

Self- Direction in Mental Health

Choice. Recovery.
Independence.



NATIONAL RESOURCE CENTER *for*
PARTICIPANT-DIRECTED SERVICES

Rooted in principles of recovery, independence, self-sufficiency, and choice, self-direction recognizes that all people can determine and achieve their goals. Self-direction also holds that every person has basic human needs for fulfillment, as well as unique interests and preferences for living a meaningful life.



FOR MANY YEARS, people who receive disability-related support services have used self-direction to live independently in their communities. Now people with serious mental health conditions are using self-direction to transform their lives.

In self-direction, people with serious mental health conditions enrolled in publicly funded programs control a monthly budget, and, in some states, purchase goods and services to help them reach their goals for recovery and independence. People in self-direction can be creative, as long as their purchases directly support the goals they have identified in the life plans they develop for themselves. For example, they may choose to put some of their funds toward continuing their education, securing stable housing, or joining a gym.

People who self-direct say it is inspiring. “Self-Directed Care was truly recovery,” says Julie, a Pennsylvania resident. “It was about receiving care that encouraged, that nurtured, and that met me where I was.”

Her experience is in line with evidence, both from the United States and abroad, showing that self-direction

in mental health works—and at a cost similar to or lower than that of traditional service programs.

Fundamentally, self-direction recognizes that effective supports are not one-size-fits-all. Every person’s journey of recovery is unique. That journey does not necessarily require a large amount of money. A little bit can go a long way—but flexibility in how to use funds is important.

Having choice and control makes a big difference in people’s lives. In England’s self-direction pilots, evaluators found that people who had more choice and control over a personal budget also had better outcomes and lower inpatient and outpatient service costs. In particular, quality-of-life outcomes were better in program models that gave participants greater flexibility in what they could purchase and promoted their informed, active engagement.¹

Fundamentally, self-direction recognizes that effective supports are not one-size-fits-all. Every person’s journey of recovery is unique.

¹ Forder J, Jones K, Glendinning C, Caiels J, Welch E. Evaluation of the Personal Health Budget Pilot Programme. Department of Health, 2012.



Self-direction took root as a way for people to live more independently.

The best-known form of self-direction, Cash & Counseling, demonstrated the effectiveness of self-direction for Medicaid enrollees who managed a monthly budget based on what Medicaid would have paid a home care agency to assist them with personal assistance services, like bathing, dressing, and getting out of bed. The results of this large, controlled experiment were overwhelmingly positive. People who self-directed had fewer unmet needs, the same or better health outcomes, and higher satisfaction with their everyday lives than people who did not.

Later, with funding from the federal Substance Abuse and Mental Health Services Administration (SAMHSA) and the Retirement Research Foundation, researchers found that more than 20 percent of Cash & Counseling participants also needed mental health services. Those participants had markedly better outcomes across a range of health measures, compared to people in a control group who received similar mental health services but did not manage a budget.^{2,3} This finding provided the first clue that self-direction might have transformative potential for the publicly funded mental health sector.

Because of Cash & Counseling, many states today have substantial experience with self-directed models, but publicly funded mental health systems have relatively little experience with these models. Several states have

experimented with self-direction in mental health on a small scale as pilots or demonstration projects.

A large-scale project examining implementation issues and outcomes may support the spread of self-direction in mental health. Funded by the Robert Wood Johnson Foundation (RWJF) and the New York State Health Foundation, with support from SAMHSA, the Demonstration of Self-Direction in Behavioral Health is exploring the impacts of mental health self-direction in several states.

Currently, Florida, Michigan, New York, Pennsylvania, Texas, and Utah are part of the project's Learning Collaborative. These states all exercised considerable flexibility in designing and operationalizing self-direction. For three years, they have worked together, sharing experiences, tackling common concerns, receiving technical assistance in the areas they requested, and capturing their varied approaches for making self-direction real. Products from this project will include a report that describes best practices and lessons learned. The report will also detail how states have adapted and implemented self-direction.

