Alchemy: Research Turns Into Policy

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If a tree falls in a forest and no one is around to hear it, does it make a sound?
Attributed to Bishop George Berkeley, 1710

The results from the randomized controlled experiment of Cash and Counseling, involving 6,700 elderly and younger adults with physical and developmental disabilities, made the case for the option of allowing people, alone or with the assistance of a representative, to direct their own supports and services. Individuals in the treatment group were more satisfied with particular aspects of their services, had fewer unmet needs, and had the same or better health outcomes. And they realized major gains in their overall satisfaction with life—all without major cost increases.

In Arkansas, people who managed their own budgets, compared with those who continued to use traditional services, experienced an 18% reduction in nursing facility usage (Dale & Brown, 2006). And, the positive results were not limited to participants; primary caregivers experienced less physical, financial, and emotional stress, and even the workers whom participants hired gave positive feedback (Foster, Dale, & Brown, 2007).

But, whereas strong positive research results were critical, the program’s success did not depend on them alone. Effective communication to multiple audiences was differently—but equally—important over the course of the research demonstration. Policymakers, for one, needed to be inspired to turn research findings and subsequent messages into meaningful vehicles (legislation, regulation, and program initiatives), if the research results were to eventually affect policy and programs.

In this paper, we will explain some of the strategies and tactics used to communicate with key audiences, and then we will discuss some of the mechanisms used to turn the research messages into viable program options.

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We will organize our points focusing on actions taken before, during, and after the controlled experiment and replication. We will then conclude with some present-day examples of how research can affect policy and practice.

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Before

Laying the groundwork for affecting programs and policies began before the experiment got underway. As part of the process for selecting states for the Cash and Counseling controlled experiment, the Robert Wood Johnson Foundation (RWJF) wanted to secure the buy-in and commitment of the Governor’s office in each of the demonstration states. This was deemed necessary as each demonstration state would need to recruit thousands of people, and then the state would need to put stock in the evaluation and uphold the integrity of the randomization process.

In Arkansas, the Democratic Governor, Jim Guy Tucker, had been indicted and was about to leave office, so we interviewed the Republican Lieutenant Governor, a former Baptist minister by the name of Mike Huckabee. We had little idea how he would respond, but he quickly endorsed the approach saying, “who better than individuals with their families to decide what supports are needed?” Governor Huckabee then wrote a letter to that state’s 14,000 home care recipients telling them of this new participant-directed option (also called consumer- or self-direction). Later, when he was Chair of the National Governor’s Association, Huckabee became the most prominent national spokesperson and champion for participant direction.

From the start, we knew that this effort must remain bipartisan if it were to succeed. Fortunately, there are aspects of the model that appeal to the philosophies of both major political parties—concern for society’s have-nots (a core Democratic value) and a market-based social innovation (a core Republican value). We believe we made the right call by committing to this bipartisan stance as, before the end of the controlled experiment, leadership in all three states and the federal government changed parties.

A funny example shows the benefit of this consensus approach. During the replication phase, when the National Program Director for Cash and Counseling testified before a joint session of the Kentucky legislature’s Human Services Committee, which was considering expansion of the participant direction option, a young Democratic Senator rose to praise the program. He was followed by an elderly Republican Senator who began his remarks by addressing his younger colleague saying, “Son, this is the first thing we agreed on, other than the fact you’re new.”

Another critical decision was to involve CMS (the Centers for Medicare and Medicaid Services), which at that time was called the Health Care Financing Administration in all of the planning, site selection, and evaluation design. For nearly ten years, representatives from CMS joined staff from the Department of Health and Human Services (DHHS) Office of the Assistant Secretary for Planning and Evaluation (cofunder of the Cash and Counseling evaluation), the RWJF, the National Program Office, and Mathematica Policy Research (the outside evaluator) in weekly meetings to coordinate the demonstration and evaluation. CMS came to see Cash and Counseling as its own, and helped write and negotiate the federal waivers and establish templates so other states could replicate this budget authority option.

