Promising Practices in Mental Health Self-Direction

2021 HCBS Technical Assistance Series
May 20, 2021 3:00-4:30 p.m. ET

Agenda

- **Welcome (ACL)**

- **Opening Remarks (CMS)**

- **Introductions of Guest Presenters and Presentations**

- **Q&A/Interactive Discussion**

WELCOME & OPENING REMARKS

Andrea Callow

Program Analyst

Office of Policy Analysis & Development

Center for Policy & Evaluation

Administration for Community Living

Michele MacKenzie

Technical Director

Division of Long Term Services & Supports

Disabled & Elderly Health Programs Group

Center for Medicaid & CHIP Services

Centers for Medicare & Medicaid Services

PRESENTERS

Molly Morris, MSW

Senior Technical Assistance Consultant, Applied Self-Direction
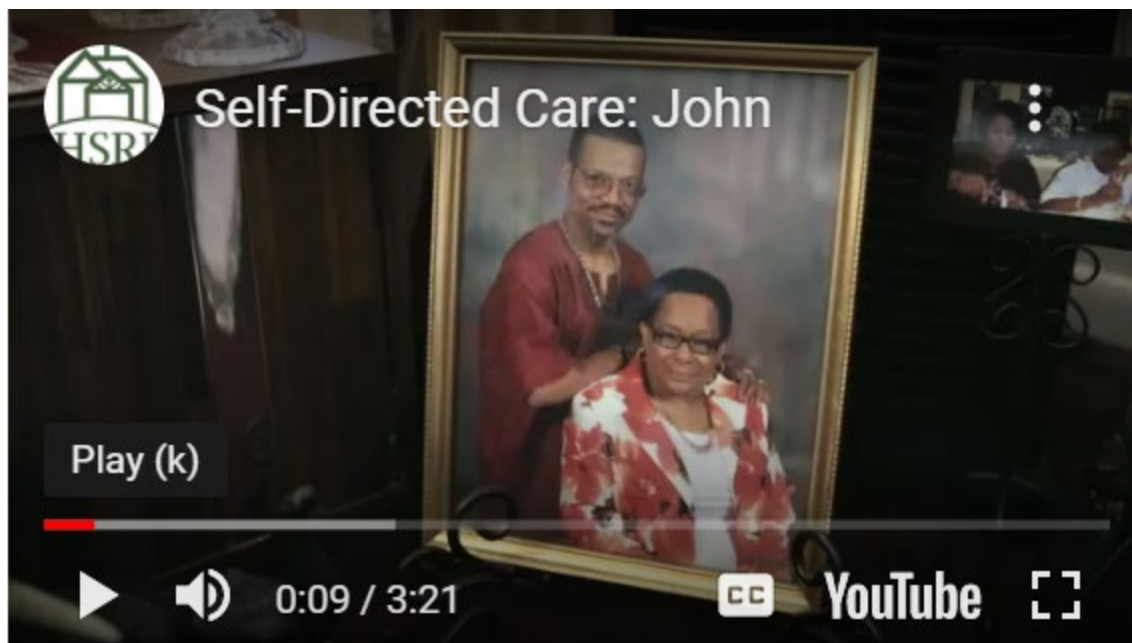
Judith Cook, PhD

University of Illinois at Chicago, Department of Psychiatry

Center on Mental Health Services Research & Policy

Dena Stoner

Director, Innovation Strategy, IDD/BHS, Texas Health and Human Services Commission

www.mentalhealthselfdirection.org

Video link: https://www.youtube.com/watch?v=R4DgBnn0V9g

Mental Health Self-Direction: The Basics

May 20, 2021

Acknowledgements

- [National Inventory of Self-Directed Long-Term Services & Supports Programs](#) (2020)
  - Collaborators: AARP Public Policy Institute, Penn State University

- [www.mentalhealthselfdirection.org](#)
  - Collaborator: Human Services Research Institute
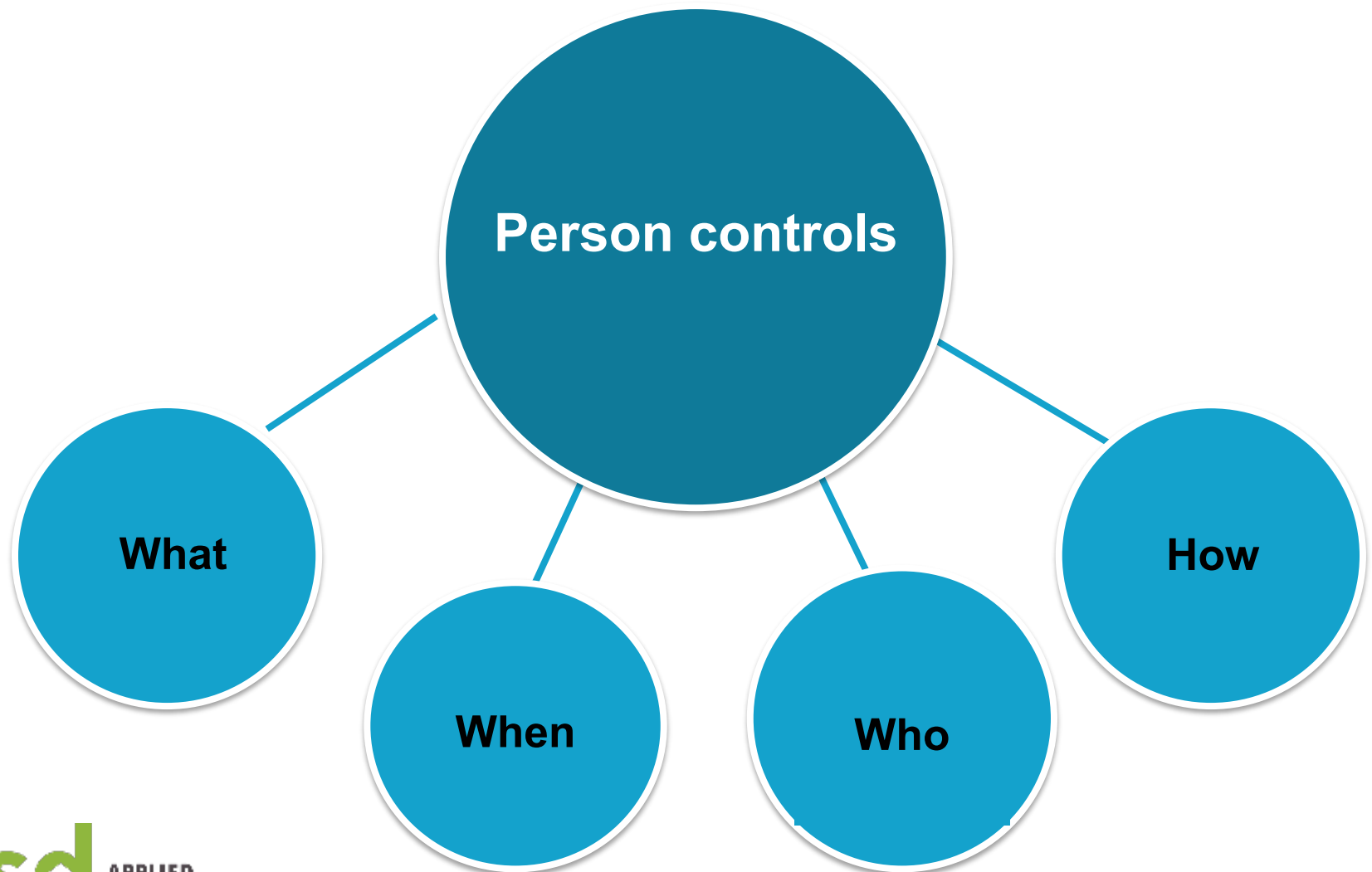
Overview