The National Resource Center for Participant-Directed Services (NRCPSD) at Boston College serves as the National Program Office and is partnering with the Human Services Research Institute (HSRI) on this effort.

² Shen C, Smyer M, Mahoney KJ, Loughlin DM, Simon-Rusinowitz L, Mahoney EK. Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling program. *The Gerontologist*. 48(1): 939-104.

³ Shen C, Smyer MA, Mahoney KJ, Simon-Rusinowitz L, Shinogle J, Norstrand J, Mahoney EK, Schauer C, Delvecchio P. Consumer-directed care for beneficiaries with mental illness: Lessons from the New Jersey Cash and Counseling Program. *Psychiatric Services*. 59(11): 1299-1306.

THE FUNDAMENTALS OF SELF-DIRECTION

Every state has flexibility to design and implement self-direction in alignment with its own culture, values, and needs. Self-direction is based on the concept of “nothing about us without us.” People with lived experience of mental health recovery must be meaningfully represented at all levels, including leadership and oversight. Self-direction approaches generally share the following basic elements:

PERSON-CENTERED PLANNING is the foundation, drawing on the individual’s strengths, capabilities, and potential, along with the assets available in the community. Each person develops a life plan with concrete goals reflecting his or her priorities for quality of life and independence. These goals may address issues related to health and well-being, social connectedness, education, employment, and other priorities. The life plan integrates supports for everyday needs like housing, employment, and physical and behavioral health services with self-directed funding to achieve the goals outlined in the plan.

BUDGETING is highly flexible and intended to reflect individual choice and preferences. Individual budgets typically are determined based on the value of publicly funded services the person otherwise would have received. Participants have an array of options for spending their funds on goods and services that support their independence, in accordance with their life plans; these options vary depending on the state. By controlling their budgets, participants do not lose access to medications or emergency services.

SUPPORT BROKERS, sometimes called recovery coaches or life coaches, work closely with program participants to develop, implement, monitor, and adapt their life plans as their circumstances change. Some programs employ peers—people with lived experience of mental health recovery who have received training in mental health support—as support brokers.

MONITORING AND SUPPORTIVE QUALITY MANAGEMENT are ongoing. Every state has mechanisms for regularly monitoring service use and expenditures. Participants can change services as needed within the constraints of their budgets, in consultation with their support brokers. Misuse of funds has been rare.

FINANCIAL MANAGEMENT SERVICES are available to help program participants with responsibilities such as writing checks, preparing tax returns, and tracking budgets.

Despite having these elements, mental health self-direction efforts are developing differently than those used in other delivery systems. People in mental health self-direction tend to use their budgets differently than those with other conditions, perhaps reflecting their different preferences and needs, and differences in the delivery systems themselves.

USING DATA TO CREATE INDIVIDUAL BUDGETS

Texas has successfully used encounter claims data to identify Medicaid beneficiaries who use outpatient mental health services and to help determine expenditure levels for program design purposes.



Wesley

ACHIEVING INDEPENDENCE THROUGH SELF-DIRECTED CARE

Wesley's journey of recovery has taken him from hopelessness to a place he never dreamed possible: making recovery possible for thousands of people like him, as the statewide coordinator of integration and recovery services for the Florida Department of Children and Families' Office of Substance Abuse and Mental Health.

Florida's Self-Directed Care program helped him get there.

It started with his first recovery coach, who came to Wesley's home to meet him. They talked for hours. She wanted to know what mattered most to him and what he wanted to do with his life moving forward.

"She empowered me," Wesley says. "She used language I'd never heard before. 'I can.' 'You will.' She encouraged me to try new things I'd never thought were possible."

With his coach's support, Wesley developed a life plan. From day 1, Wesley's goal was to secure full-time employment and become financially independent.

It took time to reach that goal. Wesley needed to learn how to manage stress and he needed to build his confidence.

