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

JOHN
Mental Health Self-Direction Elements

Person-Centered Plan
- Based on participants’ strengths, capabilities, preferences, goals
- Creativity and flexibility are essential

Individual Budget
- Amounts and methods for setting the budget vary
- Often used for non-traditional goods and services and traditional services

Brokerage Support
- Works with the person to develop the plan and administer the budget
- Peers with lived experience often act as support brokers
Core Principles of Self-Direction

Recovery, independence, self-sufficiency, and choice

With adequate support, everyone is capable of self-direction

Every person is unique and knows best what works for them
Three Priorities from a 2015 International Learning Exchange

Self-direction represents a culture shift for value-based system change

People with lived experience are involved and supported at every level

Stakeholder communication is essential and must include quantitative data and personal narratives

Who is Self-Directing in the US?

- More than 300 programs with over a million participants
- In 2013, 700 individuals with serious mental health conditions were enrolled in mental health self-direction
- ~500 more expected to enroll in 2018

**Populations Self-Directing**

- Older adults with long-term care needs
- People with physical disabilities
- People with intellectual and developmental disabilities
- People with traumatic brain injury
- Families of children with autism
- Veterans
- More recently, people with serious mental health conditions and substance use disorders
# U.S. Mental Health Self-Direction Efforts

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Florida Self-Directed Care</strong></td>
<td>• Established in state legislature</td>
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<td></td>
<td>• Largest and longest-standing effort to date</td>
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<td><strong>Michigan Self-Determination</strong></td>
<td>• Certified Peer Specialists are Independent Support Brokers</td>
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<td></td>
<td>• Financed through Medicaid Managed Care Waiver</td>
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<td><strong>Utah Mental Health Access to Recovery</strong></td>
<td>• Established in Salt Lake County in 2014</td>
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<td></td>
<td>• Based on Access to Recovery for substance use populations</td>
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<td><strong>Pennsylvania Consumer Recovery Investment Fund-SDC</strong></td>
<td>• Brokers and leadership are Certified Peer Specialists</td>
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<td></td>
<td>• Financed through managed care reinvestment funds</td>
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<td><strong>Texas Self-Directed Care Project: My Voice, My Choice</strong></td>
<td>• Randomized trial with approximately 360 participants</td>
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<td>• Adults in the Medicaid STAR+PLUS program in the Travis SDA</td>
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<td><strong>New York Self-Directed Services</strong></td>
<td>• Pilot in two sites underway</td>
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<td>• Part of state’s Medicaid Managed Care efforts</td>
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Demonstration and Evaluation of Self-Direction in Mental Health: Components

• **Formative Process Evaluation**
  - Document implementation activities
  - Develop guidelines for replication and expansion

• **Systems-Level Outcomes Evaluation**
  - Cost and service use implications
  - Analysis of administrative data in some sites

• **Individual-Level Local Outcomes Evaluation**
  - Look different in each state and involve collaborations with local researchers
How do Participants Use their Budgets?
FloridaSDC Spending by Purchase Category, July 2010 to April 2015

- Transportation: 18% of Total Spending ($583,084), 11% of all purchases (n=1104)
- Dental: 13%
- Medical Services: 9%
- Computer: 9%
- Psychiatric Medications: 8%
- Outpatient Therapy: 10%
- Employment: 6%
- Housing: 5%
- Miscellaneous: 4%
- Vision: 5%
- Physical Health Services: 4%
- Hobbies: 3%
- Clothing: 5%
- Education: 5%
- Utilities: 3%
- Telephone: 3%
- Entertainment: 1%
- Food: 2%
- Furniture: 2%
- Personal Care: 2%
Recovery Dynamics and Self-Direction

Compared to people with similar characteristics who did not self-direct, FloridaSDC participants were...

1.73 times more likely to experience a positive employment outcome

2.04 times more likely to experience a positive housing outcome

The above figures are odds ratios from logistic regressions predicting a positive outcome from SDC enrollment, controlling for observed factors. All findings were statistically significant at p < 0.001

Policy Implications and Research Limitations

• Self-direction is associated with positive gains in recovery

• Clearer program implementation/fidelity standards needed

• Poverty and system inadequacies are critical contextual factors

• Limitations
  – Generalizability
  – Administrative data
  – Unobserved variables

When I finally found myself working full-time, I received benefits and insurance that I’d never had before, and all of that on my own. I was making enough to sustain myself. I had achieved it.” — Wesley
What about Cost?

• Current research is limited
• A 2012 study of 412 people with mental health conditions in England found lower outpatient and inpatient mental health service costs for self-directing participants\(^1\)
• Cost impact depends on multiple factors
  – Financing (e.g. Medicaid, state general revenue)
  – Size and scope of budget
  – Source of cost savings calculation

Self Direction in New York

• CMS approved a five-year pilot of Self Direction in the state’s 1115 waiver
• The service was approved as an HCBS service in a specialty managed care product called a HARP (Health and Recovery Plan)
• The pilot scope and participation is limited to HARP members
The first 2 contracts in NY were awarded in 2017 for 2 years; others may be forthcoming before the pilot completion date in 2022
- Independent Living Center in Newburgh, NY serving the Mid Hudson Valley Area
- Community Access in New York, NY serving all 5 boroughs of the city

Annual budget of 379K; 100 participants served at end of 2 years
Enrollment Requirements

- Enrolled in a Medicaid Managed Care Health and Recovery Plan (HARP)
- Resident of NYC
- Desire and motivation for change
- Two tiers of participation:
  - HARP enrolled members can budget $8,000 with purchasing authority
  - HARP enrolled members with HCBS assessment can budget $16,000 with purchasing and employer authority
Staffing

