grant staff felt at times that they were being relied on too heavily for accommodations, and that they were being held to unnaturally high standards as a result of the early difficulties during the "revolt."

"Individuals with disabilities were much more critical about accommodations when arranged by [CHPR] than when arranged by one of their peer groups."

Grant staff stressed that it was important to move towards making accessibility a universal process by having everyone involved in meetings take on some

responsibility for accessibility, not just one particular organization.

"I think that our process for transportation was necessary for that time. Now that trust is built and an understanding for such support is recognized, think it would make sense to make the transportation more consumer-driven. The use of transportation budgets may be more sustainable as it would put the consumer in charge of transportation (thus decreasing administrative burden) while assuring the accommodation was provided. Even so, I feel that there should be some level of administrative support available for those who need assistance."

As mentioned previously, CHPR not only insured appropriate accommodations, but they also served as an intermediary between consumers and state partners. This role was viewed positively by both state partners and consumers. Grant staff reflected about their role as an intermediary, and voiced concern that this put them in an awkward position because they were not always seen as neutral parties at the table.

"At times, it felt like we were safe targets of misdirected frustration that was meant for other stakeholders or state partners."

"I would've recommended hiring an independent facilitator for the consumer group so that all consumers would have a chance to voice their concerns. It was a mistake to assume that the university could assume this role, at least in the beginning, because we are viewed as too closely associated with the state agency."

State Partners

State partners felt very positive towards CHPR and the role that CHPR played as both facilitator and provider of accommodations with no exceptions.

"[Grant staff] was good about making sure we had agendas and materials; without their role in the process it would have been tough."

"UMass did an excellent job of providing accessibility to anyone who needed it, including cognitive accessibility, which is unusual to find in most situations."

Cross-Disability:

Participants mentioned many strengths of the CPIG model. However, the most common theme to emerge was the strength of its diverse representation—an approach that cut across age and disability. This includes the representation within the CPIG itself, the fact that CPIG members felt that the group came to represent all persons with disabilities and elders. There was also overarching

agreement between grant staff, state partners and consumers that the creation of policy across age and disability was the best approach; allowing for strength in numbers, the cost-effective utilization of scarce financial resources, and the ability to build consensus on policies that eliminated the traditional silos.

Cross-Disability on the CPIG: Who Was at the Table?

The Nominating Committee strove to create a CPIG that was truly representative across age and across-disability. "Cross-disability representation [on the CPIG] was fantastic." Since the CPIG was meant to be a cross-disability and cross-age group, it is especially important to examine who was at the table and who was not. The CPIG was comprised of persons with physical disabilities, mental health disabilities, developmental disabilities, sensory impairments, as well as advocates for people with brain injury and elders. Most members of the CPIG were consumers, one was a family member, one was a service provider, and others were both consumers and service providers.

The disability rights movement stemming from the 1970s and 1980s was heavily focused on persons with physical disabilities and the rise of Independent Living Centers. As a result of this, often persons with other disabilities have been silenced, even if inadvertently. Initially, the CPIG followed that pattern. Those CPIG members with physical disabilities who had a history with the Independent Living movement tended to dominate conversation in the beginning of the process due to their experience and confidence.

As one CPIG member stated:

"[In the beginning] I think that people involved in the Independent Living Centers sought out people with other disabilities, but weren't really prepared to make other people feel welcome--but that's completely natural."

Over time, however, CPIG participants with historically underrepresented disabilities (such as sensory impairments, developmental disabilities and mental health disabilities, elders, and minorities) were heard and accepted at the table as equals.

"There could be respect for minority contribution across race, age and disability."

"People from other disability groups began to support people with cognitive and developmental disabilities more."

"I really loved to see some of the newer people at the table. Particularly people that typically were not involved in cross-disability work. People with head injuries, people with cognitive disabilities, that we hadn't done good work with over the years. Having them at the table was great. Seeing them become empowered."

