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Independent Evaluation of the New York State Self-Directed Care (SDC) Pilot Program

Interim Evaluation Report

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Executive Summary

Through the New York Medicaid Redesign Team (MRT) Section 1115 Demonstration, the State of New York pursued the goal of improving access to and quality of health care for the Medicaid population through a managed care delivery system. The Demonstration included reforms specifically targeted to Medicaid beneficiaries with behavioral health (BH) needs (hereafter, Behavioral Health Demonstration). These included the creation of the Health and Recovery Plans (HARP) program and authorization of a pilot demonstration of the BH self-directed care (SDC) program funded and managed by the State. The SDC pilot program provides HARP-enrolled individuals also eligible for BH Home and Community-Based Services (HCBS) with authority to use public dollars to purchase self-directed goods and services that contribute towards meeting recovery goals. Non-treatment goods might include a bicycle to use in commuting, and services might include fees for an educational program. Participant enrollment began in January 2018, and current contracts with the two existing pilot site agencies run through June 30, 2022. The expected next phase of the pilot demonstration entails using Medicaid funding and management under the Medicaid Managed Care (MMC) system.

The SDC pilot program evaluation was designed to determine the extent to which three goals of the program were achieved during its first two years (January 1, 2018 to December 31, 2019). These goals are:

1. Implementation of a viable and effective SDC program for HARP enrolled/BH HCBS eligible individuals throughout NYS
2. Improvement in recovery, health, BH, social functioning, and satisfaction with care for SDC participants
3. Maintenance of Medicaid cost neutrality overall and reduction of BH inpatient and crisis service utilization and cost for SDC participants.

The SDC pilot program evaluation used both primary (qualitative) and secondary (quantitative) data in a mixed methods empirical investigation of the program's impacts. The evaluation examined SDC pilot program research questions related to pilot program implementation and beneficiary and system-level outcomes. Outcomes pertain to enrollment of eligible participants; access to outpatient services (primary and preventive services, BH services); utilization of acute care—namely, inpatient and emergency department (ED) services; Medicaid spending; satisfaction with care; health and wellness, social outcomes (education, employment, community tenure), quality of life, social connectedness; and a variety of qualitatively assessed outcomes.

The SDC Program

The SDC program is grounded in the belief that greater autonomy and choice will permit a better match between individuals' needs and health care and related services; as such, it aims to promote progress toward recovery goals, health, and stability in the community. The SDC pilot program enables HARP enrollees eligible for BH HCBS to use public funds, currently provided entirely by the State, to purchase individual directed goods and services. Participants' annual budgets are set at a maximum of $8,000 if they are eligible for Tier 1 HCBS (Individual Employment Support, Education Support, and Peer Services) or $16,000 if they are eligible for Tier 2 HCBS (Tier 1 services plus additional services for beneficiaries with a higher level of need). Spending decisions are made with the assistance of a support broker. The support broker works with the SDC participant to develop personal recovery goals, with the broader clinical aim of decreasing the need for other Medicaid services, promoting inclusion in the community, and increasing the participant's safety in the home environment. The support broker then assists the participant with the creation and implementation of a budget to purchase the goods and services required to meet the recovery goals. The goods and services eligible for self-direction can be other services, equipment, or supplies that address an identified need in the service plan and are not otherwise available to the beneficiary. Not all goods and services are eligible for self-direction—ineligible items include experimental treatments, room and board in an assisted living or other residential facility, and services or goods that are recreational.

Two agencies, one in NYC and one in Newburgh (a small city close to Poughkeepsie), were chosen as SDC pilot sites. The agencies are responsible for recruiting and enrolling participants and for hiring, training, and supervising support brokers. Support brokers work with a fiscal intermediary based at NYS OMH who provides training, support, and monitoring for the authorization and purchasing of goods and services. Contracts between the agencies and NYS were finalized in July 2017; the two-year SDC pilot program was launched in January 2018 with the expectation that it would serve 200 participants recruited through outreach and advertisement activities (Table ES.1).

Table ES.1. Timeline of SDC Implementation

Year	Date	Event
2014	February	SAMHSA awarded OMH a Transformation Transfer Initiative to fund the design of the SDC program for individuals with serious mental illnesses (SMI)
2015	March	New York State Health Foundation (NYSHF) provided start-up funding to OMH to conduct a preliminary evaluation of the SDC pilot program
	August	Amended Section 1115 Demonstration behavioral health reform initiatives include SDC
	September	OMH conducted preliminary activities for SDC (e.g., site selection, hiring an OMH fiscal intermediary, creating a web-based SDC portal)
2017	July	Contracts finalized with two SDC pilot site agencies
	October	Both sites began advertisement and outreach activities to recruit participants
2018	January	Start of 2-year SDC pilot
	March	Substantive pilot program enrollment begins
2019	May	219 participants enrolled (166 active)
	August	SDC Pilot Program Implementation Evaluation Report Released by OMH
2020	June	Contracts with site agencies are extended through June 30, 2022

TERMS: SAMHSA - Substance Abuse and Mental Health Services Agency

Evaluation Design

RAND conducted an independent evaluation of the SDC pilot program that adhered to the evaluation standards set forth in the Special Terms and Conditions for the Section 1115 Demonstration.[1] Designed as a mixed methods investigation, the structure of the evaluation is built around research questions and testable hypotheses that sought to determine whether the beneficiary- and system-level impacts of the SDC pilot program had been achieved. Quantitative methods were used for descriptive purposes and to assess the outcomes of the program (outcome evaluation), and qualitative methods were used to provide context for the quantitative findings and to gather administrative, provider, and SDC participant perspectives on the SDC pilot program's functioning and effectiveness (process evaluation).

The quantitative component of the evaluation drew on several administrative and clinical databases that were collected through the operation of the program. No new data were collected. The four data sources are summarized in Table ES.2. Medicaid claims data were available on all SDC participants and the larger group of eligible beneficiaries from which they were drawn. Data on care provided in state-operated facilities that were not covered by Medicaid were available from the Mental Health Automated Record System dataset maintained by the state. Data collected directly from participants through surveys and clinical assessments were available from the SDC portal and the HARP Perception of Care Survey.

Table ES.2. Sources of Data for Quantitative Analyses

Data Source	Description
Medicaid Data	Enrollment and use of Medicaid services
SDC Portal Data	Program enrollment, assessments, and activities
Mental Health Automated Record System (MHARS) Data	BH service use in state operated facilities
HARP Perception of Care Survey	Satisfaction with services

A significant limitation of the quantitative analyses, resulting from limitations in the data available for the evaluation, was the lack of a control group against which the SDC participant group could be compared to estimate effects of the program. Data on the SDC participant group was available over time from the Medicaid and MHARS datasets. These data were used to estimate interrupted time series models to test differences in utilization and cost outcomes between the pre-SDC and SDC periods among SDC participants. Other data sources were limited to the SDC group during the period that they were enrolled in the SDC program, and those analyses are useful in providing information on participants but not for assessing the impact of the program. In particular, data on outcomes related to recovery, health status, functioning, and satisfaction with care were limited to SDC participants during the period in which they were enrolled in the SDC program.

The qualitative component of the SDC pilot program evaluation consisted of interviews with key informants and participants in the pilot program, and a review of program-related policy documents. Key informants included stakeholders from the pilot site service provider organizations (e.g., support brokers, program leadership), state agencies (e.g., fiscal intermediary, agency leadership), and advocacy organizations. These interviews focused on understanding how the SDC program was being implemented, the roles of various stakeholders in operating and overseeing the program, the perceived impact of the program, challenges, and factors that might impact potential program scale-up. Interviews were also conducted with SDC participants to understand their perspectives on how the SDC program was being implemented, their satisfaction with the program, and how it has impacted their access to services/resources, progress toward goals, and their health and well-being.

Findings

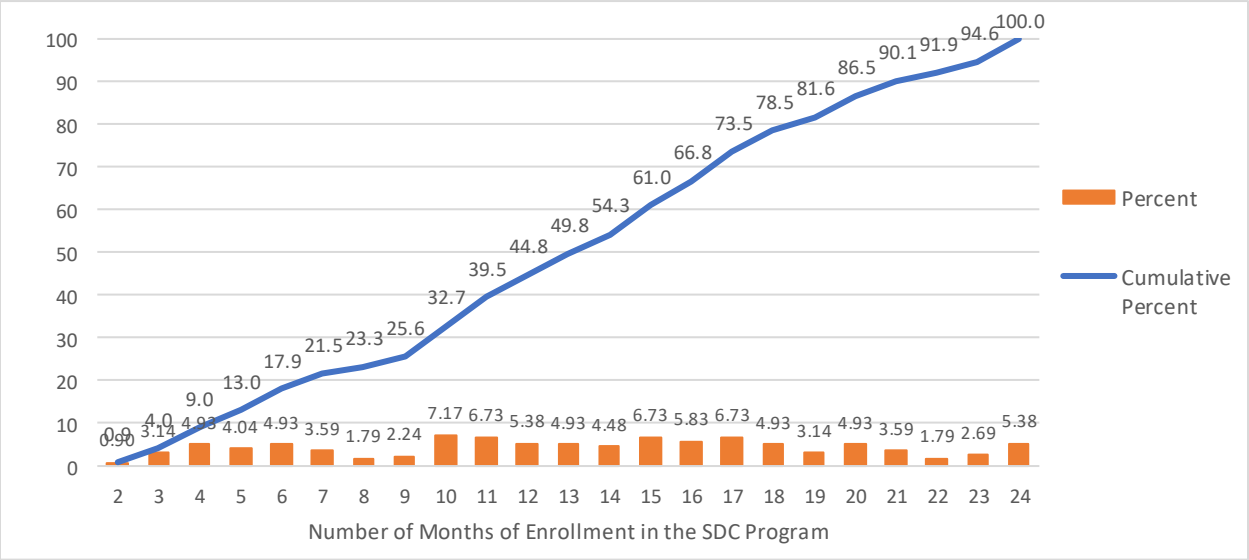
Program Participation

A total of 223 participants were enrolled in the SDC program for at least one month during the evaluation period. However, duration of enrollment varied widely because recruitment continued throughout the study period and a small number of people dropped out during the study period. Figure ES.1 shows the distribution of months of enrollment for all program participants (orange bars) and the cumulative proportion of the sample with enrollment at or

below each number of months (blue line). Total duration of enrollment ranged from 2 to 24 months. Only a small proportion, 5.38 percent, were enrolled for the entire 24-month evaluation period; about half of the participants (49.8 percent) were enrolled for 13 months or fewer. In early phases of the pilot, both SDC pilot sites engaged in recruitment activities to enroll participants in their geographic area. They focused on providing informational material (e.g., brochures) and conducting presentations to other outpatient mental health providers, at community events, and to other programs internal to their organization. As interest in SDC quickly expanded, the pilot sites conducted less active outreach, and referrals or submission of applications to the program more commonly happened through word of mouth.

Formal eligibility criteria for SDC consisted of active HARP enrollment/BH HCBS eligibility, which was confirmed by each site for potential enrollees. While sites described enrolling individuals with confirmed eligibility primarily on a first come, first served basis, stakeholder discussion regarding enrollment processes also indicated informal exploration of participant fit in some cases (see heading Participant Recruitment, Eligibility, and Enrollment for further description). Compared with Medicaid beneficiaries who were eligible for the SDC program but did not participate due to being in an area without access to a program or not enrolling in a program to which they had access, the SDC participants were younger, more likely to have a diagnosis of a serious mental illness, and less likely to use outpatient and acute care services for both physical and behavioral health care. The SDC program located outside of New York City had higher prevalence of substance use disorders than the larger population of eligible beneficiaries.

Figure ES.1. Duration of SDC Participation, Pilot Sites Combined (N=223)



SOURCE: Authors analysis of SDC enrollment data

Perceptions of the SDC Program Among Participants and Staff

SDC programs were located in agencies providing a broad range of services to people with serious mental illnesses. These programs already had a culture of valuing recovery orientation of services, and this orientation was reflected in the individuals selected to be support brokers. The support brokers and their supervisors had experience in mental health services and were committed to fulfilling the role of a support broker. They focused on individualized support for reaching self-identified goals more broadly than simply administering the financial and oversight components of the SDC program, responding to issues raised by clients that went beyond the narrow confines of the program. Support brokers took time to get to know participants individually and develop goals and plans over time.

Early in the program support brokers required regular input from OMH personnel; as norms for practices were developed, these interactions were less frequent. Issues related to approval of participant purchases arose frequently early in the program, but these issues decreased over time as brokers and participants became familiar with the program guidelines that limit expenditures to items directly related to participants' treatment plans. The frequency of incidents of misuse of funds was lower than expected. Most cases of misuse were misunderstandings. For instance, a participant may have planned to buy one pair of shoes and bought two less expensive pairs for the same total price. Brokers believed that the regulations were overly strict. SDC participants had generally very positive perceptions of the program, but they noted several ways in which it could be improved, mostly concerning transparency in decisionmaking about approvals of purchases and more regular meetings with support brokers. SDC program staff had concerns about the processes of administering the system; they highlighted challenges in using the current reporting and monitoring systems and lack of transparency in denials of approval for payment. Staff emphasized the need for a good fit between the person-centered approach of the SDC program and the culture of the agency in which the SDC program was housed.

Participants described overwhelmingly positive experiences with the process of identifying goals and using the SDC program to make purchases that contributed to achieving those goals. The SDC program was perceived as being very different from other services that participants had received, with a focus on their own personal needs and goals that was initially surprising but greatly appreciated. Participants appreciated not only the ability to make purchases that they otherwise would have been unable to do, but the entire process of working with the broker to identify their goals and implementing a plan to achieve those goals. The brokers were perceived to have a different role from traditional service providers in supporting the goals identified by participants and helping them use the SDC resources rather than simply providing direct support, counseling, or advice.

Participants also reported positive impacts of the SDC program on their quality of life, including benefits to their general physical and behavioral health and success with recovery-oriented goals. Participants reported making relatively small but meaningful material changes to

their personal space that had powerful impacts on their overall well-being. Purchases funded by the SDC were considered by the participants to have been critical to their careers, relationships with family members, and participation in fulfilling social activities. Staff were concerned that some features of the program, such as the length of tenure in the program and rules regarding misuse of SDC funds remain unclear and should be clarified for future participants. Finally, staff had concerns about some of the technical components of the program, including the debit card system and the data portal used to store participant information.

Recovery, Health, Functioning, and Satisfaction with Care Among SDC Participants

As mentioned, due to unanticipated limitations in the data, we are unable to draw conclusions regarding the impact of the SDC program on recovery, health, functioning, and satisfaction with care. We found one instance of a statistically significant difference across years: an improvement in the total quality of life scale scores. While this improvement may signal a positive impact of the program, without a control group and more robust follow-up of the SDC population, the finding should not be interpreted as a strong indication of an SDC impact. Other measures of program impact generally showed no statistically significant differences over time. It is equally important to point out that the lack of significant differences in the outcomes should not be interpreted as evidence that the program did not have an impact on these findings.

The findings reported here are valuable in identifying some important characteristics of the SDC population that will be useful in future evaluation work. The data provide baseline information on the engagement of SDC participants in employment and educational programs. The proportion of participants who were either in an educational program or completed an academic degree was surprisingly large. It may be that the participants who were selected for the program were likely to be involved in educational pursuits. In future evaluations, selection into SDC programs should be carefully examined in the design of comparison groups.

Changes In Use of Services and Costs of Care

Contrary to the expectation that outpatient behavioral health and primary care utilization would increase, our analyses showed that relative to the pre-period, post-period utilization of outpatient behavioral health and non-behavioral health services was in fact lower (or unchanged, in the case of receipt of primary and/or preventive care). We note, however, that these hypotheses contemplated a longer follow up. On the other hand, our analyses provide partial support for the State's hypothesis that SDC participation would result in decreased behavioral health inpatient and emergency department utilization: while the probability of that utilization and other forms of acute care utilization (including crisis respite HCBS) all experienced pre-post declines, intensity of outpatient behavioral health utilization did not decline. Although the State's hypotheses regarding costs of outpatient and acute-care services were not supported by our findings (i.e., the former did not increase and the latter did not decline), our analyses do provide

support for the State's hypothesis that SDC participants' overall Medicaid spending would not change between baseline and follow up.

Conclusions and Recommendations

The goal of the SDC pilot was to implement a program in which participants work with their representative to control a range of services and supports provided by the Medicaid program. Our interviews with staff and participants at the two sites and OMH staff involved in administering the program for the state showed clearly that the program was successfully implemented largely as intended. Due to unexpected data limitations, the evaluation was unable to examine the impacts of the SDC pilot program on recovery-oriented outcomes or service utilization and costs. However, the qualitative information about perceptions of the program and the analyses of utilization and costs provide a basis for recommendations for the issues to be considered as the state considers whether to scale-up the SDC program and, if so, how the scale up should be done. Based on the findings, the evaluation team suggests the following recommendations:

- Improve data collection for program monitoring and evaluation
- Develop assessment instruments to capture features that participants value about SDC
- Assess fit between agency culture and SDC program goals in identifying new sites
- Review and update SDC program rules related to:
    - Caseload size
    - Consequences of minor misuse of funds
    - Varying levels of support across participants
    - Decisionmaking processes for external review of purchase requests
- Address limitations of current card system used to make purchases
- Upgrade the SDC portal to expand functionality.

The SDC pilot program was well received by both participants and staff at the program level and within the New York State Office of Mental Health. Some of the adverse outcomes that were feared, such as misuse of funds by participants, turned out to be rare events of minor significance to the program according to both participants and staff. Some participants attributed dramatic improvements in their quality of life to the program. Unfortunately, data were not available to conduct a rigorous controlled examination of the impact of the program on many of the outcomes with which the state was concerned. Despite data limitations, the strength of the qualitative data suggests several areas for program improvement that should be considered should the state decide to scale up program implementation in the future.

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Abbreviations

ACA	Affordable Care Act
ANOVA	Analysis of variance
BH	Behavioral health
CAHPS	Consumer Assessment of Health Providers and Systems
CCDE	Cash and Counseling Demonstration and Evaluation
CMH	Community Mental Health
CMS	Centers for Medicare & Medicaid Services
CRG	Clinical Risk Groups
DOH	Department of Health
DSRIP	Delivery System Reform Incentive Payment
ED	Emergency Department
EDC	Episode Diagnostic Categories
FFS	Fee for Service
HARP	Health and Recovery Plans
HCBS	Home and Community-Based Services
HEDIS	Healthcare Effectiveness Data and Information Set
HH	Health Home
IP	In Patient
ITS	Interrupted Time Series
MCO	Managed Care Organizations
MHARS	Mental Health Automated Record System
MMC	Medicaid Managed Care
MRT	Medicaid Redesign Team
NYC	New York City
NYS	New York State
NYSHF	New York State Health Foundation

OASAS	Office of Addiction Services and Supports
OMH	Office of Mental Health
OUD	Opioid Use Disorders
PCS	Perception of Care Survey
PMPM/Y	Per Member per Month/Year
POP	Performance Opportunity Project
PPC	Provider Preventable Conditions
PPS	Performing Provider System
PROS	Personalized Recovery Oriented Services
ROS	Rest of the State
SAMHSA	Substance Abuse and Mental Health Services Agency
SDC	Self-Directed Care
SMI	Serious Mental Illness
SNP	Special Needs Plans
SSI	Supplemental Security Income
SUD	Substance Use Disorder
VBP	Value-Based Payment

1. Introduction

1.1 Overview of the Self-Directed Care Pilot

Through the New York Medicaid Redesign Team (MRT) Section 1115 Demonstration, the State of New York pursued the goal of improving access to and quality of health care for the Medicaid population through a managed care delivery system. The Demonstration included reforms specifically targeted to Medicaid beneficiaries with behavioral health (BH) needs (hereafter, Behavioral Health Demonstration). These included the creation of the Health and Recovery Plans (HARP) program and authorization of a pilot demonstration of the BH self-directed care (SDC) program funded and managed by the State. The SDC pilot program provides HARP-enrolled individuals also eligible for BH Home and Community-Based Services (HCBS) with authority to use public dollars to purchase self-directed goods and services. Participant enrollment began in January 2018, and current contracts with the two existing pilot site agencies run through June 30, 2022. The expected next phase of the pilot demonstration entails using Medicaid funding and management under the Medicaid Managed Care (MMC) system.

1.2 Overview of the RAND Evaluation

The RAND Corporation, a private non-profit research organization with a mission to provide policymakers with objective, rigorous, and credible research evidence to inform decisionmaking, was selected to conduct an independent evaluation of the SDC pilot program.[2] The objective of this evaluation is to examine the implementation and impact of the SDC pilot program. This report describes the SDC pilot program and its policy background, the questions the independent evaluation aims to answer, the proposed methodology to conduct the SDC evaluation, and the evaluation findings. This report supersedes the interim report, published in November 2020.[3]

The SDC pilot program evaluation was designed to determine the extent to which three goals of the program were achieved during its first two years (January 1, 2018 to December 31, 2019). These goals are:

1. Implementation of a viable and effective SDC program for HARP enrolled/BH HCBS eligible individuals throughout NYS
2. Improvement in recovery, health, BH, social functioning, and satisfaction with care for SDC participants
3. Maintenance of Medicaid cost neutrality overall and reduction of BH inpatient and crisis service utilization and cost for SDC participants.

The SDC pilot program evaluation used both primary (qualitative) and secondary (quantitative) data in a mixed methods empirical investigation of the program's impacts. The evaluation plan was oriented to research questions that address three goals of the pilot program,

as shown in Table 1.1. The research questions concern how the program was implemented in addition to beneficiary and system-level outcomes and were to be addressed using the data sources listed in Table 1.1. Outcomes pertain to enrollment of eligible participants; access to outpatient services (primary and preventive services, BH services); utilization of acute care, which in addition to inpatient and emergency department (ED) services included crisis respite HCBS for acute BH care; Medicaid spending; satisfaction with care; health and wellness, social outcomes (education, employment, community tenure), quality of life, social connectedness; and a variety of qualitatively assessed outcomes.

Table 1.1 SDC Pilot Program Evaluation Goals, Methods, and Research Questions

Goal	Methods	Research Question
1. Implementation of a viable and effective SDC program for HARP enrolled/HCBS eligible individuals throughout NYS.	Analyses of Medicaid claims and encounter data and SDC portal data; interviews with key informants.	1. What are the characteristics of SDC participants and how do they compare to the larger HARP and HCBS eligible population? 2. What was the experience of HARP enrolled/HCBS eligible individuals participating in the SDC Pilot program in relation to satisfaction with the SDC program and its impact on their recovery, quality of life, and benefit from health and BH services? 3. What was the experience of non-participant stakeholders in the SDC Pilot program (e.g., Support Brokers, pilot site agency staff, State program development/ oversight staff, fiscal intermediary) in relation to SDC implementation including State oversight and contracting, fiscal policies and procedures, hiring of SDC staff, recruitment and work with participants, and coordination with the fiscal intermediary? 4. What were the facilitators and challenges to SDC Pilot implementation and how would they impact statewide roll-out?
2. Improvement in recovery, health, BH, social functioning, and satisfaction with care for SDC participants.	Analyses of SDC Assessment and HARP PCS data.	1. Do HARP members have improved quality of life after participating in SDC? 2. Do HARP members show improved indicators of health, BH, and wellness after participating in SDC? 3. Do HARP members show improvement in education and employment after participating in SDC? 4. Do HARP members show improvement in community tenure (i.e., maintaining stable long-term independence in the community) after participating in SDC? 5. Do HARP members show improvement in social connectedness after participating in SDC? 6. Do HARP members report increased satisfaction with health and BH services after participating in SDC?
3: Maintenance of Medicaid cost neutrality overall and reduction of BH inpatient and crisis service utilization and cost for SDC participants.	Analyses of Medicaid claims and encounter data and MHARS data.	1. Does participation in SDC result in increased use and cost of outpatient BH services and primary care? 2. Does participation in SDC result in decreased use and cost of BH inpatient, ED, and crisis services?

TERMS: MHARS - Mental Health Automated Record System

1.3 Report Organization

The remainder of this report is structured as follows:

- Section 2 presents an overview of the SDC Pilot implementation, including the timeline of implementation.
- Section 3 provides an overview of the study design, with the methodology as related to the type of data collection and the related RQs.
- Section 4 presents the findings organized by RQ, along with a summary of findings across the evaluation.
- Section 5 discusses the policy implications, based on the study findings.
- Section 6 reviews the interactions with other State initiatives.
- The appendices follow the body of the report, offering information on study protocols as well as selected data tables.

2. SDC Pilot Description

2.1 Landscape Prior to the SDC Pilot Program

The SDC program is grounded in the belief that greater autonomy and choice will permit a better match between individuals' needs and health care and related services; as such, it aims to promote progress toward recovery goals, health, and stability in the community.

An earlier version of the SDC program began to be offered in the 1990's by state Medicaid programs as part of the optional state plan personal care services benefit. With support from the Robert Wood Johnson Foundation, self-direction of Medicaid services has evolved over the years; currently, states have a number of mechanisms available to finance the self-direction option to Medicaid beneficiaries.[4]

In 2014, the NYS Office of Mental Health (OMH) was awarded a Substance Abuse and Mental Health Services Administration (SAMHSA) Transformation Transfer Initiative grant to fund the design of a self-directed care model to be pilot-tested and eventually scaled-up for delivery to eligible Medicaid beneficiaries with serious mental illnesses in a managed behavioral health delivery system.[5] At that time, the BH benefit for most eligible beneficiaries was carved out of existing managed care arrangements. However, that changed in 2015, first with the MRT Section 1115 Demonstration[1] followed by an amendment to the Demonstration targeted to beneficiaries with BH needs implemented in August 2015, which we refer to as the BH Demonstration.

The BH Demonstration sought to improve health care quality, costs, and outcomes for the State's Medicaid BH population and transform the BH system from an inpatient-focused system to a recovery-focused outpatient system. The BH benefits were made available through all mainstream MMC plans and through a separate coverage product, the HARPs, which are specialty lines of business operated by qualified mainstream MMC plans and available statewide. The HARP program was phased in, launched first in New York City (NYC) in October 2015 and the Rest of the State (ROS) in July 2016. BH HCBS were only available to qualified HARP and HIV Special Needs Plans (SNP) enrollees; the BH HCBS were offered beginning in January 2016 in NYC and in October 2016 for ROS.

BH HCBS are delivered to HARP and HARP-eligible HIV SNP enrollees under a two-level tier structure determined by a person-centered plan of care developed by the Health Homes or other state-designated entities. Tier 1 services include Individual Employment Support, Education Support, and Peer Services. Tier 2 services include all Tier 1 services plus additional services for beneficiaries with a higher level of need. Eligibility for BH HCBS is assessed through the BH HCBS Eligibility Assessment, a standardized clinical and functional assessment tool derived from the interRAI™ CMH Assessment,[6] and also referred to as CMH screen. The CMH screen is required annually for all HARP and HARP-eligible HIV SNP enrollees, including SDC pilot participants.

2.2 The Self-Directed Care Pilot Program

Table 2.1 shows a timeline of implementation of the SDC program. Following an award from SAMHSA in February 2014, OMH began conducting preparatory activities to implement a BH SDC pilot program (e.g., selecting sites, creating a web-based portal) targeted to HARP enrollees in September 2015. Under the Demonstration extension approved December 7, 2016, a program making self-direction services available to eligible individuals was authorized for the period January 1, 2017, through June 30, 2022, as a pilot initiative with the goal of testing the viability and effectiveness of SDC prior to a statewide implementation.

Table 2.1 Timeline of SDC Implementation

Year	Date	Event
2014	February	SAMHSA awarded OMH a Transformation Transfer Initiative to fund the design of the SDC program for individuals with serious mental illnesses (SMI)
2015	March	New York State Health Foundation (NYSHF) provided start-up funding to OMH to conduct a preliminary evaluation of the SDC pilot program
	August	Amended Section 1115 Demonstration behavioral health reform initiatives include SDC
	September	OMH conducted preliminary activities for SDC (e.g., site selection, hiring an OMH fiscal intermediary, creating a web-based SDC portal)
2017	July	Contracts finalized with two SDC pilot site agencies
	October	Both sites began advertisement and outreach activities to recruit participants
2018	January	Start of 2-year SDC pilot
	March	Substantive pilot program enrollment begins
2019	May	219 participants enrolled (166 active)
	August	SDC Pilot Program Implementation Evaluation Report Released by OMH
2020	June	Contracts with site agencies are extended through June 30, 2022

The SDC pilot program enables HARP enrollees eligible for BH HCBS to use public funds to purchase individual directed goods and services. For this pilot implementation phase of the SDC program, the State opted to finance the program entirely with State (OMH) funds; the start-up and maintenance costs included those related to the salaries of the support broker and administrative staff and the purchase of goods and services. SDC participants select a support broker with whom they work to identify recovery goals. The support broker then assists the participant with the creation and implementation of a budget to purchase the goods and services required to meet the recovery goals. SDC participation is voluntary, and participants may opt out at any time. Eligible enrollees wishing to participate after capacity has been exceeded are placed on a waiting list.

Two agencies, one in NYC and one in Newburgh (a small city close to Poughkeepsie), were chosen as SDC pilot sites. The agencies are responsible for recruiting and enrolling participants and for hiring, training, and supervising support brokers. Support brokers work with a fiscal intermediary based at NYS OMH who provide training, support, and monitoring for the

authorization and purchasing of goods and services. Contracts between the agencies and NYS were finalized in July 2017, and the two-year SDC pilot program was launched in January 2018 with the expectation that it would serve 200 participants (Table 2.1 provides a timeline).

Although at program launch the expectation was that HARP members would be enrolled in Health Homes and would be assessed for BH HCBS eligibility with the CMH screen at enrollment and annually, Health Home enrollment was low, and even if enrolled, only a fraction of enrollees was administered the CMH screen as planned. To address this barrier, the State deemed SDC pilot participants who had not yet been assessed to be BH HCBS eligible (Tier 1), allowing them an annual budget of $8,000. Access to the higher annual budget of $16,000 did require assessment with the CMH screen and determination of Tier 2 eligibility. (These amounts correspond to caps on annual utilization of HCBS set by the state.) Eligibility for Tier 2 services, higher relative to Tier 1 services, requires evidence of at least "moderate" level of need as indicated by an OMH-designated score on the CMH Screen (see Figure 2.1 for eligibility criteria). The original criteria were more stringent: Until June 2018, eligibility for Tier 2 services required moderate need on at least four domains or extensive need on at least one domain. In addition, a third criterion permitting previously eligible BH HCBS users to continue receiving services was added in June 2019.