During

Large-scale controlled social experiments take a long time. In our case, the states were selected in 1996. Arkansas got underway in December 1998, New Jersey in November 1999, and Florida in June 2000. Data collection was complete by the summer of 2003. So how do you keep a policy-relevant experiment in the public eye? The management team decided to develop and release issue briefs, reporting only on the treatment group, as interesting patterns emerged, and it became clear that participants were very satisfied with this new option.

Since Arkansas got underway well ahead of the other states, we published its results as soon as they were available. We then moved on and published results from children with developmental disabilities in Florida as the recruitment of children took very little time and this was a new policy audience. We made a conscious decision not to delay the release of findings for inclusion in a final report, but instead to publish state-specific results as soon as they became available. A steady drumbeat of communication was a key to engaging people whose support we would need to take this idea “national.”

Throughout the demonstration, we worked with and through the RWJF. Through its CONNECT program, we updated senators and representatives on this new home care option, so they could provide relevant service to their constituents. We also were intentional about seeking media attention, landing regular media coverage in each of the three states, as well as a segment on the PBS News Hour that validated the importance of this innovation. We found that stories about real people who benefited from this option were often more captivating and influential than statistics alone in capturing the attention of policymakers and potential beneficiaries in the public.

One of the most important achievements, during the replication phase, was the fostering of a National Participant Network to advocate for participant direction at the state and national levels and to inform the work of the National Program Office. Interested participants were offered the opportunity to join the National Program Office as liaisons, and in this role, support the development of the National Participant Network. There were two goals: (a) ensure that the NPO’s own work was appropriately informed by those we sought to empower and (b) form a national network of Cash and Counseling participants who could play a meaningful role in the design, implementation, and evaluation of participant direction programs while advocating for their growth and preservation. Following its creation in 2007, the National Participant Network grew to over 2,000 members in 30 states and incorporated as an independent nonprofit corporation.

A number of specialized research projects, primarily funded by DHHS (ASPE and the Administration on Aging), were initiated to improve the administrative infrastructure
needed to effectively and efficiently implement self-directed services options and to ward off political threats to self-direction. These efforts focused on improving financial management services and related information technologies, preventing fraud and abuse, addressing liability concerns, enabling access to affordable workers’ compensation, and making the case for allowing family members to become paid caregivers.

After

As mentioned above, rather than release results through one large formal report and a national conference, we relied on a multipronged approach that included:

1. Long and short brochures summarizing research results, participants’ experiences, and state policymakers’ testimonials, written for and distributed to federal and state policymakers and national membership organizations.
2. A special issue of *Health Services Research* in 2007 capturing the research results for the academic community.
3. *Developing and Implementing Self-Direction Programs and Policies: A Handbook* was commissioned to aid future state program implementers. In many cases, states did not receive grant funding to launch Cash and Counseling programs and had very limited budgets for hiring consultants. However, they were able to develop their own self-directed services programs with little or no help from the National Resource Center for Participant-Directed Services (NRCPSD) other than making extensive use of the “how to” handbook available on the Center’s website.
4. A strategy of getting the word out by working with and through national membership and advocacy organizations such as the Alzheimer’s Association and the National Council for Independent Living.

In 2005, in the midst of these and other outreach activities, deliberations on the Budget Reduction Act offered an opportunity for more progress. The challenge was how to raise the issue before Congress without crossing the line into lobbying. The National Program Director traveled to Clark College in Dubuque, Iowa, to serve on a long-term care panel with Senator Charles Grassley, who chaired the Senate Finance Committee. This led to an invitation to meet with Senate Finance Committee staff from both political parties to discuss potential expansion of the Cash and Counseling option. In turn, at the initiative of the policymakers themselves, these educational meetings led to the inclusion of a provision (1915(j)) allowing all states to offer the budget authority option under their Medicaid state plans.