This acceptance occurred because members of the CPIG came to realize over time that they needed to learn more about others' disabilities, and that having a disability does not make one an expert on all disabilities. According to the grant staff members who facilitated early CPIG meetings:

"Though individuals were able to articulate the issues related to their own disability, they were often insensitive to others. Individuals needed to be reminded to slow down, to avoid using technical terms and acronyms, and to explain things that were not familiar to the whole group."

"As for some in the group with physical disabilities, I found that there appeared to be assumptions about what was good for the group, based on their own experiences... we had two struggles going on, one struggle was the group as a whole seeking a consumer voice in systems change, and the other was individual struggles to get various disability voices heard and respected."

Several CPIG members mentioned that mutual understanding between persons with different disabilities occurred; however a lot of groundwork needed to happen as people were coming from very different backgrounds.

"There were mindsets that needed to change. I think that some of those mindsets were in the minds of the people with disabilities. Some of the folks we asked to sit at the table were so used to being tokenized that, when it came time to express their true feelings and make demands they weren't used to it. They had a difficult time. They needed to be coached and encouraged to speak their minds, and that was surprising to me."

"We have a lot to offer each other [and there is a] real need for us to understand each other."

Not only did this lead to a greater variety of voices heard at the table and thus a more accurate representation of people with disabilities as a whole, but it also led to intrapersonal growth among participants. CPIG members acknowledged the benefit of feeling accepted by other members of the CPIG who may have had much more experience with activism. Participants described this as:

"Being accepted for myself"

"Becom[ing] part of the family"

"[Feeling that] I had arrived" [after being elected as a co-chair]

Representation on the CPIG of persons with developmental and cognitive disabilities resulted in a greater understanding of that population at a more global level by the CPIG.

"Slowly over time we made ourselves well known as we became more comfortable within ourselves and with who was all there."

"MR/DD (Mental Retardation/Developmental Disability Community) network has been accepted and now noticed."

Most CPIG members felt that, with few exceptions, the CPIG came to represent all persons with disabilities.

"[The] CPIG represented individuals at the forum immediately, and then it represented everybody with disabilities."

"In the classical way, it represented as many kinds of disability that people could think of."

"[The CPIG represented] everybody that would benefit from home and community-based services, families, providers, consumers, and spouses... beyond those of us sitting at the table."

Several respondents felt that there were some groups who were not represented by the CPIG. The most common response related to diversity-- most commonly racial and ethnic diversity, but also age-related diversity. Some CPIG members grappled with inviting elders and representatives of elder services to the table, but eventually understood that the needs of elders and persons with disabilities were more similar than different, and thus a synergistic fit. Additionally, several CPIG members mentioned the omission of children, and institutionalized members of the mental health community from both the pilot and their internal discussions as a concern.

"There could have been more people of color"

"Elders were on the low end initially"

"[There were] a number of subgroups that weren't really represented... people already institutionalized were not invited at all even though they are still front-line users of these services."

Reasons for Creating Cross-Disability Initiatives such as the CPIG

The cross-disability approach of the CPIG was commonly mentioned as a strength by almost all respondents. Overall, taking a cross-disability approach, both in the formation of the CPIG, and in the group's work, was thought to increase the strength and legitimacy of the effort. CPIG participants mentioned several reasons for working across disability. The most common were: similar needs across-disability, maximizing the impact of financial resources, and promoting understanding.

CPIG members felt that the need for similar resources was one reason to create cross-disability policy:

"[Persons with disabilities have] more in common than we do in difference."

"[We] all need Personal Assistance Services (PAS), we all want to have jobs."

Maximizing access to scarce government resources was also mentioned as a reason to create cross-disability policy and programs. Individual disability groups competing for small amounts of money was seen as an inefficient method of getting people the supports they needed, a "waste of time," and a potential means of pitting one group against another.

"It's better to compete for large pieces together than small pieces for each. [It's not a] more for you less for me approach; we all get more."

"If you work together ...you're so much more dynamically strong [resulting in a] project that has much more of an impact."