Figure 2.1 Determination of BH HCBS Service Eligibility

A. Criterion 1: Tier 1 Services
   i. For Individual Employment Support, person must express desire to receive employment support services.
   ii. For Education Support, person must express desire to receive education support services to assist with vocational goals.
   iii. For Peer Support, person must express desire to receive peer support services.

B. Criterion 2: Tier 2 Services
   i. Meets threshold score for MODERATE need on at least one domain of Functional and Safety Needs* OR
   ii. Meets threshold score for EXTENSIVE need on at least one domain of Functional and Safety Needs.*

C. Criterion 3
   i. Individuals who receive or have previously received BH HCBS in the past six months will maintain their eligibility level for the current assessment (i.e., algorithm will return the higher of the two scores to prevent loss of potentially beneficial services).

* Domains of Functional and Safety needs include employment/education, instrumental activities of daily living (IADLs), cognitive skills, social relations, stress and trauma, co-occurring conditions, engagement, substance use, and risk of harm.

The SDC pilot sites recruit participants through provider or self-referrals following outreach to HARP providers in their areas, informational sessions held at their agencies and others, and advertisements at community events and social media. Potential candidates are asked to participate in individual or group sessions where SDC eligibility criteria, procedures, and

benefits are explained, and are eventually recruited if they meet criteria and are willing to participate.

2.3 Services Eligible for Self-Direction

The goods and services eligible for self-direction can be other services, equipment, or supplies that address an identified need in the service plan and are not otherwise available to the beneficiary. These items or services must decrease the need for other Medicaid services, promote inclusion in the community, and increase the participant's safety in the home environment. Not all goods and services are eligible for self-direction—ineligible items include experimental treatments, room and board in an assisted living or other residential facility, and services or goods that are recreational. A non-exhaustive list of goods and services is presented in Table 2.2.

Table 2.2 SDC Non-Treatment Goods and Services

Goal	Resource/Good or Service Purchased
Wellness Activities	Gym/health club membership Wellness coaching Smoking cessation tools/education Dental care Eyeglasses/care Out of network health/BH/specialty services Family planning and sexual health education services Acupuncture/pressure Yoga classes/meditation guidance Massage/reiki /shiatsu/tai chi instruction Pet adoption funds, including appointments/resources related to pet health and maintenance Workout equipment and clothing Nutritional supplements and vitamins
Occupational/Skills Development	Computer literacy Resume development Interview preparation PC/communication technology Personal preparation/resources to prepare for interviews or enhance confidence during employment Resources for entrepreneurial development, including business cards, website development Educational course fees and materials
Transportation	Public transportation costs Car repair/maintenance Bicycle and related costs
In-Home/Social/Community Supports	Training and supports for daily living including nutrition classes and others Housing start-up (down payments), non-recurring housing bills, or costs related to home maintenance Groceries Travel to and from family or social functions Meetings in the community with friends or family members promoting social inclusion Financial contributions at social activities including church services Registration fees for conferences, trainings, community activities Membership dues for groups, societies, guilds, leagues

2.4. Review of the Research Literature

In this section, we provide a summary of our review of the research literature, grey and peer-reviewed, focused on Medicaid-financed SDC programs implemented in the United States; the literature we reviewed includes an evaluation covering the first 18 months of New York's SDC pilot program conducted by OMH.[7] Table 2.3, presented after this section, provides an overview of the literature presented here.

SDC programs are intended to more effectively match the services that participants receive with their needs, thereby enhancing their progress toward recovery and maximizing their opportunities to live independently in the least restrictive community-based setting of their choice.[7,8] Some proponents hypothesize that SDC programs can also reduce the use of high-cost care such as inpatient and emergency care.[9] However, the launch of SDC programs for people with behavioral health needs has evoked concerns about the ability of people with behavioral health needs to effectively direct the services they receive.[10,11]

While the antecedents of SDC have existed since the Second World War, the first large scale, rigorously evaluated SDC program—the Cash and Counseling Demonstration and Evaluation (CCDE)—was not launched until the late 1990's. Early initiatives included a Veterans Administration program to help World War II veterans with disabilities hire personal assistants; the California In-Home Supportive Services program, which was launched in 1973 and originated with a 1953 program to hire personal assistants; and self-directed service model pilots stimulated by the independent living movement in the 1960's and 1970's.[8] CCDE, a randomized controlled trial of SDC with over 6,500 participants that was funded by the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation and evaluated by Mathematica Policy Research, operated in three states—Arkansas, Florida, and New Jersey—from 1998 to 2003. CCDE served frail elderly adults and adults with physical disabilities in all three states and children with developmental disabilities in Florida. Overall, treatment group members were more likely to receive paid personal care, had increased satisfaction with care, had fewer unmet needs, and were no more likely to experience health problems than control group members.[12] CCDE was continued in all three states and replicated in 12 additional state Medicaid programs.[13] Since CCDE, CMS has supported the use of SDC for people with a broad range of disabilities.[14]

In the 2000's and 2010's, several states launched SDC programs for people with some combination of SMI, SUD, and eligibility for state programs. These states included Florida, Texas, Utah, Michigan, and Pennsylvania.[7] The Supreme Court's 1999 *Olmstead* decision, which emphasized state responsibility to help people live in integrated community environments, and President George W. Bush's New Freedom Commission, which recommended "self-directed services and supports for people with mental illness"[15] stimulated these programs.[7,16] A recent inventory of SDC programs identified 19 programs for adults with serious mental illness across

the 50 states and the District of Columbia as of 2019.[17] (According to the inventory's definition, a state could operate more than one SDC program.)

Evidence about SDC Effects on People with Behavioral Health Needs

We summarize evidence relevant to Medicaid beneficiaries with BH needs from 11 studies reporting on SDC and its impacts. This body of research includes three early studies focusing on CCDE and Florida SDC; studies described in a systematic review of the research literature published through April 2013; three studies that focus on kinds of goods and services SDC participants purchased; three more recent studies that provide higher quality evidence about the impacts of SDC; and a study with preliminary findings on New York's SDC pilot program. Table 2.3 presents key information about each study.

Early Studies: CCDE and Florida SDC

Early studies of SDC in the United States focused on the impact of SDC for people with mental illness in the CCDE and the impact of Florida SDC, the nation's oldest and longest running SDC program. Shen et al. evaluated the impact of CCDE programs in Arkansas and New Jersey on measures of participant satisfaction with paid caregiver; satisfaction with the way he or she was spending his or her life; and adverse events, health problems, and health status.[18,19] Participants were elderly Medicaid enrollees with mental illness in Arkansas and nonelderly Medicaid enrollees with mental illness in New Jersey. Shen et al. compared differences in outcomes among participants with mental illness who were randomized into the SDC treatment group and the non-SDC comparison group. On most measures of satisfaction with caregivers, SDC participants experienced better outcomes than non-SDC participants. For example, SDC participants in Arkansas were more than twice as likely as non-participants to say that their caregiver always completed tasks, and SDC participants in New Jersey were more than four times as likely as non-participants to say they were very satisfied with their overall care arrangement. SDC participants in New Jersey were more likely to report satisfaction with the way they were spending their lives, although SDC participants in Arkansas were no more likely to report overall life satisfaction than non-participants. On measures of adverse events, health problems, and health status, there were no significant differences between SDC participants and non-participants in either state. Shen et al. concluded that CCDE had positive effects on caregiving and wellbeing without increased risk of adverse events.

Cook et al. evaluated change in self-reported functioning and days living in a community setting, as opposed to an inpatient or forensic setting, among Florida SDC participants after the program's first 19 months of operation.[16] Participants were adults diagnosed with a mental disorder, current or former recipients of disability income, and residents of a specific geographic area within Florida. On average, participants scored higher on the Global Assessment of Functioning, a standardized assessment of psychological, social, and occupational functioning.[20]

In addition, they spent a higher number of days in the community compared to inpatient or forensic settings.

Webber et al. conducted a systematic review of studies published up to April 2013 on SDC for people aged 18 to 65 with mental health problems.[11] It included 11 studies in the United Kingdom and four studies in the United States, including Cook's work in Florida and Shen's in New Jersey summarized above. The studies included two randomized controlled trials and four quasi-experimental studies that compared change over baseline but lacked comparison groups from random assignment, with the remaining studies cross-sectional or qualitative. Together, the studies covered four domains: choice and control of care and support; quality of life or overall satisfaction; service use, including inpatient and community mental health services; and cost effectiveness. Webber et al. concluded that the studies provide "some evidence that personal budgets [the name for SDC] can have positive outcomes for people with mental health problems." Generally, SDC was associated with positive outcomes in the domains. However, Webber et al. described the overall quality of studies as "moderate at best" and noted that the studies featured "a large number of methodological shortcomings," including small sample sizes, short timeframes, and "less 'complex" patients.

Spending by SDC Participants

Three studies focused on types of goods and services purchased by SDC participants. Spaulding-Givens and Lacasse examined purchases by Florida SDC participants during the 2009–2010 state fiscal year.[21] Croft and Parish examined purchases by participants in two unidentified SDC programs that were established in the early 2000's and funded by a combination of state, local, and Medicaid dollars.[22] Snethen et al. examined spending by participants in a Delaware County, Pennsylvania SDC program within a Medicaid managed care context.[23]

All studies found that participants used a substantial percentage of their budgets to meet basic needs. Common uses of the individualized budget included transportation, groceries, clothing, housing expenses, and dental and eye care. Snethen et al. found that participants with different mental health conditions used their budgets in different ways: those with schizophrenia more often requested items to support fitness, like workout shoes, while those with bipolar disorder and major depression more often requested items to help manage stress, like money to pay an electric bill or divorce fee. Croft and Parish identified barriers to participants using their budgets to meet their needs, including lack of knowledge or confusion about how the budget could be used and limited availability of providers in some geographic areas that limited access to some kinds of mental health treatments. Spaulding-Givens and Lacasse found that most participants did not report severe psychopathology and lived independently in the community; however, almost none worked or earned income. As a result, they posited that Florida SDC could create a disincentive to work and enable dependency. They proposed that program administrators link

vocational rehabilitation and supported employment with other services provided by the program to facilitate work.

Recent Studies: Stronger Designs and Data Sources

More recent studies have used experimental or quasi-experimental designs and administrative data to provide stronger evidence about SDC programs for people with behavioral health needs. Cook et al. used a randomized controlled trial of Texas SDC participants to evaluate the program's effects on a variety of mental health and social outcomes, as captured by validated survey instruments; participation in employment and in education; and service use and costs.[14] Compared to the non-SDC control group, the SDC treatment group improved significantly on recovery outcomes, self-esteem, coping mastery, and perceived autonomy. Although general severity of psychiatric symptoms did not decrease significantly among the treatment group, the severity of physical symptoms from psychological distress—such as dizziness, pain, nausea, shortness of breath, and numbness—decreased significantly. In addition, treatment group members were more than twice as likely to be employed and more than four times as likely to be enrolled in formal education as control group members and expressed higher satisfaction with mental health services than control group members. Total service cost per participant did not differ significantly between the treatment and control groups; the treatment group had lower per-person costs for some types of services and higher costs per person for others. Specifically, the treatment group had lower per-person cost for inpatient treatment and higher per-person cost for psychotherapy. Cook et al. concluded that the program achieved superior client outcomes to traditional service delivery system with no added cost and did not lead to fraud or misuse of funds.

Croft et al. compared change in employment and housing outcomes among Florida SDC participants and a matched comparison group with similar demographic characteristics that did not enroll in SDC.[24] They found that treatment group members were significantly more likely than control group members to increase or maintain days worked in the last month and to attain or maintain independent living status versus living with a group or being homeless. However, the program's effect sizes were small: to achieve a positive employment outcome for one participant, 18 participants would need to be enrolled for 3 years; to achieve a positive independent living outcome for one participant, 16 participants would need to be enrolled for three years. Croft et al. noted that most participants enrolled in the program before the baseline assessment that was used to measure change over time in outcomes. As a result, their estimates of the program's effects may not reflect the full effect of the program.

Croft et al. used three years of Medicaid claims data to examine change in service use and costs per month among participants in a continuation of the Delaware County, Pennsylvania program described by Snethen et al.[23,25] Notably, participants could choose to reduce or "bank" some traditional mental health services—such as outpatient clinical services, peer support, and psychiatric rehabilitation—and apply funds saved toward nontraditional services. This differed

from most other SDC programs, where the portion of the budget directed by a participant was administered separately from most clinical services. The study included costs per month of crisis and inpatient services, mental health clinical and community support services, and substance use outpatient and community support services. Snethen et al. found no significant difference in the percentage of participants who used any service and no significant difference in total cost per month before and after SDC. Of all services, only cost per month for mental health outpatient services changed significantly, decreasing by about half. The study lacked a comparison group, meaning that external factors that affected costs and were correlated with program implementation may have biased the study's estimates of the program's effects.

Table 2.3 Empirical Evidence on SDC Effects

Study	Program	Participants	N	Study Period	Outcome Measures	Method
Shen 2008a	CCDE Arkansas	Elderly Medicaid enrollees with mental illnesses	203	December–August 1998	Satisfaction with caregiving; overall life satisfaction; adverse events, health problems, and health status	Randomized controlled trial
Shen 2008b	CCDE New Jersey	Nonelderly Medicaid enrollees with mental illnesses	228 (109 treatment, 119 control)	1999	Satisfaction with caregiving; overall life satisfaction; adverse events, health problems, and health status	Randomized controlled trial
Cook 2008	Florida SDC	Current or former disability income recipients 18 or older with mental illnesses	106	Nov 2002–Jun 2004	Functioning, days in community versus inpatient or forensic settings	Pre-post
Spaulding-Givens 2015	Florida SDC	Indigent adults with severe and persistent mental illnesses	136	2009–2010	Types of goods and services purchased	Cross-sectional
Croft 2016	Two SDC programs (unidentified state)	People on Medicare, Medicaid, Veteran's benefits, or uninsured	30	Unknown	Experience with program, types of goods and services purchased	Cross-sectional, qualitative
Snethen 2016	Consumer Recovery Investment Fund SDC (I), PA	Medicaid beneficiaries 18–65 with schizophrenia, major depression, or bipolar disorder	60	2010–2011	Types of goods and services purchased	Cross-sectional
Croft 2018	Two programs within Florida SDC	People 18 or older with serious and persistent mental illnesses receiving publicly funded mental health care	1,370 (271 treatment, 1,099 control)	Program A: 4.8 years beginning July 2010; Program B: 3 years beginning July 2012	Employment, independent living	Matched sample analyses (controlled design)
Cook 2019	Texas SDC	Department of State Health Services clients 18 or older with serious mental illnesses and moderate to severe level of need	216 (114 treatment, 102 control)	24 months (start and end dates unspecified)	Level of recovery from mental illness, psychosocial status, psychiatric and somatic symptoms, participation in employment and education, service use and cost	Randomized controlled trial

Study	Program	Participants	N	Study Period	Outcome Measures	Method
Croft 2019	Consumer Recovery Investment Fund SDC (II), PA	Medicaid beneficiaries 18–65 with schizophrenia, major depression, or bipolar disorder	45	March 2012 to July 2015	Service use and costs	Pre-post
Chung 2019	New York State SDC	HARP enrollees with State-defined serious and persistent mental illnesses or substance use disorders	219	2018–2020	Quality of life, types of goods and services purchased	Pre-post

3. Evaluation Design and Methods

3.1 Overview of the SDC Evaluation

RAND conducted an independent evaluation of the SDC pilot program that adhered to the evaluation standards set forth in the Special Terms and Conditions for the Section 1115 Demonstration.[1] Designed as a mixed methods investigation, the structure of the evaluation is built around research questions and testable hypotheses that sought to determine whether the beneficiary- and system-level impacts of the SDC pilot program had been achieved. Quantitative methods were used for descriptive purposes and to assess the outcomes of the program (outcome evaluation), and qualitative methods were used to provide context for the quantitative findings and to gather administrative, provider, and SDC participant perspectives on the SDC pilot program's functioning and effectiveness (process evaluation).

The data sources included qualitative data collected during the course of the evaluation as well as administrative and survey data previously collected by the New York State DOH, the OMH, and New York State Office of Addiction Services and Supports (OASAS) during the course of health care administrative or clinical operations.

Discussions with Experts to Refine Approach to the Evaluation

To better understand the policy context, objectives, and challenges to the implementation of the SDC pilot program, the evaluation team held calls with SDC subject matter experts to discuss the background and implementation of the program. The evaluation team used the information gathered in these calls and the internal report on OMH's preliminary evaluation of the SDC pilot program (not publicly available) to inform the qualitative component of the evaluation and to revise and enhance the planned quantitative analyses.[7] In addition, the evaluation team held discussions with data experts within DOH, OMH, and the OASAS to review the data available on the SDC population and the feasibility of fully addressing the research questions, given the constraints on data availability. As a result, the evaluation plan was refined to better reflect the information available.

Evaluation Approach

The evaluation used a combination of qualitative and quantitative methods to address the evaluation goals as shown in Table 3.1. Qualitative methods were used to collect data on perceptions of the SDC program by participants, staff within the two pilot programs, and personnel administering the program within OMH. Data for quantitative analyses were drawn from existing administrative and clinical datasets. The available data sources were examined in detail to determine the best uses of the data to address the evaluation goals. Based on preliminary

analyses, the evaluation team along with NYS DOH developed the plan described in more detail below.

Goal 1 concerns the implementation of the SDC program. The evaluation is comprised of descriptive data on enrollees in the program and qualitative interviews related to program operations, impacts, facilitators and barriers. Goal 2 concerns the impact of the program on participant recovery-related outcomes and is addressed with data collected by the pilot programs. Based on preliminary examination of available data, the analyses addressing Goal 2 research questions did not include control groups or pre-SDC program data and are therefore descriptive in nature. Goal 3 concerns the impact of the program on use of services and costs of care. After preliminary analyses of the claims data, these analyses were designed as uncontrolled interrupted time series analyses.

Table 3.1. Outcome Measures by Goal and Research Question

Goal	Research Question	Data Source	Outcome Measures
1. Implementation of a viable and effective SDC program for HARP enrolled/BH HCBS eligible individuals throughout NYS	1. What are the characteristics of SDC participants and how do they compare to the HARP and BH HCBS eligible population?	SDC Assessment Data	Count of SDC participants stratified by sociodemographics, health status/clinical characteristics, and functional status
		Medicaid Data (Claims and Encounters)	
	2. What was the experience of HARP enrolled/BH HCBS eligible individuals participating in the SDC Pilot program in relation to satisfaction with the SDC program and its impact on their recovery, quality of life, and benefit from health and BH services?	Interviews with SDC participants	Description of participant perspectives on SDC program, staff, and process; impacts on their recovery, quality of life, health, and BH; satisfaction with services
	3. What was the experience of non-participant stakeholders in the SDC Pilot program (e.g., support brokers, pilot site agency staff, State program development/oversight staff, fiscal intermediary) in relation to SDC implementation including State oversight and contracting, fiscal policies and procedures, hiring of SDC staff, recruitment and work with participants, and coordination with the fiscal intermediary?	OMH administrative documentation	Description of program policies regarding selection, agreements, ongoing monitoring of SDC sites and fiscal intermediary, participant eligibility criteria, budgeting/use of funds, conflict of interest, and complaint/incident handling
		OMH administrative staff interviews	
		Pilot site staff interviews	
		Pilot site documentation on hiring, training, and supervising of support brokers	Description of support broker and supervisory staff demographics, credentials, training, supervision, and their perspectives on the pilot program and their relationship with participants and fiscal and State oversight
		Interviews with support brokers, pilot site agency leadership/supervisory, fiscal intermediary, and State oversight staff	
		Pilot site administrative documents	Description of pilot site agencies' process for recruiting participants, educating participants about what SDC is and how they can participate, enrolling participants, and facilitating ongoing participation
		Pilot site staff interviews	
		Interviews with SDC participants	

Goal	Research Question	Data Source	Outcome Measures
		Fiscal intermediary administrative and technical documents Interviews with fiscal intermediary staff, pilot site staff, State oversight staff	Description of fiscal intermediary's policy and infrastructure for providing payments, monitoring payments, and supporting customers
	4. What were the facilitators and challenges to SDC Pilot implementation and how would they impact statewide roll-out?	Interviews with State oversight, fiscal intermediary, pilot site agency staff Interviews with SDC participants	Description of facilitators and challenges to the implementation of the SDC Pilot program
2. Improvement in recovery, health, BH, social functioning, and satisfaction with care for SDC participants between baseline and three (3) year and subsequent follow-up	1. Do HARP enrollees have improved quality of life after participating in SDC?	SDC Assessment	Risk-adjusted percentage of SDC participants whose quality of life is improved as a result of the program, by annual period when data are available
	2. Do HARP enrollees show improved indicators of health, BH, and wellness after participating in SDC?	SDC Assessment	Risk-adjusted percentage of SDC participants whose BH, overall health, and wellness is improved as a result of the program, by annual period when data are available (i.e., experience reduction in substance abuse/other harmful behaviors, misuse of prescription medications)
	3. Do HARP enrollees show improvement in education and employment after participating in SDC?	SDC Assessment	Risk-adjusted percentage of SDC participants whose employment status/hours worked in competitive employment and educational status/enrollment in educational programs is improved as a result of the program, by annual period when data are available
	4. Do HARP enrollees show improvement in community tenure (i.e., maintaining stable long-term independence in the community) after participating in SDC?	SDC Assessment	Risk-adjusted percentage of SDC participants whose community tenure is improved as a result of the program, by annual period when data are available (i.e., experience improved residential status/housing stability, reduced criminal justice system involvement, are under Assisted Outpatient Treatment order, achieve functional independence)
	5. Do HARP enrollees show improvement in social connectedness after participating in SDC?	SDC Assessment	Risk-adjusted percentage of SDC participants whose social connectedness is improved as a result of the program, as manifested by social relationship strengths and level of social activity, by annual period

Goal	Research Question	Data Source	Outcome Measures
	6. Do HARP enrollees report increased satisfaction with health and BH services after participating in SDC?	HARP PCS	Risk-adjusted percentage of SDC participants who report that quality of care and helpfulness of services are improved as a result of the program, by annual period when data are available
3. Maintenance of Medicaid cost neutrality overall and reduction of BH inpatient and crisis service utilization and cost for SDC participants, between baseline and three (3) year and subsequent follow-up.	1. Does participation in SDC result in increased use (and cost) of outpatient BH services and primary care?	Medicaid Data (Claims and Encounters)	Risk-adjusted percentage of SDC participants receiving BH services and primary care/preventive services, by annual period
	2. Does participation in SDC result in decreased use and cost of acute care services (BH inpatient, ED, and crisis services)?	Medicaid Data (Claims and Encounters) MHARS	Risk-adjusted SDC participant rates of inpatient admissions and days for BH inpatient stays; rates of BH ED use; rates of non-BH ED use; and rates of BH crisis service use, by annual period
	3. How does participation in SDC impact overall Medicaid spending?	Medicaid Data (Claims and Encounters)	Risk-adjusted Medicaid PMPM costs, by annual period (PMPM/Y), for: BH outpatient services; primary care/preventive services; acute care services (ED use, BH inpatient use, and BH crisis services); overall

3.2 Qualitative Methods

The qualitative component of the SDC pilot program evaluation consisted of interviews with key informants and participants in the pilot program and a review of program-related policy documents. Key informants included stakeholders from the pilot site service provider organizations (e.g., support brokers, program leadership), state agencies (e.g., fiscal intermediary, agency leadership), and advocacy organizations. These interviews focused on understanding how the SDC program was being implemented; the roles of various stakeholders in operating and overseeing the program; the perceived impact of the program; and challenges and factors that might impact potential program scale-up. Interviews were also conducted with SDC participants to understand their perspectives on how the SDC program was being implemented; their satisfaction with the program; and how it has impacted their access to services/resources, progress toward goals, and health and well-being. Efforts were made to ensure that a broad range of perspectives were represented in the SDC participant sample, including diversity of demographic and clinical factors, and that diverse geographic areas were represented. The qualitative analysis was also informed by a review of OMH documents that described various aspects of the program's design. These documents included the SDC manual, program overview presentations, policies regarding purchasing and receipts, descriptions of training and support broker and fiscal intermediary roles and responsibilities, and documents provided to participants (e.g., self-assessments, goal worksheets, purchase guidelines).

The interviews and documents were analyzed by the evaluation team to understand how the SDC pilot program was operating and to identify issues that arose in the course of the implementation of the SDC pilot. Analysis of qualitative interviews provided an opportunity to obtain a more nuanced understanding of the barriers and facilitators to program implementation, as well as the impact of SDC on participant recovery, wellness, and quality of life. For instance, the evaluation team asked key informant leadership from state, advocacy, and pilot site agencies whether implementation of the SDC program has gone according to expectations, whether they have concerns about barriers to successful implementation, and whether there are aspects of the implementation that have been particularly promising. SDC participants were asked to describe their experiences with different aspects of the SDC program (e.g., enrollment, goal identification, SDC support broker services, the approval and purchase process) and how participating in the program has impacted an array of life domains (physical health, mental health, empowerment, pursuit of meaningful activity). Finally, analysis of interview data also served to identify aspects of the SDC program's implementation process that would need to be considered were SDC to be scaled-up beyond the pilot program phase, as well as to identify potential suggestions for areas of program improvement. Issues raised by key informants and SDC participants were summarized and compared across categories of informants and stakeholder type throughout the analysis stage.

Protocol Development

A semi-structured interview guide for key informants representing a diversity of SDC pilot program stakeholders was developed (Appendix A). Interview guides were informed by introductory discussions with DOH, policy-related documents, and NYS' prior internal evaluation findings. It covered topics including barriers and facilitators to SDC pilot implementation; clarity of roles and adequacy of training for key personnel (e.g., financial intermediary, support brokers); adequacy of policies, procedures, oversight, and monitoring from agency leadership and NYS; integration of SDC within agency services; coordination between NYS, pilot sites, and the financial intermediary; recruitment and enrollment of SDC participants; provision and receipt of SDC services including experiences developing recovery plans and budgets; and participant outcomes.

A semi-structured interview guide for SDC participants was developed, similarly informed by introductory discussions with DOH, policy-related documents, and NYS' prior internal evaluation findings (Appendix B). It focused on topics including participant perspectives regarding enrollment; the process of identifying goals, developing recovery plans and budgets, and making purchases; relationships between participants and support brokers; satisfaction with the SDC program and other health and BH services; and the impact of SDC on participants' recovery and quality of life.

Key Informant Selection

The evaluation team used a purposive sampling approach to recruit key informants. To capture a range of perspectives, key informants representing various stakeholder organizations were recruited, including the two pilot sites, the NYS Office of Mental Health, and advocacy/provider/trade associations. An initial group of key informants with in-depth knowledge of the SDC program was first identified through state and pilot site-provided lists, and additional informants were selected based on recommendations from stakeholders who completed interviews. Key informants from the two pilot sites included SDC direct provider staff (i.e., support brokers), other pilot site staff serving participants enrolled in SDC (e.g., care coordinators), and SDC program and agency leadership (Table 3.2). Key informants from OMH were recruited from several divisions/departments and generally represented leadership at the program or senior executive management level as well as staff directly involved in administering the program (e.g., fiscal intermediary functions). Key informants from the advocacy/provider/trade associations represented staff from the senior executive leadership level. The evaluation team conducted 18 interviews with 20 key informants.

Table 3.2 SDC Key Informant Participants (N=20)

Key Informant Type	N (%)
Support Broker	6 (30)
Site Leadership	4 (20)
Other Site Staff	2 (10)
OMH Fiscal Intermediary	2 (10)
OMH Leadership	5 (25)
Provider/Advocacy Association	1 (5)

To identify SDC pilot participants for interviews, evaluators utilized maximum variation and convenience sampling strategies resulting in 14 pilot participant interviews conducted by the evaluation team (Table 3.3). To capture a range of perspectives, the evaluation sought to maximize the diversity of SDC participants who completed interviews, considering factors such as the referring pilot site, length of time in SDC, SDC utilization patterns, and a range of demographic characteristics (e.g., gender, race, psychiatric diagnosis).

Table 3.3 SDC Pilot Program Participant Characteristics (N=14)

Participant Characteristics	N (%)
Participants	
Site 1	8 (57.14)
Site 2	6 (42.86)
Time Enrolled in SDC	
Mean years (SD)	2.61 (.56)
>3 years	7 (50.00)
Age: Mean (SD)	45.21 (11.21)
Gender	
Female	7 (50.00)
Male	6 (42.86)
Other	1 (7.14)
Race/Ethnicity	
Hispanic	3 (21.43)
Non-Hispanic Black	4 (28.58)
Non-Hispanic White	5 (35.71)
Multiracial/Other	2 (14.29)
Education	
Some High School	2 (14.29)
High School Graduate or GED	6 (42.86)
Some College	3 (21.43)
College Graduate or Higher	3 (21.43)
Employment	
No	10 (71.43)
Yes, part-time	1 (7.14)
Yes, full-time	3 (21.43)
Currently in School	
No	12 (85.71)
Yes, part-time	2 (14.29)
Yes, full time	0 (0.00)
Self-Reported Physician-Confirmed Behavioral Health Diagnoses*	
Anxiety Disorder	11 (78.57)
Major Depression	9 (64.29)
Bipolar disorder	3 (21.43)
Schizophrenia/Schizoaffective Disorder	2 (14.29)
Alcohol Use Disorder	8 (57.14)
Drug Use Disorder	6 (42.86)

*Participants could report multiple diagnoses

Respondent Recruitment

Potential key informants received an e-mail inviting them to participate in the evaluation interview and subsequently contacted the evaluators if they were interested in participating. An information sheet explaining the evaluation and interview process was e-mailed to key informants in advance of scheduled interviews and reviewed prior to commencing the interview.

SDC pilot site staff identified potential SDC participants and provided them with a flyer and information about the evaluation. SDC participants interested in participating contacted the evaluators directly or informed SDC staff that they consented to having the evaluators contact them. SDC participants were contacted by phone or e-mail and were sent an information sheet explaining the evaluation and interview process in advance of scheduled interviews and reviewed prior to commencing the interview.