During this same period, the DHHS Office of the Assistant Secretary for Legislation facilitated a meeting between ASPE staff and staff at the House Energy and Commerce Subcommittee on Health, which resulted in a hearing on the results of the Cash and Counseling Demonstration and Evaluation. Similar discussions, and the advocacy of the Assistant Secretary for Aging (Josefin Carbonell), informed the 2006 Reauthorization of the Older Americans Act (OAA), providing impetus for states to offer the participant direction option with their OAA funds.

Also in 2005, CMS revised its process of applying for, amending, and renewing 1915(c) home and community-based care waivers, which included an online application process. This was a massive undertaking and took place just as the RWJF replication grants were getting into full swing. CMS sought to establish a standardized process and used this opportunity to weave questions on participant direction into the woof of the new waiver template so every state needed to address this issue. Because of the timing of the implementation of the new uniform process, the Cash and Counseling replication states were the testers that helped CMS debug the new system. This resulted in much faster, streamlined approval of self-directed services options within home and community-based services (HCBS) waivers.

The next major impetus for growing participant direction and building the nationwide infrastructure needed for its expansion came from the Veterans Health Administration (VHA), in partnership with DHHS (the Administration on Aging, now Administration for Community Living and regional aging and disability network agencies). Veteran-directed home and community-based services is a participant-directed, employer and budget authority program, designed to provide home-based care for veterans who might otherwise have no option other than nursing home care. Through August 2015, the program had grown to cover 58 (out of 153) Veterans Affairs Medical Centers in 33 states, Puerto Rico, and the District of Columbia. It is currently serving nearly 2,000 veterans and has served close to 4,000 veterans over the life of the program.

The VHA has plans for VC-HCBS to be available to all eligible veterans by the end of 2017. These plans were supported when Congress passed, and President Obama signed, the Consolidated and Further Continuing Appropriations Act of 2015, which identified the veteran-directed program as a central part of the VA’s initiative to expand home and community-based care options.

Finally, the Affordable Care Act (ACA) included additional opportunities to further expand participant direction. The CLASS program would have offered a major opportunity to advance participant-managed allowances as it was based on a cash benefit. Unfortunately, DHHS found that certain legislatively mandated features of the program made it impossible for the Secretary of Health and Human Services (HHS) to guarantee, as the law also required, that the CLASS program would be actuarially sound for 75 years. Nevertheless, major opportunities remain, particularly in Medicaid Community First Choice (Section 1915(k)) with its 6% point increased Medicaid...
match as well as improvements to Section 1915(i) with potential to serve clients in the behavioral health arena. Both included—and Community First Choice (CFC) strongly emphasized—self-directed service delivery modes. As of June 2016, eight states have adopted the CFC benefit: California, Connecticut, Maryland, Montana, New York, Oregon, Texas, and Washington. Four of these states participated in the Balancing Incentive Program and used this grant program’s temporary enhanced federal financial participation to launch their CFC programs.

The ACA also extended the Money Follows the Person (MFP) grant program. This program provided enhanced federal financial participation for states to transition nursing home residents back to community living. Some states have used the self-directed authority included in MFP to allow individuals transitioning from nursing homes to control Cash and Counseling—style budgets. The goal is to support the individual’s freedom to decide upon and purchase the kinds of goods and services Medicaid would not normally pay for, which they need to move into community housing (items such as beds, mattresses, and kitchen equipment). Finally, under Section 2402(a) of ACA, the Secretary of HSS has promulgated guidance on person-centered planning and participant direction, which applies across all the programs and populations for which the federal DHHS is responsible. Lessons from the Cash and Counseling Demonstration and Evaluation and subsequent work informed this emphasis on person-centered services.

**Tracking the Long-Term Systemic Impact of Self-Directed Services**

The widespread publicity and praise for the Cash and Counseling Demonstration and Evaluation afforded unusual prestige to a controlled experimental design. This rigorous design, along with an ethnographic study resulting in case team stories describing how the program worked for real people, led to in-depth understanding of the program’s impact. These positive findings encouraged states to introduce new or expand already existing opportunities for self-direction. In many cases, however, these only permitted program participants to hire/fire and supervise individual aides of their choosing rather than control a Cash and Counseling—style budget that they could also use to purchase other disability-related goods and services.