- An introduction to self-direction in general, as well as the unique features of self-direction programs for people with serious mental illness
  - What is self-direction?
  - Prevalence
  - Models of self-direction
  - Essential program elements
  - How is it funded?

What is self-direction?

- Self-direction is a model of long-term care service delivery that helps people of all ages, with all types of disabilities, maintain their independence at home

- Self-direction is based on the principle that **people know their needs best** and are in the best position to plan and manage their own services

- People who self-direct receive support to be successful in directing their own services, including the option to select a representative

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What is Self-Direction?
Choice and Control

Traditional Services

Person

- Workers recruited and report to agency
- Program and agency set tasks
- Agency specifies salary and benefits
- Normal work hour schedule
- Worker training required by agency
- Case managers determine needs & services

Self-Directed Services

Person

- Recruits and manages workers
- Sets tasks
- Specifies salary and benefits (optional)
- Assigns flexible work hour schedule
- Trains/ arranges worker training
- Makes decisions about needs and services
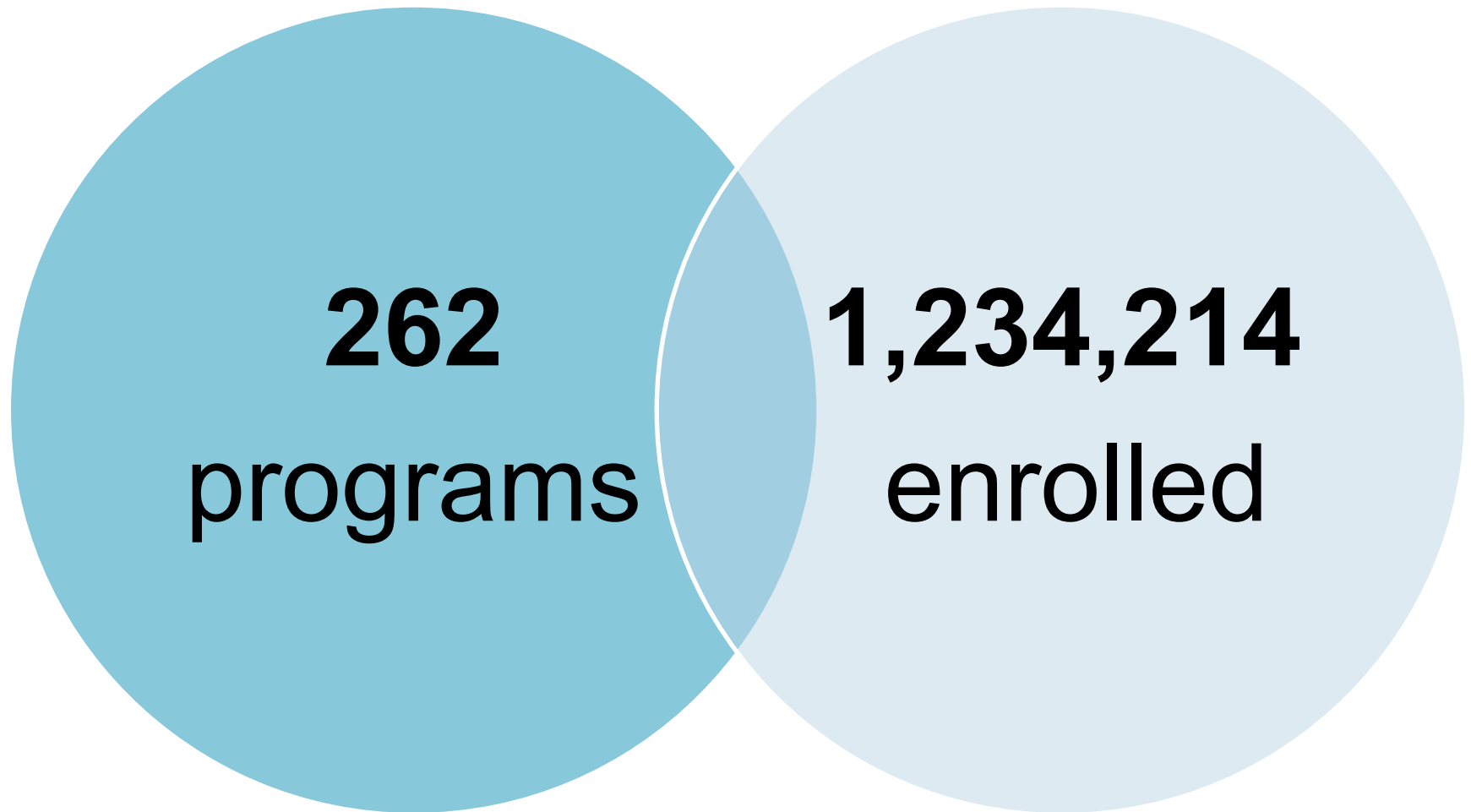
asd APPLIED SELF-DIRECTION
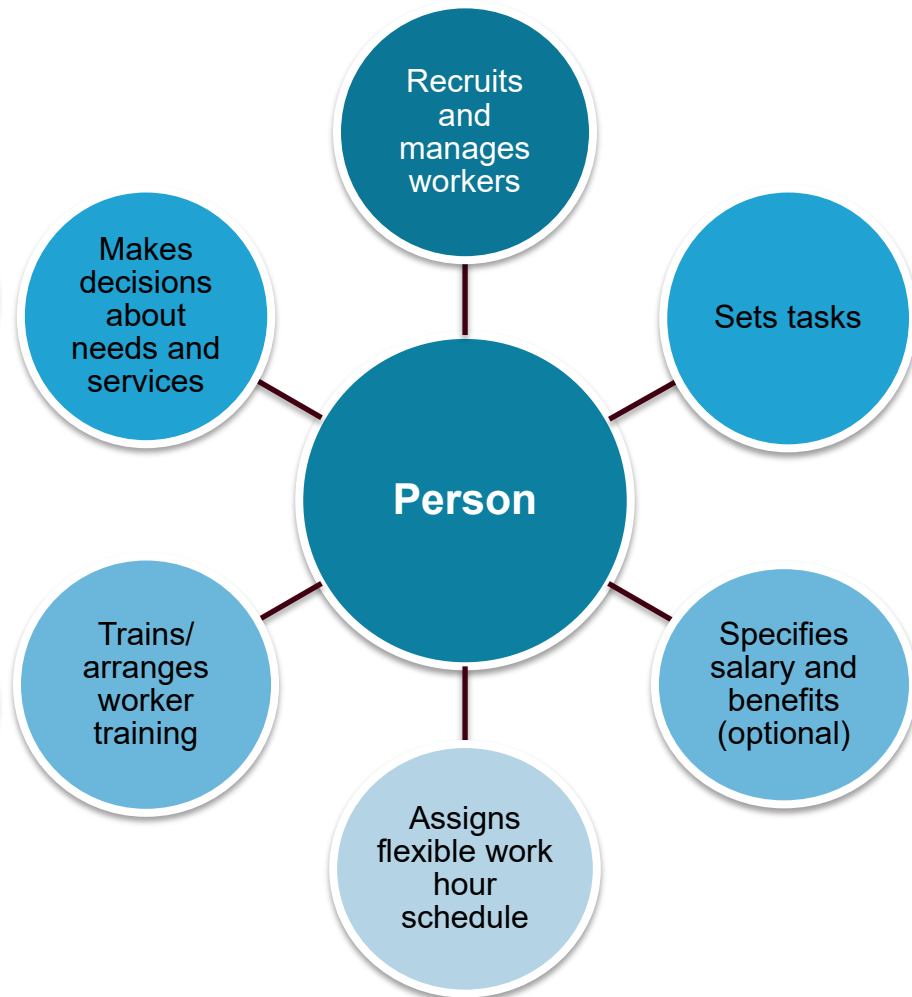
Self-Direction: A Paradigm Shift