A few caveats were mentioned regarding cross-disability policy, although no respondent stated any reasons *not* to create this type of policy. One caveat mentioned was to be mindful to reach out to disability communities that historically tend to be insular (such as those with sensory impairments). One respondent mentioned that the creation of cross-disability policy may directly go against the ingrained notions of deaf culture. Another respondent mentioned that while she felt there was no reason not to create cross-disability policy, someone who is blind or deaf may feel differently. Historically, the blind and deaf communities have tended to work for change within their respective populations and established organizations rather than within cross-disability efforts.

Another concern was that, in future groups similar to the CPIG, the needs of some participants may be ignored, because of a focus on accommodations for visible disabilities. This includes the accommodation needs of persons without physical disability (such as the need for more time to read and the need for support persons for coaching or clarification). However, consumers overwhelmingly supported and encouraged taking a cross-disability approach to policy design and implementation.

State Partners

State partners largely agreed with consumers that a cross-disability approach made the most sense both in terms of service provision and fiscal resources:

"In the past, there has been 'competition' between disabilities because they are fighting for very small piece of the pie."

"If there are issues that cut across-disability, then cross-disability policy does make sense.... [it would be] nice if we could do it more often, [it would be] nice to have a single option rather than five."

However, state partners, like consumers, recognized that different needs of individual disabilities should be accounted for. For example, one state partner mentioned that mental health is cyclical in nature, with symptoms that wax and wane over time, while other disabilities can be static. Not taking this important difference into account could do some consumers a disservice.

Grant Staff

Like consumers and state partners, grant staff were in agreement that the cross-disability approach and the creation of cross-disability policy in general, was the best approach to take. Like consumers, grant staff emphasized the value of strength in numbers, the maximization of funds, and the ability to eliminate gaps in service policy as reasons to create cross-disability policy.

"Segmenting policies by disability assures that there will be individuals who fall between the cracks, who don't receive some support they need because is not available to the group, even if it might serve their needs."

"Unlike my previous work... this was as cross-disability as it gets... Increased power and common level of understanding are two major reasons that people with disabilities may want to do cross-disability work. It helps to strengthen budget requests with more constituents. It helps to change policy if you have a larger voice."

Caveats to keep in mind when creating cross-disability policy were also similar to

consumers: remaining mindful to the unique needs and minority voices that may be further marginalized by a cross-cutting effort.

“Other groups are not as far ahead as the independent living movement, and their voices may be overshadowed by others who are stronger advocates.”

“Because it is difficult for any one individual to know and understand the unique strengths, needs and resources related to a variety of disabilities, it is still appropriate for some programs and workers to develop expertise related to specific disabilities and supports.

Other Strengths of the CPIG:

Consumers

Consumers mentioned other strengths of the CPIG model. These included the fact that the CPIG was an attempt at actual consumer involvement rather than simply a consumer advisory committee. Many consumers mentioned that their previous experiences with consumer involvement had been in an advisory capacity. The CPIG wanted a stronger role, and even their name reflected it. Consumers wanted to be directly involved in the *planning and implementation* of the Real Choice grant. Consumers wanted to be brought to the table as equal partners rather than simply as advisors whose input might or might not be taken into account.

The name of the group became important as a symbol of this level of involvement. The group was a Planning and Implementation Group—PIG—not an advisory group. The pig became a mascot for the group when one of the co-chairs found a heavy metal pig with wings that she brought to an early meeting. Someone in the group coined the expression “the system will change when C-PIGS fly.” The flying pig presided over the meetings for the next two years and represented both the challenges and possibilities of change.

As one consumer stated, previous consumer involvement had been an advisory committee model, where consumers were just given something to look at and where consumers were not “full-fledged members of the team.” There was an “adamancy of consumers” that set this group apart from previous efforts, according to another consumer.

“Consumers were involved [in the grant]. That was the real difference.”