A major federal policy goal, shared by most states, has been the “rebalancing” of state long-term services and supports (LTSS) systems away from reliance on institutional care toward HCBS. Doing so is necessary according to the Supreme Court’s 1999 *Olmstead* ruling that all Americans in need of publicly funded LTSS should have the option to receive them in home- and community-based settings if receiving care in an institutional setting is not medically necessary. In both 2006 and 2009, analyses of Medicaid Analytic Extract claims files (Borck, Peebles, Miller, & Schmitz, 2009; Wenzlow, Borck, Miller, Dory, & Drabek, 2006) found statistically significant correlations between the availability of consumer direction and higher levels of state Medicaid LTSS spending on HCBS for the elderly and younger disabled people aged 18–64 with adult-onset disabilities.

Before concluding, we would like to mention two additional areas, where research and education are intersecting to affect future policy and programs. The first deals with benchmarks and data, whereas the second focuses on the training of future professionals.

**Benchmarks and Data**

Every three years, the National Resource Center on Patient-Directed Services assembles a national inventory of the number of people self-directing and the characteristics of the programs that offer this option. The results of the inventory research are used for AARP’s Participant Direction Domain for the State Long-Term Services and Supports (LTSS) Scorecard (http://www.longtermscorecard.org/). One of the problems identified in the 2013 survey was the number of states that had switched to have managed care entities administer their long-term services. These states could no longer tell us how many people were self-directing. Whereas, previously, this information had been publicly available from states at no charge, the NRCPDS was now being told we would have to pay for it, with the final cost unclear and no guarantee of timely availability. This led the NRCPDS to make strong recommendations regarding data collection—recommendations that CMS heeded when creating the new Transformed Medicaid Statistical Information System. As a result, in the future, individual-level data on participant direction will be available no matter which Medicaid funding authority is being utilized. Without such data collection systems that flag participants in self-direction, we would not know whether self-direction is growing, declining, or staying the same and quality improvement would be impossible.

**Training for Future**

During the original Cash and Counseling Demonstration, it became evident that the switch from a medical model, where the professional knew best, to an empowerment model was a major paradigm shift requiring new knowledge, skills, and values. The Partnerships for Person-Centered and Participant-Directed LTSS Project (Partnerships Project), funded by the New York Community Trust, is a collaborative effort of the Council on Social Work Education (prime grantee) and the NRCPDS. This 3-year project will prepare future social workers (Bachelor of Social Work and Master of Social Work students) at nine schools of social work with competencies to implement and evaluate person-centered and participant-directed long-term services within the Aging and Disability Network. This project’s goal is to infuse competencies within classroom and field curricula.
At the end of the project, all of the training materials will be made available on the websites of the National Resource Center and the Council on Social Work Education for any social work program or Aging and Disability Network provider to access. These materials can also be adapted for other professions and used for interdisciplinary trainings.

**Conclusion**

As of 2013 (National Resource Center for Participant-Directed Services, 2014), there were approximately 815,000 individuals self-directing, in one form or another, in the United States—up from an estimated 486,000 individuals in 2002 (Doty & Flanagan, 2002). Every state now has at least one program in which participants can employ their own workers, and 44 states have options that allow participants to manage their own budget, along the lines of the original Cash and Counseling. There are about 250 separate programs, the majority of which are of modest size.

States such as Massachusetts have enacted legislation stipulating that all people with developmental disabilities be offered a self-directed budget option each time they are reassessed. New experiments are testing this budget authority approach in behavioral health and employment supports, while other research is focusing on the needs of the caregivers for those self-directing.

The research findings have gone global: Australia’s new National Disability Scheme will offer flexible budgets to all at the highest level of need. It is clear that research has played a defining role in the growth of this approach, one that has brought research to the attention of policymakers and then turned that research into meaningful options for improving supports and services for people with disabilities.

**References**


