From the Bottom Up

Robert Wood Johnson Foundation

THE FOUNDATION PROMISE TELLS US to step up and tackle head-on some of the most daunting challenges to Americans' health and health care. And we do. Think huge top-down issues like strengthening our public health system, improving the quality of our care, and reversing the childhood obesity epidemic.

Yes, we are well schooled in performing on the huge national stage when we have to. But sometimes, to make a real difference in the life of a single vulnerable human being, we find our stage is as small as the simple confines of someone's home and our role as finite as improving the daily details of one person's life.

This is when we work from the bottom up, one person, one outcome at a time, gathering sufficient critical mass to provoke needed changes in the policies and bureaucracies that rule so remotely from the top. We are well schooled in this, too.

For example, a modest Robert Wood Johnson Foundation (RWJF) program called *Cash and Counseling* is turning upside down the entrenched presumption—bias, really—that the poor, the old and the disabled somehow are unable, unwilling or too dishonest to responsibly manage how public funds are to be spent on their care at home.

Nothing about this problem is new. As many as 15 million people need the help of another person with the basics of daily life, such as preparing meals, eating, bathing, dressing and toileting.

When they do get help, the quality of their lives goes up and, best of all, people get to remain right at home, where they most want to be. Over several decades the "system" needlessly directed hundreds of thousands of Medicaid recipients out of their homes and away from their families, packing them into crowded nursing homes.

Those who did manage to qualify for care at home had no say over who would help meet their daily needs, how and when those needs would be met, or even which were the most pressing needs. When consumers of care and their families complained of unmet needs, the system—hidebound, inflexible and even obstructive—couldn't or wouldn't respond.

None of this made sense to us. So in the 1990s we decided to take a serious look at what would happen if Medicaid consumers were able to decide for themselves how best to get the home care they wanted and needed in the way they preferred it.

Cash and Counseling (C&C) is the result. It rejects the old system-knows-best premise and allows Medicaid clients and their families to determine how best to use public funding to organize and pay for their own care at home.

Fortunately, we found eager partners in both the U.S. Department of Health and Human Services (HHS) and in state Medicaid programs in Arkansas, Florida and New Jersey, where we launched C&C as a four-year pilot in 1999. A lot was accomplished, and in phase two, we expanded C&C into 12 more states. Under the passionate leadership of Program Director Kevin Mahoney, *Cash and Counseling* is now an option under Medicaid for every state.

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Each state has its own C&C identity, with program names that say both what it does and what it means. In Alabama, for example, it's called Personal Choices. In Washington it's New Freedom. In Pennsylvania, Services My Way.

The design is simple and similar state to state. Consumers, backed up with family and technical support, develop their own treatment plans and budgets for care at home. They hire and manage their own caregivers, who can include family members, and pay for them with a monthly allowance from Medicaid. They can even modify their homes and vehicles and pay for transportation necessary to sustain their independence.

It wasn't easy. State bureaucrats needed convincing. Managing decision-making and communications among organizations was tricky. Holding consumers accountable for spending taxpayer dollars was essential. Evaluation was mandatory from the very beginning.

Early accomplishments were striking. Needs were measurably being met with more help and more caregiver hours. Patient health improved, with fewer falls, urinary-tract infections and bedsores. Better transportation meant better access to doctors and other health professionals.

The quality of life was better, with a 20 percent increase in the number of people who were more likely to be satisfied with their lives. Caregivers, paid and unpaid, reported they were happier and less burdened, citing lessened worries over patient safety and the quality of care.

Budget-makers also were happier, after some initial concerns. Costs at first seemed higher. Then nursing home numbers started coming in, showing that C&C was not necessarily more expensive. In Arkansas, for example, Medicaid clients' use of nursing homes dropped 18 percent three years after C&C came online.

Among health policy and health care insiders, however, perhaps the greatest success came when skeptical members of Congress and federal officials turned into program champions. Persuaded by strong evidence of C&C's positive outcomes, they pushed hard for fundamental changes in Medicaid rules and regulations that now make it easier for states to offer more consumer-directed home and community-based services.

