Introduction
Since 2017, New York State has been implementing Mental Health Self-Directed Care (SDC) using NYS Office of Mental Health (OMH) funds. It is being piloted as part of a Medicaid 1115 Waiver Demonstration, which is designed to help states test new approaches to service delivery for people on Medicaid.

What’s SDC? Self-Directed Care is about autonomy and choice. It’s based on the idea that people are experts in their lives and should determine their own recovery pathways. With Self-Directed Care, people use public funds to purchase goods and services or hire service providers. All purchases are linked to specific recovery goals set by the person with support from a specially trained advisor.

Who self-directs? To take part in the SDC pilot, people had to be eligible for Medicaid Health and Recovery Plans (HARPs). These plans are designed for people with significant behavioral health needs. The SDC pilots are taking place in two sites: New York City with Community Access, Inc. and the Hudson Valley region with Independent Living, Inc.

Timeline
2015 – The Centers for Medicare and Medicaid Services approved NYS’ request to implement HARPs and pilot SDC under its 1115 waiver demonstration.

2016 – OMH prepared for the pilot, hiring a fiscal intermediary (someone who tracks budgets and arranges for purchasing), and developed a web-based portal for tracking participant and fiscal information.

2017 – OMH finalized contracts with the two sites. Participant enrollment began.

2018–Present – The pilot takes place. OMH collects information on participant characteristics, purchases, and outcomes.

Participants
As of May 2019, there were 219 participants enrolled in SDC. Participants were:

- Between the ages of 23 and 66; average age of 45
- 50% female
- 50% white, 40% black, 18% Hispanic

Participants experienced a high level of financial need and often lacked social supports.

- 42% held a high school diploma or equivalent
- 40% lived in supportive housing and 13% had unstable housing or experienced homelessness
- 19% were employed (mostly part-time)
- Many participants reported substance use disorders, physical health problems, and histories of trauma
- On average, participants rated their quality of life as just above “fair”

Goals & Purchases
Based on level of need, 37% of participants were eligible to spend up to $8,000 per year, and 63% could spend up to $16,000 per year. Yet during this first year, participants spent only 40% of the allotted amounts. As shown below, through their purchases, participants pursued fitness and good nutrition, better living environments, more social connection, and engagement in meaningful and joyful activities:
• 195 people made at least one purchase by May 2019. Of those purchases, 61% were goods; 39% were services.
• Cell phones, transportation, clothing, and computers were common across categories.

What was hardest about implementing SDC?
Evaluators interviewed SDC program staff and OMH staff involved with the SDC program about their experiences implementing SDC. Implementers faced challenges related to differing perspectives about things like:
• Authority and role of the program sites and OMH
• How to know if someone is “ready” to self-direct
• Purchasing requirements and restrictions
• What to do when someone misuses SDC funds
• Supervision and training of SDC staff

What did we learn from these early days?
• People were more likely to purchase goods than services.
• Program planners learned how long it takes to see impacts. Effects on quality of life measures and social determinants of health were visible by 6 months; cost effects take longer to materialize and measure.
• People pursued whole health goals and purchased things not traditionally considered mental health supports.
• The state and sites learned a great deal about site selection, outreach, data needs, staffing requirements and training.
• The state began to understand how self-direction can be integrated with HARPs and Health Homes.

“I’m hoping to go back to school and [SDC funds] will help with books and clothing...hoping to get back into life.”

What’s next?
The pilot will continue through 2021. If the pilot is successful, SDC will transition from a state-funded to a Medicaid-funded program. The state will also expand the number of SDC sites to other regions in the state and involve Managed Care Organizations in the expansion effort. It will also work with MCOs to create a plan for fiscal management. An additional independent evaluation will examine these expanded pilot activities. Once that evaluation is complete, OMH will decide whether and how to make SDC a statewide program.

“Being voiceless in my own care perpetuated the idea that I was broken...Self-direction is changing that.”

Source
Content for this brief was drawn from the August 2019 NYS Behavioral Health Self-Directed Care Pilot Program Implementation Evaluation Report, written by the OMH Office of Performance Measurement and Evaluation. The project was funded by the New York State Health Foundation and is part of the Demonstration and Evaluation of Self-Direction in Behavioral Health, conducted by the Human Services Research Institute and funded by the Robert Wood Johnson Foundation. For more information, visit www.mentalhealthselfdirection.org.