His coach showed him how to use his monthly budget so that he could get massage therapy to reduce his stress, buy clothes for work, and even furnish his apartment. The monthly budget also helped him pay to see the mental health professional of his choice.

While working part-time providing counseling and running support groups for other people with mental health conditions, Wesley used his Self-Directed Care funds to pay for training to become a certified peer recovery specialist. After completing that training and getting his certification, he obtained a full-time job.

"When I finally found myself working full-time, I received benefits and insurance that I'd never had before, and all of that on my own," he says. "I was making enough to sustain myself. I had achieved it."

Wesley says that the acceptance and support he received from Self-Directed Care empowered him to create a life that he never imagined.

"I found a passion and a purpose," he says. "That was a large part—and is still a large part—of my recovery."



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WESLEY

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**The Self-
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my shell.**



Susan

LIVING 'REAL LIFE' IN RECOVERY

At 69, Susan can say she's who she always hoped she would be: confident, fulfilled, connected with caring people, and looking forward to each new day.

It was a tough road, made tougher by substance use problems and a serious mental health condition. But Florida's Self-Directed Care helped Susan get where she is now.

"The Self-Directed Care program helped me come out of my shell," she says.

For the first time in her life, Susan felt surrounded by people who accepted and supported her. She developed a wonderful relationship with her recovery coach. "With her I've had a real friend," Susan says of her coach.

Six months into the program, Susan decided to run for the Self-Directed Care Board. She's now the vice chair, and is involved with various community organizations, in addition to advocating for Self-Directed Care, including meeting with legislators to talk about the program.

When Susan developed her first life action plan with her coach, her two primary goals were to stay positive and to enjoy her retirement.

Those goals changed along the way, as Susan immersed herself in the program's benefits.

Through Self-Directed Care, Susan moved out of the shelter where she'd been living. She used her monthly budget to purchase a computer, a bed, and a washing machine.

She went back to school, and developed hobbies like ballroom dancing, piano, and sculpture.

She also discovered she wasn't ready to retire—far from it. "I'm at the point where I want to get my certification as an addiction professional." She is working on a Master's degree in counseling, with the goal of becoming a licensed mental health therapist specializing in addiction.

All her life, Susan says, she felt confused and anxious, afraid that people wouldn't like or accept her. Now her life couldn't be more different.

"Every day keeps getting better and better," she says—and she attributes that to Self-Directed Care.

The real key, she says, was regaining her self-esteem, which she lost at a young age. That has made all the difference.

"I finally know what normal is, and I think I'm living as normal a life as I can," she laughs. "It's just wonderful, living real life. Real life isn't scary anymore."



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SUSAN





WHAT'S DIFFERENT ABOUT SELF-DIRECTION IN MENTAL HEALTH?

BUDGET PURCHASES

In mental health self-direction, people often use their budgets to advance their education, build a supportive social community, secure independent housing, obtain employment, and choose their mental health service providers. People can think creatively about what they can purchase to meet the needs they've identified as most important to them.

For instance, in a recent study of Florida Self-Directed Care, many self-direction participants used their monthly budgets to first meet their basic material needs, including dental and vision care and short-term housing assistance. With those basic needs taken care of, they were better positioned to focus on setting and achieving personal recovery goals.⁴

Research from Pennsylvania's self-directed care program shows that participants have applied their budget in a range of ways not traditionally available through Medicaid to support their mental health—from managing their diets and improving physical fitness to volunteering in the community. Program participants “have extremely diverse interests and needs that mental health services can never fully address,” researchers for the program wrote, adding that people frequently also have “diverse and unique ideas as to how to best address those needs.”⁵

FINANCING SELF-DIRECTION IN MENTAL HEALTH

There is no single source of funding for mental health self-direction; rather, multiple sources typically are combined or “braided” to provide funding. Potential funding sources for self-direction include:

- ▶ Medicaid, via waivers or state plan amendments
- ▶ Other federal sources, such as the SAMHSA block grant
- ▶ Local and state funding options, such as state general revenue

In addition, managed care is becoming increasingly important in Medicaid mental health self-direction.