Interviewer Training

The interviewers were two qualitative researchers, one a senior investigator and the other a doctoral-level researcher, both with expertise in qualitative interviewing and analysis, particularly within behavioral health. Prior to conducting interviews, the qualitative team received training on the SDC pilot and the context of the state pilot implementation, including relevant Medicaid policies. The training included a review of OMH documents describing the SDC program design, participation in discussions with DOH and OMH subject matter expert staff, and internal discussions with the project leads and technical advisors, who have experience with NYS Medicaid and the SDC program development. The training ensured that the interviewers were aware of issues relevant to the implementation when conducting interviews.

Conducting Interviews

Interviews with key informants representing SDC stakeholders were conducted virtually and lasted one hour, on average. The majority of data collection consisted of individual interviews with one identified key informant; however, informants were able to invite additional individuals to the interviews as needed to cover the relevant expertise and experience. Key informants did not receive reimbursement for participating in the interview. Interviews with SDC pilot program client participants were conducted by phone and lasted one hour, on average. SDC participants were reimbursed with a $25 gift card for participating in the interview.

Interviews were conducted by one qualitative researcher, with an additional researcher taking notes concurrently that then informed a written interview summary. Interviewers covered core topic areas but maneuvered flexibly through the interview guide and probed certain topics more in-depth when appropriate. Interviews were audio-recorded and transcribed verbatim. The institutional review board of the NYS Psychiatric Institute determined that activities conducted for this evaluation did not meet criteria for human subjects research and were thus exempt from review.

Analysis

Analytic methods, aligned with recommendations of Bradley, Curry, and Devers (2007), followed a grounded theory approach by developing coding structures that emphasized inductive codes emerging directly from the data. Consistent with grounded theory, qualitative analysis occurred concurrently with data collection, allowing interviews to be shaped by preliminary concepts and themes that emerged from the data. The analysis proceeded in a series of steps: development of initial codes (i.e., open coding), code validation and refinement (e.g., adding, removing, or modifying codes and how they were applied), use of the codes (i.e., coding transcripts with a final code list), clustering and interpretation of codes and associated excerpts, and development of broader findings and themes. Strategies for rigor included weekly data collection and analysis debrief meetings, development of interview summaries and memos, and the use of multiple coders.

3.3 Quantitative Methods

This evaluation adopted a pre-post analytic approach that combined descriptive statistical analyses with outcome models of the impact of the SDC pilot program. We first describe our data sources and then provide a detailed description of our approach.

Data Sources

A variety of secondary data sources were used to construct study variables (outcome measures and covariates for risk adjustment) for the quantitative component of the SDC pilot program evaluation. The data were provided by the DOH and OMH and included data from Medicaid, SDC Portal, Mental Health Automated Record System (MHARS), and HARP Perception of Care Survey (PCS).

Medicaid Data

This dataset contains information maintained by the NYS Medicaid Data Warehouse that includes Medicaid member demographics, eligibility information, enrollment, and service utilization billing records for all health care services, including pharmacy, regardless of whether the payment arrangement was fee for service (FFS) or managed care (i.e., claims and encounters). These data, available with a six-month lag, were the source of information for Medicaid enrollment status, BH HCBS eligibility status, demographics, health status, service utilization, and cost of health care for all Medicaid beneficiaries. Health status was evaluated with variables capturing BH diagnoses of interest as well as overall health status. The BH diagnoses were based on episode diagnostic categories (EDCs) and included schizophrenic disorders, severe bipolar disorder, other serious affective/psychotic disorders, any of the aforementioned serious mental illnesses (Any SMI), opioid abuse and dependence (opioid use disorders [OUD]), chronic alcohol abuse, and any of the aforementioned substance abuse-related diagnoses or other substance use disorders (Any SUD). Overall health status was evaluated using

clinical risk groups (CRGs), specifically the 9-rank core health status variable, which we collapsed into three categories (core health revised): healthy to minor chronic disease, moderate to significant chronic disease, and dominant chronic disease to catastrophic conditions. The 2016–2019 data were used in all three goals of the evaluation to construct variables describing person-level characteristics (used for risk adjustment), and utilization and cost variables (outcome measures).

SDC Portal Data

This OMH dataset, linkable to Medicaid data and collected quarterly through a secure web portal application designed by OMH for use by SDC participants and support brokers, contains information on SDC program clients and enrollment, including demographics; SDC Assessment data, which includes a quality of life scale as well as housing, education, employment, and marital information; and individual-level participant goals and expenditures through the program. The 2018–2019 data were used in Goal 1 to identify SDC participants and in Goal 2 to characterize participant outcomes, which include quality of life, educational and housing status, and social connectedness.

Mental Health Automated Record System (MHARS) Data

This OMH dataset contains information on inpatient, residential, and outpatient utilization in New York Psychiatric Centers. The dataset was used to identify psychiatric admissions falling under the Institutions for Mental Diseases exclusion and thus not captured in the Medicaid data. This dataset permitted a complete assessment of inpatient utilization by Medicaid enrollees. The 2016–2019 data were used in Goal 3 of the evaluation to construct the MHARS inpatient utilization variable (outcome measure).

HARP Perception of Care Survey Data

This dataset contained self-reported information collected through a survey of a randomly selected sample of enrollees in HARPs or HIV SNPs. The survey asked respondents about their perception of access to and quality of behavioral health care, the cultural sensitivity of their providers, their quality of life, activity limitations due to physical health problems and substance use, and social connectedness. The survey was adapted from the Experience of Care and Health Outcomes Survey, the Mental Health Statistics Improvement Program/NYS OMH Consumer Assessment of Care Survey, and others. All SDC participants are administered the HARP PCS survey. These data permit assessment of SDC participant experience and satisfaction with care; satisfaction with BH providers' cultural sensitivity; and satisfaction with wellness, recovery, and degree of social connectedness (outcome measures). As with other survey data, these data are vulnerable to non-response bias.

Cohort Construction and Analytic Considerations

For Goals 1 and 3 of the evaluation, SDC participants were included in the cohort if they met the following evaluation inclusion criteria: had at least two months of SDC enrollment, were not dually eligible Medicaid-Medicare beneficiaries, were eligible for full Medicaid benefits, had continuous enrollment in Medicaid (defined as 11 out of 12 months of Medicaid eligibility), and were 21–64 years of age. For Goal 2, all participants with at least two months of SDC enrollment were included. As a result, the sample sizes were different for Goals 1 and 3 and Goal 2.

Enrollment in the SDC pilot program was not randomized. The participants in the program are likely to differ from people who did not participate both because of who was selected from the pool of eligible individuals and who agreed to participate. Moreover, the participants come from sites that serve patients with different characteristics. In this setting, comparisons of participants with non-participants are confounded by these selection processes. One technique considered in this setting was to create a comparison group with HCBS-eligible HARP enrollees from the same geographic areas where the SDC was implemented who had not participated in SDC. Because we were unable to find a true comparison group at the geographic level due to data limitations, such matching was not feasible. As such, the evaluation team resolved to use an Interrupted Time Series (ITS) approach to provide an *exploratory* assessment of the SDC effects based on observed changes in beneficiary outcomes over time.

For analyses with very small sample sizes or rates less than 5 percent or more than 95 percent, we refrained from conducting modeling to avoid very small cells and model identification issues. For all analyses, we report estimates, their standard errors where appropriate, and a p-value as a test of significance for the ITS models. In the presentation and discussion of our findings, we only describe results as different when the difference is statistically significant (i.e., p-value of $\leq .05$).

Analytic Approaches

The quantitative methods employed in the evaluation of the SDC pilot program included descriptive statistics and a pre-post analysis of changes over time (ITS).

Descriptive Statistics

This approach was used in Goals 1–3 for simple population-level descriptions and comparisons. For Goal 1, this approach was used to describe the characteristics of the SDC pilot program population and compare this population with HCBS-eligible HARP enrollees not participating in the SDC pilot program (i.e., non-participants) who also met evaluation inclusion criteria. These analyses were conducted for both sites combined and by site; for the site analyses, SDC participants were compared with non-participants residing in the same region (NYC versus ROS). We conducted a chi-square test and McNemar's chi-square test to compare binary outcomes between SDC participants and non-participants; for continuous variables, we used the Analysis of Variance (ANOVA) F-test.

Interrupted Time Series

This pre-post quasi-experimental approach was used in Goal 3 to assess outcome changes over time for the SDC pilot program group. This model assessed for changes in the trend in the outcome variables from pre- to post-intervention and used the estimates to test hypotheses about program impacts. Because the ITS approach does not employ a control group, observed changes in outcomes may not be attributed to the program but, rather, to other independent events occurring concurrently; however, the confounding effect of other potential drivers of observed effects is minimized if it may be assumed that other drivers have a constant effect over time. Our ITS models included several adjustor variables: demographic characteristics (age, sex, race/ethnicity), BH diagnoses (Any SMI and SMI diagnoses, and Any SUD and selected SUD diagnoses), and overall health status described with the core health status revised variable. For binary outcomes, these models were conducted as logistic regressions as well as linear probability models; however, for interpretability, we only report linear probability models to make direct estimates of the pre-post changes in the outcomes of interest.

4. Findings

4.1 Goal 1. Implementation of a viable and effective SDC program for HARP enrolled/BH HCBS eligible individuals throughout NYS (Process Evaluation)

The process evaluation sought to understand how the SDC pilot program has been implemented, focusing on the elements that are critical to achieving program outcomes according to the logic model, with an eye toward informing broader scale-up of SDC. The evaluation explored issues associated with barriers and facilitators to SDC implementation; clarity of roles and adequacy of training for key personnel (e.g., financial intermediary, support brokers); adequacy of policies, procedures, oversight, and monitoring from agency leadership and NYS; integration of SDC within agency services; coordination between pilot sites and the financial intermediary; recruitment and enrollment of SDC participants; and provision and receipt of SDC services, including experiences developing recovery plans and budgets.

This component of the evaluation used a combination of quantitative and qualitative methods to address the three process-related research questions stated in Goal 1. The first question concerns enrollment in the SDC program, which we addressed through unadjusted analyses of Medicaid data (see Section 3.3, Quantitative Data Sources). The second and third questions of the process evaluation were addressed using qualitative methods, i.e., a combination of focus groups, key informant interviews, site visits, and document reviews. Participants in the qualitative components of the process evaluation included SDC participants, support brokers, pilot site agency leadership, Advisory Council members, fiscal intermediary staff, and OMH program staff, as well as any additional stakeholders identified as having relevant expertise and exposure to the SDC pilot program (e.g., policymakers, members of provider network).

Research Question 1.1: What are the characteristics of SDC participants and how do they compare to the larger HARP and BH HCBS eligible population?

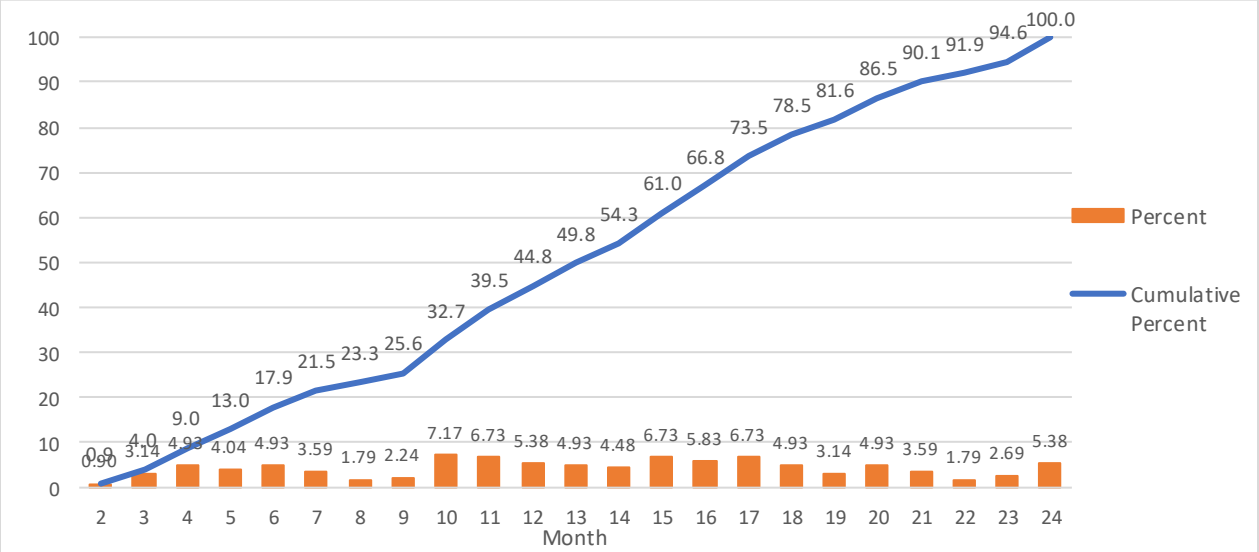
This RQ included one hypothesis:

Hypothesis 1: Members of the HARP/HCBS population will be enrolled for participation in SDC at the two (2) pilot sites.

In this section we describe enrollment in the SDC pilot programs and compare characteristics of the enrollees with the total eligible population. For the reasons described in Chapter 3 (Cohort Construction and Analytic Considerations), the cohort employed to address this RQ included 223 of the total 237 participants (94 percent), 81 of them enrolled at the New York City site and 142 enrolled in the Newburgh site. Duration of enrollment varied widely because recruitment continued throughout the study period and a small number of people dropped out during the study period. Figure 4.1 shows the distribution of months of enrollment for all program

participants (orange bars) and the cumulative proportion of the sample with enrollment at or below each number of months (blue line). Total duration of enrollment ranged from 2 to 24 months. Only a small proportion, 5.38 percent, were enrolled for the entire 24-month evaluation period; . The figure shows the distribution of months of enrollment across all program participants. About half of the participants (49.8 percent) were enrolled for 13 months or fewer out of the total 24 months of the evaluation period.

Figure 4.1. Duration of SDC Participation, Pilot Sites Combined (n = 223)



SOURCE: Authors analysis of SDC enrollment data

Table 4.1 compares individual characteristics of SDC participants with HCBS-eligible HARP enrollees not participating in the SDC program. The sample sizes reflect multiple observations per person, which are accounted for in the reported percentages and statistical tests for differences between groups. Participants in the NYC program are compared with the broader population of eligibles in the NYC region, and participants in the Newburgh program are compared with the broader population of eligibles in ROS. Across both sites, relative to all HCBS-eligible HARP enrollees not participating in SDC meeting evaluation inclusion criteria, SDC participants were younger than and had higher rates of Any SMI diagnoses or Other Serious Affective/Psychotic Disorders but had lower intensity of both BH and non-BH outpatient and acute care utilization (Table 4.1). Relative to HCBS-eligible HARP enrollees residing in NYC, the NYC site SDC participants were more female, had higher rates of schizophrenic disorders, other serious affective/psychotic disorders, and Any SMI diagnoses as well as lower rates of OUD, and lower intensity of BH and non-BH outpatient utilization. Relative to HCBS-eligible HARP enrollees residing in ROS, the Newburgh site SDC participants had higher rates of Any SUD and OUD diagnoses, and lower intensity of both BH and non-BH outpatient and acute care utilization.

Table 4.1. Characteristics of SDC Participants Relative to HCBS-Eligible HARP Enrollees Not Participating in SDC (Non-SDC), by SDC Pilot Site

	NYC Pilot Site				Newburgh Pilot Site			
	All (N=34,320)	SDC (N=235)	Non-SDC (N=34,085)	P-Value	All (N=36,904)	SDC (N=272)	Non-SDC (N=36,632)	P-Value
Age, Mean (SD)	44.8 (11.67)	42.5 (11.69)	44.8 (11.67)	0.09	41.6 (11.90)	40.1 (11.83)	41.6 (11.90)	0.17
Sex, %								
Male	51.2	39.6	51.3	**0.04**	43.8	51.1	43.7	0.11
Female	48.8	60.4	48.7		56.2	48.9	56.3	
Race/Ethnicity, %								
White	26.0	30.2	25.9	0.22	57.4	57.0	57.4	0.15
Black	49.0	44.7	49.0		29.2	33.8	29.2	
Hispanic	15.2	15.7	15.2		10.7	7.60	10.7	
Asian/American Indian/Other	9.9	9.36	9.9		2.68	1.52	2.69	
Behavioral Health (BH) diagnosis, %								
Schizophrenic disorders	48.0	59.5	48.0	**0.04**	38.2	33.1	38.3	0.23
Bipolar disorder (severe)	4.71	4.31	4.71	0.83	5.65	5.88	5.64	0.91
Other Serious Affective/Psychotic Disorders	53.7	66.0	53.6	**0.02**	56.2	64.3	56.1	0.06
Chronic alcohol abuse	21.7	19.8	21.7	0.66	24.1	30.2	24.1	0.12
Opioid abuse and dependence (OUD)	19.5	6.47	19.6	**0.00**	15.7	28.7	15.6	**0.00**
Any Serious Mental Illness (SMI) diagnosis	75.7	88.4	75.6	**0.00**	71.2	72.8	71.2	0.68
Any Substance Use Disorder (SUD) diagnosis	43.1	35.3	43.1	0.14	41.5	51.5	41.5	**0.03**
Core Health Status, %								
Healthy to minor chronic disease	3.23	4.68	3.22	0.79	5.3	4.78	5.3	0.27
Moderate to significant chronic disease	67.8	68.1	67.8		72.6	78.3	72.6	
Dominant chronic disease to catastrophic conditions	29.0	27.2	29.0		22.1	16.9	22.1	
Health Service Utilization, Per Year, Mean (SD)								
Key Behavioral Health Outpatient Visits	11.0 (1,919.45)	9.52 (144.06)	11.0 (1,913.26)	**0.01**	9.87 (1,694.17)	8.13 (128.36)	9.88 (1,689.24)	**0.00**
Non-Behavioral Health Outpatient Visits	6.13 (1,156.42)	5.29 (85.54)	6.14 (1,153.00)	**0.02**	5.19 (1,046.67)	3.08 (40.34)	5.20 (1,045.35)	**0.00**
Acute Behavioral Health Visits	4.03 (789.36)	2.87 (31.33)	4.04 (788.72)	0.15	3.46 (550.33)	2.28 (24.31)	3.47 (549.77)	**0.01**

	NYC Pilot Site				Newburgh Pilot Site			
	All (N=34,320)	**SDC (N=235)**	**Non-SDC (N=34,085)**	**P-Value**	**All (N=36,904)**	**SDC (N=272)**	**Non-SDC (N=36,632)**	**P-Value**
Acute Non-Behavioral Health Visits	4.28 (1,149.88)	3.40 (52.28)	4.29 (1,148.70)	0.08	3.96 (1,012.08)	2.59 (36.48)	3.97 (1,011.27)	**0.00**

NOTE: SDC participants may be captured more than once but analyses account for repeated measures

Research Question 1.2: What was the experience of HARP enrolled/BH HCBS eligible individuals participating in the SDC Pilot program in relation to satisfaction with the SDC program and its impact on their recovery, quality of life, and benefit from health and BH services?

This RQ included one hypothesis:

Hypothesis 1: Participants will gain experience with budgeting and using funds to meet recovery goals with resulting improvement in satisfaction with services, recovery, quality of life, and health/BH.

Qualitative Findings

Interviews with SDC participants were conducted to identify themes related to their experiences and satisfaction with the SDC program (H1). Findings to address this question are organized in three sections: The first focuses on SDC participants' experiences with enrolling in SDC and working with SDC staff; the second describes participants' perceptions of various SDC processes (e.g., requests, purchasing); and the last section describes participants' perceptions of the SDC pilot program's impact on their recovery, quality of life, health, and behavioral health.

Perspectives on Enrollment in the SDC Pilot Program and Working with SDC Staff

Initially, most participants expressed some hesitancy when first learning about the SDC pilot program. One participant explained, "It sounded too good to be true," (C-6) while another expressed skepticism about the intentions or expectations of the program prior to joining, asking, "What are the issues that may arise later on with receiving this 'free' care?" (C-10) Similarly, another participant described their initial reaction to the novelty of a program such as the SDC pilot as not necessarily concern but rather uncertainty: "I wasn't sure how it was going to work out what was going to happen, but I wasn't concerned. It was unfamiliar." (C-1)

Participant concerns were eased once the mission of the SDC pilot program was further described to them, with providers focusing on getting to know participants, emphasizing the program's voluntary participation, and the goal of helping people self-direct their own wellness and recovery. One participant expressed feeling comforted upon learning more about the program's approach.

> They stressed how our care is very important, our comfort, and that we have the option to opt out of the program at any time…And they explained how whatever funds it's given will be towards education goals, life-living goals…They emphasize the importance of the health of each member…They [SDC] explained in detail that it was completely of your choice, and nothing will be taken from you and it's just there to assist you and I was reassured, and I joined. (C-10)

Participants viewed the purpose of the SDC program "as a means of gaining independence back" as well as a program that facilitated participants' achieving their own wellness goals in a

flexible and self-directed manner, which was different from other programs they had been exposed to in the past. When describing how SDC differed from other programs, one participant noted,

> This program really makes me feel like I'm part of a family—that they really care about my goals, not just an administrative "yes" or "no" project. It's really like, "Is this working out for you…?" It's not "Okay, you're approved, or you're not approved…" [In SDC,] you do not feel like you're just a number. You really feel like you're a person. (C-8)

Once initial skepticism of the SDC pilot program subsided, participants most often expressed gratitude and appreciation for the opportunity to be enrolled in a program like SDC and all were in favor of expanding the program so that it could serve more participants. Participants seldomly conveyed significant concerns while describing their participation in the program, but they did offer some suggestions for further improvement, largely focused on aspects of the SDC request and purchasing processes, as described in later sections.

With high consistency, participants reported positive experiences working with their support broker upon enrollment in the SDC pilot program. Participants' initial encounter with their support brokers often focused on developing their own recovery plans and associated goals. Participants generally described support brokers as providers who were open-minded and centered on eliciting participants' perspectives to help formulate goals.

> The people that work there—they're open minded. They are just compassionate. They are very understanding. So it's like they see you, they hear you when you talk about your goals, and they actually advocate for you so that you can achieve it. And even if it's something you want to try, like cooking or something like that, and you find out "Oh I don't like it," but at least you finally have the opportunity to learn and try it. And that's what self-direction gives you—an opportunity that you never had before. (C-7)

Participants described ways in which support brokers approached their roles in the early stages, supporting participants with initial purchase requests that were often more general and deemed more "important" and "necessary" by the support broker, such as a cellphone or clothing. Other times, participants would approach the support broker with an entirely self-identified request (e.g., music lessons, yoga retreats). Most participants reported that goals and purchases reflected their personal desires for areas to focus on and how to progress in their wellness and recovery. "They listen to you. It's individualized—like my goals are not other people's goals and that's OK. So that's big." (C-7) For some, identifying goals and needed goods or services to support those goals was a fairly straightforward process with minimal input from the support broker. However, many participants emphasized that they appreciated input and feedback from the support broker to help identify, prioritize, and expand on goals, or identify resources that could advance their wellness, and felt that the support provided was consistent with self-direction.

> It's difficult sometimes because life moves fast…It's hard to know if I should stick to one budget because [I have] a lot of things going on in my life…and that's why it's great that it's self-directed and not one hundred percent sticking to this one budget. (C-4)

> It's definitely more self-directed than anything…but I've definitely gotten guidance from my support broker. (C-6)

Participants emphasized the nuanced ways in which support brokers would offer input, doing it in a way that was still consistent with a self-directed approach to identifying goals.

> I barely go anywhere… [My support broker] doesn't say, "Hey go outside."…[But] for example, I went to the museum and I'm like, wow, when was the last time I went to a museum? And why haven't I been to the museum? I love museums. It's kind of like forgetting that I should be going outside. He helped me to remember that. He didn't say, "Go outside!" But having that socialization and actually talking to someone… yeah, I probably need that. (C-7)

Participants often noted the various ways in which support brokers assisted them above and beyond their roles. For example, one participant requested SDC to cover the cost of a resource after her parent unexpectedly passed away, only to be initially denied. The participant recounted how their support broker not only successfully advocated to overturn the denial but was also available throughout the participant's grieving process for emotional support.

Overall, participants credited the role of the support broker as essential to the generally smooth functioning of the SDC pilot program, highlighting that they felt that brokers knew them and could be relied upon:

> I just kind of create a list of things and submit it. And they understand the process of how to verbalize with the item of service is intended for…My support broker knows my aptitude. So, it's sort of like everything that I'm doing is kind of like dominoes. It kind of falls into like the career path. (C-9)

> My broker that I work with is just very intuitive…[She] kind of just knows…So I never had the experience of having to really justify something. (C-5)

While most participants valued brokers' input and feedback, a few participants expressed tension regarding requests to meet their own goals versus those recommended by the support broker. For example, one participant described wanting to pursue a certain artistic activity, saying, "It would give me confidence…that would make me feel really good…my age has a lot to do with it…I haven't accomplished much. Now I would just like to feel like I've done something for myself to make me feel better." (C-4) However, her support broker dismissed this goal, leaving the participant wondering whether her goal was not appropriate or whether she had just not been able to adequately articulate her rationale.

> But it's like sometimes, if you don't answer the right way, you're not gonna get it… [The support broker] was asking me if I wanted more important things now

> and that 's when we got into the cleaning supplies. And we also talked about clothes...I mean I make myself more nervous because I don't want to screw this up. (C-4)

For some, the nuanced rules of SDC that could lead to unintentional misuse increased anxiety, creating a power dynamic that led to nervousness in requesting purchases later in fear of being seen as taking advantage of the program or not appreciating the value of SDC. Another participant commented on how they were thankful for the program but hesitated to ask about SDC potentially helping to pay for a medication that was no longer being covered by insurance: "They're already doing so much and…I don't wanna take advantage of nobody. I'm just that type of person I guess." (C-11)

The other challenges participants sometimes noted were variable access to their support broker, differences in provider fit, or turnover. While participants were generally satisfied with how often they were in contact with their support brokers, they described varying patterns of interaction. Some participants described that contact with their SDC broker was much more frequent and consistent in early stages of participation but decreased as time went on. Contact frequency was often dependent on participants' level of need, current life stressors, their relationship with the support broker, and the usual practice of the agency and broker themselves but occurred at minimum once a month. One participant noted a challenge as a result of decreased meeting intensity:

> I have to wait for the next meeting to bring it up because if I do bring it over before then, I'm told this is something that we will discuss in the next meeting, and it just takes longer for instance. (C-13)

While this change in meeting structure sometimes resulted in delays in requesting and processing purchases for some participants, it was not consistent across all participants, with many noting that they were in contact with the support broker once a week on-going. Further, almost all participants indicated that their support broker would touch base with them even if there was no open request purchase active at the time. Participants, especially those who were less likely to actively utilize SDC more consistently, appreciated these check ins as they not only allowed them the opportunity to consider new goals or purchase requests that could further the progress of specific goals but also made them feel cared for by their support brokers.

> She's like, "Hey what about this and why don't you do this, so why don't you do that?' Especially if a period of time has gone by and I haven't… she's very helpful that way to get me thinking about those sorts of things. (C-4)

> Well, they'll call and just check up to see how I'm doing, if I haven't called them or texted them and requested to set up a goal or anything…which is nice, because everybody wants to be loved and cared about. (C-1)

Generally, the relationship with the support broker was described as positive, but a few participants who had worked with multiple brokers as a result of staff turnover highlighted differences in relationships with support brokers. Often, more successful relationships with support brokers were those that were there characterized by easier access, higher frequency of contact, being organized, and feeling that their support broker was "in their corner."

> I have had two [support brokers] ...The first one…left the organization…He was supportive. [But] he was a little bit disorganized, more than most, about keeping track of records. I'm on my game when it comes to submitting receipts…And there were times where he would misplace things…my [current] support broker is phenomenal, just out of this world. "What can we do, what do you need, what would help you with nutrition…?" She knows me, she knows my story. She is extremely responsive. (C-5)

Another participant elaborated on the characteristics of a good support broker, which included being diligent with follow-up and having aspects of cultural background in common to facilitate a shared understanding of needs and goals.

> Someone who kind of has a similar…cultural background to understand why you would need certain things and are therefore able to communicate that to OMH or to whoever they have to convince to approve a budget of the need for a certain item or service. Also, someone who is accessible and that I'm able to maintain communication with them concerning the progress we're making towards creating a budget…[somebody] I don't have to be behind and to continue to ask about whether or not an item was submitted for approval. Somebody who is…just action-oriented and understands that some of the goals that I have tend to be, like, not urgent—like I have to [have] them tomorrow. But the fact that [they] are important and would improve my quality of life, right—and they understand that. (C-13)

Under the circumstances in which a participant began with a new support broker, challenges occurred when the support broker was new to the role and learning how to navigate the program, which could sometimes result in lengthier processing times. Additionally, changing support brokers could also lead to participants feeling some frustration at having once again to share personal histories and open up as part of starting over with someone new.

> That was a little frustrating…to start off with a new person now, and also, it's a little difficult for me to give all my personal information about my past life, who I am, and what my goals are. (C-8)

The relationship that emerged with the support broker was considered an integral part of the SDC pilot program; this same participant further explained:

> It's another thing when the person that you're interacting with understands why you need these things in your life. Instead of just saying OK, you've submitted, you've got approved, here's the money. Bye-bye. They understand what the purpose of this stuff is. And that's really important to me because I don't want to

> feel I'm taking advantage and I want them to understand how important it is to being in my life. (C-8)

Perspectives of SDC Process

Once participants worked with their support brokers to develop goals that tied into their recovery plan, they identified similar facilitators and challenges throughout the request, approval, and purchase process. Generally, participants described a standardized process that most often occurred during monthly check ins with their support broker, in which they would identify and prioritize needs to address for that month. Participants emphasized the importance of researching the item or service requested along with providing a thorough justification prior to having the support broker submit it to the fiscal intermediary. Most participants felt the process was manageable and not cumbersome:

> I feel it is pretty great…I research the item or service that I need. Get a copy of the link, the description of the recovery goal, the price, and if it's an item online, I create a PDF of the actual item. If it's a service, I can direct [them] to the website…So some research, document, submit, review, authorization, purchase, and submit the receipt. (C-9)

> I [meet with] my broker and she'll set up a goal and it gets sent to the state. And the state has the final say on whether it's approved or not. I have a debit card that they gave me and if it's approved, they load the cash onto the debit card. And you have ten days to make the purchase and you have to give them the receipts…there's a lot of lessons in it—learning to budget is something I'm not, I wasn't familiar with…Honestly, I've never had anything not approved…It's just been great…It's been a blessing…It's really a simple process. (C-1)

Participants rarely described experiences in which a purchase request was denied. Nevertheless, they noted some challenges associated with the request process including budget limits/caps, banned items, and inconsistency in the time it took from the request to approval. Participants felt that budget caps were often unexplained, arbitrary and, at times, rigid (e.g., transportation budget). Participants expressed some frustration with the inconsistency of timing from request to approval, as it could result in delays in purchasing the service or item originally requested. For example, from the time of the original submission to the approval to the receipt of funds, the price of the requested item might have changed or was no longer available, leading participants to begin the request process again. However, participants largely emphasized just not understanding the potential varying timeframes for approval.