To enable consumers to participate as equal partners, the state partners and consumers formed the aforementioned Collaborative Team. CPIG members recognized that it would be difficult to make decisions with state partners and the CPIG group in its entirety. So, the CPIG chose five consumers to join five state partners, and the ten-member Collaborative Team was formed as the decision-making body of the grant. From the beginning, Collaborative Team members agreed that decisions would be reached only by consensus. The process of reaching consensus was viewed as a strength by members of the CPIG.

"[The consensus process] was good because it forced issues [when they may have otherwise been tabled]."

"Both [consumers] and state partners found out that we were trying to work for the same causes and challenges."

"[Collaboration was] highly pronounced and fashioned in a way that collaboration became synergistic between state partners and consumers— a handshaking process."

To foster communication between the Collaborative Team and the CPIG, Collaborative Team meeting summaries were sent to the CPIG within a short time frame of the actual Collaborative Team meeting. Additionally, after each Collaborative Team meeting, grant staff assisted one of the consumer representatives in drafting a "hot topic" e-mail that was circulated immediately, listing the topics of discussion.

Grant Staff

Grant Staff mentioned several strengths of the CPIG model. These included the transparency of the process, and the success grant staff had in their role as an intermediary due to the trust-building that occurred between themselves and consumers.

Grant staff recognized that in order for the process to be successful, they had to be transparent in their actions. Consumers needed to know the grant staff's intentions, and needed to have clarity about the grant staff's role in the process in order for this effort to be successful:

"Being transparent [worked]. I find that people tend to pick up on your intentions even before you do... so trying to be something you are not does not help anyone. I never claimed to be a person who knew what it was like to be in the wheelchair... or have a developmental disability...

I did not claim to be the expert. I knew that claiming to be anyone except an agent of change would not help me or the grant."

Grant staff felt that collaboration, improved communication, and the building of trust among consumers, grant staff, and state partners was an underlying strength of the collaborative effort:

"Within the Real Choice and Independence Plus grants, there was a lot of trust building that happened between the CPIG, state partners, and the grant staff. I think this is one of the many reasons these grants were successful. There was trust building on many levels... communication also assisted in building the trust within the groups."

"One of the greatest strengths of the grant has been the emphasis on collaboration between the state agencies and consumers. This mandate of the grant helped to push the state more quickly into that approach than they might have gone without the funding mandate. Although some individual state partners were eager for this level of collaboration, the culture that had developed [prior to the CPIG] between state partners and consumers was one of suspicion and distrust."

State Partners

State partners' thoughts echoed that of consumers, recognizing that collaboration between themselves and consumers was a strength of the process.

"The members of the joint Collaborative Team were able to work through their differences by sticking with it and educating each other about their perspectives. Over time, a solid working relationship developed based on trust and respect... rarely has a group, in my history, stuck it out to develop such a strong bond and mutual commitment."

Challenges of the CPIG Approach: When the Decisions Get Tough

Sustainability: A Challenge for all parties involved

Consumers, grant staff, and state partners all recognized that sustainability was a major challenge. The concept of sustainability encompassed several areas: sustainability of the CPIG beyond the Real Choice and Independence Plus grants, sustainability of the Collaborative Team, and sustainability of the pilot that was informed by the CPIG's work. Grant activities, including the support provided to the CPIG and the Collaborative Team are finite in nature, ending when the funding runs out. All parties have worked together to find ways to continue the positive activities and momentum of the CPIG and pilot after the completion of the two grants.

All involved recognized the importance of the CPIG and the Collaborative Team

model as a change in the way that consumers were involved in the planning and implementation of grant activities, and the way in which consumers and state partners communicate. With the completion of the Real Choice and Independence Plus grants, questions and concerns have risen about the future of the CPIG model and how best to sustain it.

A state partner expressed concern regarding the sustainability of the CPIG, recognizing that while the model is strong, there could be questions about its ability to bring new members on board:

“It [would be great if we could sustain the CPIG as a group, but as a living, evolving group that is representative [and] allowing for more turnover.”