⁴ Croft B, Parish S. Participants' assessment of the impact of behavioral health self-direction on recovery. *Community Mental Health Journal*. 52(7): 781-92.

⁵ Sneathen G, Bilger A, Maula EC, Salzer MS. Exploring personal medicine as part of self-directed care: expanding perspectives on medical necessity. *Psychiatric Services*. 67(8): 883-9.

PEER COUNSELORS AND THE VALUE OF 'LIVED EXPERIENCE'

Many self-direction programs train and employ people with personal or lived experience in mental health recovery to work as peer support brokers. These peer support brokers, sometimes referred to as peer coaches or counselors, frequently forge powerful relationships with participants, who, perhaps for the first time, have someone in their lives who both understands where they are coming from and respects and encourages their independence. The relationship between program participants and their coaches is critical to self-direction. Coaches not only help program participants administer their budgets in accordance with their life action plans—they also act as an “emotional safety net.” Because recovery is

typically a process with ups and downs, this emotional support is important to participants.

Some participants decide to pursue peer counseling certification themselves as part of their recovery plans, putting their “lived experience” to work so that they can help others. Those who do frequently say that it is very gratifying for them. After becoming a certified peer recovery specialist with support from Florida’s Self-Directed Care program, Wesley found his passion—a passion that led to a job as statewide coordinator of integration and recovery services for the Department of Children and Families’ Office of Substance Abuse and Mental Health.

SELF-DIRECTION AND RECOVERY

As a process, self-direction means people setting meaningful goals for themselves and accessing the resources they need to achieve those goals. People who previously had little hope in their lives come to realize, step by step, that they in fact are the solution. “I think of recovery as a puzzle,” says Wesley, a Florida resident. “And it’s empowering to think that we get to choose the pieces that go into that puzzle.”

Research shows that, when given the opportunity, people with serious mental health conditions are quite capable of identifying non-traditional goods and services that support their well-being and independence.

THE NEED FOR CULTURE CHANGE

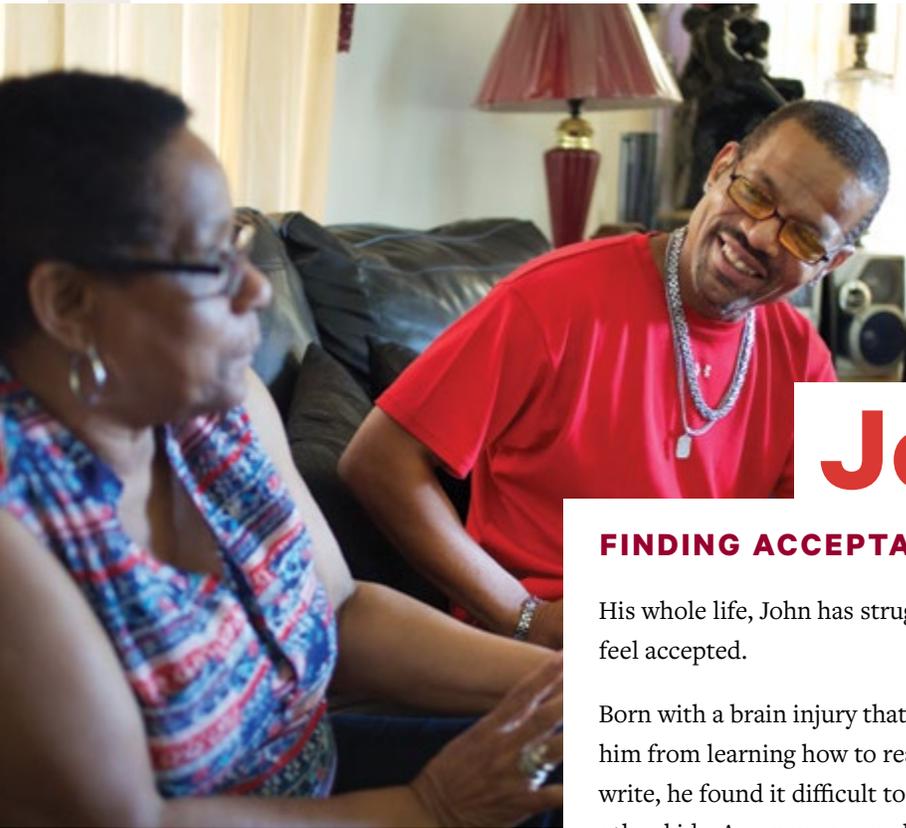
A fundamental premise of self-direction holds that all people are capable of making—and have the right to make—choices about the services and supports they want to receive. The model is designed to offer and provide support to program participants as part of the self-direction process.