- Benefits of self-direction:
  - ❑ More autonomy, self-sufficiency
  - ❑ More dignified life
  - ❑ Having services more tailored to individual needs
  - ❑ A better understanding of both formal and informal supports
  - ❑ Increased happiness and satisfaction
  - ❑ Less worker turnover

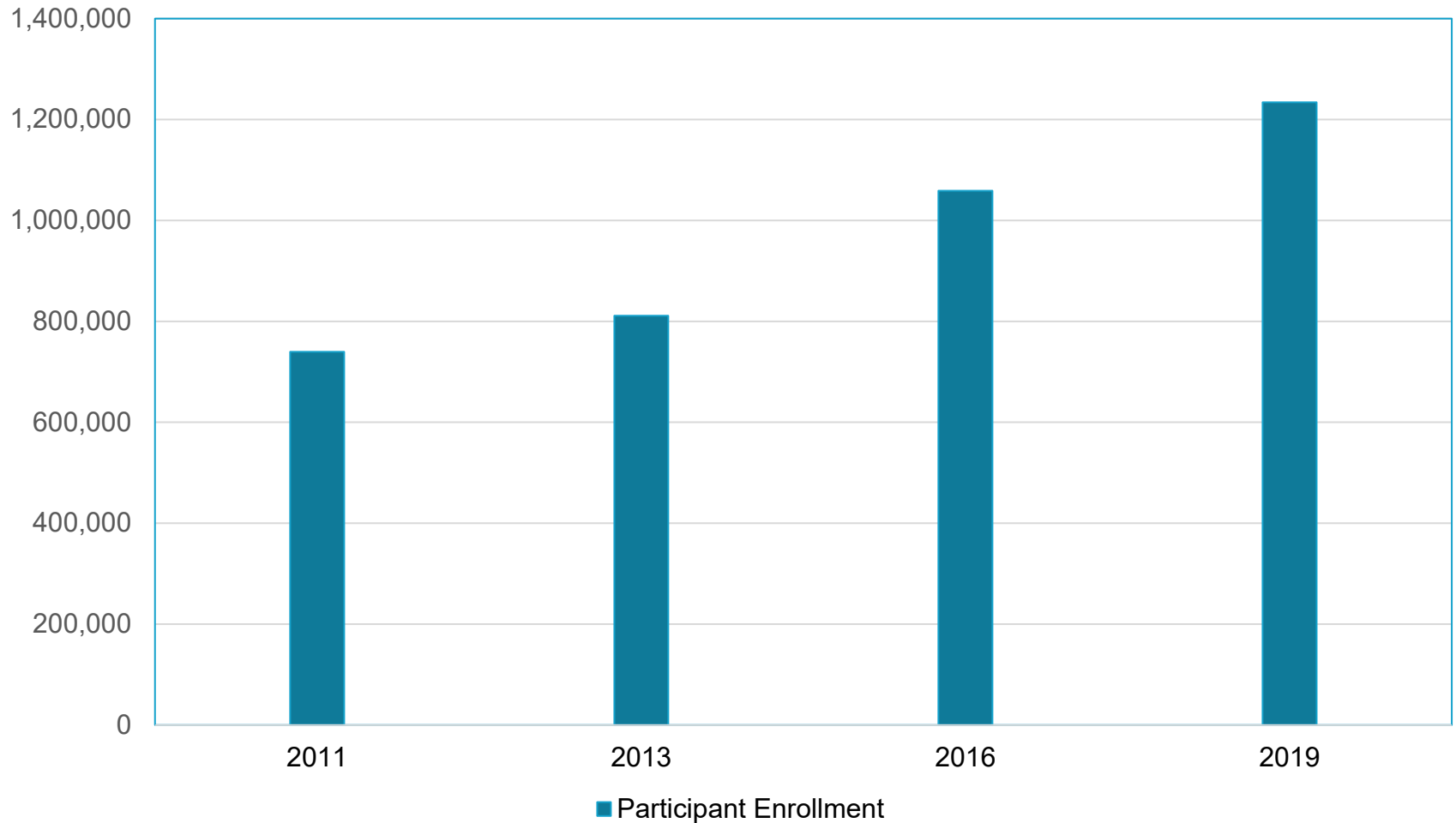- What changes with self-direction?
  - ❑ Dignity of risk
  - ❑ Empowerment and support utilization
  - ❑ Self-direction as a process

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Prevalence of Self-Direction

262 programs

1,234,214 enrolled

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Self-Direction on the Rise

Self-Direction National Enrollment Over Time

Bar chart showing Participant Enrollment for years 2011, 2013, 2016, and 2019. 2011 is approximately 740,000; 2013 is approximately 810,000; 2016 is approximately 1,060,000; 2019 is approximately 1,235,000.