From a member of the grant staff:

“The model, bringing consumers to the table to have a voice in the planning, implementation, and evaluation of elder and disability policy is essential. For as long as a respect for this process is found in new grants and new initiatives, we have sustained the model.”

The need to sustain the pilot project was also recognized. Consumers were concerned about the future of pilot participants after the completion of the grants. They recognized potential ethical concerns for participants including loss of benefits at the completion of the grant, and wanted to ensure sustainability for the pilot participants after the grants' completion.

“We wondered, what would happen after the project ended? Sustainability and getting state partners to commit to sustainability in writing was a challenge.”

"What I remember the most was two or three state partners rallying with the disability side demanding that the sustainability portion be put into place. And, I think those people had an epiphany. And the epiphany was that this is unconscionable if we don't [sustain the pilot]... and when the decision was made to fund it I felt I could walk away from that team feeling like the best work-- some of the good work is done and the best work is going to take place because model gets implemented."

From a grant staff member:

"[Sustainability] became a make or break issue for the pilot as consumers stood their ground and refused to lend their support unless the state made a commitment to some level of sustainability. Making a commitment... beyond the budget year was difficult for the state agencies...so it took a long time to reach consensus. In the end, a need to assure sustainability to CMS coupled with the strong consumer pressure for it assured that the pilot participants were given a three year continuation of services."

Other Challenges: Consumers

Consumers mentioned several challenges that occurred throughout the course of the CPIG. One challenge for consumers was grappling with what, exactly, consumer involvement meant within the CPIG, and the difference between "involvement" and "consumer control." Other barriers included the perceived level of decision-making authority of state partners on the Collaborative Team and interpersonal barriers within the CPIG itself.

Many consumers felt that the main strength of the CPIG was that it was a true consumer involvement process rather than an advisory panel. However, when asked about challenges, many struggled with the idea of what true consumer involvement meant, and how consumer involvement within the CPIG changed over time.

"Sometimes people didn't feel it [CPIG] was consumer controlled."

"The process... hid the fact that control lies with the state partners. If they weren't willing to go along, support wasn't going to happen. This is counter to the new methodology [of the CPIG]."

Several participants felt that the CPIG became complacent over time, and this contributed to the change in the idea of consumer involvement.

"We are down to four [meetings] a year. You have to keep people in a position to keep making decisions... not sure if we are in a position of having decision-making control anymore."

"That level of radicalism in the CPIG, I believe has lessened. We [both the CPIG and the disability community at large], collectively, have become a little complacent."

Several consumers felt that while having state partners at the table signaled significant progress, those state partners who were at the table were not able to make the decisions that needed to be made, particularly the commitment of future resources to sustain service to pilot participants at the end of grant. According to consumers, this unnecessarily slowed down the process, as state partners would have to take information from the Collaborative Team meetings to a higher level in order for decisions to be made.

"The state partners in small decision-making groups didn't have the power to make decisions."

"If decision-makers were at the table, we could have gotten it done a lot faster."

Other Challenges: Grant Staff

Challenges to the process included CHPR's role as a "middleman" between consumers and state partners, and the perceived over-reliance for support both by consumers and state partners, as mentioned earlier.

"I think a challenge was the amount of time and resources it took to prepare and plan for meetings. In the future, I would think about hiring a staff person just for logistics. I think it would be helpful to look into the consumer members being responsible for arranging their own transportation, while still using grant funds."

"Taking on the state and consumers' work [did not work]. It has been apparent throughout this process that state and consumer partners are extremely busy. At times CHPR would step in to facilitate progress... For true meaningful involvement, consumer and state partners need to be as invested as CHPR."

Other Challenges: State Partners

The main challenge according to state partners was finding the time to commit to Collaborative Team meetings, in the midst of having otherwise very hectic schedules. Additionally, some state partners had difficulty communicating during the Collaborative Team meetings in a way that consumers could understand.

"The state partners' ability to commit got harder and harder."