However, some policymakers, providers, and family members are skeptical that people with serious mental health conditions are capable of self-direction. The perception that people cannot make responsible decisions for themselves is a key barrier not only to self-direction, but to the rights of individuals to pursue meaningful, independent lives in the community.

But the research to date and the experiences of people who self-direct demonstrate that this perception does not need to be true—and, to some extent, may be unfounded. Research shows that, when given the opportunity, people with serious mental health conditions are quite capable of identifying non-traditional goods and services that support their well-being and independence. The breadth of people’s choices using self-direction—from support for housing, education, employment, transportation, and social connections to traditional counseling and medication management services—reflects the diversity of their aspirations and needs.

What they’re asking for—and what self-directed models provide—is truly individualized support.

At its heart, self-direction means shifting the balance of power from professionals to people who want to assume more personal responsibility for their lives. It means reforming the system so that dollars follow people and are spent accountably, according to their preferences and needs. And it means accepting that all people have the capacity to manage their lives, including learning from their mistakes and changing gears if something isn’t working.



John

FINDING ACCEPTANCE THROUGH SELF-DIRECTION

His whole life, John has struggled to feel accepted.

Born with a brain injury that prevented him from learning how to read and write, he found it difficult to fit in with other kids. As a young man, his longing for acceptance led him to use drugs. He wound up spending eight years in jail, where he was diagnosed with a serious mental health condition.

But even after quitting drugs, John still didn't know how to deal with himself. He still didn't feel accepted by others because he hadn't learned how to accept himself.

Now, after four years of participating in Pennsylvania's Self-Directed Care program, that's changing. For the first time, John feels part of a community of people who genuinely care about him.

And he feels better about himself.

With his recovery coach, John developed a life plan. Goal Number One, he says, "is for John staying well." He uses his monthly Freedom Funds budget to support that goal.

For example, John needed to earn a living to support his independence.

Freedom Funds helped him buy a car so that he can get to work. He also purchased a laptop computer and a software program to help him address his reading problems. About a year ago, he joined an adult literacy class. Through Self-Directed Care, John also began taking mental health peer counseling certification courses, and he now has eight certifications.

Advocacy is John's real passion. He travels to the state Capitol in Harrisburg three or four times a year to talk with lawmakers about mental health issues. At home, he attends regular group meetings, where he provides advice and encouragement to other people making recovery journeys.

Although he feels optimistic about the future, he prefers to focus on the present.