> Sometimes a request takes longer to be approved and I think it's the lack of consistency that would be confusing. One time I made a request, and it was submitted, but I didn't get the answer 'til a week and a half later and unfortunately by the time I did get the answer, the thing was no longer in stock…And a previous time before that, a request was accepted within two days. So, if it takes a week and a half, that's fine, as long as it could be more consistent. I'm not like, going crazy over it. It's just that the lack of consistency

> sometimes kind of made scheduling what to buy or when to buy it somewhat of an issue. (C-8)

Participants also expressed some concerns regarding the fairness and rationale of budget caps for certain items and spending categories, such as computers or transportation, or rigid rules (e.g., having to purchase the precise number of items even if a reduced price would allow for more items than originally approved): "The only issue I really had was some of the categories, I felt I should have more of a budget…which was frustrating because that would have helped my goal [but] there was a limit on that category." (C-8) Despite these concerns, participants also noted exceptions in which OMH would allow for the purchase of some items that exceeded the standardized budget caps. Often, this would result in a compromise between the original higher-level version of a requested item and the more standard version of the item (e.g., computer).

Impact on Recovery, Quality of Life, Health and BH, and Satisfaction with Services

All participants identified how SDC had positively impacted their recovery and led to significant improvements in their quality of life, health, and behavioral health. Participants described the SDC pilot program as a "bridge back to life" and explained that, while other behavioral health programs also encouraged participants to pursue goals, SDC finally gave them the resources needed to actually pursue those goals.

> In programs, they always say, "yYu should do all this stuff, all these activities," but who has the money to do that? Nobody. So, with self-direction, you actually are able to reach those goals that they talk about in the [other programs] but never have any money to actually do. (C-7)

Many stated that SDC gave them "self-confidence" and a reason to "fight" for themselves or "feel proud" of themselves for the first time in a long time. Participants considered SDC as their first real chance for achieving recovery after having been "stuck in a dark place" for a very long time. One participant described the different ways in which SDC transformed his life, emphasizing how being able to obtain basic household items was connected to a range of life domains and recovery goals, including housing stability, physical health, self-esteem, and overall well-being.

> Things [that] I couldn't afford to have a well-being, to have a mental well-being….At that time, I was living on a blow-up plastic bed… I have back problems... So, the program bought me a bed and they bought me sheets, bought me things to make me feel like I lived in a home there…I really [had] nothing 'til they help[ed] me to get my self-esteem back in order…Just buying me stuff for a normal life… to be able to get up and feel proud of yourself. And I feel like, you have some integrity and, rugs for my floor and curtains on my window. So, I felt like I lived in a home and not an extension of jail. (C-8)

Many participants commented on how the support of SDC had helped them to have appropriate clothing and an environment in which they were able to function, that felt like a

home. This in turn made them "feel norma,l" (C-1) "like I'm living more like a person" (C-6) and feeling "a lot more…like I exist…" (C-4).

With the support of SDC, participants felt that it "made my life less stressful" and that "it takes a lot of pressure off." Many described how, with SDC, they were able to change their perspective to finally focus on pursuits that would promote their mental health and recovery versus mere survival. As one participant who bought a Seasonal Affective Disorder lamp explained,

> $60 is a huge ask. It's not something that I can casually save up for. So to be able to ask [SDC] for something like this, to see if it will help my mental health, and it does, that's an amazing feeling to be able to have money set aside for things that I need that aren't…life or death stuff, like food and rent." (C-6)

Another participant similarly explained how being in SDC facilitated a shift from basic survival toward pursuing higher-level recovery:

> [My goals] have broadened out…I'm writing a book now and they've paid for my writing classes... [When I started the program] I was very damaged and I had just gone through a lot of trauma. And my goal really was just to survive…I was really in a bad place…And my reality was my dark place. That was who I was, and it defined me. And because of the program I would be able to get out of that. (C-8)

Participants also repeatedly highlighted how the overall approach of SDC and the resources purchased increased their independence, including helping them to have something that most people would take for granted, such as a phone, that now helps the participant manage their own appointments and insurance.

> The phone to call my doctor, Medicare... [It's made] a big difference and I know my [other program counselor] is glad 'cause she had to do everything, but this way with the phone, I can do it myself…It's nice to do things on my own. (C-11)

> Take the help and help yourself, so you can help yourself again in the future without having to lean on someone to do it for you. And that's what I've been doing. This program taught me how to really stand on my own, to be honest with you. (C-2)

SDC participants described various ways in which SDC directly impacted many domains of their recovery. As highlighted earlier, participants repeatedly explained how a request for a resource may have been made with a specific goal in mind, but that the resource's impact spread across multiple goals and life areas. For example, one participant who experienced chronic pain remarked that purchasing a chair eased his pain; however, the participant further explained that this also finally allowed him to sit comfortably to complete his GED classes and attain his GED. Many participants described how having the funds to purchase specific goods (e.g., bicycles, cleaning supplies, clothes, vitamin supplements, computers) and services (e.g., dental services,

acupuncture, chiropractor, biblical counseling, yoga sessions, life-coaching) contributed to their overall wellbeing. Several participants described ways in which SDC allowed them the opportunity to address their physical health (e.g., gym memberships to lose weight, a bed to increase sleep quality) while later also contributing to an improvement in their mental health. Similarly, funds provided through SDC increased access to services to address physical health conditions that they would otherwise not have been able to afford.

> Well it helped me in ways that I would never have been able to help myself. For example, I suffer from lower back pain. And I was seeing a lot of back doctors and getting injections…And the program funded [me] to be able to see an acupuncturist. And now I've been seeing this acupuncturist for a year, and I've never been back to a doctor… The acupuncture really worked...It's changed my posture…It all has been totally interconnected. Once the back issues have greatly improved, I am getting depressed less because I could move around, I could do more physically, which helped with my depression. (C-8)

The ability to utilize funds to address long-standing physical health issues and subsequently improve one's mental health was also described by the following participants:

> I have jaw pain… that I couldn't address right away that was devastating for me. And the fact that the grant was able to cover [a surgery not covered by Medicaid] that could have taken me—if I were able to work to afford it—could have taken me another 10 years to get…. that was [a] profound thing that this grant was able to do for me. It was a huge level of anxiety for me when it came to my physical health, which right there is the mental connection. (C-6)

> The old bed, it was really damaged, and it was affecting my sleep and hurting my back. And so being able to have a mattress that has adequate support has improved the quality of my sleep… [which is] a very important part of regulating my mood. So it's been really helpful. (C-13)

Another participant commented on how SDC had helped them see an autism specialist, not covered by insurance, which allowed them "emotionally to better understand myself and that's something I felt self-direction helped me to do; to be able to understand myself socially or emotionally in relation to society." (C-9) Another participant explained their shift in mental health:

> [When] you're dealing with PTSD to this level of sheer madness, it is a bright light when a program comes along and helps you obtain a goal that you felt so deeply about, or feel so deeply about, that it puts a smile on your face through all of that. (C-2)

In addition to numerous ways in which SDC increased access to resources that helped improve physical and behavioral health, SDC offered participants the ability to make progress with education and employment goals. For example, SDC supported participants interested in

pursuing educational or employment goals to purchase textbooks and school materials, or to fund transportation so they could get to school or work.

> I mostly focused on my education, I was in college during this time…with textbooks, transportation… They were able to help me purchase some items that I've used for recording—like I made this short documentary for my thesis film…. I just graduated…last year. I really want to get out there and make more documentaries. It's difficult to not have access to the equipment at the school, but with the help of the program assisting me…it makes it all possible. This has pretty much been the focus of as to why I joined the program, to assist me with education and…pursuing my career. (C-10)

Additionally, participants were able to request funds from SDC to invest in their own businesses and pursue employment opportunities. This included approving the purchase of devices needed to roll out a podcast, covering materials and expenses needed to publish their own book, or financing the cost of equipment related to participants who were trying to be self-employed. Participants expressed how having this opportunity gave them both a source of income and a sense of purpose and direction.

> I wrote a children's book after I graduated and they helped me publish it, self-publish it. Now it's available and I didn't realize that that was like an actual business…Which is good because even though I can't really socialize with other people or leave the house, they're helping me to still find meaning in my life. And without that I'm really suicidal and depressed. So, it's really great that they're helping me find a reason to be here …It's also opened up into a marketing business. So, I'm helping other authors as well [to] market their books. (C-7)

> I ended up going back to school to further my education and to become licensed… [With SDC], I was able to get a [new computer] ...And they recently helped me pay for my licensing exam…also, study materials so that I can pass it. (C-5)

> Self-direction pays for Internet service, which anyone who lives [now] would understand how important that is…I first requested the Internet so that I could be able to do online coursework to get my state certification, because I'm a peer specialist. (C-13)

Several participants described ways in which SDC had helped them to reconnect with others or to integrate into the community in ways that had been limited to them before. One participant described how recurring physical victimization had them living in constant fear and thus isolating from the outside world. SDC provided unique opportunities to address their trauma and regain a fundamental sense of enhanced safety. Participants described how SDC helped increase their quality of life and improved their mental and physical health by covering expenses that increased social connection through meaningful activities.

> I've been attacked so many times by men. I really wanted to have martial arts skills… so that I could actually protect myself from attacks…That also came into play with me losing weight and socializing. Because of being attacked so many times out there, I don't go outside too often; I have high anxiety and I'm always afraid…The whole thing (taking self-defense classes) was very beneficial for me. So, it went above and beyond just paying for a class that I couldn't afford. (C-7)

> I have to do things to help people…If I don't do it, the nightmares…will start coming back. [So] I stay involved…SDC bought me [printing equipment] …I remember the first time out, it was [for] cancer patients. They were children [in the hospital] …It's gut-wrenching…but I've noticed those t-shirts and hats make them smile and I guess give them a sense of hope…They look forward to seeing me coming back. (C-2)

Another participant explained how the purchase of simple, tangible things, such as a train ticket and yoga class, create a path that ultimately translates to personal wellness as well as relationship transformation.

> I [hadn't] seen my father for thirty years [before SDC] …It saved my relationship with my family…Other than buying the [train] ticket, there really wasn't anything that they could [tangibly] supply me with…Other than being able to see him. But again, making me feel better about myself made my relationship with my father better. Because I had a lot of shame about going to jail…So being able to take a writing class or take a yoga class or have a computer to work on, getting a website…made me feel like a real person. So when I spoke to my dad, I wasn't defined by [being] his son that just got out of jail. I was defined by this person who had a life and one who had a direction and a journey. And I could say to him, "Well, I'm taking a writing class and I just took my yoga class." I didn't have to say, "I have to go see my parole officer." I felt confident. It gave me confidence. And not only [with] my dad, in society…I'm not trying to be nice because the program has bought me things…This program really helped me and not because of the "things." (C-8)

Another participant explained how purchasing a bicycle through the program helped them to engage in activities in the community, while also fostering a sense of independence.

> It's easier for me to just go out and take a ride…I can't go out and walk like I used to, cause [of] my [foot problems]. But I can get on my bike and ride around…I'm not just sitting in the same four walls, staring at the wall all day, watching TV…NA meetings, Bible study…it helps me get out to those things. It still gives me a level of independence...I don't have to always search for a ride…Sometimes it just feels good just to do things on my own. (C-1)

Some participants also commented on the intersection of their mental health and spirituality, and that SDC helped them pursue spiritual activities, such as yoga or a spiritual retreat, which helped promote their well-being.

> One of those services that self-direction helps pay for me [is] the spiritual counseling…the biblical counseling that's been really important for me…I still also see a therapist but having a [spiritual] counselor has helped me to identify and work through things that I realized [a therapist] would not be able to counsel me. (C-13)

Finally, participants also explained the significance of SDC in helping them maintain long-term recovery from substance use.

> It is the longest time I have sustained sobriety…in my adult life…The additional supports that SDC was able to help me implement in my recovery absolutely were essential because it also gave me a little bit of motivation—well here's this program that's helping me. I don't want to screw that up…When I think about the number of treatment episodes I had prior to starting since that last period of sustained sobriety—I feel the goal of the program—to keep people from utilizing those crisis service responsibilities…in my case was very successful. I'm not going to say my whole recovery is because SDC helped me. But…it was a big additional support. (C-5)

> This program came along and even like little things…Little things, I couldn't even do that. So without them, I wouldn't have had those things where…I may still be using, if it weren't the case. I'm able to try to do things on my own, like I've always done, and you know it doesn't always work out. It took me a long time to learn that [sometimes you can accept support]. (C-1)

Research Question 1.3: What was the experience of non-participant stakeholders in the SDC Pilot program (e.g., Support Brokers, pilot site agency staff, State program development/ oversight staff, fiscal intermediary) in relation to SDC implementation including State oversight and contracting, fiscal policies and procedures, hiring of SDC staff, recruitment and work with participants, and coordination with the fiscal intermediary?

This RQ included five hypotheses:

Hypothesis 1: OMH administrative staff will develop selection criteria, contract deliverables, and procedures for ongoing monitoring for both pilot site agencies and the fiscal intermediary.

Hypothesis 2: OMH administrative staff will develop fiscal policy and oversee fiscal intermediary and pilot site implementation.

Hypothesis 3: Support brokers will be hired, trained, and supervised by pilot sites and will interact with SDC participants and supervisory, fiscal intermediary, and State oversight to facilitate SDC among participants.

Hypothesis 4: Pilot sites will work within OMH administrative policy to recruit, enroll, and facilitate ongoing participation in SDC.

Hypothesis 5: Fiscal intermediary will develop a web-based system for entering, approving, and monitoring participant spending and will provide customer service to support brokers and SDC participants.

Qualitative Findings

Findings for this question draw from the document reviews (e.g., OMH and fiscal intermediary administrative documentation, pilot site administrative and participant orientation material) and qualitative interviews with informants representing key stakeholders (e.g., Support Brokers, pilot site agency staff leadership, State program development/oversight staff, fiscal intermediary, advocacy organization) across the SDC Pilot Program. Findings for this question are organized into four sections: The first addresses SDC pilot site selection and an overview of OMH oversight; the second focuses on SDC pilot site staff roles and the nature of support provided to SDC participants; the third presents a range of findings associated with key SDC processes including eligibility and enrollment, rapport-building, recovery planning/goal development, budgeting, and purchasing; and the last section further elaborates on OMH oversight including request reviews and approvals, and the role of the fiscal intermediary.

SDC Pilot Site Selection

The two agencies chosen to participate in SDC were purposefully selected by the Office of Mental Health for their knowledge of self-directed care or related expertise but with eye toward distinct differences in their mission, experience, and context. When selecting pilot sites, state agency staff emphasized the need for community-based programs that already had experience with Medicaid and Medicaid Managed Care (given the HARP population to be served) and additionally highlighted both sites being peer-run as beneficial. The sites chosen also offered an opportunity to pilot the program among agencies that differed in geography (e.g., urban, suburban), and operating structure and programmatic expertise, with one site focusing on a wide range of services within mental health and the other offering comprehensive services across a range of disabilities, including prior experience with operating self-directed care for people with developmental disabilities.

> They take slightly different approaches, but we looked to standardize the policies between them and the procedures, but they took a slightly different approach based on the staff and culture, resources that their agencies began with. (OMH-10)

In addition to implementing the SDC pilot, each agency offered a comprehensive array of other services including supportive housing, education and employment, health and wellness, and care coordination. The SDC pilot was generally described as well-integrated into this existing infrastructure and other services, and most participants received other services in addition to SDC. Many referrals to SDC had originated within the client population served by the two respective agencies; other participants, newly affiliated with the agencies through SDC,

could also be connected to other services as SDC staff recognized participants' additional needs that could be addressed beyond their program. These high levels of integration into existing agency infrastructure and the close linkages to other support services was beneficial to SDC program operations.

Stakeholders from one site in particular also highlighted how the SDC program being immersed in the agency's culture of person-centered and recovery- and advocacy-oriented services facilitated implementation of SDC operations and processes that promoted the self-directed nature of the program.

> It's a natural fit…The program is self-directed. The pilot program is situated within a grouping of other types of support and services that are very recovery-oriented and I think it has an ethos to it, so to speak. That is something that I think is shared amongst many of the other programs in [the] division so that it's really trying to enhance and highlight the participants' own perspectives on what they need to move forward in their recovery process… So we see some referrals from other programs within the same division…other parts of the agency as well certainly. But I think it's sort of similarities in how we approach participants in these types of programs that make it a smooth integrated part of the rest of the division. (L-2)

SDC Sites and OMH Oversight: Enhanced Communication and Collaboration and Evolving Guidelines

Stakeholders described initial stages of the pilot as a learning process that required extensive communication and coordination from all parties (e.g., participants, staff, leadership, and OMH) while deliberating and developing parameters within which the program would operate. There was broad consensus that a closer and more efficient collaboration between OMH and site staff emerged over time, with reduced need for ongoing meetings and less time and effort needed for clarification regarding various aspects of the approval and purchase process. Stakeholders emphasized that everyone had developed "greater understanding across the board" regarding how to relate purchases to goals, what factors go into approval decisionmaking, and what the overall parameters were for budgets and purchase requests, and that this meant that "things just run smoothly."

> In the beginning…we were meeting with fiscal almost on a daily basis and now I would say it's probably less than 1 percent of the purchases that they have questions on. Most of [the requests], the support broker supervisor approves them, fiscal gets it, looks at it, if they have a question they'll ask us, but very few at this point… I think that there is greater understanding across the board, not only from our folks internally, but from the agencies who were working with the individuals receiving the service, as well as the individuals themselves. (OMH-16)

Stakeholders noted that the process of developing policies was often collaborative and ongoing, taking into account multiple factors and a range of emerging scenarios from different perspectives. For example, stakeholders described this approach within OMH:

> Our guidance comes from the federal guidelines on this program and then the state interprets those guidelines based on leadership feedback. So fiscal and program [divisions] may see eye to eye on the interpretations or have different interpretations of particular parameters of the federal guidance. So, we'll discuss those as they come up in the pilot. We generally have an understanding that fiscal's doing the day-to-day operations of the fiscal work and program is doing day-to-day operations of the program side, and we interface where those two things overlap. (OMH-10)

Overall, stakeholders described the process of developing certain monitoring procedures and fiscal policies as generally geared towards building a sustainable SDC program that would align with Medicaid guidelines.

> [OMH is] really thinking about how we are going to make this viable. How are we going to make this replicable, making sure that it goes through the Medicaid guidelines for the program to move forward, and what would be considered an allowable expense? So that's the lens they're looking at things through. And that's usually the feedback that I would get. (L-3)

The next section reports on pilot staff roles, including support brokers and supervisors, as well as descriptions of how SDC participants are supported within the program.

SDC Pilot Program Staff

While staffing patterns fluctuated at both sites, at later phases, both sites implemented a SDC pilot program staffing structure consisting of three support brokers, a full-time program manager for direct supervision, and a program director for additional oversight.

Support Broker Role. The support broker role was essential to the operation of the SDC pilot program. Almost all support brokers hired had prior experience in behavioral health, with many having experience in case management or care coordination. Stakeholders emphasized that in addition to prior experience in behavioral health, orienting staff to the SDC program and the role of support broker needed to combine both formal training, especially in topics such as motivational interviewing, trauma-informed care, and how to develop SMART goals, as well as on-the-job shadowing of other support brokers. Sites also participated in joint training and technical assistance provided externally by consultants with expertise in SDC or by OMH, particularly in early phases of the program. Given high levels of individualized decisionmaking and tasks that are not usually part of other behavioral health services broadly (e.g., ongoing client budget tracking), this job shadowing allowed staff to see potential challenges that might arise and the range of support that participants might need. Given the self-directed nature of the program, there was a need to ensure that orientation and training helped support brokers to fully embrace and empower participants taking the lead in identifying goals.

> A lot of people [with a history of mental health service use] …have been told what they need by different experts and different clinicians in the context of mental health recovery for so long. [So there's a need to put] a lot of emphasis on self-determination as a core value and thinking about how to even set up a conversation with a participant around what that means for them in the context of

> this program…I think new participants are oftentimes unsure about how to even utilize this program because nobody has ever really asked them these types of questions in this way. So, there's a certain skill set and training that's required, I think, to really approach a participant… around where [they are at], what they would like to be accomplishing. (L-4)

In describing their role within SDC, support brokers referenced many of the tasks stated in their job descriptions:

> [We] assist people with identifying goals related to all different types of wellness…along the 8 Dimensions of Wellness…and getting people to activate on them and make a plan for things, items, or services that they need to achieve that goal and then we assist them in budgeting process, helping make sure that people are getting the things they need to stay on track for recovery. (SB-11)

These ongoing daily tasks included helping participants identify goals and potential resources/services needed; entering goals and purchase requests in the State portal in ways that clearly articulated the specific need and justified the requisite dollar amounts; keeping track of individual participants' budgets; ensuring purchases were made within the required timeframes; requesting receipts from participants and uploading them to the portal; helping to record and mediate grievances and appeals; and keeping supervisory staff appraised of participants' goals, requests, and purchases. However, SDC staff also emphasized that each participant required a highly individualized approach—"You can't cookie cut your approach to everyone; it's just not going to work"—and that some required extra support to ensure successful participation in the program. Factors identified as influencing the extent of support that support brokers needed to provide included participants' ability to identify goals and manage the purchase process and budgeting, as well as how connected participants were with other providers, and the degree to which SDC staff were able to collaborate with those other providers. For example, SDC staff support could be less intense for participants who were closely connected and willing to work with care managers who were also responsive to communication with SDC staff.

> Being connected to other services is helpful, especially when they are internal to the agency as there can be multiple staff to help support a participant going through something… I'll just pick up the phone or send an email or a text like, "Hey, something's going on with [participant], can you give me a call?"…So in-house we work great together. (SB-5)

Supervisor Role. Given the fairly unique role of support brokers within a program focused on behavioral health, as well as the complexities of navigating SDC processes and external partnerships with the State, supervisors played a key role in ensuring daily program functioning. Supervisors described their role as providing support and guidance to support brokers, conducting internal reviews and approvals of goals and purchase requests, providing coverage for support brokers and further addressing participant concerns as needed, and serving as the managing liaison with OMH, including advocating on behalf of participants (e.g., providing

additional rationale for OMH to reconsider a purchase request that had been denied). Supervisors also noted that their role included developing the structure of the program to ensure that support brokers had sufficient resources and support to fulfill their roles effectively. As the program matured at each site, supervisors were seen, in particular, as providing essential guidance to support brokers on how to translate potentially ambiguous rules, processes, and individual scenarios into everyday goal planning and purchase requests.

> [My supervisor,] he kind of will do the buffer work where it's like, "I think OMH is also going to push this back. So maybe just add this one thing here, this one thing there." He does a good job of proofreading all of our budget[s]…[If] I entered everything, and he feels I'm missing maybe one more thing…he'll tell me. (SB-12)

Supporting SDC Participants

SDC staff often emphasized their main responsibility was to best support participants in their own self-direction towards wellness and recovery. While the sites shared an overall SDC program manual, each site further developed materials to help support brokers with policies and procedures, and to orient participants to the program and support them with goal exploration (e.g., goal worksheets) and budgeting. As one support broker described, the process of developing goals might look a little different, depending on the degree to which participants themselves already had a clear vision of what they wanted to achieve, but ultimately the process focused on helping the participant to elicit and articulate potential goals.

> The idea is that these people are really guiding their own care and they're coming up with their own wellness goals and they're coming up with their own budgets…I am at large [an] extension to bridge between them and [fiscal]…I think my job becomes much more conversationally involved…with the participants when they're not exactly sure what they want to do in terms of their wellness goals…[so I have to] do that thing where I'm listening to what they say, but maybe guiding it in a certain way…But a lot of participants, they are guiding themselves completely. They come to the meetings with a literal Excel spreadsheet that has "I have this goal in mind and I want to do this, and I want to do this and I'm going to purchase this for this many dollars…" But across the board at the end of the day it is completely self-directed. (SB-6)

Beyond individualized support to help participants deliberate and prioritize goals, staff noted that some participants needed extra support to research and review guidelines regarding what is and is not covered by their Medicaid plan, coaching on how to use technology to identify and purchase goods/resources on the internet, and that brokers also often needed to maintain a listening/supportive presence during times when participants experienced additional stress (e.g., death of parent) or mental health challenges (e.g., increased anxiety). Stakeholders also emphasized that participants sometimes had unmet basic needs (e.g., food), experienced stressful life events, or simply felt lonely. Because "people have so many extra needs that are involved in the program," support brokers had to negotiate how best to prioritize supporting participants with

SDC-specific activities and wellness goals, while also ensuring that they were responding empathically to a range of participant concerns:

> Sometimes my clients are gonna call…They're having a bad day and they might just need to talk to somebody for 10–15 minutes to get whatever off their chest…So just to say that you're going to speak to your client, you're gonna help them with their goals, you're gonna get their budgets made, get their money, get their budgets approved, let them know that the money's ready, get the receipts—that's not it. The role is so much more expansive that just that…We do have a job description we have to adhere to, but sometimes you have to be human, and human does not mean that I'm adhering just to what's black and white. (SB-5)

In navigating the boundaries of their role, support brokers noted they might provide some additional direct support as needed that might "not technically" be within their role (e.g., referral to a food pantry), offer basic guidance on navigating a different benefit system (e.g., housing applications), or connect the participant to other providers whose "primary role" would be to offer the more enhanced and ongoing support outside the scope of SDC. As noted, support brokers having to step beyond a straightforward process of documenting goals, developing budgets, and processing requests was more extensive when other providers' involvement was more limited, whether due to turnover of other providers or participants' comfort level in working with providers outside of SDC:

> It's a unique relationship [participants have with us] and they don't have as much interest in involving other people in the process [even though] they might have multiple supports…So due to that…we had a little more than we expected to take on with some individuals. (L-3)

When discussing SDC broker caseloads, staff weighed the most significant factors that contributed to their perceptions of feasible caseload ratios. This included the extent of support that participants needed, the degree to which participants were connected with other providers, whether participants were newly enrolled or more established with the program, and the time that support brokers needed for administrative tasks and travel to see participants. Given variation across these factors, providers' perceptions of feasibility generally centered around ongoing caseloads between 25 and 30 participants.

> The caseload now for each individual is somewhere around 22 to 25 each, depending on the individual, and we're looking to ramp that up with each person. We're hoping that we can get to about 30…Part of the original structure…was to not just meet people in an office, but to meet people in a place of their choosing… [At this location], it can take an hour and a half to get from one area to another. So as that ramps back up, we'll have to re-evaluate where our caseloads can stand…But right now, we feel we have the capacity to at least get to 30 each. (L-3)

The next section focuses on describing various SDC pilot program processes including eligibility and enrollment and the use of a person-centered approach to developing goals and recovery plans, budgeting, and purchasing.

Participant Recruitment, Eligibility, and Enrollment

A prior evaluation of the SDC pilot reported that referrals came from providers and interested individuals who had heard about the program through advertisements or word of mouth. As before, especially in earlier phases, sites reported that they relied heavily on their internal client population being served by other programs for referrals while also attempting to reach individuals external to their agencies:

> We had done some email blasts to various different HCBS service providers, housing providers, all different types of mental health agencies, clubhouses, PROS programs, and presentations to several of those that we could. Word of mouth seems to be the biggest referral source over time. (L-3)

However, given that the focus of the SDC program was widely well-received but that slots were highly limited to 100 per site for the pilot, there was quickly higher demand than capacity, especially when sites experienced hiring delays and turnover, and the sites had to start waitlists.

> I was a little anxious starting the program…We can only work with 100 people…There's 80,000 people that are technically eligible for this service…We got to [a] waitlist pretty quickly on…First it was referrals and then we just had an application. That's not—there's no denial piece, but we wanted to make sure we knew people's Medicaid numbers to check their HARP because people often didn't know if they were HARP enrolled. (L-3)

While there were minor differences between sites, stakeholders described an enrollment process, especially in later phases, that generally consisted of participants completing an application, attending an information session, confirmation of SDC eligibility (i.e., HARP enrollment), and preliminary engagement and completion of paperwork through individual meetings with support brokers. Both sites developed informational materials to provide to participants, as well as introductory worksheets or forms for purposes of orientation and enrollment. The eligibility and enrollment process was generally estimated to take approximately four to eight weeks, after which participants would receive their card and be able to make purchases.

> It takes about a minimum of…three to four [weeks] before the card is issued. We have our first introductory meeting where it's just one on one…We're just chatting and getting to know them. And then we fill out the basic paperwork of "Who are you, what would you want to start your goals?" …At the second meeting is when we do real paperwork. We're talking about Medicaid numbers, things like that. And then, the third and fourth interview is…where we get down to the nitty gritty of "What have you been through. What do you want? What do you see for yourself…?" [At] about the fourth meeting after that meeting, that's when the card is in-transit and it's getting ready to be theirs. (SB-12)

Overall, stakeholders identified limited staffing and staff turnover as the biggest barrier to SDC enrollment, particularly vacancies in the support broker roles. While both sites were now, generally, fully staffed, stakeholders noted that program stability and capacity had been achieved more recently. Filling support broker vacancies had been particularly challenging during a stretch of time at one of the sites, thus resulting in a pause in enrollment of several months and overall fewer participants served to date.