Participant Enrollment

Majority of States have 1,000 – 5,000 Participants Self-Directing

Number of Participants

▲ Fewer than 1,000 participants
⊡ 1,000-4,999 participants
▨ 5,000-24,999 participants
✚ 25,000-100,000 participants
▬ Greater than 500,000 participants

Source: 2019 National Inventory of Self-Direction Programs

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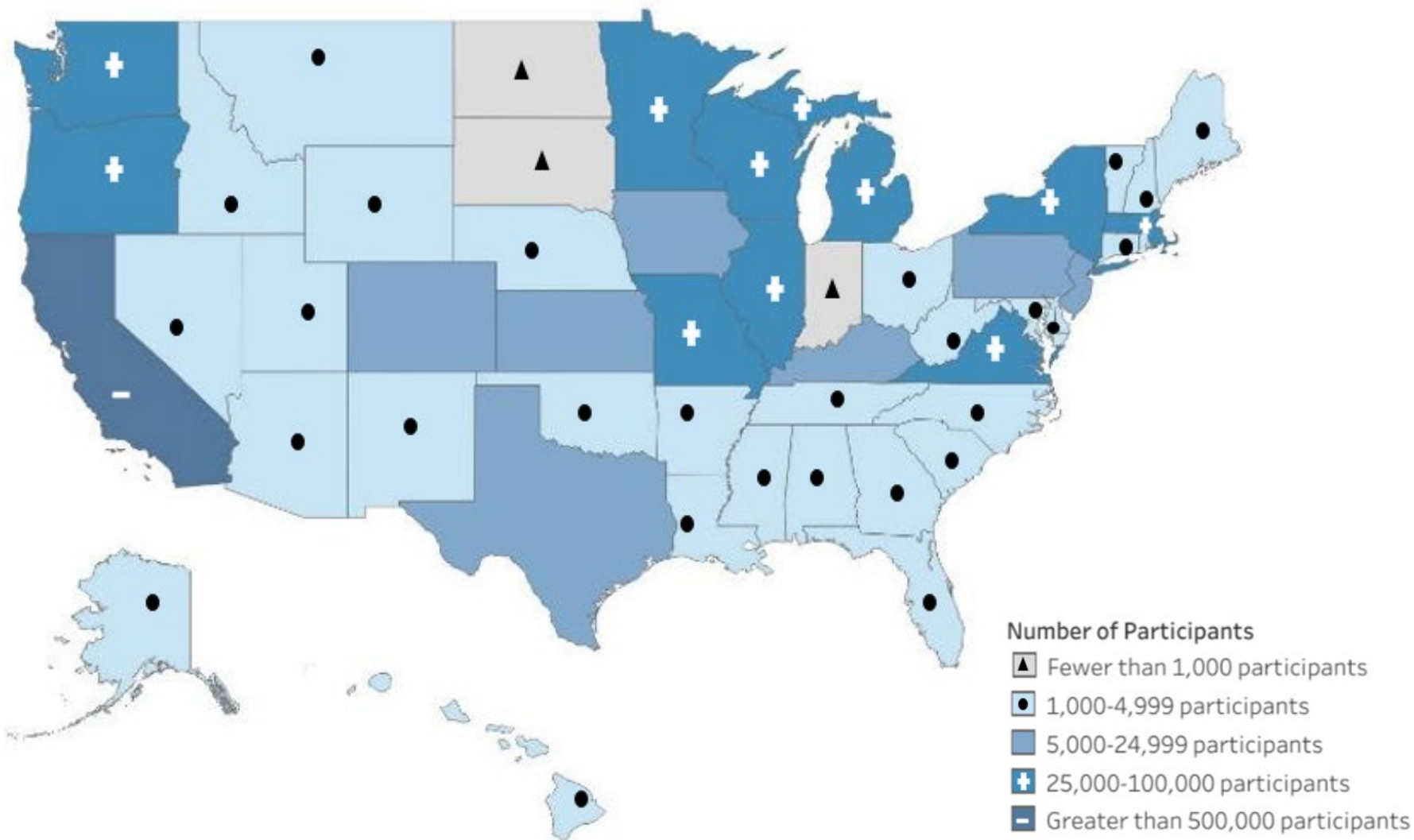
Serving Many Populations

Number of Programs by Population in 2016 & 2019

Legend: # of Programs in 2016 | # of Programs in 2019

Populations: Adults 65+, Adults ID/DD, Adults PD, Adults SMI, Children ID/DD, Children PD, TBI, Veterans, Other

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Mental Health Self-Direction