"The way that [state partners] shared information was less accessible to some [consumers]. State partners would talk amongst themselves at the table sometimes."

"We could learn to do better... there was a big rush when grant money becomes available. We should involve consumers from the beginning,

but it's hard pulling in consumers three quarters of the way through makes their input limited in its impact."

Lessons Learned

Consumers

From consumers, several lessons clearly emerged. These included the importance of involving consumers from the very beginning in the research and policymaking processes, and the continued need to address the disconnect between the real-life concerns of persons with disabilities and the priorities of policymaking and research. Upon reflection, consumers realized that they gained great insight into the workings of state policy (both positive and negative), and that they became increasingly comfortable with couching arguments and challenging state partners.

The importance of involving consumers early in the grant process was the most commonly mentioned when consumers were asked about lessons learned. Consumers felt that much of the animosity that came out of the early meetings of the CPIG could have been avoided if only consumers had been involved in the grant process from the very beginning. However, because consumers learned a great deal about the grant writing process they also recognized the challenges to bringing consumers to the table early when the time table is tight.

"Get people with disabilities involved early--that's it."

"People expressed themselves and the whole thing turned around; that could've happened a few steps back."

"Time is a challenge, people need time to learn and think about these things."

Consumers also mentioned the disconnect between the real-life pressing needs of persons with disabilities in the process of policymaking and research. Consumers eagerly voiced their concern with "reinventing the wheel" when money could be, in their opinions, used for direct service after learning from previous research efforts.

"Working for success is different from measuring success or codifying success for a research study."

"Using money to get people services they need is where we need to put the money, not into more pilots."

"As long as political, academic and medical predispositions prevail regarding their respective service constituencies, grant dollars will be

appropriated in ways most favorable to the continued goal of those who work in these establishments."

Many consumers stated that they learned a great deal about state policy making—both positive and negative, and through this process became skilled at presenting arguments and communicating with state partners. This was especially true for those consumers who served on the Collaborative Team.

"I learned a great deal about the politics and pressure that the State has to work under."

"Public policy is a lot more complex than consumers want to give it credit for."

"[It was] good to have state partners there to help policy work. Many times they are fighting for the same things we are."

"I began to understand what it means to be a state person".

Grant Staff

Like consumers, Grant staff felt that one of the strongest lessons learned was involving consumers early in the process, and in addition, having the patience and time to allow trust to develop, even if that means giving up some control of the process.

"[If given the chance to repeat the process] I would've established a consumer committee from the beginning and insisted that the state agencies recognized that this was a requirement of the grant."

"It is important to meet consumers where they are and to assist them to find their way. This means taking the risk of supporting opportunities for them to learn from one another and meet as peers to develop their ideas and formulate an agenda."

"Get consumers involved from the beginning in developing the grant proposal... with [future] grants, we have included consumers in the grant writing since the policies being developed are to assist individuals with disabilities in the community. They should be involved from the beginning."

This involvement must also be meaningful to the consumer—a departure from the traditional, and more simple, advisory model.

"Many [consumers] felt that they had been part of the consumer advisory group in the past... often called 'punch and cookie groups', where they would receive refreshments, get updates, provide

recommendations and then be sent on their way only to watch their advice ignored. The group was intent on making sure this did not happen with the Real Choice grant.”

“[This] very assertive, opinionated (and sometimes aggressive) representation of disability advocates kept pressing for the best. We would not have gotten anywhere near where CHPR is now in terms of the accessibility and awareness of meaningful involvement if they were not as strong as they were.”

State Partners

State partners were in agreement with grant staff and consumers regarding the necessity of early consumer involvement, and also starting that process *before* grants are released. They also recognized that learning from the CPIG model has implications for future grants.

“A single important lesson is not to wait for a grant to bring folks together to make systems change. That process should be the foundation from which everything else flows.”

“Staying true to what we committed to the CPIG [is important]. [Knowing] that their input is very important and being taken into account in any implementation that the state’s plans around these grants...[the CPIG] will serve state government well as long as we stay true and maintain communication.”