> The original thoughts on paper were a caseload of 40…Over time, we were recognizing that we actually needed more staff to be able to reach those numbers…We shifted things around [budgetarily] so we would be able to hire an additional staff member…Almost that same time, we lost one of [our] resource consultants…And it took a really long time to hire people…I'd say about six months, maybe longer. It was just me and one other resource consultant holding down the fort. (L-3)

Stakeholders specified that assessing eligibility entailed confirming that applicants were Medicaid Managed Care members who were enrolled in a HARP and that from there, applicants were enrolled "quite literally based on the time they applied for the program, so almost like a first come, first serve." While stakeholders emphasized that a central tenet of the program is that "anyone is able to self-direct with enough support" and, as noted, that enrollment into the program was "first come, first serve" for those HARP members who were interested in joining, there was, nevertheless, also some discussion that signaled possible consideration of potential participants' readiness and "fit"—"If it's not gonna be a good fit…'we'll get back to you…'" Factors that appeared to play a role in potentially thinking through applicant fit with the program included staff perceptions of how applicants were intending to use the program (e.g., to meet recovery goals versus simply to purchase things they desired), how eager/insistent applicants were to begin making purchases, or whether they had significant competing basic needs that might impact their ability to participate in the program as intended (e.g., experiencing homelessness):

> Their ability to "self-direct" kind of makes the determination. There're some people that come in and right away before they even see if they're eligible, they're coming in for their 'check'…You haven't even gotten to what the program is, or what it does, or how it'll help them, but they have a shopping list of things they wanna get. That's a "No, because you're not going to use this program the way it was meant to be used." (SB-5)

While there was some discussion of fit, it was unclear the degree to which these informal deliberations of participants' fit with the program actually resulted in not accepting certain participants perceived as potentially having a "red flag," or whether it resulted in a more extended and enhanced enrollment process, with staff adopting a more cautious approach to initial purchases for certain participants. Additionally, stakeholders indicated that though the pilot site agencies maintained databases of participants referred and enrolled in SDC, there was

currently no process built in for systematic tracking and reporting of flow into the program that would allow for a complete accounting, for example, of the number of participants referred or who applied, how many were eligible and of those eligible, how many were not enrolled, and reasons why. Nevertheless, non-participant stakeholders overwhelmingly emphasized that, from their perspective, applicants choosing to not continue with the intake process was the most common reason for eligible individuals not enrolling.

Building Rapport, Goal Development, Budgeting, and Purchasing

Building Rapport. Upon enrollment, site staff described a phased approach to supporting participants with identifying goals, developing recovery plans, and managing budgets and purchases. They noted that in the early phases of a participant's tenure in the program, support brokers focus on building rapport with the participant, clarifying the purpose and parameters of the program, helping participants to prioritize goals, and testing out the purchase process with participants.

During the first several weeks upon enrollment, staff described spending time to try to get to know each participant by having "open and honest dialogue," with conversations that focus on understanding different aspect of participants' lives: what "they want to [do] and what exactly is preventing them from doing some other things," and "what they want to get out of the program." In addition to getting a better understanding of participants, staff also dedicated time and effort to ensure that participants developed a clear understanding of the program and what it entailed, underscoring that "you just don't get a bank account full of money."

> When we first start the process with an individual and we're getting to know them, self-direction is very new…It takes a while to get everyone on board with what specifically we can do and what we won't do, and how we operate. And we want to spend some time getting to know them, really understanding all of their wellness goals. (L-3)

Goal Development. Much of the initial (as well as ongoing) work within SDC involved supporting participants with developing wellness goals that reflected participants "really guiding their own care." Particularly for participants starting the program, there were differences with respect to how well they were able to identify and articulate goals. For those with multiple ideas for goals, site staff explained that part of their support involved assisting participants to prioritize goals that they may want to work on. In the beginning, this often meant helping participants to identify one immediate goal—frequently centered around addressing a basic need (e.g., cellphone to maintain contact with SDC staff, adequate clothing, furniture that allowed the participant to function with less pain, or supplies for maintaining a more home-like environment)—that would allow participants to experience the purchasing steps required, give staff a sense of the participant's ability to adhere to program guidelines, and help participants secure some fundamental resources before moving along to more higher-order or long-term goals.

> A trend with people in the beginning with us is getting basic needs met…just making sure their housing and life at home is stable and comfortable. [For] some people, mattresses is a big one…Things that a lot of people get: transportation…[to] be able to baseline get around. And then a lot of clothing and things like laptops, just to have an equal opportunity to present themselves confidently and hygienically and then also have the tools to seek things like classes or trying very actively to get back into work in some situations. (SB-11)

Stakeholders discussed the SDC budgeting process, which would occur in tandem as SDC participants and their support broker would identify one or more measurable goals, and the services and goods required to help achieve each goal. During the process of developing budgets, support brokers helped participants to understand certain limits on maximum allowable amounts for certain categories or certain items, while also explaining there is a need to develop budgets that can keep pace with someone's participation in the program. For example, support brokers would encourage participants to think of their participation in the program long-term and that their budgets would need to last for multiple goals that they may have now, as well as goals that they develop in the future. Program budgets were, therefore, generally structured in quarterly breakdowns to help participants pace their spending, and most SDC participants did not reach the annual maximum spending caps (i.e., $8,000 or $16,000).

> The program is about goals related to your recovery in relation to those eight dimensions of wellness…Just because you can use up to $16,000…you can't just go out and buy $16,000's worth of stuff. Every purchase has to relate back to a goal and usually the goals are foundational. So they will hopefully build towards another goal. (L-2)

As participants' tenure in the program increased, they were then more likely to pursue more long-term goals, have more goals related to maintaining their wellness, manage multiple goals simultaneously.

> We would help them prioritize where they want to start…we always kind of start with one thing first. And as we move along in the program, and as they've maybe started the first goal, made that first purchase, [they were] able to get us that first receipt. Then we start to add more and more items. And then we'll see people have some goals that might be more of a maintenance goal over time that they can do—a goal about maintaining their lower stress levels by utilizing a gym at the same time as an education goal…Our participants will [often] have about maybe five goals active at one time if they've been in the program for a while, because some of those might be maintenance, and it's regular acupuncture, and some of them might be more education or I'm trying a new hobby… (L-3)

Staff noted that there were also participants who entered the program with few ideas for goals and uncertainty about how they could move forward in their recovery. For these participants, staff had to assume a more proactive role in further exploring possible goals,

engaging in more in-depth conversations to help kindle and create a sense of hope and possibility for clients, while being careful not to compromise the self-directed nature of the program:

> I think with some clients who have been frequent users of the system—there's been a little bit of learned helplessness that has come about, and the clients will… say, "Oh well, I don't know what to do, I can't do anything." And it is like, "Okay, well now we have got plenty of time, we can work on this with you…I can help navigate, but you are in the driver seat. You need to kind of direct everything," and with a lot of clients that can be a challenge sometimes. (SB-9)

> With certain individuals, it will take some time to understand and help them articulate what they're going to see out of some of the things that they want to do with their time. And we found that working on goals related to experiencing joy is an important part of the program. We want to make sure that goals aren't just about reducing negative symptoms or reducing stress or reducing depression or sadness, but we want to frame things in a positive way as well. And we want people to…try to experience things that is going to put a smile on their face, which inherently is going to relax them and make them feel stress free as well. (L-3)

Further, most SDC staff explained that they would generally try to minimize the degree to which they would decline to move forward with an individual's purchase request internally, and that they would instead try and spend additional time and effort to help the participant further articulate their goal and how the requested resource was actually connected to it.

> We don't do as many [rejections] of those internally…if we feel it's not super approvable, we're almost trying to get a better understanding of how it relates to someone's goal. But if it isn't relating to a goal, you're going to have to let someone know, "We need a better understanding or we're not going to be able to move forward." …There's one individual that was talking about wanting [an item] for quite some time, and it ended up being something that we could see how it related to their goals, but it did take several meetings to understand. So, we were really trying to work with them to figure out how they were going to utilize this… [to further] a goal in a goal-related fashion… It didn't come out right away, but [over time working with them] they were…going to be going to school…and we're like, well, that makes sense now, that we understand. Like, this is also related to education. (L-3)

Finally, providers noted that they also needed to help participants formulate goals in ways that would be measurable and [theoretically] achievable, citing that it was important to be able to conceptualize how benchmarks and progress could be identified along the way. They explained that this explicitly did not mean asking participants to abandon goals that others might perceive as unrealistic but helping them to tailor the language to better align with potential indicators of progress.

> When we're saying it's achievable, we're talking about taking a goal and figuring out what are the steps that are required to get from [A to B]. It is to think about framing those steps in a way that it is, in principle, actually something that can be

> accomplished. Because sometimes people could write goals in ways where the language is such that it's something like how would you even know if that was achieved? (SB-4)

Purchasing. Most stakeholders noted that there were some enhanced parameters regarding making purchases in the very beginning, allowing staff to get a sense of how the participant would be able to identify and research purchases, manage making requests, and follow-through with purchases and receipts within required timeframes. While there were some differences in how stringently site staff approached this early phase, overall, this meant that initial purchases were generally formulated to be of more modest cost and, as noted, to meet a more immediate short-term wellness goal that did not involve multiple open requests at one time. Once participants developed familiarity with request and purchase processes, they were then able to explore resources/goods that may involve more substantial cost and—as appropriate—make multiple requests and have access to higher card balances.

> We start out a bit more modestly assisting in that direction [of their goal], and if they actually are successful and they need help to move to the next level, we could provide that help. But we don't make a very large expenditure on the front end until the person demonstrates their willingness to pursue it and their ability to pursue it. (OMH-16)

Importantly, while SDC used some of this phased approach, there was still a focus on aligning program operations with participants' goals by strategizing creative ways to facilitate access to needed resources.

> In the case of the photographer…the camera that he requested was really expensive. So, we weren't going to pay for that, but what we did is we allowed him to rent a camera and then we rented some studio time for him to take some pictures and again to start to get his business to come back. And then after I would say six months, he requested a more modest camera that we did pay for. (OMH-16)

Misuse of Funds. Misuse of funds was defined as instances wherein participants spent SDC funds on resources for which they were not approved, whether in terms of a mismatch between the type of resource approved versus purchased, or by exceeding the number or allotted dollar amounts of the resource that were originally approved. The most consistent finding regarding misuse was that almost all stakeholders reported that participant misuse of funds occurred far less than had been initially expected and that, overall, misuse was fairly infrequent.

> It was next to none. I was surprised how few abuses there were, but I think the critical part of that is we had real time data through (the card company) and we had a fiscal intermediary. As soon as something was purchased that was sort of outside of the line, they would immediately suspend all the funds on the card, pull the funds off the card, inform the agency, the agency would contact the individual… It was immediately flagged. (OMH-16)

Stakeholders elaborated on the different types of misuse and procedures for addressing them. Misuse was described as primarily unintentional or accidental, reflecting instances where the participant neglected to request permission for additional, but legitimate, fees associated with a purchase (e.g., tax, shipping, etc.), stayed within their budget limit but bought different quantities of an item than they were approved for (e.g., purchased two pairs of shoes at a lower price instead of one more expensive pair), or used the funds approved for one item to buy another item that had not been requested (e.g., not noticing the SDC card had been set as the default payment on an online platform when completing a purchase unrelated to SDC).

> If we're buying clothes and we want to say, "You're buying three pairs of pants and two shirts" and you buy five pairs of pants and two shirts, technically even that is considered misspending because…you want to buy exactly this amount. (SB12)

The other form of misuse, described as more intentional misuse or abuse of funds, was even less common, but occurred when participants were approved for one item but bought another item, knowingly exceeded the budget limit of their purchase, or purchased an explicitly prohibited item:

> [There's] been small, repeated times [of misuse], where it seems without my support with every purchase, the person was not completing it correctly. And there are some cases where people did buy things like alcohol or cigarettes, but that's also pretty rare. (SB-11)

Program staff differed in the degree to which they described adopting a standardized and firm stance toward participant misuse of funds versus a more individualized and flexible approach. Nevertheless, most noted that there was a moment of taking a step back or a pause in response to misuse, but that the nature of the misuse and a participant's prior purchase history also influenced how the misuse was addressed. Some described a more automatic pause in response to any form of misuse, with the participant being placed on a hold from making purchases, followed by possible discharge if misuse recurs: "When it's a misuse, whatever the case may be, they go on a 30-day hold…They're informed the next misuse is a potential discharge…" Others described a more individualized response that factored in the type of misuse and the context in which it occurred:

> We try to understand where the misspending came from…Were they being honest when we asked them questions or did they purposely kind of lie about how the money was spent…We want to work with people throughout their challenges…and we look at discharge as the last resort. (L-3)

Many staff recognized the extensive challenges that made it difficult for some participants to fully comprehend budgeting and purchasing rules. For participants who experienced these struggles, staff described implementing a series of strategies to provide greater safeguards on participants' spending and assumed more control over the actual purchasing process, while still

supporting the participant to maintain self-direction. These strategies included only allowing the participant to have one approved purchase at a time, having the program directly supervise or complete the actual item purchase, or temporarily further limiting the amount of money that a participant could have on their card.

> There's a couple different ways that misuse of funds comes up and it just depends on from participant to participant…There's one participant where, for example, we try to go as many times as far as we can, before we move to the stage of removing the card from the possession of the participant and…we just complete the purchase ourselves online or only during a meeting with the participant…[Other] participants will kind of get moved to a slower system of approvals, where those participants won't have three things approved at the same time. They'll have one thing approved. And after they submit that receipt…then they'll move on to the next thing. (SB-12)

Staff also noted the importance of not only reminding participants of program rules and imposing consequences, but also engaging them in conversations to troubleshoot how and why the misuse happened, which would inform strategies to try and prevent misuse in the future.

> We have sort of used a strike system and it involves a rich conversation behind it: why [did] this situation happen, what happen[ed] leading up to it, were there any barriers they felt like they couldn't discuss beforehand with me or another program staff member to explain what might be happening. And then, if we've done a pause on spending, "Okay, you might have purchased this thing that was not approved, so for a month we're going to check in, but we can budget it again next month." (SB-11)

Differences in staff approaches to misuse were partially influenced by the philosophical perspective of the staff member with respect to participants' misuse. Some staff were generally more skeptical of participants' intentions in using the program and were more likely to perceive misuse as participants "taking advantage" of the program, whereas others were more likely to view misuse as arising from the challenging circumstances of extreme financial hardship in which participants lived. Another factor contributing to differing perceptions of misuse was the more recent hiring of staff who were still gaining experience and supervision on the job:

> We have tried to make a system for [misuse] so it doesn't feel arbitrary, but it is difficult when working with a few new staff members and taking in new participants. Some of that gets lost, especially as we hired some of the staff right before the pandemic shutdown…so it's difficult to get everyone on the same page. (SB-11)

The next section further expands on OMH oversight and the role of the fiscal intermediary, including the process for reviewing requests and purchases, factors involved in approval decisionmaking, and use of the portals.

Review, Approval, and Monitoring of Requests and Purchases

When discussing what reviews of purchase requests entailed, stakeholders identified several factors that fiscal intermediaries considered, such as if the requested item was allowable under the guidelines of categories and items that were explicitly prohibited; if it was cost appropriate (e.g., the average cost of such an item, was it considered a reasonable cost given its intended use), and the degree to which the request was connected to the participant's wellness goal.

> We have the parameters of the program; we do have some prohibitions on certain types of purchases. You're not supposed to pay for people's rent or [most] ongoing [costs]. So, if we get a request that does not fit into the parameters, [the] approved categories of requests…there are limitations, so, we look to make sure that the purchases and the goals are appropriate to the program. I mean that's probably the first major pass. (OMH-10)

Stakeholders highlighted that in later phases of the SDC implementation, reviews of purchase requests became more straightforward, with both the sites and OMH having developed a better understanding over time of what may or may not be approved. Nevertheless, stakeholders also noted that there was still a more complex and nuanced decisionmaking process for certain purchase requests. There was also a lack of consensus regarding whether budget limits for certain items were to be interpreted merely as guidelines or as stringent caps. Factors that could make decisionmaking more complicated was when there were deliberations regarding the appropriateness of costs for a certain item, the reasonableness of the request given participants' prior purchases or goals, greater scrutiny of whether a request was perceived to be the most appropriate way of achieving a particular goal, and a range of other factors (e.g., how will participants prevent a costly item from being stolen). This meant that questions would arise such as in what amounts or with what frequency should individual participants be allowed to purchase similar items, could there be potential safety concerns (e.g., what would otherwise be a valid and fundable transportation cost being reconsidered during COVID-19), or which category might a particular service or good fall under (e.g., calm app subscription falling under the entertainment category versus kindle app subscription falling under education).

> There are finer levels of discretion…if it seems like it's an appropriate category, but we have concerns about the request for [a] particular item… [for example, if something] is not FDA approved, if it's like some kind of supplement or something that might run afoul of the law…. (OMH-10)

> It's really nice to be clear with the participants about what they can expect. Like there just are some parameters around this…And that said, we also recognize, and I think OMH does too, that there are always exceptions, but that makes sense…I think the difficulty…arises out of situations where sometimes an exception has been made and then you're stuck in the future being like is this similar enough to a situation where we made an exception, or we want to make it again? (SB-4)

Stakeholders also acknowledged that, given that the SDC pilot relied on state public funds, there were inherent challenges to approving resources that were arguably credibly connected to participants' wellness but were perhaps more controversial.

> There's the politics around whether or not the state government wants to deal with, is it an appropriate purchase based on using state money to spend on those types of things? So those are questions that would get run up the flagpole and leadership…would have an opinion. So, there's definitely specific requests that might seem to be within an approvable category, but for some reason there may be objections to it… (OMH-10)

Given the range of potential factors that were sometimes considered in the decisionmaking process, stakeholders noted that there was still not necessarily consistency in reviews and approvals.

> There's been a lot of back and forth sometimes and kind of personal bias when it comes to things that get approved versus things that don't get approved… There's been a couple of times… [intermediary staff] would disapprove something that we advocated for…They would say "no" and then we would resubmit that same exact thing and maybe ask for it to just get pushed to a higher up. And when it does, it gets approved because they're like, "Oh we don't see why this wouldn't get approved in the first place." So a lot of times, there's been instances of the fiscal intermediary themselves just deciding what is wellness for the participant. (SB-12)

> There is a significant disconnect between who we are and who we serve and our knowledge about the demographics [of the people] we serve and the fiscal people at OMH…I submitted the budget [for an item], it's under the threshold… [I'm] thinking it's going to be an easy thing. I got the pushback saying that "Oh well, we bought him [something similar] a year ago…" I fought the fight. I advocated. And they still did not want to…I think they finally approved [it], but it was a month…there's a little too much scrutinization, where[as] if we had clearly defined parameters and if the parameters [are] met, [it] should be an approval…So then they started giving us some parameters…We've kind of grooved to them as they've come down and change a little bit here and there, but sometimes it just doesn't seem there's a rhyme or reason…Sometimes there's, I think, there's a little more personal opinion…that might cloud the process. (L-2)

However, stakeholders also credited more nuanced decisionmaking processes with significant advantages as well, because they created the space and opportunity for participants to have their unique needs and circumstances addressed, as would be needed in order to align with the program's self-directed premise.

> I am happy to see that, in certain circumstances, we're still able to look at things on an individual basis, which I think the program really strives for. (L-3)

Beyond reviewing and approving requests, one of the primary roles of the fiscal intermediary consisted of monitoring spending and the status of purchase requests using both the SDC portal and the credit card portal. Through these mechanisms and generating custom monthly reconciliation reports they were able to identify any potential card misuse or leftover funds. The fiscal intermediary was then responsible for notifying pilot site staff and/or OMH oversight of any potential issues that may have arisen during this process.

> [I had] a custom report that we had [OMH division] create…. I wanted the ID number, [the pilot site], the purchase ID, the budgeted cost, when it was submitted, when it was approved by a supervisor, when it was approved by me, if it was approved by me. It's blank on there if I haven't approved it yet, which immediately flags me to the fact that I didn't approve it. And then if a receipt has been uploaded and if it's been completed or dropped. (OMH-17)

> I do like to review if there is a lot of money left on a person's card…[and] identify whether or not all of the purchases have been made, if all of the receipts are there, so that I know whether or not I need to take money off the card before I go ahead and add more money…[Then I] check with the provider to see if there's a reason that something hasn't been purchased or if that money can be removed…[For] the purchase itself—if it's a cell phone, Wi-Fi, something like that—those are easily identified whether or not it's a normal amount of money or if there's something strange with it. There are things that have been approved in the past for specific clients that you would also approve unless the money is an outstanding amount of money. If normally acupuncture is coming in at less than five hundred dollars and this particular request is for more than five hundred dollars for acupuncture, I would send it to the next level and say, "This is more than we would normally approve… What are your thoughts?" So then at the next level they can review it and they can say, "Yeah it's fine because it has this additional reason why they need this extra." (OMH-18)

Research Question 1.4: What were the facilitators and challenges to SDC Pilot implementation and how would they impact statewide roll-out?

This RQ included one hypothesis:

Hypothesis 1: State oversight, pilot site agencies, and SDC participants will encounter both opportunities and barriers in the SDC process.

Qualitative Findings

Interviews with State oversight, fiscal intermediary, pilot site agency staff, and focus groups with participants revealed facilitators and challenges to the implementation of the SDC pilot program that would impact state-wide roll-out. Specifically, areas that need to be addressed when considering potential scale-up of the SDC program statewide included: balancing program flexibility/personalization versus standardization (clarifying factors that are considered in approval decisionmaking), streamlining some routine purchase requests while expanding communication regarding denials, ensuring fit between organizational/staff philosophies and the person-centered approach of SDC, exploring sustainability of current budget allocations/limits,

clarifying participant tenure in the program, and increasing administrative efficiency (e.g., upgrading the portal).

Given high levels of satisfaction from participants' perspective, they noted generally minor areas where the program could improve. This included wanting to have greater understanding of why certain purchases are not allowed (e.g., education-related debt); greater consistency of purchase approval times; more routine monthly meetings where brokers systematically review participants' available budget, spending, and purchases; and minimizing challenges associated with making purchases on the card (e.g., vendors reject the card, zip code issues).

Balancing Program Flexibility/Personalization vs. Standardization

While all stakeholders reported that the SDC program operated within certain parameters, they also acknowledged there were some grey areas that allowed the program to operate more flexibly, which generally contributed to the program's success. This flexibility allowed for decisions to be tailored to individual circumstances, providing participants the opportunity to secure key resources that truly matched their needs and goals. When deemed appropriate, this flexibility allowed for purchases that may have exceeded certain pricing guidelines (e.g., a more expensive laptop with the advanced functionality needed to match the participant's use of it for their particular work goal), exceptions to the general prohibition on certain item categories (e.g., allowing payment for a subscription service because it was needed for accessing school books or make-up for a participant enrolled in cosmetology school), and developing creative solutions to facilitate a goal while avoiding an outright purchase denial (e.g., paying for supplies but not labor in making car repairs so a participant would have transportation to get to work). As noted, while having this grey area was generally viewed favorably and as being responsive to the unique context of each participant's wellness needs and goals, the downsides included that it introduced some inherent subjectivity to decisionmaking and was more labor-intensive and time-consuming. Having grey areas, for example, meant that it was not always clear whether similar factors were being considered consistently in decisions to submit and approve purchase requests.

> There're differences in how cases are considered depending on which people in which office are reviewing it…This [has] lessened as time has gone on. But in the past, there was a clear difference between a sort of financial office versus the office of the recovery programs, which is a reflection I think of training and perspective. (SB-4)

Further, this type of individualized decisionmaking required greater time investment as well as a significant amount of communication between support brokers, supervisors, fiscal intermediaries, and a range of other State personnel.

> It's a lot of conversation and back and forth. It's looking at an average cost of things that are out on the market and going middle of the road. A lot of times we've consulted our [other division] staff… "OK you have a sense of what the state pays…What would be sort of, not cheap, but not the most expensive. And what would you expect on it?" …And then it's a meeting of the minds—program

> and fiscal sit down, "OK, well we think this is a reasonable threshold. What do you think?" …At some point…everybody agrees. (OMH-15)

As mentioned, stakeholders reported that over time, the program had become more standardized with clearer understanding of various parameters and decisionmaking processes, while still maintaining a high level of individualized decisionmaking and flexibility. A key question that emerged when considering program expansion was how to minimize instances where decisions felt more arbitrary, and perhaps even more importantly, how to balance this individualized and flexible approach with the possible need for greater efficiency that might be achieved through more robust standardization if more people needed to be served.

> Hopefully, as these opportunities expand for other people in New York, that there would be a lot of work to be done there to both keep the flexibility that makes this program successful in place, while also having enough structure set so that there's not just sort of constant back and forth about interpretation of the policies. (SB-4)

> You lose some flexibility. You lose that potential to tailor something to an individual who just needs another $25 on this…We have that flexibility right now, which is great, because we can address specific situations in a reasonable way. But that kind of flexibility doesn't lend itself to scale. (OMH-15)

However, most acknowledged the inherent difficulty of putting "a cut and dry directive out" and standardizing a program that is centered around self-direction.

> That's sort of [the] tricky part that there may be work to do, to make some more robust policy statements around that because it's hard to make policy around these sort of ambiguous grey areas…Hopefully as these opportunities expand for other people in New York that there would be a lot of work to be done there to both keep the flexibility that makes this program successful in place while also having enough structure set so that there's not just sort of constant back and forth about interpretation of the policies. (SB-4)

Managing Purchase Requests

SDC staff perceived the current timeline of enrollment as acceptable and were uncertain whether it could or should be further streamlined or expedited so that participants can start the request process sooner. Potential suggestions, nevertheless, included having slightly longer but fewer sessions or having participants—who are able—preliminarily complete some of the more routine paperwork that does not relate to goal development on their own.

Though drastically reduced from earlier stages, providers explained that there were still times when more information or context from fiscal intermediaries would be helpful, particularly regarding certain purchase denials or request approval times that extended beyond the usual two to five days. While longer approval times and request denials were much rarer in later phases of the pilot, there were still instances when providers noted having more "adequate information" would be helpful to fully understand the process behind a lengthier review or the rationale for a

denial, particularly so that they could then relate this to participants. While OMH stakeholders articulated several steps that would often occur "behind the scenes" to try and facilitate review, there may have been times when providers on the ground were less aware of the steps involved for more nuanced reviews and consultations across various departments.

> A better understanding for those few times things are not approved, we need to let [participants] know why someone might have been waiting a really long time…So just a little more context sometimes to know why this wouldn't be something that's approvable by the program. (L-3)

> We used to have meetings with the staff in Albany— the program managers, director, and the brokers as well and then it just went to the program managers and the staff in Albany. I think the brokers need to be inclusive of those meetings again. We're getting information trickled down from the program manager and that's absolutely wonderful, but we're kind of on the front lines and the lines of communication need to be open with everyone. (SB-5)

While providers noted that they were able to request that a denial be reconsidered, staff suggested that potentially outlining a "more formalized process of review [for things that are new or a little bit unusual] could be helpful…[a] policy around how this all works, and somebody can sort of appeal something and ask for a more detailed explanation and things like that."

Stakeholders also deliberated whether it was feasible to streamline certain purchase requests, especially those that were recurring in nature (e.g., phone and internet bills) or those that were almost universally recognized as acceptable and appropriate, thus minimizing some of the administrative burden across all parties and potentially reducing lag times for approvals—for example, having a recurring expense request approved for as long as the goal is still active, and the treatment plan does not need to be reviewed.

> Especially if it's an easy thing and it's something recurring…Give us some guidance and parameters and if it's close and it's under the threshold of whatever, it should be an easy approval. And sometimes I think things have gotten, kind of, taking more time to look over the budget. "And what about this one, what about that." And I think that kind of creates a cumbersome flow. (L-2)

Finally, because the role of the fiscal intermediary was so essential and yet also unique, requiring much nuanced program knowledge and understanding, stakeholders emphasized the need to ensure adequate coverage of the role.

> We had a three-week, almost month-long pause in approvals…And just having to go on for almost a month telling participants, "As soon as we figure stuff out, we'll let you know." We had people's recurring purchases like bills and Wi-Fi things and phone bill things that weren't able to get paid because there weren't precautions. (SB-12)

Ensuring Philosophical Fit

Stakeholders identified organizational and staff fit with the philosophy underlying self-direction as key to expansion. This included selecting agencies that have person-centered approaches as part of their organizational mission/culture, providing training on person-centered services, and ensuring staff buy-in for person-centered approaches and self-direction.

> I feel the staff that's hired…need to have a mentality of radical person-centered approach. Because if you're questioning people, like, "Why do you really need that?" or "What do you mean by this?," it's kind of taking away from the experience of self-directed care… Sometimes I can see when other providers are involved, I can see hints of a different model in their mind that we're trying to work against. (SB-11)

The emphasis on ensuring philosophical fit allows for agencies to implement an SDC program that supports each participant's individualized path of recovery and wellness goals while still following parameters placed by OMH. Agencies that embrace person-centered approaches and empowerment of participants can appropriately apply the flexibility inherent within the SDC program to stay true to the mission of self-direction.

> There's nuts and bolts that are just there—the workflow procedures that are just part of doing this. But then the rest is really up to us. So, [it's really central] to define and to understand…what kind of relationship with the participant would need to be there in order for this to be effective…How are we going to communicate [things] to the participants…and framing goals…in ways that [are] understandable from the perspective of somebody sitting in a separate office in a different part of the state for the final approval process…The values of self-determination that are so central to what we do…outside of just nuts and bolts… What [gets] emphasize[d]…a lot of it is up to….interpretation of how things should go, including the kind of relationship that you need to have with clients. (SB-4)

> If it's an agency that's not person-centered…it could become, in my personal opinion, more clinical rather than more self-directed or [a] non-medical model… There has to be buy-in and not like this medical-model, clinical ideology and it really should be at agencies who value person-centeredness, person first… You have to have the mentality that's all about the person. [OS-8]

Sustainability of Current Budget Allocation

While acknowledging that most participants did not reach budget spending thresholds, there was concern, particularly among state-affiliated stakeholders, whether current allocations were sustainable if the program was to be available more broadly. It was suggested that if the SDC program were to be scaled up, the budget allocation may need to be "scaled down," so that it would increase the feasibility of such a program.