Small, under 100

19 Programs Nationally in 2019

Only 4 Programs in 2016

Pilot programs

7% of SD Programs

Potential for growth!
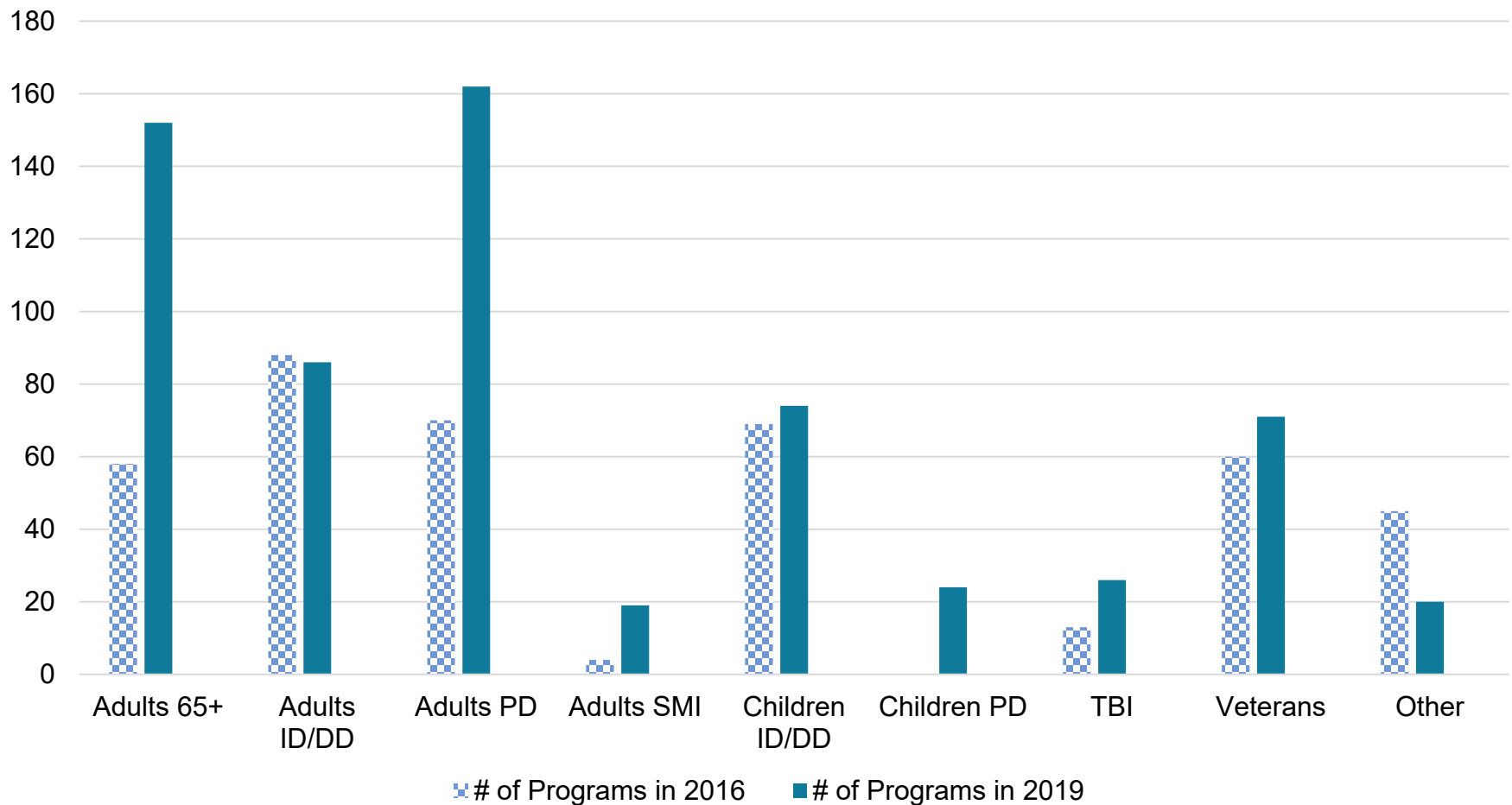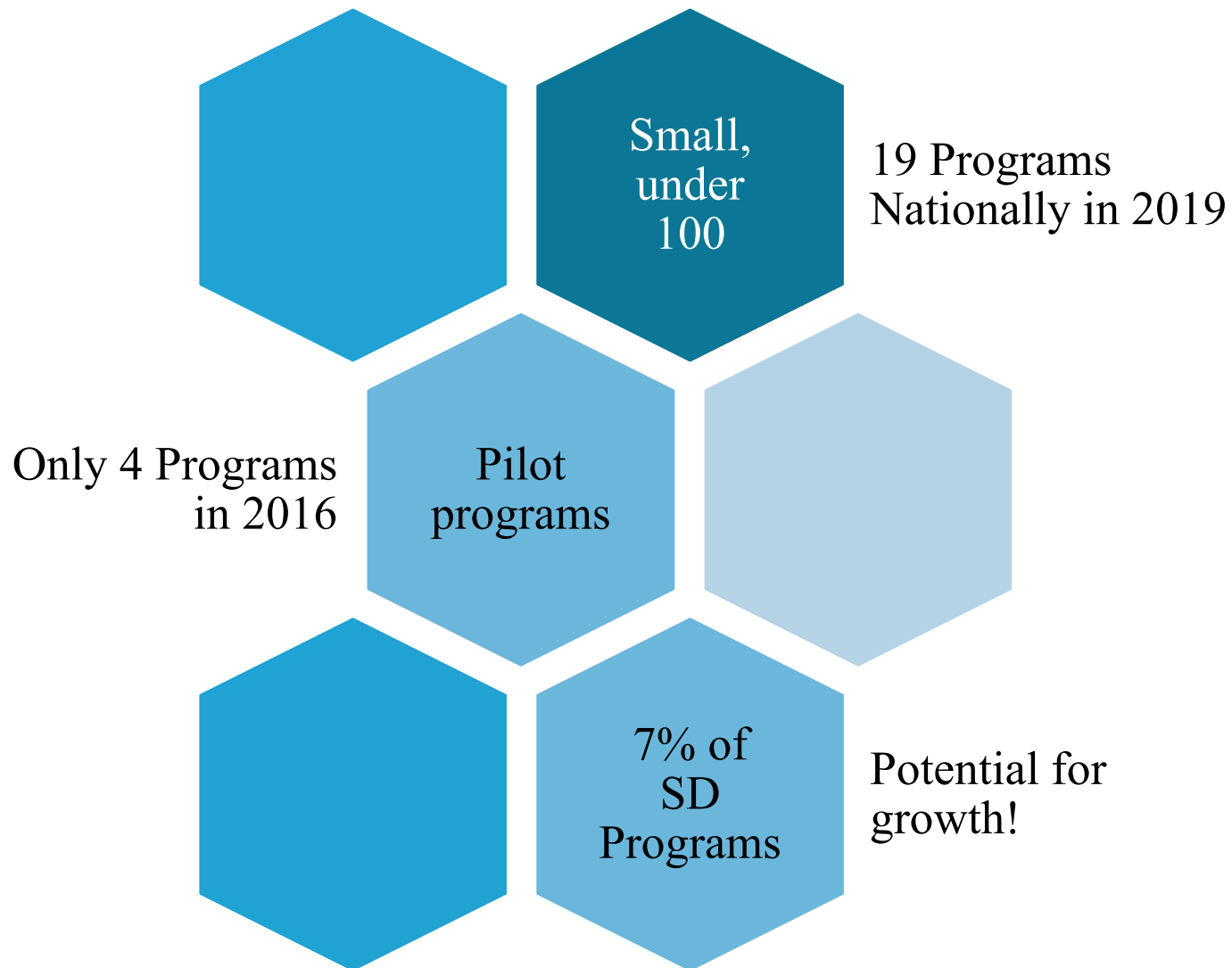
Two Models of Self-Direction