Implications for Future Policy

Consumers, grant staff, and state partners largely agreed that the CPIG model had implications for future policy related to elders and persons with disabilities in Massachusetts. However, CPIG members were split about the groups’ ability to impact future policy. Some consumers believe the model will have an impact on future policy while others believe the model will have little or no impact.

“Because of the CPIG, things are starting to change slowly.”

“[The CPIG was] a real successful model for other projects similar to us around the country. A person with a disability is [co-]chairing the steering committee of the Systems Transformation grant. That would’ve never happened before.”

“Models [like the CPIG] have an impact, but it’s marginal. The models exist and have existed for years...and don’t have to be continually reinvented every time there’s a new grant.”

In 2005 CHPR, in collaboration with the Massachusetts Executive Office of Health and Human Services and the Executive Office of Elder Affairs were awarded a Systems Transformation grant from CMS. The CPIG members are involved in this grant but it remains to be seen whether the approach will be truly collaborative as it was in the Real Choice and Independence Plus grants. Consumers are involved in this grant in a slightly different way than they were in the previous grants. Rather than the Consumer Planning and Implementation Group, consumers are involved on subcommittees for the three goal areas of the grant: housing, quality improvement, and nursing home diversion. Several consumers voiced concern that the Systems Transformation grant was not adequately utilizing what has been learned about consumer involvement.

“I fear the Systems Transformation [grant] went right back to the old way of doing things. The Real Choice grant has proven that the system can work. If they don’t learn from this initiative than Real Choice will be a failure.”

However, when asked about implications for future policy on a broader level, some CPIG members and grant staff became reflective, thinking about how far consumer involvement in Massachusetts had come since January, 2003.

From a CPIG member:

“[A]t least we tried...in many cases we in the past haven’t been... able to have the opportunity to change things. So, that’s real important. People shouldn’t feel like things didn’t happen right. I also think people should look at this very, very carefully and learn some lessons about how you... interface with the bureaucracy—how you really get systems change to occur in a mammoth system.”

From grant staff:

“When I started, the state and consumer group were not meeting in one room, never mind sitting at the table to discuss policy. Now consumer and state partners are presenting together at state conferences and national conferences. They joke together about the ‘revolt.’ State partners [now] think about a method to seek consumer input on policy well before the implementation phase. There are groups already in place that the state knows they can tap into rather than just talking to one or two specific advocates in hopes that they are representing a larger voice. I think people tend to forget all this change in the fear of losing ground. But it would be nice to instead recognize this progress in the hope of growth.”

Conclusion

Consumers, grant staff, and state partners who informed this report were willing to speak candidly about their experiences with consumer involvement. Many were eager to reflect on how far they had come as a group since the January, 2003 forum. More often than not, consumers, grant staff, and state partners were in agreement about the strengths and challenges of the CPIG model. Areas where consumers, grant staff, and state partners agreed included the importance of making policy that cut across-disability and age, ensuring that all meetings were as accessible as possible for all participants, ensuring sustainability for the pilot project, and involving consumers in a meaningful way in grants as early as possible. Even when the groups disagreed, the process made them more aware of the other side of the argument, and more aware of each other’s feelings. Although participants had differing views about the impact that the CPIG model could have on future policy, they were able to look back and see that progress had been made in spite of what had seemed to be insurmountable odds. This is the final proof of the model’s success.

November 30, 2006

Appendix A:

The Real Choice and Independence Plus Consumer Experience Project

For all Participants:

Instructions:

Please take the time to answer the following questions to the fullest extent possible. Under each question, you will notice prompting questions. These questions are to assist you to think about your answer when writing. Please try to touch upon each area. Please also feel free to provide additional information as you see fit.

If you need any accommodations or assistance filling out the questionnaire, please contact Nicole Lomerson at 508-856-1758 or at Nicole.Lomerson@umassmed.edu.