> I think that's way too much money. Personally, for two different reasons: one being, that's a lot of money to hand over to somebody to spend and it's taxpayer dollars and [two], the fiscal realities are there's just not enough money at those two price points to take it statewide. Given the potential pool of people who

> would qualify… the eight and 16 thousand price points are way too high even based on that amount being available. You really have to scale it down. (OMH-15)

Program Duration and Participant Tenure

Another area that stakeholders highlighted with implications for program implementation and expansion was the nature of participants' tenure in the program. Stakeholders noted that most participants continued to stay in the program, and that there were only a few participants who had moved on or "graduated." Those who graduated tended to have very limited and specific goals that they had achieved and felt comfortable moving on from the program, while others had utilized the program more extensively and had successfully obtained employment and become more "financially independent."

Most stakeholders were uncertain whether the program could be available to individual participants indefinitely as long as they continued to meet eligibility criteria or whether there was an expectation of graduation. On the one hand, stakeholders noted that individual goals could be achieved and wondered whether an overarching goal of the SDC program should explicitly include helping to "get [participants] to a point where they didn't need the program." On the other hand, stakeholders also acknowledged that the majority of participants enrolled would likely face chronic financial challenges impacting their wellness and recovery long-term, and, of course, further emphasized that the whole concept of wellness is ongoing: "Wellness is a lifetime thing. [Individual] wellness goals, of course, are achieved…but wellness is an eternity."

SDC participants also deliberated how to conceptualize program tenure, with most offering that decisions regarding program tenure should be individualized.

> I think that depends on the individual circumstances because I know there's those who may need life-long assistance. [Others may] use self-direction for occupational—the schools where you train in a field and start working. And if you become financially [stable]—when you start working…That would be a reason for graduating from the program…being able to afford the services on your own and not needing it…It really depends on what the wellness goals of the participants is…It can work both ways. (C-10)

There was also some concern on the part of state agency staff as to whether participants receiving support for repeat, ongoing purchases, such as Wi-Fi or gym memberships, might create long-term dependence on the program versus promote participants' ability to develop alternate means of covering those costs in a more independent way.

> This program could pay for money management courses… I think that there should be some things that are automatically available to help them become independent and not be dependent on this program. Why pay for cell phones all the time? Help them to work towards being able to pay for their cell phones on their own. (OMH-17)

Nevertheless, most stakeholders acknowledged that the significant financial constraints that characterized participants' lives made it challenging to identify how best to ensure participants' ongoing needs for critical resources were being met while promoting more financial independence from the SDC program.

Addressing Infrastructure and Administrative Efficiency: Tracking, Managing, and Accessing Budgets, Requests, and Purchase Activities

There was near universal consensus among non-participant stakeholders that the most significant challenge to operating the program was the process of tracking and managing participant budgets and purchases. Stakeholders emphasized that complicating factors included pilot site staff not having direct access to participants' transaction history and card balances; lack of database integration such that purchase requests and goals were in a different portal from actual transaction histories and card balances; and that the portal into which detailed information was entered had highly limited functionality, with neither site staff nor fiscal intermediaries being able to run reports directly. These limitations created extra steps for all program-related staff, required more vigilance and communication, involved extra personnel, and resulted in administrative redundancy and inefficiency. Because support brokers could not access participants' transaction histories directly, they had to rely on participants to report that they had made a purchase or request a transaction report from OMH staff. Not having direct access was somewhat cumbersome since brokers might have to reach out to participants to inquire if a purchase was made several times, especially for those participants who may not be as diligent at initiating communication or submitting receipts immediately after completing a purchase. Having direct access to participants' transaction history could allow support brokers to monitor purchases in real-time, validate whether they were within the appropriate parameters, and only send reminders to participants about completing a purchase or submitting a needed receipt within required timeframes as appropriate.

> Giving us that receipt is our acknowledgement that [participants] have completed the purchase. And if they don't give that to us, then we don't know if they've completed a purchase…[If] it's been 10 days…I would give them a quick call to find out if they have completed the purchase and if they could give me the receipt… If it's a specific situation where we need to find out if the participant has completed a purchase, then I can actually reach out to OMH and they can send me the ledger for the participant….[But] it would be very helpful if we also have access to the transactional history…It would be much more efficient if we were able to just have it on access. (SB-6)

While there was consensus that it would be beneficial for pilot site staff to have access to participants' transaction history, stakeholders differed in whether it would be appropriate for participants to have direct access as well. Some emphasized the importance of prohibiting participants' access to their own card balances, partially as a safeguard against potential

inclinations to make non-approved purchases with unspent balances, while others indicated that participants having access to their own transaction history could be helpful.

> The card system we use doesn't give them access to their ledger ballots, so they rely on just us telling them how much is on the card and how much they have spent with their receipts to be able to know what's left…[When] it's multiple little items, it does get tricky…Like literally they have to ask us. We don't have access. We have to ask fiscal at OMH. So, it's not a live process where someone can instantly know what's left on their card…And I really wish that was something that they had live access to…where they could easily go into their phone or the web and be, like, I was approved for these five items. And it shows I've already spent this…So, this is what's left or whatnot, or even to submit their receipts independently to make it easier in the moment. (L-3)

Stakeholders universally appreciated the ability of the program to use alternate forms of payment for purchase requests when there were problems with card acceptance, such as having checks issued, but they also identified the need to address some on-oing issues regarding the cards used by participants to make purchases. Some challenges identified were somewhat smaller issues, such as to try and resolve "glitches" related to participants having to enter credit card zip codes that didn't match their own address, and others noted a range of factors that could be improved.

> The big problem is that zip code…just because of the zip code, they were going to send the [purchase] to the [State address]. We had a big thing with that. So that's one thing that needs to get fixed. That zip code really does need to get fixed, it's gonna get a person jammed up. (C-2)

> The way that it works with the cards is tricky…It would be nice if there was a way to make the cards not work for certain things…They don't work perfectly. Some places don't take them…It's very difficult to control the card in general, people use Amazon Prime a lot. So, this card gets stored on their Prime and then they go to buy something for personal use, and it accidentally goes on this card…That's the biggest pain part is the card. Plus (the card company) people are not nice, and they don't like us, and I feel it's very difficult to work with them. I'm still waiting on a December report from them that I've asked for so many times. (OMH-17)

Overwhelmingly, however, stakeholders identified challenges with the current system used for inputting, tracking, and managing purchase requests and budgets as the most significant barrier to effective program operation.

> The portal doesn't necessarily work all that well…I can't run reports out of the portal so that would be helpful if I could. I have to ask IT to run them for me because they don't work properly… There're also times when the emails don't generate properly that alert me that there's something for me to approve…I said, "Is there a way that we can get a weekly report showing outstanding purchases?" So, we did start getting that report, and then we ended up pushing that to twice a week because we do sometimes not get those emails or there're some times

> where we get a ton…It would be helpful [to be able to generate it whenever I want it]. But this is a custom report that we had them create. It's not one that I can just pull out of the portal myself… (OMH-17)

> The one thing that has been a real challenge for us…The database, the portal okay, needs some updating…For example…my manager and then also the fiscal manager say, "Hey, which kind of budgets are outstanding at the moment for your client list? Let us know who's pending, what the status is, and what's going on." At the moment, we have no way to generate a report or to sort our client lists by the date that the budget was submitted, or the date of the budget was approved by OMH…We have to literally go through our client roster. (SB-9)

Because the functionality of the portal was highly limited and there were challenges to developing a centralized system for tracking information, there was administrative inefficiency. For example, in addition to entering and tracking information in the portal, both pilot site staff and fiscal intermediaries described creating and manually maintaining their own spreadsheets to track and manage participant purchases and budgets, which, while somewhat less cumbersome than initially, was still time-consuming and introduced redundancy, with both providers and staff entering the same data in multiple databases.

> I have a lovely Excel spreadsheet…I think all of the resource consultants have this, actually. It's a template that we all use that pretty much includes a rundown of what participants we have, and which ones have open purchases, what purchases are open, and when they were approved, and the column also that explains whether or not they've given receipts… (SB-6)

> I just keep a lot of notes for myself, and I have a spreadsheet of all my consumers…I'll put a little dot…Once the budget is approved, I make one line through it…Once the client gives me the receipt, and I upload the receipt into the portal…it'll create an X letting me know that budget is done. (SB-7)

> I created myself a spreadsheet to try to keep track of things and what's outstanding, so I used to spend a lot more time per day than I do now…(OMH-18)

Stakeholders emphasized that upgrading the portal and improving administrative efficiency would be essential to allow for capacity of program scale-up.

> The portal is not very user-friendly, and I think there's a lot of functionality that's missing. I don't even think it's even consistently accurate, in terms of the data we get pulled out or the data that is pushed to us through automatic notification…It is not an effective portal and software platform, and if it does move beyond this initial demonstration or pilot, it really would need to be significant improvements to support the programs…the State…and the fiscal intermediaries that are managing the program. (OMH-10)

> We need the portal to be upgraded…It would be ideal if the current configuration of the OMH portal would allow us to do sorting capabilities for either our respective client loads and our client rosters under the broker's name, or just if we were to look at everybody who's currently an SDC client and sorted by SDC

> client number or name or something but we don't have that capacity…The other thing that would be helpful would be being able to create or generate reports or print a client list of our respective rosters. (SB-9)

> From the perspective of running a program, [it] would be great if the staff and [key personnel] could run reports in the portal…We can really only put information into [it] and we can view what we put in. But it's not set up to run reports. I think it'd be incredibly beneficial for understanding trends, following up on practical things, receipts and things like that, [if] we were able to more adequately run reports. I think that we can run some reports and then we can request them and have them send them to us… (SB-4)

Expanding Access to SDC

Finally, the most common response from both SDC pilot program staff and participants for suggestions to further improve the program was to make it available more broadly to others. Recommendations included to expand capacity beyond the pilot to serve more individuals, and other areas of the state, as well as to expand the populations that might be eligible—for example, those on Medicare.

> The one main improvement would be to open it up to other people. (C-9)

> I would recommend it be expanded so more people can benefit from it. (OS-8)

> I know this program is not for Medicare participants but that would be great for them…I don't think that should limit a client being accepted into the program because they're on Medicare. 'Cause I think a lot of Medicare recipients need this program as well as Medicaid. (SB-7)

Summary of Findings

Participants described overwhelmingly positive experiences with the process of identifying goals and using the SDC program to make purchases that contributed to achieving those goals. The SDC program was perceived as being very different from other services that participants had received, with a focus on their own personal needs and goals that was initially surprising but greatly appreciated. Participants appreciated not only the ability to make purchases that they otherwise would not have been able to do, but the entire process of working with the broker to identify their goals and implementing a plan to achieve those goals. The brokers were perceived to have a different role from traditional service providers in supporting the goals identified by participants and helping them use the SDC resources rather than simply providing direct support, counseling, or advice.

Participants also reported positive impacts of the SDC program on their quality of life, including benefits to their general physical and behavioral health and success with recovery-oriented goals. Participants reported making relatively small but meaningful material changes to their personal space that had powerful impacts on their overall wellbeing. Purchases funded by the SDC were considered by the participants as having been critical to their careers, relationships with family members, and participation in fulfilling social activities.

SDC programs were located in agencies providing a broad range of services to people with SMI. These programs had a culture of valuing recovery orientation of services, and this orientation was reflected in the individuals selected to be support brokers. The support brokers and their supervisors had experience in mental health services and were committed to fulfilling the role of a support broker. They focused their work on individualized support for reaching self-identified goals more broadly than simply administering the financial and oversight components of the SDC program, responding to issues raised by clients that went beyond the narrow confines of the program. Support brokers took time to get to know participants individually and develop goals and plans over time.

Early in the program support brokers required regular input from OMH personnel; as norms for practices were developed, these interactions were less frequent. Issues related to approval of participant purchases arose frequently early in the program, but these issues decreased over time as brokers and participants became familiar with the program guidelines. The frequency of incidents of misuse of funds was lower than expected, and most cases were misunderstandings, including instances where the brokers themselves believed the regulations were overly strict. SDC participants had generally very positive perceptions of the program, but they noted several ways in which it could be improved, mostly concerning transparency in decisionmaking about approvals of purchases and more regular meeting with support brokers. SDC program staff had concerns about the processes of administering the system, focusing on challenges in using the current reporting and monitoring systems, including the highly limited functionality of the SDC portal and challenges associated with not being able to directly access participants' transaction histories through the current card system. They also expressed concerns about the lack of transparency and consistency in certain aspects of intermediary decisionmaking and denials of approval for payment. Staff emphasized the need for a good fit between the person-centered approach of the SDC program and the culture of the agency in which the SDC program was housed. Finally, staff were concerned that some features of the program, such as the length of tenure in the program, remain unclear and should be clarified for future participants.

4.2 Goal 2. Improvement in Recovery, Health, BH, Social Functioning, and Satisfaction with Care for SDC Participants (Outcome Evaluation)

The outcome evaluation addressed several research questions related to person-and system-level outcomes associated with the implementation of the SDC pilot program. Goal 2 concerns improvement over time among SDC participants with respect to recovery, physical and behavioral health status, social functioning, and satisfaction with care. The evaluation was initially designed to address these questions using data from the HARP PCS assessments, which were expected to be available for a large portion of SDC participants at multiple time points so that trends within individuals over time could be examined. However, due to the low frequency of completion of HARP PCS assessments, the initially planned analyses could not be conducted.

The HARP PCS data were only used for one research question (Goal 2 Research Question 6) where other data sources were unavailable.

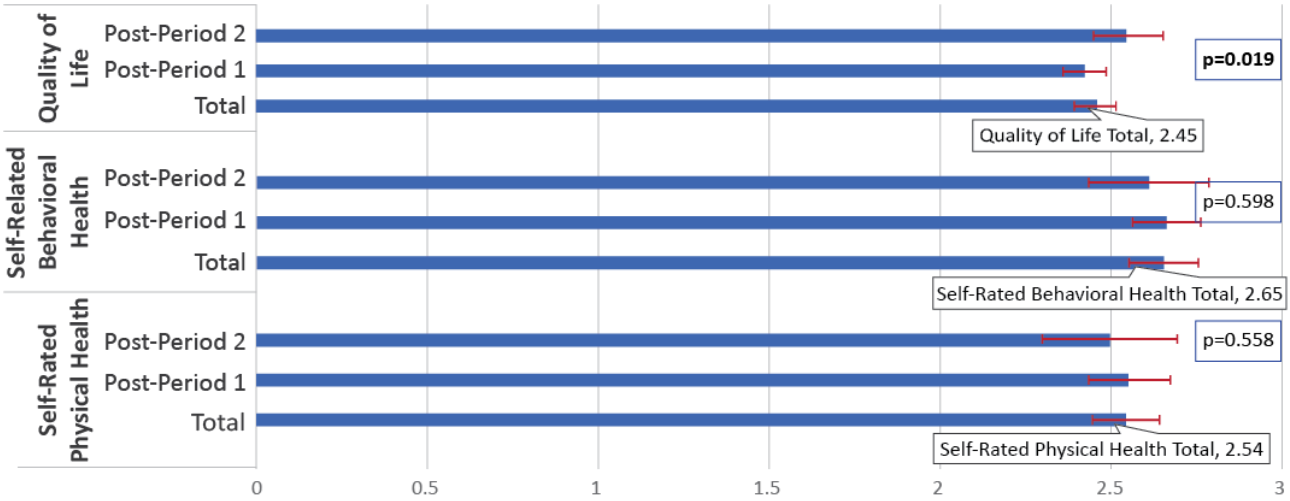
Given the lack of data from the HARP PCS assessments, the evaluation team examined the potential for using an alternative data source recommended as a substitute by NYS DOH and OMH. The alternative data source is the SDC portal, which includes assessments of SDC participants that overlap in some domains with the HARP PCS assessments. The evaluation team determined that the SDC portal data could be used to address some of the Goal 2 research question, though significant limitations of the data were also noted. The data portal includes assessments on 236 SDC participants from post-period 1 and 69 SDC participants from post-period 2. Data from the two time periods could be compared to provide evidence of change over time in the outcomes covered by the SDC assessment. However, limitations of these analysis should be noted. We are not able to adjust the comparisons for differences in the characteristics of the samples across the two time periods, which is a concern given that the sample in post-period 2 is much smaller than that in post-period 1. Second, we are not able to examine within-person change because of the small number of SDC participants with assessments in both periods, and we do not have a control group of non SDC participants to compare our sample with. Third, the small sample size provides weak power to detect differences across time periods. For this reason, the analyses are limited to group-level comparisons over time within the SDC portal data.

Research Question 2.1: Do HARP enrollees have improved quality of life after participating in SDC?

Hypothesis 1: Quality of life will improve between baseline and three (3) year and subsequent follow-up for SDC participants.

To address RQ1, the evaluation team used data from a 16-item quality of life scale included in the SDC portal. Each item was answered on a 1 to 4 scale, with higher numbers indicating higher quality of life. The quality of life indicator, calculated as the mean across the 16 quality of life items, increased significantly (p=.019) from 2.42 (SE=.03) in post-period 1 to 2.55 (SE=.05) in post-period 2 (Figure 4.2).

Figure 4.2. SDC Self-Reported Quality of Life



SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Research Question 2.2: Do HARP enrollees show improved indicators of health, BH, and wellness after participating in SDC?

Hypothesis 1. Indicators of BH will improve between baseline and three (3) year and subsequent follow-up for SDC participants.

Hypothesis 2. Health indicators will improve between baseline and three (3) year and subsequent follow-up for SDC participants.

To address RQ2, the evaluation team used two items from the quality of life scale described above, one measuring self-rated mental health and one measuring self-rated physical health (Figure 4.2). Differences between the time periods do not reach statistical significance for either measure. The average for self-rated mental health was 2.66 (SE=0.05) in post-period 1 and 2.61 (SE=0.09) in post-period 2 (p=0.598), and the average for self-rated physical health was 2.55 (SE=0.06) in post-period 1 and 2.49 (SE=0.10) in post-period 2 (p=0.558).

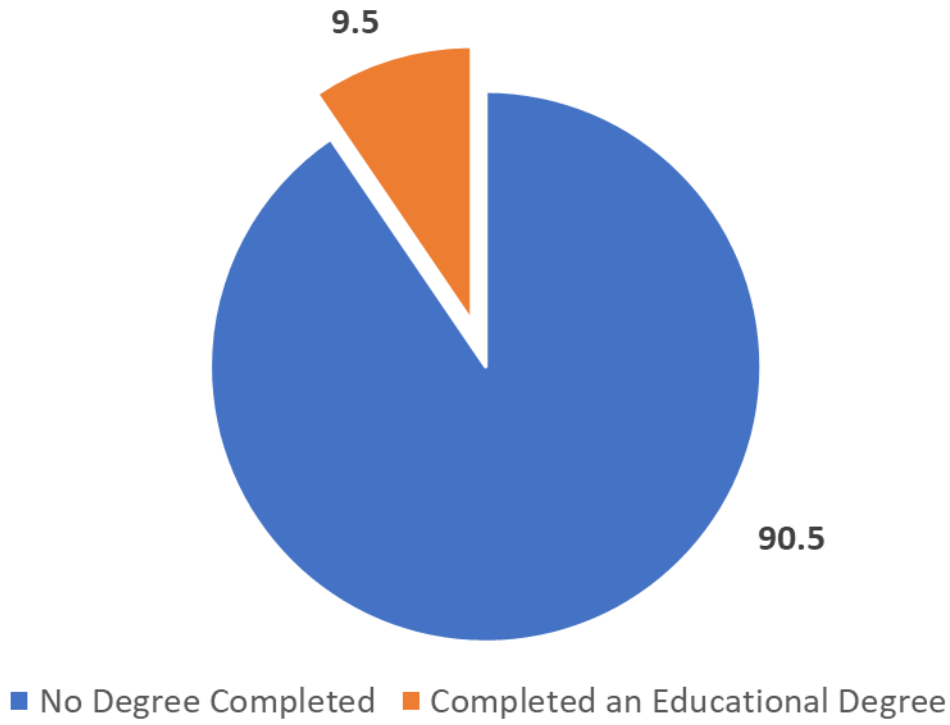
Research Question 2.3: Do HARP enrollees show improvement in education and employment after participating in SDC?

Hypothesis 1: Participation in employment and/or educational activities will increase between baseline and three (3) year and subsequent follow-up for SDC participants.

Educational attainment: The SDC portal data include information on the number of participants who completed an educational degree in the past year, whether the participant is enrolled in an educational program, and the type of educational program they are enrolled in. Over the entire post-period, 9.5 percent of participants completed an educational degree (Figure 4.3). The percentage enrolled in an educational program did not differ between the periods, with 27.9 percent enrolled in post-period 1 and 28.4 percent enrolled in post-period 2 (p=0.679). Of those enrolled in a degree program during the entire post-period, 16.5 percent (4.6 percent of the

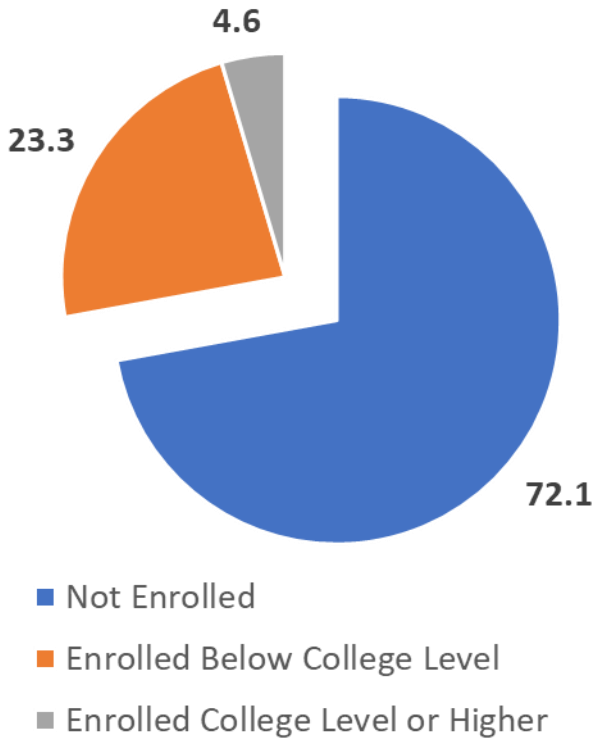
total) were enrolled in a college degree program and 83.5 percent (23.3 percent of the total) were enrolled in a non-college degree program (Figure 4.4). The type of degree programs in which SDC participants were enrolled did not differ across the time periods (p=0.677).

Figure 4.3. SDC Self-Reported Educational Attainment



SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

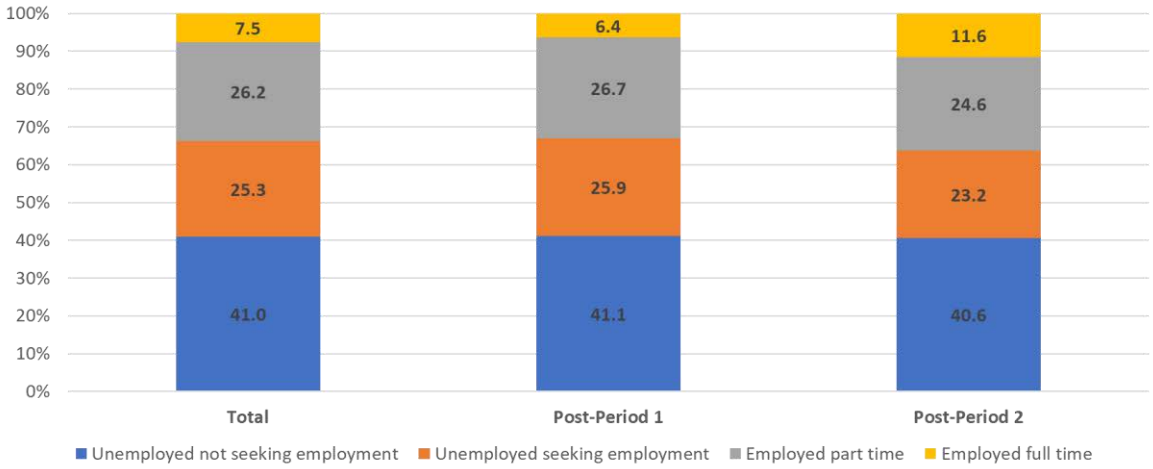
Figure 4.4. SDC Self-Reported Educational Enrollment



SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Employment: The SDC portal data include information on whether participants are unemployed and not seeking employment, unemployed and seeking employment, employed part-time, or employed full-time. Employment status did not differ across the two periods (p=.546) (Figure 4.5). In the combined sample, 41 percent were unemployed and not seeking employment, 25.3 percent were unemployed and seeking employment, 26.2 percent were employed part-time and 7.5 percent were employed full-time.

Figure 4.5. SDC Self-Reported Employment



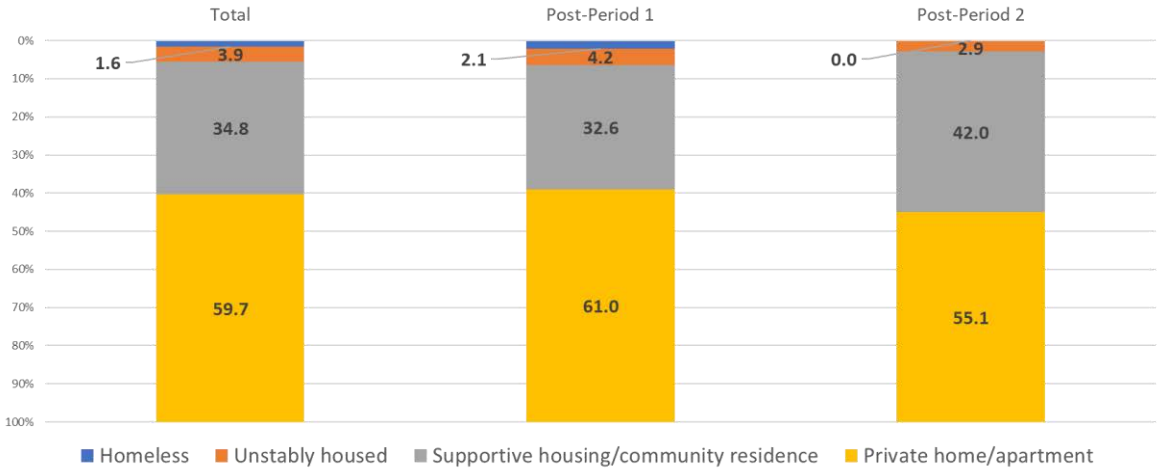
SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Research Question 2.4: Do HARP enrollees show improvement in community tenure (i.e., maintaining stable long-term independence in the community) after participating in SDC?

Hypothesis 1: Stability in the community will improve between baseline and three (3) year and subsequent follow-up for SDC participants.

Residential status: The SDC portal data include information on whether participants were homeless, otherwise unstably housed, living in supported housing, or living in a private home. The majority of SDC participants, 59.7 percent, were living in a private home, and a large portion, 34.8 percent were living in supported housing. 3.9 percent were unstably housed and 1.6 percent were homeless (Figure 4.6). Since there were no participants who were homeless in post-period 2, we were unable to conduct a test for change over time using all the housing categories. When the four categories were grouped into three by collapsing homeless and unstably housed into a single category, the difference over time was not statistically significant (p=.2443).

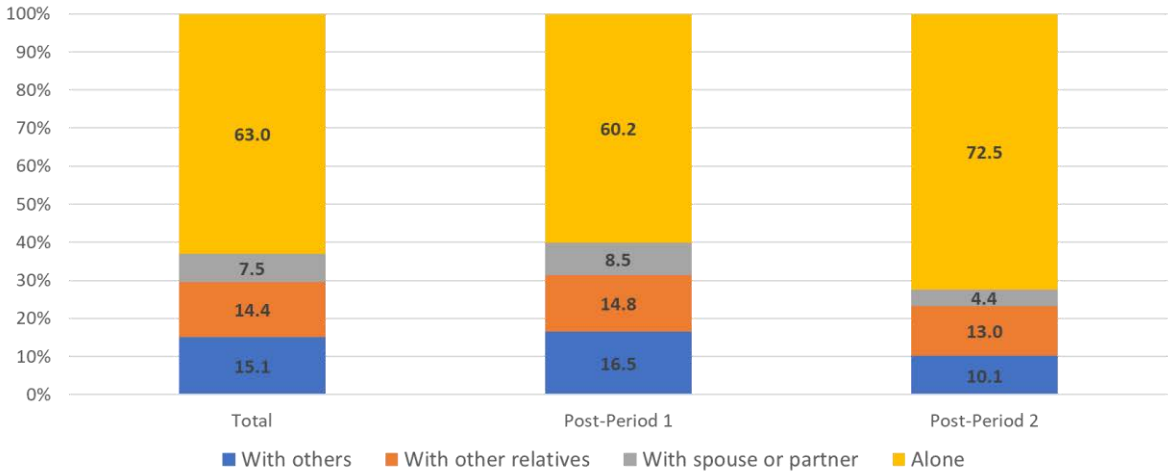
Figure 4.6. SDC Self-Reported Residential Status



SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Living Arrangements: The SDC portal data include information on whether participants were living with non-relatives, with relatives, with a spouse or partner, or alone. Living arrangement did not change significantly across the periods (p=.093). The majority of participants were living alone (63.0 percent). 7.5 percent were living with a spouse or partner, 14.4 percent were living with relatives, and 15.1 percent were living with non-relatives.