- Employer Authority
  - Person recruits, hires, supervises, and manages worker
  - Person fulfills employer/payroll related tasks (with support)
  - Person or agency may serve as the common law employer

- Budget Authority
  - Person manages a budget
  - May be able to set the rate of pay for workers
  - May be able to make decisions about purchasing goods and services
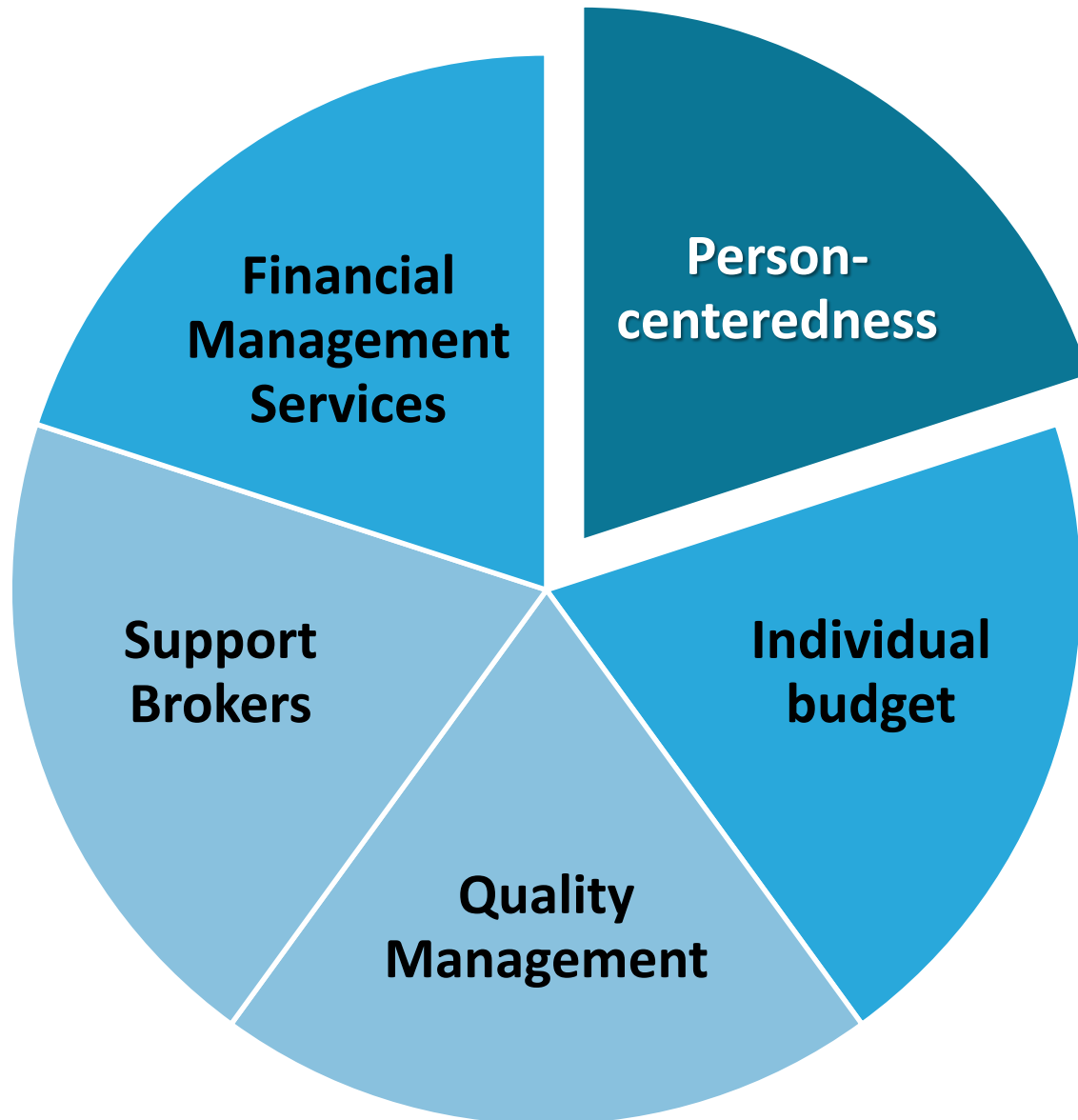
Budget Authority Breakdown

77% of all programs use a budget authority model

73% of SD programs targeting MH offer a budget authority model

83% of budget authority programs allow a wide range of goods & services

100% of BH SD with budget authority allow a wide range of goods and services

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Self-Direction Program Components

Person-Centered Planning (PCP)

- Recognizing that people are the experts in their lives.
    - Who is the person?
    - What are their goals?
    - What is important to them?
    - What do they think their needs are?
    - How would they like to meet their needs?

- Person-centered planning is the foundation, drawing on the individual's strengths, capabilities, and potential, along with the assets available in the community. Each person develops a life plan with concrete goals reflecting his or her priorities for quality of life and independence.

- Learn more: NCAPPS

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Source: Self-Direction in Mental Health

PCP for Mental Health Self-Direction

- Central to self-direction for all populations, but tends to be particularly expansive and holistic in the context of self-direction programs for people with serious mental illness:
  - Specific focus on recovery
  - May address issues related to health, well-being, social-connectedness, education, employment, housing, etc.

I think of recovery as a puzzle, and it's empowering to think that we get to choose the pieces that go into that puzzle.
– Wesley, Florida

Support Brokers

- Works with the person to create a person-centered plan to self-direct

- Provides guidance with recruiting, hiring and managing staff and/or managing a budget

- Monitors plan implementation

- This role can vary by state and program design

- Learn more: [Care Management and Self-Direction: Compatible?](#)

Support Brokers in MH SD

- In a mental health self-direction context, sometimes called a recovery coach or life coach

- This role may be filled be a peer. A peer coach is a person with lived experience of mental health recovery who has received training in mental health support
  - Some people who self-direct choose to pursue peer counseling certification as part of their own recovery plan

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

– Wesley, Florida

Source:

asd

Individual Budget

- Self-direction programs vary in what types of purchases are allowable. Some allow very narrow options, while others offer expansive, flexible options. Not all self-direction programs include an individual budget option.