Challenges do remain. The system's failure to recognize individual needs and preferences remains deeply rooted and resistant to change. Reconfiguring even part of the Medicaid complex entails new costs of its own. And still unresolved is whether or not the IRS considers the C&C allowance taxable income.

Still, C&C is "social experimentation at its best" and "the most significant long-term-care policy experiment undertaken in more than a decade," according to health policy experts from Penn State, reporting in *Health Services Research* (HSR). They concluded that C&C is an "archetypal example" of using research to change public policy.

Of course, the strategic application of research is a signature RWJF strength. Jim Knickman, former head of Research and Evaluation at RWJF, also writing in HSR, put it this way: The C&C public-private partnership "is an illustration of how public dollars can be leveraged effectively to examine a pressing policy issue and to produce information that can be translated into better policy and practice."

Our collaboration with HHS, he continued, "allowed the federal government to invest in the development of a strong evidence base and the Foundation to support and expand a policy-oriented demonstration project that may ultimately become a pivotal strategy in most states' efforts to build stronger home and community-based service systems."

That all sounds pretty good. But perhaps a better measure is in the profound difference C&C makes in the lives of real people.

Take Josie Dickey of Fort Smith, Ark., for example. Josie, in her 80s, had no choice but to move into a nursing home after suffering a massive stroke. But she was neglected there and contracted pneumonia. After a few weeks, her daughter, Brenda, brought Josie home. It was tough. Help came in the form of a revolving door—about 30 home health aides in the space of three years.

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Nothing seemed to work well for long. Then Brenda heard about Arkansas' Cash and Counseling, IndependentChoices. In a flash, Brenda quit her $13-an-hour job to work as her mother's caregiver, even though for less than half that pay. Josie's now healthier and more active.

"She's participating in life—and that's a great big deal," Brenda happily reports.

Back East, in Trenton, N.J., Calvin Dodson, blind, in his 50s, impaired from a car accident and regularly needing kidney dialysis, used to get a different home health worker every week and a new home-care agency every three weeks.

"I was always having to explain everything from the beginning, every time," Calvin recalled. "And those that came usually came late or left early, and never wanted to do the jobs I needed them to do."

Now enrolled in New Jersey's C&C program, Calvin only hires people he can rely on—like his sister—and has had only three different workers in six or seven years. He also spent C&C funds on a voice-activated microwave and voice-recognition software so he can shop online for groceries, clothes and other necessities.

"I tell other folks [that] it's me who is in control," says Calvin. "I know that the money is paying for what it is supposed to pay for."

In Miami, Fla., Karla Herrera, now in her early 20s, was born with microcephaly, cerebral palsy and spastic quadriplegia. Her whole life she's needed constant help and supervision.

Before enrolling in Florida's C&C program, a home health agency managed Karla's personal-assistance needs. Now, thanks to C&C resources and flexibility, she can handle many day-to-day activities on her own. Through specialized assistance, Karla can walk for the first time, reads fluently and uses a portable picture-based computer system to communicate. She recently graduated from high school and plans on attending a culinary program at a vocational school.

Karla "will always need someone to guide her," explains her mom, Yolanda. "But she has done a lot in a very short time. And we're not done yet. By next year she will be living a typical life, with assistance."

As the program takes hold, we expect more and more people to find help, hope and extended independence through this remarkable program that began when we:

- Listened to the small voices of our most at-risk, isolated and vulnerable people.
- Gave stature and standing to a small and fragmented field.
- Created a public-private alliance of partners.
- Designed a way to meet the needs of disabled and elderly Americans.
- Put the design to the test in small pieces.
- Measured, evaluated and measured again.
- Tested, perfected and replicated the model.
- Attracted support among state and federal policy-makers.
- Used change on an intimate, personal level to leverage system change.

This is a checklist of our philanthropy working exactly as it should. Behind it is a wonderful story of the power of our philanthropy to turn individual need into fulfillment, helplessness into security, and dependence into self-reliance. And we didn't need a big stage to get it done.

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