Figure 4.7. SDC Self-Reported Living Arrangements



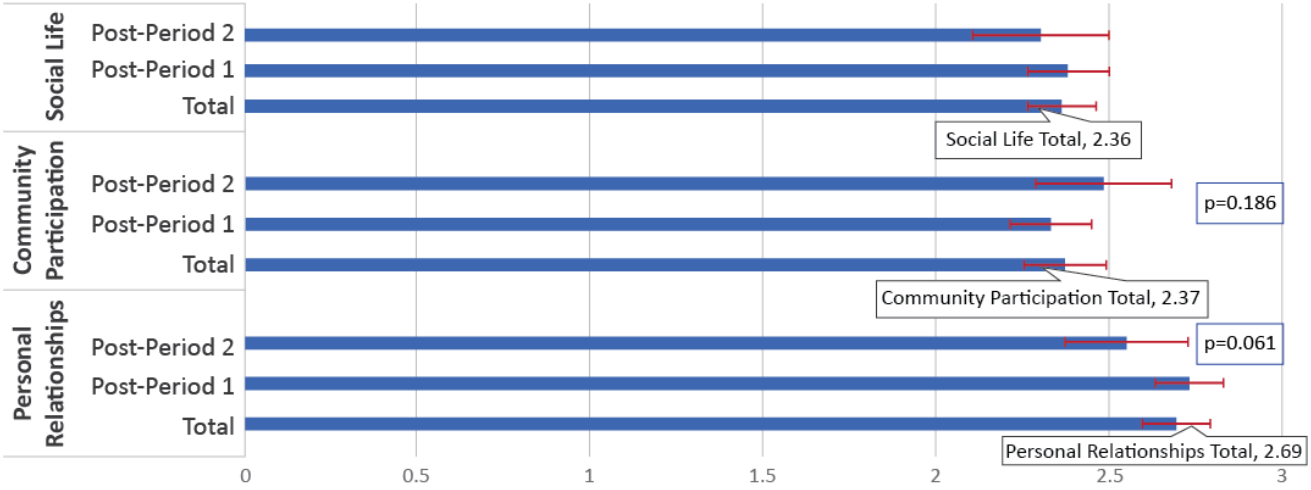
SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Research Question 2.5: Do HARP enrollees show improvement in social connectedness after participating in SDC?

Hypothesis 1: Social connectedness will increase between baseline and three (3) year and subsequent follow up for SDC participants.

Data to address social connectedness were drawn from items in the quality of life measure presented above that assess personal relationships, community participation, and social life. There were no differences in any of these items across the study periods (Figure 4.8).

Figure 4.8. SDC Self-Reported Social Connectedness



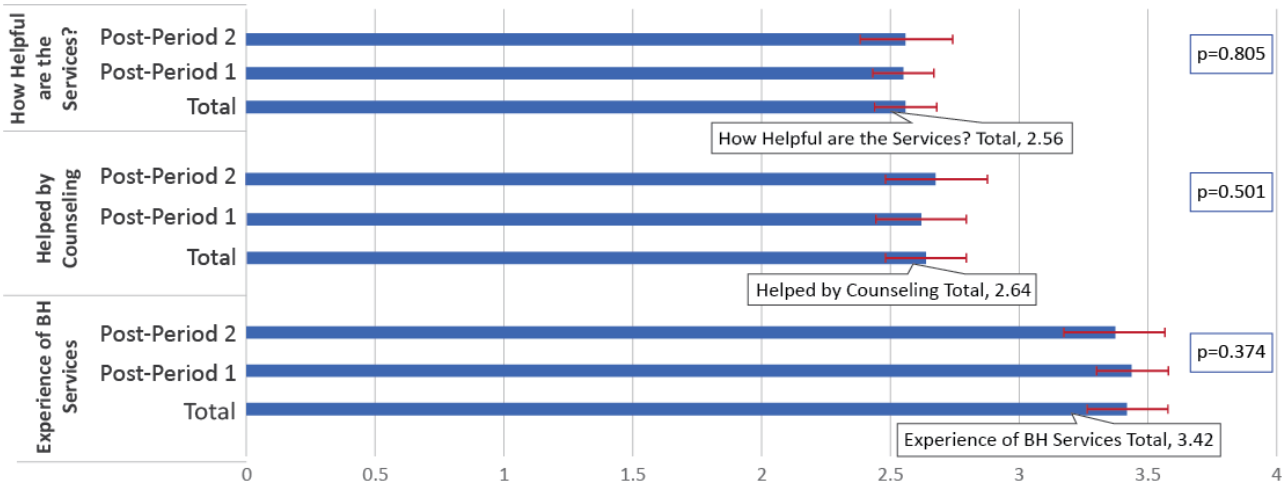
SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Research Question 2.6: Do HARP enrollees report increased satisfaction with health and BH services after participating in SDC?

Hypothesis 1: Satisfaction with care for BH services will improve between baseline and three (3) year and subsequent follow up for SDC participants.

Measures of satisfaction with care came from the HARP PCS and were available on a small number of SDC participants, ranging from 67 to 77 over the three items reported below. The items addressed participants' perceptions of the helpfulness of the services they receive and their overall satisfaction with the behavioral health services they received. There were no significant differences in these measures across the study periods (Figure 4.9).

Figure 4.9. SDC Self-Reported Satisfaction with Care



SOURCE: Authors' analysis of SDC Assessment data, 2018-2019

Summary of Findings

Due to unanticipated limitations in the data available to address the Goal 2 research questions, we are unable to draw conclusions regarding the impact of the SDC program on the listed outcomes. We found one instance of a statistically significant difference across years: an improvement in the total quality of life scale scores. This is a robust difference over time that may signal a positive impact of the program, but without a control group and more robust follow-up of the SDC population, the finding should not be interpreted as a strong indication of an SDC impact. Other measures of program impact generally showed no statistically significant differences over time. Again, the lack of a significant difference here should not be interpreted as evidence that the program did not have an impact on these findings.

The findings reported here are valuable in identifying some important characteristics of the SDC population that will be useful in future evaluation work. The data provide baseline information on the engagement of SDC participants in employment and educational programs. The proportion of participants who were either in an educational program or completed an academic degree was surprisingly large. These findings provide some context for interpreting other aspects of the program, but they should not be interpreted as effects of the program. It may be the case that the participants who were selected for the program were likely to be involved in educational pursuits. In future evaluations, selection into SDC programs should be carefully examined in the design of comparison groups.

4.3 Goal 3. Maintenance of Medicaid Cost Neutrality Overall and Reduction of BH Inpatient and Crisis Service Utilization and Cost for SDC Participants (Outcome Evaluation)

The outcome evaluation was used to address several research questions and related hypotheses related to person- and system-level outcomes associated with the implementation of the SDC pilot program. Goal 3 includes three RQs concerned with service utilization and Medicaid costs—outcomes of high policy significance for any new publicly financed program, more so when the ultimate goal is to expand and scale up. As described in Chapter 3, although our approach was quasi-experimental, we may not draw causal conclusions from our findings because we do not empirically control for the effects of concurrent initiatives.

For the reasons described in Chapter 3 (Cohort Construction and Analytic Considerations), the cohort employed to address all Goal 3 RQs included 223 of the total 237 participants (94 percent). Our analyses estimated changes in outcomes from the two-year pre-period (pre-SDC time) to the post-period of up to two years (post-SDC time). Our outcomes were *annual rates of any utilization* of multiple forms of outpatient and acute care, depending on the RQ, as well as *annual per member per month (PMPM) costs* associated with the utilization of each of these service categories estimated as total annual mean costs paid by Medicaid divided by the number of months of utilization.[1] We report linear regression estimates as mean changes in the percent probability of utilization (a binary outcome) or mean changes in costs associated with the utilization of those services and expressed as dollar amounts (a continuous outcome), and their respective standard errors (see Section 3.3 for adjustor variables). Our sole data source was the Medicaid data.

Research Question 3.1: Does participation in SDC result in increased use and cost of outpatient BH services and primary care?

This RQ included two hypotheses:

Hypothesis 1: Outpatient BH service use will increase between baseline and follow up for SDC participants.

Hypothesis 2: Use of primary care will increase between baseline and follow up for SDC participants.

Our main outcomes were utilization of *Any OP BH services*, a composite measure capturing all outpatient BH care, and receipt of *primary and/or preventive care*, assessed with the Provider Preventable Conditions (PPCs) measure created by the NYS DOH. For adults, PPCs captures

[1]When interpreting costs for the acute care composite measures, the reader should bear in mind that the PMPM costs of the less expensive and/or more frequently utilized services will have an important effect on mean cost estimates calculated on a larger population; thus, there should not be an expectation that the components will add to the composite, e.g., BH IP and BH ED may not add to the composite Acute BH care, since their sample sizes are different (this concern is also valid for utilization outcomes).

information collected as part of the Healthcare Effectiveness Data and Information Set (HEDIS) measure "Adults' Access to Preventive/Ambulatory Health Services" (AAP), which defines such access based on evidence of office-based evaluation and management and preventive care visits with a physician or physician extender.[26] Because the PPCs measure is constructed to report lack of receipt of primary and/or preventive care, we inverted it so that we could report receipt of such care. We report two additional composite measures of outpatient utilization: *Any Key OP BH Services,* a measure that captures utilization of any of several BH specialty services of potential interest to the State due to their relevance for individuals with BH needs,[2] and *Any OP Non-BH services*, a measure that captures utilization of PH care encompassing primary and/or preventive care and all other forms of outpatient PH care.

We also assessed PMPM cost outcomes for each of these utilization categories except for utilization of *primary and/or preventive care,* as cost data were not available for this outcome.

Adjusted Findings (Interrupted Time Series Model Results)

These analyses were conducted for all SDC participants in our cohort and compared their rates of any utilization and PMPM costs in the post-period relative to the pre-period (Table 4.2).

In both sites combined and relative to the pre-period, SDC participants had a 6.4 (1.66) percent lower post-period probability of utilization of Any OP BH services and a 10.2 (2.15) percent lower post-period probability of utilization of Any Key OP BH services. However, mean post-period costs of these services were unchanged relative to the pre-period.

While no pre-post differences were observed for receipt of primary/preventive care, SDC participants had a 16.8 (3.11) percent lower post-period probability of utilization of Any OP non-BH services relative to the pre-period. However, post-period costs of Any OP non-BH services were unchanged relative to the pre-period.

Table 4.2. SDC Impacts on Utilization and Costs of Outpatient BH and Non-BH Services, Post-period Relative to Pre-period, SDC Participants (both Sites Combined)

Service Category	Any Utilization			Total Costs Among Users		
	Sample Size	Estimate@ (SE)	p-value	Sample Size	Estimate@ (SE)	p-value
Receipt of Primary or Preventive Care	737	-1.00 (1.49)	0.50			
Receipt of Any OP BH services	866	-6.38 (1.66)	**0.00**	808	-52.1 (53.75)	0.33
Receipt of Any Key OP BH services	866	-10.2 (2.15)	**0.00**	758	-79.8 (50.50)	0.11
Receipt of Any OP Non-BH services	866	-16.8 (3.11)	**0.00**	747	22.5 (23.48)	0.34

@ Linear regression estimates represent mean changes in the percent probability of utilization (a binary outcome) or mean changes in costs paid by Medicaid associated with that utilization and expressed as dollar amounts (a continuous outcome), and their respective standard errors.

[2] Assertive Community Treatment (ACT), Personalized Recovery Oriented Services (PROS), OMH Outpatient Clinic and other OMH services, OASAS Outpatient Clinic and other OASAS services, Partial Hospitalization, BH HCBS, with the exception of crisis respite services, etc.

Research Question 3.2: Does participation in SDC result in decreased use and cost of BH inpatient, ED, and crisis services?

This RQ included two hypotheses:
Hypothesis 1: Inpatient stays for BH will decrease between baseline and follow up for SDC participants.
Hypothesis 2: ED and BH crisis service use will decrease between baseline and follow-up for SDC participants).

Our main outcomes were utilization of inpatient psychiatric services (*BH IP*), which for utilization analyses was captured separately as Medicaid and MHARS IP admissions; psychiatric ED services (*BH ED*); crisis respite HCBS; and Non-BH ED care. Additional outcomes were *Any Acute BH Care*, a composite measure of acute BH care capturing BH IP or BH ED care; several high-acuity SUD services (SUD ancillary withdrawal services, hospital-based detoxication (detox) services, and SUD inpatient rehabilitation (rehab) services); *Any Acute BH Care Plus*, a composite measure capturing acute BH care as well as crisis respite HCBS and the high-acuity SUD services; Non-BH IP; and *Any Acute Non-BH Care*, a composite measure capturing Non-BH IP or ED care. An additional acute care outcome was BH IP inpatient days, a measure of utilization intensity. We also assessed PMPM cost outcomes for each of these utilization categories. We note that we were unable to model MHARS IP admissions or crisis respite HCBS outcomes due to these services' low utilization rates (see Section 3.3, Cohort Construction and Analytic Considerations), but these outcomes were captured in the acute BH care composite measures.

Adjusted Findings (Interrupted Time Series Model Results)

These analyses were conducted for all SDC participants in our cohort and compared their rates of any utilization (and for BH IP, days of utilization) and PMPM costs in the post-period relative to the pre-period (Table 4.3).

In both sites combined and relative to the pre-period, SDC participants had a lower probability of post-period utilization of all forms of acute care, although no differences were observed for BH IP days. For instance, relative to the pre-period, SDC participants had a 10.2 (1.93) percent and 17.8 (2.64) percent lower post-period probability of BH IP and BH ED utilization, respectively, and a 21.8 (2.82) percent lower post-period probability of Any Acute BH Care Plus Utilization. A similar pattern was evident for non-BH acute care utilization; for instance, the probability of non-BH ED utilization was 16.7 (3.29) percent lower in the post-period relative to the pre-period. However, post-period costs of these services were unchanged relative to the pre-period.

Table 4.3. SDC Impacts on Utilization and Costs of Acute Care and Total Medicaid Spending, Post-period Relative to Pre-period, SDC Participants (both Sites Combined)

Service Category	Any Utilization			Total Costs Among Users		
	Sample Size	Estimate@ (SE)	p-value	Sample Size	Estimate@ (SE)	p-value
BH IP (Medicaid) admissions	866	-10.2 (1.93)	**0.00**	87	11.2 (1974.04)	1.00
BH IP (Medicaid) admissions (days)	87	1.92 (5.06)	0.71			
BH ED visits	866	-17.8 (2.64)	**0.00**	195	64.0 (53.24)	0.23
Acute BH care	866	-19.1 (2.68)	**0.00**	209	-481.5 (726.64)	0.51
Acute BH care plus	866	-21.8 (2.82)	**0.00**	248	-238.2 (670.64)	0.72
Non-BH IP admissions	866	-7.23 (2.08)	**0.00**	101	-91.8 (2575.29)	0.97
Non-BH ED visits	866	-16.7 (3.29)	**0.00**	446	48.9 (37.16)	0.19
Acute Non-BH care	866	-17.0 (3.29)	**0.00**	450	93.6 (479.64)	0.85
All non-pharmacy services (Total Medicaid costs)				864	83.4 (172.07)	0.63

NOTE: We were not able to model Crisis Respite HCBS separately due to low utilization, but the services are captured by the Any acute BH Care Plus measure.
@ Linear regression estimates represent mean changes in the percent probability of utilization (a binary outcome) or mean changes in costs paid by Medicaid associated with that utilization and expressed as dollar amounts (a continuous outcome), and their respective standard errors.
SOURCE: Authors' analyses of Medicaid data (2014–2019)

Research Question 3.3: How does participation in SDC impact overall Medicaid spending?

This RQ included four hypotheses:

Hypothesis 1: Spending on BH outpatient services (including non-traditional services) will increase between baseline and follow up for SDC participants.

Hypothesis 2: Spending on primary care will increase between baseline and follow up for SDC participants.

Hypothesis 3: Spending on ED and BH inpatient and crisis service use will decrease between baseline and follow up for SDC participants.

Hypothesis 4: Overall Medicaid spending will stay the same between baseline and follow up for SDC participants.

Because hypotheses 1–3 have already been addressed in the previous RQs, in this RQ we focus on the last hypothesis (Overall Medicaid spending will stay the same between baseline and follow up for SDC participants).

Our only outcome was total costs borne by Medicaid (overall Medicaid spending), a measure that captured PMPM costs of all non-pharmacy services.

Adjusted Findings (Interrupted Time Series Model Results)

These analyses were conducted for all SDC participants in our cohort and compared their total costs in the post-period relative to the pre-period (Table 4.3).

In both sites combined and relative to the pre-period, SDC participants' total costs were unchanged relative to the pre-period.

Summary of Goal 3 Findings

Our analyses do not support the State's hypotheses that OP BH and primary care utilization would increase; in fact, our analyses showed that relative to the pre-period, post-period utilization of OP BH and non-BH services was in fact lower (or unchanged, in the case of receipt of primary and/or preventive care). We note, however, that these hypotheses contemplated a longer follow up. On the other hand, our analyses provide partial support for the State's hypothesis that SDC participation would result in decreased BH IP and ED utilization: While the probability of that utilization and other forms of acute care utilization, one of them including crisis respite HCBS, all experienced pre-post declines, intensity of BH IP utilization did not decline. Although the State's hypotheses regarding costs of outpatient and acute-care services were not supported by our findings (i.e., the former did not increase and the latter did not decline), our analyses do provide support for the State's hypothesis that SDC participants' overall Medicaid spending would not change between baseline and follow up. We note that these costs do not include start-up and maintenance costs including those related to the purchase of self-directed goods and services, which as described in Section 2.2 (The Self-Directed Care Pilot Program), were borne by the State in this pilot implementation phase. Finally, we also note that the two tiers of SDC participation differed in the amounts to which participants had access, $8,000 vs. $16,000, but we were not able to investigate differential impacts of these amounts on study outcomes.

5. Policy Implications

The goal of the SDC pilot was to implement a program in which participants work with their representative to control a range of services and supports provided by the Medicaid program. Our interviews with staff and participants at the two sites and OMH staff involved in administering the program for the state showed clearly that the program was successfully implemented largely as intended. Program participants were selected and enrolled and were successful in completing the processes required to identify goals and purchases and in executing those purchases using the system implemented by the state. Beyond the implementation of the program, our evaluation was also concerned with how the program was perceived by both participants and staff at the program and state levels, with impacts of the program on recovery-oriented outcomes, and with impacts on service utilization and costs. Due to unexpected data limitations, the evaluation was unable to examine the impacts of the SDC pilot program on recovery-oriented outcomes or service utilization and costs. However, the qualitative information about perceptions of the program and the analyses of utilization and costs provides a basis for recommendations for the issues to be considered as the state considers whether to scale-up the SDC program and, if so, how the scale up should be done.

5.1 Improve Data Collection for Program Monitoring and Evaluation

One of the reasons for the lack of robust data for evaluating the impact of the SDC program on recovery outcomes was that the original evaluation plan relied on external data from the HARP PCS assessment. That assessment system turned out to be ineffective for reasons completely unrelated to the SDC implementation. Data were collected more effectively through the SDC portal, but since those data are collected only on the SDC participants they are not useful for comparison with a control group. For purposes of future evaluations, identification of a control group with data on relevant recovery outcomes will be important. For purposes of monitoring of program outcomes over time, the current SDC portal system could be improved to (1) ensure more consistent data collection and recording; (2) expand outcomes to assess outcomes more directly relevant to the SDC program, including information on brokers as well as participants, and (3) include larger numbers of participants.

Other improvements to data collection systems should also be considered. The utility of the system could be enhanced by additional tracking of eligibility for the SDC program, outreach to potential participants, enrollment in the program, and reasons that eligible participants give for declining to participate. These data could help over time in better characterizing the population that benefits most from the program and would improve overall program transparency. In addition, if SDC staff had direct access to participants' transaction histories and card balances

and were able to run reports on the data portal directly, they would be in a better position to track and manage budgets, requests, and purchases at the agency level.

5.2 Develop Assessment Instruments to Capture Features That Participants Value About SDC

In addition to the lack of participant and control individual level data on recovery-oriented outcomes, there are other outcome domains that were found in the qualitative interviews to be important to participants for evaluating the impact of the program. Many of the highly positive perceptions that respondents shared may not have been reflected in the measures that were originally designed to assess impact. In particular, assessments of the experience of care in the program should focus explicitly on the participants' perceptions that the program is helping them identify and achieve personal recovery goals and perceptions that the support broker in particular has helped them identify through this process.

5.3 Assess Fit Between Agency Culture and SDC Program Goals in Identifying New Sites

Qualitative data highlighted the importance of an agency's commitment to patient-centered care and recovery-oriented outcomes to implementation of the SDC program. In addition to providing a broad range of services that are available to participants, the program should embrace the goals of empowering participants to exercise self-determination and engage in self-direction consistent with program design. The SDC program will rely on referrals from the broader agency into the SDC program and on integration of the SDC program with other services that participants are receiving. For this purpose, agencies could be required to demonstrate their commitment to the program goals by documenting a history of patient-centered care before being able to offer an SDC program. Prior SDC participants and/or peer support specialists could also be involved in assessing the readiness of programs for implementing SDC.

5.4 Provide Appropriate Training and Support for Support Brokers

The qualitative interviews with SDC participants and support brokers revealed that the role of a support broker is complex. The support broker role is not limited to managing the funds designated by the SDC program. Rather, the broker takes on a large role in the participants' lives as a support in the participants' self-definition of life goals and development of strategies for using the SDC resources to achieve those goals. This role is different in important ways from more traditional roles of care managers or supportive counselors, and these differences were extremely important to the participants. Most of the brokers in the pilot program were individuals with long work experience in mental health services, and they were apparently able to adapt effectively to their new role. However, as the program expands, this level of experience

and adaptability cannot be assumed. A full understanding of the support broker role is important for identifying the skills and experiences that should be required for new hires and for orientation and training of these new brokers.

Brokers should have an understanding of the reactions that people with SMI may have to the SDC program, including reticence to ask for help or advocate for their own goals. Brokers should be prepared to support participants through major life stressors, acute episodes of illness, and other difficulties that are not directly related to the SDC program itself. Brokers should also have training in motivational interviewing and skills in clear communication. Training for brokers in new programs could take advantage of the pilot program by involving brokers and participants in creating educational materials. A learning collaborative style system, where new programs have access to experts with more experience from established programs, could also be considered.

Brokers should also be trained to recognize the potential varying levels of support that participants need to identify goals, complete purchasing, and cope with life stressors, as well as supervisor support for broker negotiation of role tasks and boundaries and coordination with other providers. Given the unique responsibilities of the support broker role, minimizing staff turnover and hiring delays while maintaining training and fit with SDC is key to sustaining capacity. Further, given that SDC supervisors are familiar with participants across the caseload, greater involvement of these supervisors during periods of turnover may help facilitate support broker transition, offering participants some continuity of contact while also passing along to support brokers prior knowledge of participants and their goals to help them better orient to a new caseload.

5.5 Review and Update SDC Program Rules

SDC participants and brokers reported areas of uncertainty about some SDC program rules and how they were applied. One of the challenges of the program that may become more acute with scale-up is the lack of clarity regarding approvals for use of program funds. To some extent approvals involve subjective assessments of whether a proposed purchase is or is not justified by the participant's treatment plan. These issues could be partially resolved through the development of greater transparency and consistency, which might develop over time as OMH and the agencies gain experience. The procedures for communicating between the agencies and OMH and communicating program expectations and decisionmaking to participants should be carefully reviewed with input from staff and participants. Some aspects of communication between agencies and OMH could be automated to decrease the amount of time needed to make decisions. Revisions should focus on strategizing how best to balance maintaining a flexible and individualized decisionmaking approach that is conducive self-directed care while having a transparent, consistent, and standardized process that lends itself to scale. Other areas where

rules and guidelines should be reviewed include caseload size, consequences of minor misuse of funds, and support for participants.

Caseload Size

One of the agencies reported a plan to increase caseload size from 22 to 25 to about 30 per support broker. The ideal size or the maximum size that a broker can effectively manage while providing quality care is not known but should be carefully examined. It is likely that future programs may tend to increase caseload size given the difficulty of hiring staff and the high level of demand for the program. Developing evidence-based standards for caseload size will be important for maintaining quality as the program expands.

Consequences of Minor Misuse of Funds

Many of the cases of misuse of SDC funds were accidental or based on misunderstandings. According to the support brokers who manage the spending, when misuse was intentional, it was frequently very small in scale. Having a range of less severe consequences for minor cases of misuse of funds could prevent unnecessary dismissal from the program. Additionally, developing more formalized processes for appealing decisions or procedures for enhanced review may be warranted.

Varying Levels of Support Across Participants

Future programs may be more effective in targeting support and levels of oversight to the needs or stage of participation by individual participants. More experienced brokers and more experienced participants could have additional flexibility with respect to monitoring of purchases. Some reoccurring purchases could receive pre-approvals to streamline processes.

5.6 Support Ongoing Communication Between Programs

There was a desire among both participants and program staff for increased clarity and consistency regarding factors that should be considered in the decisionmaking about purchase approvals. As innovative programs the two pilot programs and any programs added in a future expansion would benefit from sharing information about implementation strategies and skills on an ongoing basis. Communication across programs could contribute to development of consensus about program guidelines and applications of program rules. Involvement of OMH in these networks could provide a forum for communicating about reasons for denials and other issues that have emerged as concerns during the pilot. Any steps that can be taken towards achieving greater consensus on issues such as participant tenure and program duration, including criteria or processes regarding program graduation, would also be helpful.

5.7 Scale up Slowly

If the SDC program is to be expanded to additional sites, we recommend scaling up slowly in a way that enables maintenance of fidelity to the program with necessary tailoring to new agencies and settings. The two pilot sites are geographically diverse, lending initial support to the generalizability of the program to additional sites. However, the small scale of the pilot suggests that caution is still warranted and that unanticipated implementation issues may arise. Moreover, rapid expansion may outstrip the ability of personnel involved in the initial pilot program to provide needed expertise and support to new programs. Finally, given that the two pilot site programs were selected for their demonstrated commitment to the principles of SDC, this requirement should be maintained for selection of agencies for new SDC programs. The state could benefit from developing criteria through which agencies can demonstrate their commitment to these principles, perhaps involving prior SDC participants or other peer advocates in these assessments.

5.8 Strengths and Limitations

The major strength of the evaluation lies in the consistency of the qualitative findings with respect to the overall positive assessment of the program's impact on participants and relatively minor implementation challenges. Although the qualitative data were collected on a non-random sample of the participants, the results were remarkably consistent not only with respect to the outcomes but also with respect to the mechanism, which are likely to be more generalizable. The range and consistency of findings across these in-depth participant reports suggests that a high degree of saturation may have been reached and that new content was not likely to emerge without significantly altering the sampling design (further commented on below). Reports from the SDC staff, who have experiences with most, if not all, of the participants in the two pilot programs, were also consistent, reinforcing the strength of the findings. These respondents are in positions where they directly observe individuals participating in the program and would have direct knowledge of adverse effects or missed opportunities. Qualitative interviews with SDC participants, pilot site staff, and OMH also offer extensive findings that inform broader scale-up of SDC, including suggestions for improving the program and factors to consider when planning for expansion.

Given that recruitment for SDC participant qualitative interviews relied on referrals from SDC pilot sites, there is a possibility that those who participated in the process evaluation were more likely to have positive views of the program. While there was a diversity of participants in the qualitative sub-sample that broadly reflected the SDC participant population as a whole, future evaluations should expand efforts to recruit individuals who are Black and who have schizophrenia spectrum diagnoses, as their perspectives may have been under-represented. As we have noted, the evaluation was limited in its ability to produce causal effect estimates of the impacts of the SDC program on the recovery-oriented outcomes in Goal 2 and the service

utilization and cost outcomes in Goal 3. Hence, observed differences may not be attributable to SDC but rather to policies or other factors independent of SDC that are happening concurrently over the course of the evaluation period. In addition, the length of follow-up for SDC participants was highly variable across individuals, with a large share of participants having less than one full year of participation during the study period. The maximum time of follow-up was two years. The results may be different with a longer period of follow-up. In the short term, participants' behavioral health conditions and overall health status are unlikely to show dramatic changes. The changes that the SDC program enables participants to make may have impacts on service utilization and, potentially, also costs over a longer period of time through their impact on self-management skills, quality of life, and social determinants of health.

Another potentially important issue that we were not able to address is the impact of having a larger or smaller amount to spend through the SDC program. The two levels differed dramatically in the amounts that were made available for participants to spend—$8,000 versus $16,000. It is reasonable to expect that there might be some difference between them, and it may be important for the design of future SDC programs to understand the impact of the program with different amounts. For instance, evidence that the impact of the program was similar for the two groups, adjusting for differences between them, might suggest that the higher level is not necessary to achieve the policy goals. In the current study, we did not have access to complete information on the amounts that participants qualified for or information on their individual characteristics that would enable us to investigate this question.

6. Interactions with Other State Initiatives

This section describes health care delivery policies, payment policies, and other initiatives that were launched around the time the SDC Pilot was launched or that reached maturity during the SDC Pilot timeframe, since the effects of these initiatives may have affected outcomes for SDC Pilot participants. A variety of major health care initiatives were implemented within this timeframe, including other components of New York's Medicaid Redesign Team Section 1115 Demonstration and specific provisions of the Affordable Care Act. These initiatives may have affected outcomes targeted by the SDC Pilot, such as rates of BH and non-BH service use; indicators of BH, PH, and wellness; and social outcomes, such as education and employment, community tenure, and social connectedness. While it would be impossible to disentangle the effects of these initiatives from the SDC Pilot in our analysis, this section describes the initiatives and their potential effects to help readers interpret our results.

We identified the five initiatives listed below through a scan of publicly available documents and meetings with state officials to discuss background and implementation of the SDC Pilot. Two of the initiatives were included in the April 2014 amendment to the Demonstration, two other initiatives were provisions of the Affordable Care Act (ACA), and the remaining initiative was a State-initiated quality improvement project. We then conducted nine 60-minute interviews with state key informants with the goal of eliciting their opinions on the likely effects of these initiatives on SDC Pilot participants. In addition, we expanded our document review to achieve a greater understanding of these initiatives.[27-33]

We describe five initiatives in this section:

- April 2014 amendment to the Medicaid Redesign Team Section 1115 Demonstration
    - Delivery System Reform Incentive Payment (DSRIP) Program
    - Value-Based Payment (VBP) Roadmap
- Patient Protection and Affordable Care Act (ACA)
    - Health Homes (HHs)
    - Medicaid eligibility expansion under the ACA
- Performance Opportunity Project (POP).