• 1 Program Manager/Resource Consultant - Maximum caseload of 20

• 2 Resource Consultants - Caseload of 40 each

• 1 Part-Time administrative assistant
Start Up and Outreach

• Started working with individuals internally already receiving services from Community Access
• This allowed us some space and time to best understand how the program could optimally operate before widening our scope
• We first provided info sessions to care coordinators, program managers, and respite center counselors
  – This generated around 70 inquires about the program
Outreach Beyond Community Access

- We began email blasts to agencies who work with HARP eligible individuals and Facebook posts about our program and upcoming info sessions.
- We are starting to set up info sessions outside of our agency.
• Wanted to step away from traditional images of mental health programs

• Wanted something modern that would still speak to what the program offers

• Tested two different advertisements online to see which was more successful
Self Direction: Resources for Wellness

Self Direction is a new approach to providing support designed to empower decision-making and promote recovery among individuals with mental health concerns. Through Self Direction, individuals work with Resource Consultants to create an action plan based on personal wellness goals and to receive funds to spend on selected goods and services that support individualized recovery. Self Direction has proven to be a successful way to empower individuals to have more independence and freedom of choice.

Individuals can use Self Direction in many ways. A Resource Consultant works with participants to explore all facets of their lives and to identify the areas in which they would like to take action. In other states, individuals have used Self Direction to obtain goods and supports such as:

- Living personal or a peer support network during crises
- Obtaining alternative treatment methods such as acupuncture for pain
- Improving physical health through purchasing a gym membership, gym clothes, or nutritional counseling

The New York State Office of Mental Health (OMH) and Community Access is one of two agencies currently providing Self Direction. Community Access is serving all five boroughs of New York City and the Independent Living Center of Newburgh, NY is serving the Mid-Hudson Valley region.

Eligible participants are:

- Residents of NYC
- Enrolled in a NYS Medicaid Managed Care Plan
- Have a desire to work toward recovery goals

If you are interested in learning more, joining one of our upcoming informational sessions or being added to our mailing list, please contact us.

selfdirection@communityaccess.org
(212) 281-2400, ext. 7818

communityaccess.org

SAMHSA
Substance Abuse and Mental Health Services Administration
Changes in Enrollment Along the Way

• Application Process
  – Allows us to get a sense directly from potential participants of their interest
  – Asks direct questions about recovery goals

• Info Sessions for Participants
  – Began to be the first step to enrollment
  – Allows us to clarify what the program is about, what participation looks like, and includes a goal-prioritizing workshop at the end
Program Structure

- Application
- Info Session
- Complete self assessment, goal exploration
- 1:1 meetings for goal development, resources exploration, and budgeting
- Meeting at least 1x monthly with quarterly reviews of progress
Program Beginnings

• Researched tools utilized in other Self Direction programs as well tools used in CA programs
• Developed our own Personal History and Goal Exploration form for Self Direction
• Revised in March for participant ease, reduced size by over 50%
• We recognized an early-on need for more focus on the goal work and to better educate individuals prior to participation
Exploring different dimensions of wellness based on participants’ choice and priorities, this form starts to develop a holistic picture of recovery goals.

Example:
Social and Relationship Wellness

*In this section the focus is your social connections and relationships. We want to understand how you receive support from family, friends, community members, and other people in your life. You can also share goals related to socialization and expanding your social network.*

Tell me about the people in your life. In what ways do they support you?
Main Focus of Work

Goal Development
Finding creative ways to measure goals and directing wellness goals to include impacts on mental health

Value Exploration
Assisting participants in understanding what goods and services are of best value to meet their needs

Resource Exploration
Finding available resources to assist individuals in reaching their goal, and education about new options that could assist with succeeding in their goal

Goal Review
Continuing to check in on goal progress, whether additional supports are needed, or if goal was met

Goal Setting
Documenting the Work

• Progress Notes, participant agreements and all forms kept in AWARDS, our electronic database
• All goals, budgets and Self Assessments go into a Web Portal designed by OMH, which acts as the Fiscal Intermediary
  – Budgets are reviewed by OMH in the portal and, when approved, the portal notifies the third-party vendor that manages the money to load the funds on a debit card
  – All goals, budgets, and purchase histories are accessible by program employees and OMH
Approvals and Purchases

- Goal and budget submitted
- Program Manager approval
- Fiscal Intermediary approval
- Funds are directly loaded onto participant’s program debit card
- Participant completes purchase and provides receipt
Learning Along the Way

• Goal setting
  – Understanding what context is needed in documentation to demonstrate how the budget aligns with the goal
  – Considering how long-term goal setting is navigated with participants and approved budget-setting in a manageable way, with clear steps of progress and continued need
  – Use of SMART goals
• Approval process
  – Consistent communication with OMH and the FI have yielded faster approvals, as we start to understand how to articulate goals, align goals with budget items, and demonstrate specifics around needs (i.e. why one brand of item is preferred over another)
  – Goal language that participants use can be very different from what providers may use, and the resource consultants must act as a translator while remaining authentic to both the participant and the program scope
Ongoing Program Goals

• Motivational Techniques to assist with activating on goals
• Standardizations for program model, purchase criteria
• Purchasing HCBS services from approved or participant-selected providers
• Managing misuse of funds
Ongoing Program Goals

- Self Direction as it intersects with poverty – how can this service benefit many on an ongoing basis without becoming an entitlement
- Managing the application process – enrolling individuals who will have success without denying eligible individuals the opportunity to experience Self Direction
- Sustaining Wellness after success with Self Direction
- Ensuring Self Direction is viable and started in other pilot areas around the state
Participant Experience

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goes by “Zisa”

Visit my website:

http://Truths89.com
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I finally know what normal is, and I think I’m living as normal a life as I can. It’s just wonderful, living real life. Real life isn’t scary anymore.”

SUSAN

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