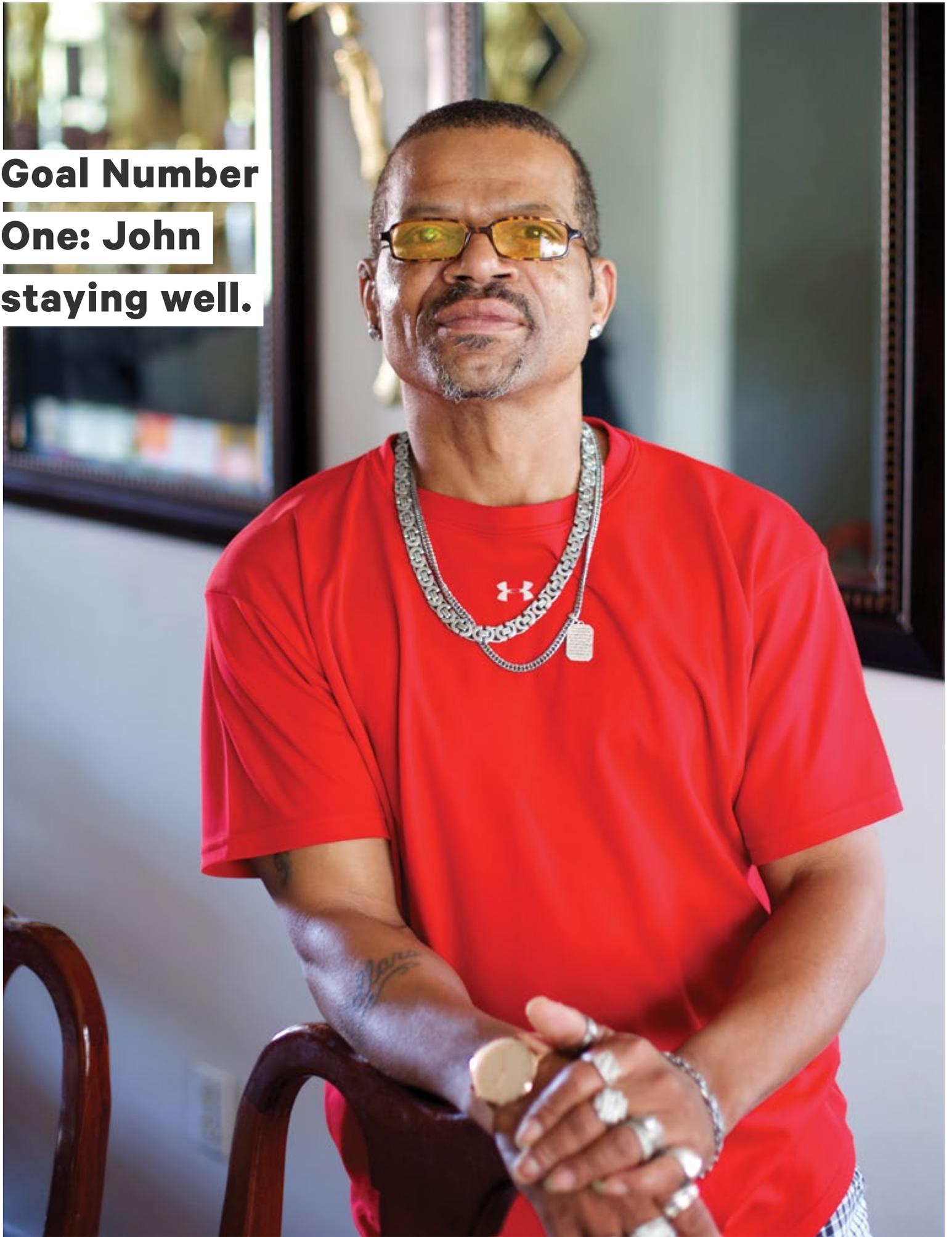
"In the 55 years I've been on this planet, this is the best that I've felt, being in this program," John says of Self-Directed Care. "It's given me what I've been looking for all my life: a way and a means of feeling accepted, feeling like I could be me. And when I feel that, I can excel."



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JOHN

**Goal Number
One: John
staying well.**





THE FUTURE OF MENTAL HEALTH SELF-DIRECTION

For many people, the current publicly funded mental health system is not working. Meanwhile, a growing body of evidence^{6,7} shows that self-direction can improve quality of life across a number of domains, including:

Employment and education

Meaningful relationships

Community participation

Independent, stable housing

Self-sufficiency and self-esteem

Culturally competent support

Access to health services

Evidence on the costs associated with mental health self-direction, while encouraging, is not yet conclusive. Research establishes that people use fewer traditional mental health services when they self-direct and suggests other potential cost savings to be had in the housing, disability, and health care systems.