Once you have completed the questionnaire, please use the self addressed stamped envelope to return to Nicole Lomerson.

Participant Questionnaire Consumer Planning and Implementation Group (CPIG)

1. Please explain your experiences with consumer involvement in the Real Choice and Independence Plus grants. When answering this question, please think about any or all of the following:
 - How did this consumer involvement process differ from other initiatives you've been a part of in the past?
 - What worked?
 - What did not work?
 - What have you learned?
 - What would you change about the process?
2. Please explain your experiences with the CPIG as a cross-disability initiative. When answering this question, please think about any or all of the following:
 - Have you been involved in any other cross-disability initiatives?
 - If so, how did this compare?
 - What are the reasons to create cross-disability policy? What are the reasons not to?
 - How could we have done it better?

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3. Please share your experiences, thinking about any or all of the following:
 - What led to the creation of the CPIG?
 - Was the CPIG appointment process effective?
 - Who did the CPIG represent? Who did it not represent?
 - What kinds of support helped the CPIG do its work?
 - Should we have done things differently? If so, how?
 - How did your experiences on the CPIG change over time?
 - What were your experiences related to accessibility?

4. Please share your experiences, thinking about any or all of the following:
 - How was this model different from your other grant experiences?
 - What were some challenges at start up?
 - What were some barriers to progress?
 - What are some lessons learned that could be applied to future grants?
 - What were your experiences related to accessibility?

5. **Collaborative Team Members Only:**

Please share your experiences, thinking about any or all of the following:

- Why do you feel that the Collaborative Team was formed?
- What worked well? What didn't work well?
- What are the strengths and challenges of this model?
- What should we learn from this approach that applies to other policy work?

Participant Questionnaire Grant Staff

1. Please explain your experiences with consumer involvement in the Real Choice and Independence Plus grants. When answering this question, please think about any or all of the following:
 - How did this consumer involvement process differ from other initiatives you've been a part of in the past?
 - What worked?
 - What did not work?
 - What have you learned?
 - What would you change about the process?

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2. Please explain your experiences with the CPIG as a cross-disability initiative. When answering this question, please think about any or all of the following:
 - Have you been involved in any other cross-disability initiatives?
 - If so, how did this compare?
 - What are the reasons to create cross-disability policy? What are the reasons not to?
 - How could we have done it better?

 3. Please share your experiences, thinking about any or all of the following:
 - What are the strengths of the grant? What are the weaknesses?
 - What were some start up dilemmas? What should have been done differently?
 - What were your experiences related to accessibility?
-

Participant Questionnaire Nominating Committee

1. Please share your experiences, thinking about any or all of the following:
 - Was there cross-disability representation of the Nominating Committee?
 - Was the Nominating Committee appointment process effective?
 - What should have been done differently?
 - What were your experiences related to accessibility?
-

Participant Questionnaire State Partners

1. Please explain your experiences with consumer involvement in the Real Choice and Independence Plus grants. When answering this question, please think about any or all of the following:
 - How did this consumer involvement process differ from other initiatives you've been a part of in the past?
 - What worked?
 - What did not work?
 - What have you learned?
 - What would you change about the process?

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2. Please explain your experiences with the CPIG as a cross-disability initiative. When answering this question, please think about any or all of the following:
 - Have you been involved in any other cross-disability initiatives?
 - If so, how did this compare?
 - What are the reasons to create cross-disability policy? What are the reasons not to?
 - How could we have done it better?

3. Please share your experiences, thinking about any or all of the following:
 - How was this model different from your other grant experiences?
 - What were some challenges at start up?
 - What were some barriers to progress?
 - What are some lessons learned that could be applied to future grants?
 - What were your experiences related to accessibility?

4. Please share your experiences, thinking about any or all of the following:
 - Why do you feel that the Collaborative Team was formed?
 - What worked well? What didn't work well?
 - What are the strengths and challenges of this model?
 - What should we learn from this approach that applies to other policy work?

For more information, please
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