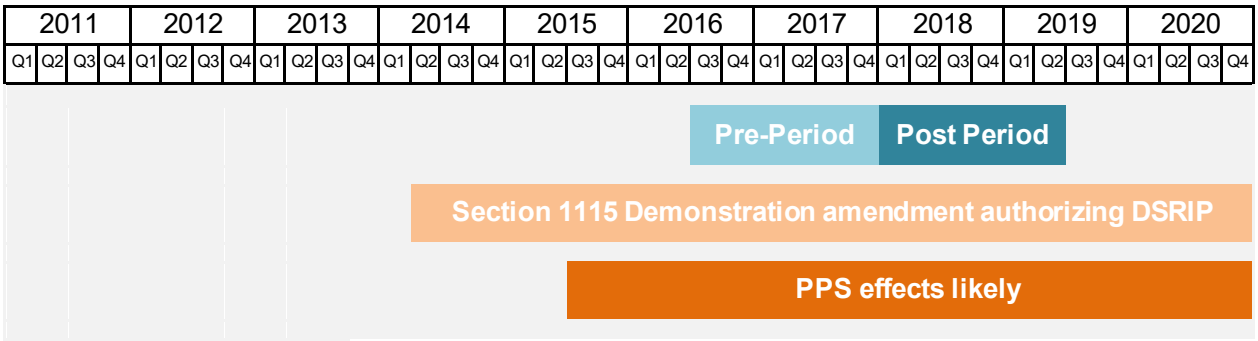
For each initiative, we provide a timeline that compares the timing of its launch and operation with the time periods of the *data* we used to evaluate the SDC Pilot. As described in Section 3 of this report, our evaluation covers a three-year period that includes a July 2016 to December 2017 pre-program period and a January 2018 to June 2019 post-program period. The timeline for each initiative shows how the initiative might have affected the data for the evaluation.

6.1 April 2014 Amendment to New York State's Medicaid Redesign Team Section 1115 Demonstration

The April 2014 amendment to the Demonstration included two components that may have affected outcomes for the MMC BH carve-in and HARP populations: the Delivery System Reform Incentive Payment (DSRIP) program and the Value-Based Payment (VBP) Roadmap.[34]

Delivery System Reform Incentive Payment (DSRIP) Program

Figure 6.1. Overlap of SDC and DSRIPs in NYC and ROS



NOTE: Light shaded bars indicate time periods for pre-program data used in the evaluation. Dark shaded bars indicate launch and operation of mainstream MMCs and the SDC Program.

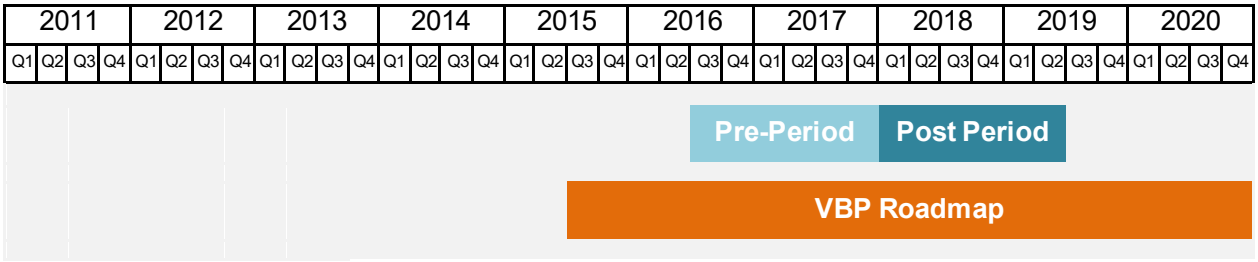
The DSRIP program was aimed at reducing avoidable inpatient hospital and emergency department use, using incentives to drive system transformation, and improving clinical management and population health. DSRIP enabled the state to create 25 Performing Provider Systems (PPSs), coalitions of safety net hospitals, clinics, and other eligible providers that were tasked with carrying out health improvement projects in four domains.[35] PPSs were required to select health improvement projects from a menu of options provided by the state and could earn incentive payments based on improvement in performance metrics associated with each project. The menu included multiple projects with the potential to improve outcomes targeted by the SDC Pilot, including projects to integrate primary and BH care, improve care coordination, and connect different care settings. PPSs were required to select at least one behavioral health project from a menu of five projects, and 15 of 25 PPSs selected more than one behavioral health project. The first performance measurement year for awarding incentive payments to PPSs began one year before the pre-period for the SDC Pilot began, and PPSs could earn incentive payments throughout the SDC pre- and post-periods.

State informants for our evaluation reported that PPSs targeted clinical quality improvement activities to people with co-occurring physical and behavioral health conditions to help achieve the goal of reducing inpatient use. They also reported that provision of integrated physical and behavioral health care by primary care providers and federally qualified health centers increased because of PPS efforts. Consistently with these reports, the federally required summative

evaluation of PPSs[35] conducted by an independent external evaluator, found that nearly all PPSs reduced potentially preventable hospital admissions, and most PPSs reduced potentially avoidable emergency department visits, overall and for behavioral health populations. Except for initiation of alcohol and drug treatment, most PPSs improved performance on BH utilization measures, although improvement varied among PPSs. Thus, it appears likely that PPSs improved outcomes targeted by the SDC Pilot. However, PPSs would have started working on their health improvement projects a year before the pre-period for SDC evaluation data. As a result, it appears likely that the effects of PPSs were evident during the pre-period, the baseline for our analysis, and it is unlikely that they biased our estimates of the SDC Pilot's effects.

Value-Based Payment (VBP) Roadmap

Figure 6.2. Overlap of SDC and VBP in NYC and ROS



NOTE: Light shaded bars indicate time periods for pre-program data used in the evaluation. Dark shaded bars indicate launch and operation of mainstream MMCs and the SDC Program.

In addition to authorizing the creation of PPSs, the April 2014 amendment to New York's Section 1115 Medicaid Demonstration[34] required the State to create a VBP Roadmap that set forth the state's goals for increasing the use of VBP arrangements in Medicaid and described requirements for Medicaid managed care organizations (MCOs) to include VBP arrangements in their contracts with health care providers.[27] CMS approved the Roadmap in July 2015 and updated it in each waiver year. The Roadmap committed New York to achieving the goal of channeling 80 percent of MCO spending through VBP arrangements—including 35 percent in FFS arrangements with upside and downside risk sharing or prospective payment with a quality component—by 2020 and described payment arrangements that would qualify as VBP arrangements for the purpose of meeting the target. These included payment arrangements for the general population of Medicaid enrollees and payment arrangements for special needs populations, including HARP enrollees, people with HIV/AIDS, people with intellectual or developmental disabilities, and people eligible for Medicaid long term care. Qualifying payment arrangements exposed providers to some level of financial risk (i.e., potential savings or losses) and included a set of quality measures that MCOs could use to adjust savings or losses (i.e., to reduce savings to providers that performed poorly on quality or reduce losses incurred by providers that performed well on quality). The Roadmap required New York State to create

financial incentives for MCOs that executed VBP arrangements with providers and impose financial penalties on MCOs that fell behind Roadmap goals for VBP contracting.

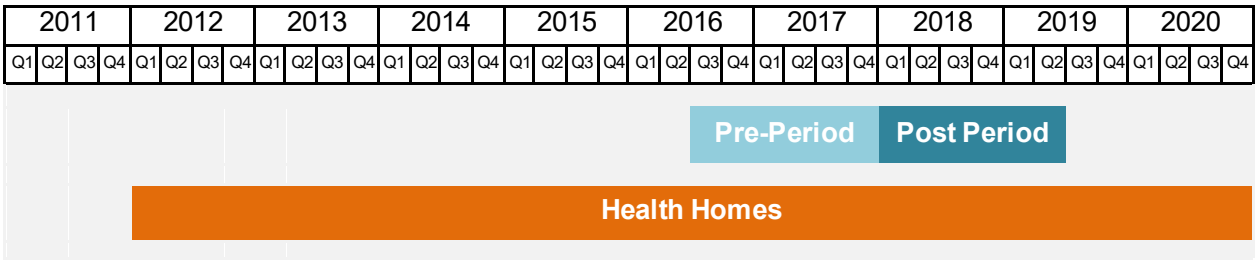
Informants for our evaluation reported that most MCOs adopted VBP arrangements for general Medicaid populations, rather than for special needs populations, to meet the Roadmap's targets. In most of these arrangements, MCOs targeted performance incentives to primary care providers, who were not always equipped to provide or arrange for the full complement of services needed by people with high levels of BH needs and who were less well connected than BH providers to this population. Moreover, MCOs chose quality measures for their VBP arrangements that were generally less relevant to beneficiaries with SMI. Thus, it appears unlikely that New York State's VBP Roadmap meaningfully affected health care outcomes for people with significant BH need, including HARP enrollees participating in the SDC Pilot.

6.2 Affordable Care Act (ACA)

The Affordable Care Act (ACA) of 2010 included a variety of provisions to increase health care coverage, contain health care costs, and improve the performance of the health care delivery system.[36] We focus on the potential effects of two of them among MMC BH carve-in and HARP populations: the option for states to establish a Health Home program and the Medicaid eligibility expansion.

Health Homes (HHs)

Figure 6.3. Overlap of SDC and HHs in NYC and ROS



NOTE: Light shaded bars indicate time periods for pre-program data used in the evaluation. Dark shaded bars indicate launch and operation of mainstream MMCs and the SDC Program.

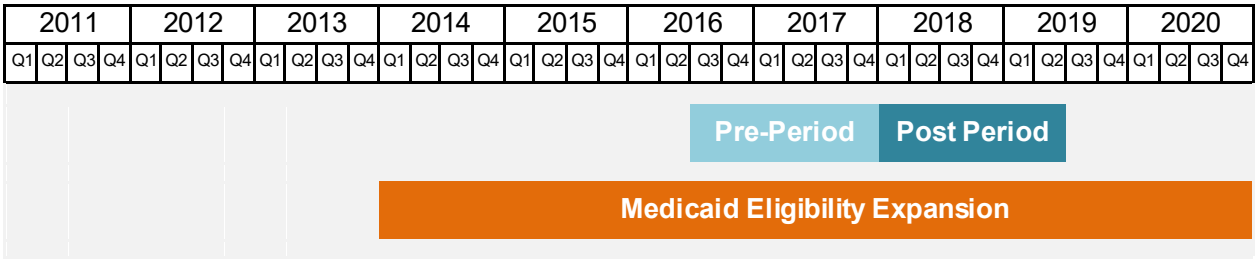
The ACA enabled states to establish organizations called Health Homes (HHs) for the purpose of coordinating health care and health-related services for people with chronic conditions, including physical health, mental health, and substance use conditions.[37] An HH provider could be an individual health care provider, a team of providers, or a provider organization. The ACA provided enhanced federal matching funds for services provided by HHs and allowed states to tailor the populations targeted by their HH programs. Through its HH program, New York merged existing care management programs for specific populations into one initiative that served a broader population.[37] New York's Health and Recovery Plans

(HARPs) were directed to work with HHs to enroll and develop a person-centered plan of care for eligible Medicaid enrollees although HARP enrollees could opt out of HH enrollment.

State informants for our evaluation described HHs as positively impacting populations with BH needs and as an important component of the HARP program for the HARP enrollees who enrolled in HHs. Consistent with these reports, a recent study indicated that New York's HHs improved care for people with SUD.[38] It found that that New York's HHs were associated with reduced acute care service use and increased outpatient medical visits among HH enrollees with SUD relative to a matched comparison group. It is very likely that SDC participants benefited from any improvements in access to health care services—and any consequent improvements in health, wellness, and social outcomes—resulting from their engagement in HH services. However, the HH program launched over four years before the pre-period for the SDC Pilot began. Thus, it is unlikely that HHs affected our estimates of the Pilot's impact.

Medicaid Eligibility Expansion

Figure 6.4. Overlap of SDC and Medicaid Eligibility Expansion in NYC and ROS

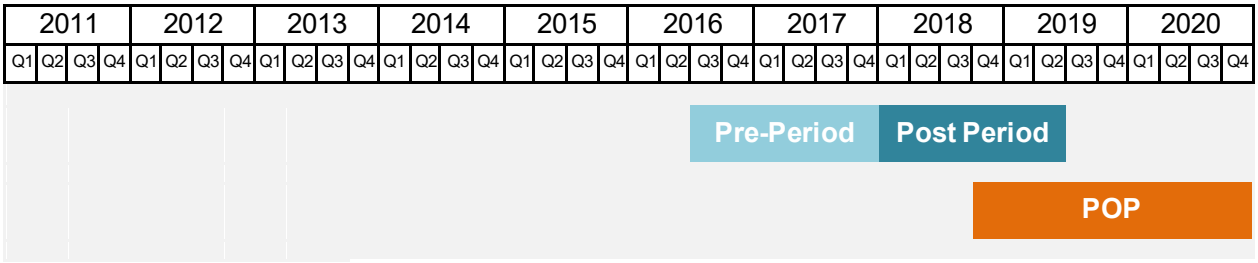


NOTE: Light shaded bars indicate time periods for pre-program data used in the evaluation. Dark shaded bars indicate launch and operation of mainstream MMCs and the SDC Program.

Starting in 2014, the ACA provided states with the opportunity to expand Medicaid eligibility to all non-Medicare-eligible people under age 65, including adults without dependent children, with incomes up to 133 percent of the federal poverty level.[36] New York State chose to expand its Medicaid program in 2014. Medicaid expansion could have negatively impacted access to care for SDC Pilot participants if a sufficiently large population gained health care coverage through expansion and used their new coverage to access health care services, thereby "crowding out" SDC Pilot participants. However, the increase in New York State's Medicaid enrollment following expansion was modest relative to other states,[39] and state informants did not believe that expansion substantially impacted access to care or quality of care received by NYS's Medicaid beneficiary population. Thus, it is unlikely that the ACA-related Medicaid expansion affected health care outcomes attributed to the SDC Pilot in our analysis.

6.3 Performance Opportunity Project (POP)

Figure 6.5. Overlap of HARP and POP in NYC and ROS



NOTE: Light shaded bars indicate time periods for pre-program data used in the evaluation. Dark shaded bars indicate launch and operation of mainstream MMCs and the SDC Program.

The Performance Opportunity Project (POP) was a New York State program that awarded incentive payments to Medicaid MCOs for increasing the use of two interventions among high users of acute mental health services: Intensive Care Transition Services, a nine-month program of care management aimed at helping members transition from a psychiatric hospital to community-based care; and treatment with clozapine, an antipsychotic drug for treatment-resistant and severe schizophrenia, among members with a diagnosis of schizophrenia or schizoaffective disorder.[40] In its initial phase, which spanned October 2018 to September 2020, POP targeted members age 16 to 64 with four or more mental health emergency department (ED) visits or inpatient visits per year. An analysis conducted by OMH found that inpatient costs, mental health inpatient costs, and mental health ED costs decreased substantially among POP enrollees who reached milestone four, five, or six of the program's six milestones for contacts with care managers.[40] However, only 12 percent of POP-eligible members enrolled in the program (i.e., had an episode of care initiated) and less than one-fifth of enrolled members reached more than two of six milestones. Interviews with state informants indicated that a lack of teams with expertise in a specific care transition model may have impeded the scaling up of POP.

While POP had the potential to improve outcomes for SDC Pilot participants, it is unlikely that the program would have affected our analysis because it enrolled relatively few eligible members and began relatively late in the post- period for our analysis.

6.4 Conclusion

Evidence from our key informant interviews and recent studies indicates that New York's HH program and PPSs positively impacted several outcomes targeted by the SDC Pilot, including access to care and integration of BH and PH services. However, these initiatives were launched before the pre-period for our evaluation, which serves as baseline for assessing the SDC Pilot's effects. Thus, the impact of these initiatives is likely "baked in" to baseline outcomes and unlikely to affect our estimates of the SDC Pilot's effects. In contrast, PPSs would

have started working on their health improvement projects around the time of the SDC Pilot launch, and their efforts may have upwardly biased our estimates of the SDC Pilot's effects. Other initiatives described in this section are unlikely to have affected our estimates of the SDC Pilot's effects since the available evidence indicates that they did not widely impact outcomes for people with BH needs, the target population for the SDC Pilot.

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Appendix A. Key Informant Interview Protocol

Interview Guide: Non-Client Agency Leadership Stakeholder

Participant ID: _____ Interview Date: _____

Region: NYC ___ Beacon ____

Stakeholder Type: _____

Agency Type: _____

Interviewer: _____

The purpose of this interview is to explore your perspective and experience with the Self-Directed Care pilot program. The Self-Directed Care program allows individuals with behavioral health needs who are participating in the pilot program to use State funds to purchase goods and services and/or to hire service providers that can facilitate the person's recovery. The SDC pilot seeks to increase autonomy and choice over benefits in order to enhance participants' progress toward recovery goals and improve health for individuals with behavioral health needs. The SDC pilot is being implemented at two behavioral health agencies in New York State.

Before we begin, I want to discuss the process of this interview. The interview will take approximately 60 minutes to complete. Again, the goal of this interview is to learn about your views and experiences regarding the implementation of the SDC Pilot Program. There are no right or wrong answers to these questions. We are only interested in your honest opinion. Any questions before we begin?

<< BEGIN RECORDING >> << BEGIN RECORDING >> << BEGIN RECORDING >>

Role:

1. What is your current role at [organization]?
   Probe: How do your responsibilities relate to the SDC pilot?

<u>SDC Pilot</u>

2. How would you describe the mission and goals of the SDC pilot?
3. What has been your experience with the SDC program?
4. How were participants enrolled in the program?
    a. How was eligibility assessed? Were there any challenges?
    b. To what degree is it reaching the target population?
    c. What were the most common reasons that participants were not eligible? Would this need to be changed if the program were to scale-up?
    d. What motivated participants to join the SDC program?
    e. How many participants were eligible but did not enroll? Why?

5. What have been some of the benefits of implementing SDC?
    a. What has gone well with SDC? For participants? For the organizations? For the overall system of care?
    b. How would you define success for SDC?

6. How has the SDC program impacted SDC participants?
    a. How has it impacted the paperwork they have to do (e.g., purchase requests) regarding managing their benefits?
    b. How has it impacted their access to services?
    c. How has it impacted their access to goods?
    d. How has it impacted participants' sense of autonomy and choice?
    e. How has it impacted participant outcomes (e.g., recovery, quality of life, health/wellness, community integration, functioning)?
    f. For whom does the program work well?
    g. For whom does it not work as well? Can you give an example?

7. What services or goods has SDC increased access to the most?
    a. How do these services or goods meet participants' needs?

8. What services or goods have been more challenging for SDC participants to utilize?
    a. What has been challenging about accessing these services or goods?

9. How does access to goods and use of services differ between SDC participants and other people with behavioral health needs served by [organization(s)]?
    a. What goods/services are SDC participants more likely to use/access?
    b. What goods/services are SDC participants less likely to use/access?

10. How well has the process of SDC participants identifying goals and needs, requesting funds, and having them reviewed been going?
    a. Developing participant goals? Developing budgets?
    b. Participants identifying goods/services needed?
    c. Participants requesting funds?
    d. Review/approval of funding requests?
    e. Placing funds on participants' cards?
    f. Which parts of the process do participants need the most support with?

11. What are some of the most common reasons that participants' purchase requests are denied?
    a. How is it determined whether requests are an appropriate use of SDC funds?
    b. How is it determined whether requests are related to goals?
    c. Can participants appeal request denials?

12. What is the process for identifying misuse of funds?
    a. What are the most common ways in which funds have been misused?
    b. Do any changes need to be made to the types of oversight that are now in place?

13. What have been some of the challenges of providing SDC services?
    a. Engaging participants?
    b. Staff delivering the services? Staff retention?
    c. Communicating/coordinating across staff/agencies?
    d. Reviewing/approving purchases?
    e. Timeliness with which requests/purchases are completed?
    f. Funding for SDC?
    g. Administrative burden for organizations/agencies?
    h. Any dilemmas or ethical issues that arise?
    i. What could be improved? What would help address some of these challenges?

14. What changes would you suggest to the program?
    a. What changes would be needed to help scale-up the program to other organizations and participants throughout the state?

Support Brokers

15. What is the role of the support broker within the organization?
    a. To what degree does the work of the support broker match how the role was planned?
    b. What aspects of the role have had to be clarified or negotiated over time?
    c. What changes might need to be made to the role of the support broker?

16. How did the organization select a support broker to work with participants?
    a. Were there any challenges to hiring the support broker?
    b. Any challenges to integrating this role into the agency?
    c. To what extent do support brokers work with other staff at the organization?

17. How were support brokers oriented and trained in the SDC program?
    a. How are they introduced to participants?
    b. What additional training might be needed for support brokers?

18. How are support brokers supervised?

a. Who provides supervision?
b. Do supervisors receive any specialized SDC training?
c. What type of issues are discussed in supervision/with supervisors?

19. What are the benefits of having the support broker role compared to folding this into other staff roles?

20. What are the challenges of having the support broker role?

21. How does the SDC pilot fit in with other types of behavioral health services that are delivered by the [organization(s)]?

Fiscal Intermediary Role:

22. What is the role of the fiscal intermediary?
    a. To what degree does the work of the fiscal intermediary match how the role was planned?
    b. What aspects of the role have had to be clarified or negotiated over time?
    c. What changes might need to be made to the role of the fiscal intermediary?

23. What is communication/coordination like between the fiscal intermediary as part of SDC?

24. What are the benefits specifically of having the fiscal intermediary role?

25. What are the challenges of having the fiscal intermediary role?

Overall Program Evaluation

26. How would you evaluate the overall success of the program?

27. Do you believe the program should be expanded?
    a. Probe: Why or why not?

28. Any thoughts on how to improve the program?

29. What are the next steps for SDC?
    a. Probe: Do you believe that SDC is an effective and viable program for HARP enrollees across NYS?
    b. Long-term sustainability?

30. Is there something we didn't ask that you would like to add?

Appendix B. Client Interview Protocol

SDC Pilot Interview Guide: Client Stakeholder

Participant ID: _____ Interview Date: _____

Region: Site 1 ___ Site 2 ____

Stakeholder Type: _____

Interviewer: _____

The purpose of this interview is to learn about your thoughts and experience with the Self-Directed Care pilot program. The Self-Directed Care program allows individuals who are participating in the program to use State funds to purchase goods and services and/or to hire service providers that can help them meet their wellness and recovery goals.

Before we begin, I want to discuss the process of this interview. The interview will take approximately 60 minutes to complete. Again, the goal of this interview is to learn about your views and experiences with the SDC Pilot Program. There are no right or wrong answers to these questions. We are only interested in your honest opinion. Any questions before we begin?

Enrollment

31. How long have you been in the SDC program?

32. How did you hear about SDC?
    a. How did you get connected to the SDC program?
    b. Do you receive any other services at [site] other than SDC?

33. How would you describe the SDC program?
    a. How would you describe the mission and goals of the SDC program?
    b. Was the program what you expected it to be?

34. What made you want to join the SDC program?
    a. Did you have any concerns about joining the program? If so, what were those concerns?
35. What was the process like to join the SDC program?
    a. Can you walk me through the steps?
    b. How long did it take?
    c. What were some of the things that were good/helpful about the process?
    d. What were some of the things that were hard about the process?
    e. How did you feel about the paperwork you had to complete?
    f. Was there ever a time when you were discouraged during the enrollment process?

g. Would you change anything about the process of joining the program?
h. Did your needs or goals change from when you heard about the program to when you started making purchases?

36. What do you have to do to stay in the program?
    a. What are the rules or requirements?
    b. Any requirement or rule that you didn't understand?

Goals, Purchases, Support Broker

37. How do you work with your support broker/resource consultant?
    a. What does the support broker help you with?
    b. How often do you talk with the support broker?
    c. Does the support broker ever work with other service providers that support you (e.g., care manager)?
    d. Are there any challenges working with the support broker?

38. What are some of the goals that you've had while in the SDC program?
    a. How did you come up with those goals?
    b. What kind of input does the support broker/resource consultant have in terms of the goals you work on?
    c. Have you ever had trouble coming up with a goal?
    d. What happens if you and the support broker disagree about your goals?
    e. What happens if you want to change a goal?

39. Tell me about some of the goals that you've achieved or made progress on while in the SDC program?
    a. What helped you to make progress on those goals?

40. What's the process like from identifying a goal to being able to completing a purchase?
    a. Can you walk me through some of the steps? How long does it usually take?
    b. Developing budgets?
    c. Identifying goods/services needed?
    d. Requesting funds?
    e. Having funding requests approved?
    f. Submitting receipts?

41. What are some of the things that you have purchased while in the program?
    a. What types of services have you purchased?
    b. How did you figure out what things or services to purchase?
    c. What kind of input does the support broker have in terms of the things or services you purchase?
    d. What happens if you and the support broker don't agree about the things or services you should purchase?

42. What have been some of the benefits of being in the SDC program?

a. Tell me about some goals you've been able to achieve or make progress on?
b. What has changed for you since you've been in the program?
c. How has the program helped you?
d. Has it made it easier to get the services or things you need?
e. What are you able to do and have now that you could not have or do before SDC?

43. Tell me about some of the goals that you've had a harder time achieving or making progress on?
    a. What has made it hard to move forward with those goals?
    b. Any specific goods or services that would help you with those goals?
    c. Have there been any services or things that would help with your goals, but you've had a harder time accessing or purchasing them?

44. What kinds of things are you not allowed to buy with SDC funds?
    a. Have staff ever told you that one of your requests was denied or a purchase was not allowed?
    a. Can you give me some examples of when that happened?
    b. How did the program explain why it was not allowed?
    c. If a request is denied, what are your options?
        i. Did you change the request, or did you drop it all together?
    d. Has there ever been a time you were not allowed or not able to purchase goods/services at all? Have you ever been on hold from purchasing things?
        i. If so, why?
    e. What might get someone removed from the program?

Overall and Suggestions

45. How is SDC different from other types of behavioral health services you use?

46. How has SDC impacted your ability to make choices or have a say in your wellness and recovery?
    a. Has it impacted how you think about behavioral health services in general?

47. What changes would you make to the SDC program?
    a. Would you make any changes to how you work with the support broker?
    b. Any suggestions for improvement?

48. Is there anything else that you would like to add?

THANK YOU FOR YOUR PARTICIPATION!

Appendix C. Client Interview Survey

Self-Directed Care Pilot Evaluation
Client Interview Survey

To be completed by Research Staff

Today's Date: _____/_____/_____ **Subject ID: _____**

Site ID: __1_____2_____

Instructions: Please **check or fill** in the appropriate answers. Please note that all information provided will be kept confidential and not linked to your name.

1. **What is your age?** _____

2. **How long have you been a participant in the SDC program?** _____

3. **How long have you been a client/member of this agency?** _____

4. **Do you receive any services from this agency other than the services you get from the SDC program? (Check One)**
   - ❑ Yes
   - ❑ No

5. **What is your gender?** (Check One)
   - ❑ Male
   - ❑ Female
   - ❑ Other (Specify): _____

6. **What is your ethnicity?** (Check One)
   - ❑ Hispanic/Latino (Specify): _____
   - ❑ Non-Hispanic/Non-Latino

7. **What is your race?** (Check One)
   - ❑ Asian
   - ❑ Black/African American
   - ❑ Native American/Alaskan Native
   - ❑ Native Hawaiian/Pacific Islander
   - ❑ White
   - ❑ Multiracial/multiethnic

❑ Other (Specify): _____

8. **What is the last grade you completed / your highest level of education?** (Check One)
   - ❑ Grammar school or middle school
   - ❑ Some high school
   - ❑ High school graduate or GED
   - ❑ Post high school technical training
   - ❑ Some college/university
   - ❑ College graduate or higher

9. **A. Are you currently school? Full-time or part-time?** (Check One)
   - ❑ Yes, full-time
   - ❑ Yes, part-time
   - ❑ No

10. **A. Are you currently employed?** (Check One)
    - ❑ Yes, full-time
    - ❑ Yes, part-time
    - ❑ No

11. **A. Have you ever been told by a doctor or mental health provider that you have any of the following mental health conditions?** (Check all that Apply)
    - ❑ Major Depression
    - ❑ Bipolar disorder
    - ❑ Schizophrenia
    - ❑ Schizoaffective Disorder
    - ❑ Schizophreniform
    - ❑ Delusional Disorder
    - ❑ Other Psychotic Disorder
    - ❑ Borderline personality disorder
    - ❑ Autism Spectrum Disorder
    - ❑ Anxiety disorder (Panic Disorder, Phobia, etc.)
    - ❑ Substance abuse or dependence
    - ❑ Other (Specify):_____

SDC CLIENT SATISFACTION QUESTIONAIRE (CSQ):

Source: Larsen et al. (1979). Assessment of Client/Patient Satisfaction: development of a general scale. Evaluation and Program Planning, 2, 197-207. Roberts et al. (1984). Assessing the Client Satisfaction Questionnaire in English and Spanish. *Hispanic Journal of Behavioral Science, 6*, (4), 385-395.

We are interested in what you think of the services and help you have received from the Self-Directed Care Program. We are interested in your honest opinion.

CSQI1 How would you rate the SDC program in assisting you with your wellness and recovery goals? ____ CSQI1b

Code: 1 = Poor, 2 = Fair, 3 = Good, 4 = Excellent

CSQI2 Did the SDC program assist you in achieving your health and wellness goals? ____ CSQI2b

Code: 1= No, definitely not, 2 = No, not really, 3 = Yes, really, 4 = Yes, definitely

CSQI3 To what extent did the SDC program meet your needs? ____ CSQI3b

Code: 1 = None of my needs have been met, 2 = Only few of my needs have been met, 3 = Most of my needs have been met, 4 = Almost all of my needs have been met

CSQI4 If a friend were in need of similar help, would you recommend the SDC program to them? ____ CSQI4b

Code: 1 = No, definitely not, 2 = No, I don't think so, 3 = Yes, I think so, 4 = Yes, definitely

CSQI5 How satisfied are you with the amount of help you received from the support broker and other SDC staff? ____ CSQI5b

Code: 1 = Quite dissatisfied, 2 = Indifferent or mildly dissatisfied, 3 = Mostly satisfied, 4 = Very satisfied

CSQI6 Has SDC helped you deal more effectively with your wellness and recovery? ____ CSQI6b

Code: 1 = No, they seemed to make things worse, 2 = No, they really didn't help, 3 = Yes, they helped somewhat, 4 = Yes, they helped a great deal

CSQI7 In a general sense, how satisfied are you with the SDC program? ____ CSQI7b

Code: 1 = Quite dissatisfied, 2 = Indifferent or mildly dissatisfied, 3 = Mostly satisfied, 4 = Very satisfied

CSQI8 If you were to seek help again with your wellness and recovery goals, would you come back to the SDC program? ____ CSQI8b

Code: 1 = No, definitely not, 2 = No, I don't think so, 3 = Yes, I think so, 4 = Yes, definitely