Additional research will help more fully understand the magnitude of these savings; findings from the RWJF/SAMHSA demonstration will undoubtedly contribute to that understanding.

Most importantly, as shown in the stories presented here, people in self-direction value the freedom and choice that it represents. They say they have used self-direction to change their lives.

We encourage policymakers, program administrators, advocates, family members, and mental health service users to learn more about mental health self-direction and how it can work in their state. Find out what people in your community need. Talk with self-direction program administrators in other states, as well as with regional and national offices of SAMHSA and the Centers for Medicare and Medicaid Services regarding funding options.

And stay tuned for research findings from the Demonstration of Self-Direction in Behavioral Health by visiting www.participantdirection.org.

6 Webber M, Treacy S, Carr S, Clark M, Parker G. The effectiveness of personal budgets for people with mental health problems: a systematic review. *Journal of Mental Health*. 23(3): 146-155.

7 Croft B, Simon-Rusinowitz L, Loughlin D, Mahoney K. An environmental scan of self-direction in behavioral health: A summary of major findings. National Resource Center for Participant-Directed Services. <http://www.appliedselfdirection.com/resources/environmental-scan-self-direction-behavioral-health-summary-major-findings>.

MOVING FORWARD WITH SELF-DIRECTION

When Julie opened the letter from her insurance company asking if she would like to be part of a new program in Pennsylvania called Self-Directed Care, she had no idea it would change her life.

She said yes, and her journey of recovery took a powerful—and positive—turn.

“Self-Directed Care was truly recovery,” Julie says. “It was about receiving care that encouraged, that nurtured, that met me where I was.”

Julie’s Self-Directed Care recovery coach worked with her to develop a life plan with goals to support her recovery—goals that included improving her health, developing her interests, and advancing her education.

With her monthly Self-Directed Care budget, Julie decided how she wanted to achieve those goals.

“I grew by leaps and bounds,” she recalls.

To develop better eating habits, Julie stocked up on meats and fresh produce—healthy foods that she hadn’t been able to afford for a long time.

Julie also wanted to explore her interests. She bought a camera and became skilled at photographing flowers. She visited the Baltimore aquarium. She loves to read, and she used her budget to buy used books. She expanded her social life by starting a regular group of friends in recovery who got together to discuss books, do crafts, and watch movies.

“I also purchased a computer, which allowed me worldwide access to information, to other people, to learning and growing and becoming more than I’d ever been before,” she says.

She took training courses and workshops to get peer counseling certifications. She stepped up her advocacy on behalf of the homeless and people with mental health conditions, meeting with legislators and speaking three times at the state Capitol.

Julie hopes to someday get a job with the Mental Health Association of Southeastern Pennsylvania, where she’s currently a volunteer.

Looking back, Julie says she’s done more for herself in the nearly seven years she’s been with Self-Directed Care than during her entire life. “In a Self-Directed Care program, you can only move forward,” she says. “There’s no going back. It’s always forward.”



Julie

In a Self-Directed Care program, you can only move forward. There’s no going back. It’s always forward.”

JULIE



RESOURCES

NATIONAL RESOURCES

Applied Self Direction

WEBSITE: www.participantdirection.org

WEBSITE: www.appliedselfdirection.com

Human Services Research Institute (HSRI)

WEBSITE: www.hsri.org

EMAIL: bcroft@hsri.org

National Association of State Mental Health Program Directors (NASMHPD)

WEBSITE: www.nasmhpd.org

Substance Abuse and Mental Health Services Administration (SAMHSA)

WEBSITE: www.samhsa.gov

Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities

WEBSITE: www.tucollaborative.org

University of Illinois-Chicago(UIC) Center on Integrated Health Care & Self-Directed Recovery

WEBSITE: www.center4healthandsdc.org

TWITTER: [@UICHealthRRTC](https://twitter.com/UICHealthRRTC)

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