- Individual budgets in self-direction for people with serious mental illness tend to be highly flexible and connected to one's unique recovery plan
  - Budgets may support goals related to education, housing, employment, mental health care not otherwise covered, community integration, physical health care (including dental and vision)

Source: Self-Direction in Mental Health

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Financial Management Services

- Support person with financial transactions

- Manage regulatory responsibilities

- Prepare tax returns

- Ensure expenditures meet program rules

- Generate regular reports

- In self-direction for people with serious mental illness, typically the primary need for FMS support is to help manage the individual budget

Quality Management

- Essential elements for quality management:
    - Assessment is person-centered and thorough
    - Person-centered plan is sufficiently detailed, individualized, and realistic
    - The person self-directing is committed to the plan
    - FMS spends according to the plan
    - Support broker monitors quality and safety
    - State staff support all team members

- Learn more: Quality Management in Self-Direction Programs

How is Self-Direction Funded?

All Self-Direction Programs by Funding Source

Legend: Medicaid · VHA · State Funds Only · Other
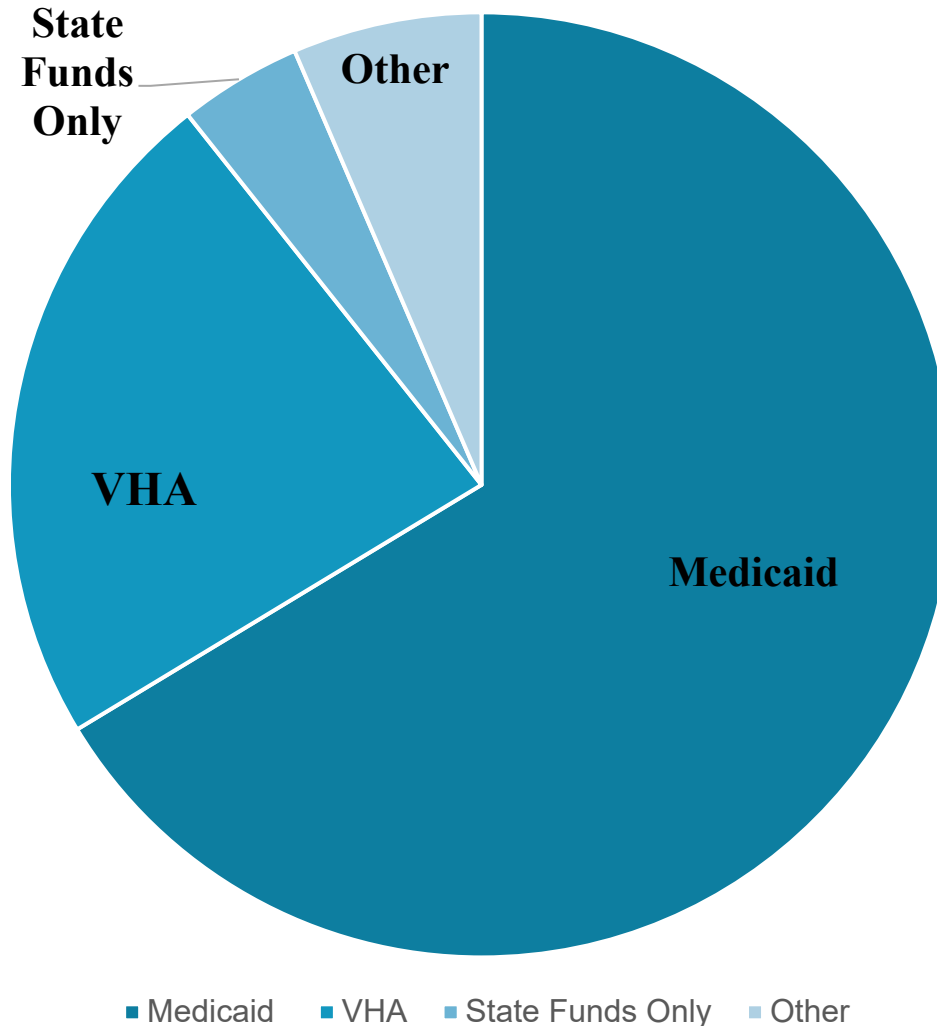
Funding Sources for all SD

Funding Source	# of Programs	% of Total
Medicaid State Plan	17	7%
Medicaid 1115 Demonstration Waiver	13	5%
Medicaid 1915(b) Waiver	3	1%
Medicaid 1915(c) Waiver	142	60%
Medicaid 1915(i) State Plan Option	2	1%
Medicaid 1915(j) State Plan Option	5	2%
Medicaid 1915(k) State Plan Option	4	2%
Veterans' Administration	31	13%
State General Revenue	7	3%
Other funding mechanisms	11	5%

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Funding Features of MH SD

- Multiple sources are often combined or 'braided' to provide funding

- Typical funding sources include:
    - Medicaid, via waivers or state plan amendments
    - Other federal sources, such as the SAMHSA block grant
    - Local and state funding options
    - Managed care

Source: <u>Self-Direction in Mental Health</u>

Conclusion

- Self-direction offerings for people with serious mental illness are limited nationwide, but on the rise

- These programs are small, but innovative, using individual budgets in flexible, transformative ways

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, Florida

Source: <u>Self-Direction in Mental Health</u>

APPLIED
SELF-DIRECTION

Contact Information

Molly Morris, MSW

Senior TA Consultant

Applied Self-Direction

molly@appliedselfdirection.com

www.appliedselfdirection.com

Self-Directed Financing of Services for People with Serious Mental Illnesses

Judith A. Cook, PhD

University of Illinois at Chicago, Department of Psychiatry

Center on Mental Health Services Research & Policy

Presented at ACL/CMS Webinar: Promising Practices in Mental Health Self-Direction, May 18, 2021

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Collaborators

Jane K. Burke-Miller, PhD
Jessica A. Jonikas, MA
Samuel E. Shore, MSW
Matthew Ferrara, BSW
Dulal Bhaumik, PhD

Funding

(Cook, 2019)

Self-Directed Care:

The Basics

(Cook, 2019)

Mental Health Self-Directed Care

Funds ordinarily paid to service provider agencies are controlled by service recipients

1. People develop person-centered recovery plans
2. They create budgets allocating dollar amounts to purchases that achieve the plan's goals
3. Brokers help people develop plans & budgets, & purchase services & goods named in plans
4. Fiscal intermediary provides financial management services such as provider payment

(Cook , Russell et al., *Psychiatric Services,* 2008)

(Cook, 2019)

The Ultimate Goal –
Cost Neutrality
i.e., SDC costs no more than traditional services

(Cook, 2019)

Self-Directed Care:

The Evidence

(Cook, 2019)

Evidence: SDC for other groups

➢ **Randomized evaluation of Cash & Counseling in FL, NJ, & AK for people with developmental, physical disabilities & the elderly using personal care attendants**

- ✓ SDC medical outcomes as good or better than regular fee-for-service (FFS)
- ✓ SDC recipients received more services than FFS
- ✓ Budget neutrality prevailed by end of 2nd year
- ✓ Consumer satisfaction was significantly higher in SDC
- ✓ Incidences of fraudulent behavior were low

(Foster, Brown et al., *Health Affairs,* 2003)

(Cook, 2019)

Mental Health Self-Directed Care in Texas

(Cook, 2019)

Texas SDC Program

- Based on average outpatient costs in the prior year, up to $4,000/year allocated to individual budgets
- Participants could retain current service providers if enrolled in the SDC provider network
- Support brokers provided free of charge
- SDC program director approved budgets
- Budgeting guideline: 60% traditional services/40% non-traditional

(Cook, Shore, et al., *Psychiatric Rehabilitation Journal,* 2010)

(Cook, 2019)

Managed care carve-out as home for SDC RCT

- Managed care waiver already in place in the 7-county NorthSTAR area

- Braided funding system in place for Medicaid, State general revenue, and other funds

- MCO (ValueOptions) already administered a network of diverse MH providers

- Local mental health authority (NTBHA) was a conflict of interest-free willing partner

(Cook, 2019)

TX SDC Braided Funding

❖ Medicaid

❖ State general revenue

❖ Mental health block grant (federal)

❖ Transformation grant dollars (federal)

❖ Local foundation funds (Meadows Foundation)

❖ Research & training funds (NIDILRR)

The Challenge: Being accountable for all expenditures separately at the back-end, while remaining seamless to the consumer at the front-end.

(Cook, 2019)

Research Findings

(Cook, 2019)

Characteristics of 206 Study Participants:
SDC Members (n=114) & Services as Usual (n=102)

Female	62%	Physical condition/impairment	48%
White	50%	Working at baseline	12%
African American	48%	Average age (yrs)	41
Latinx	15%	Diagnosis	
High School/GED	66%	Schizophrenia	34%
Baseline funding		Major depressive dis	40%
Medicaid	74%	Bipolar 1 or 2	26%
Med Indigent	26%		

(Cook, 2019)

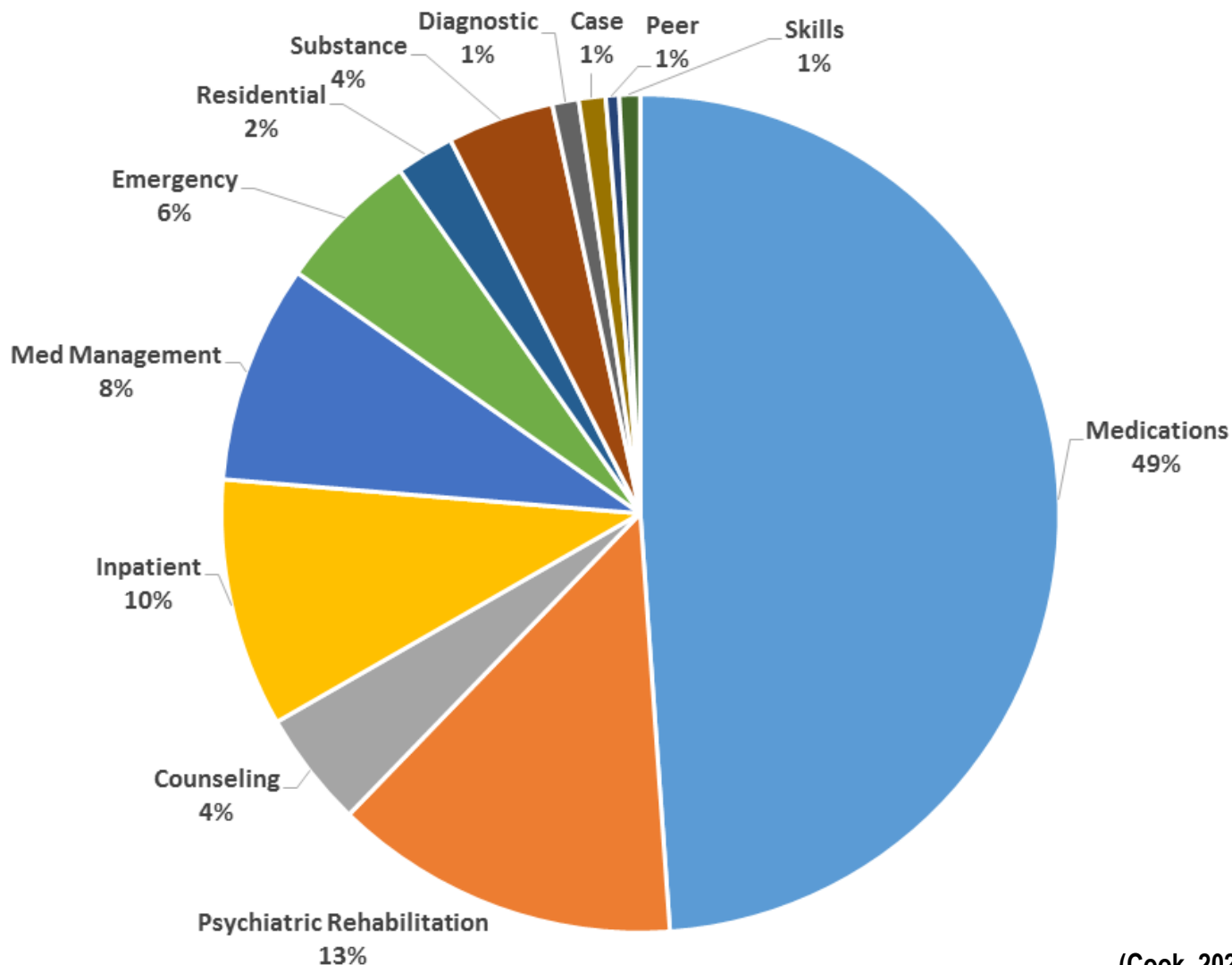# Participant Outcomes: SDC vs. controls over 24 months*

(Cook, Shore et al., *Psychiatric Services,* 2019)

⬆ *EMPLOYMENT*

⬆ *TAKING CLASSES*

⬆ *SELF ESTEEM*

⬆ *COPING MASTERY*

⬇ *SOMATIC SYMPTOMS*

⬆ *ABILITY TO GIVE & RECEIVE SUPPORT*

⬆ *ABILITY TO SET & PURSUE GOALS*

⬆ *PERCEPTION OF SERVICE SYSTEM AS CLIENT-DRIVEN*
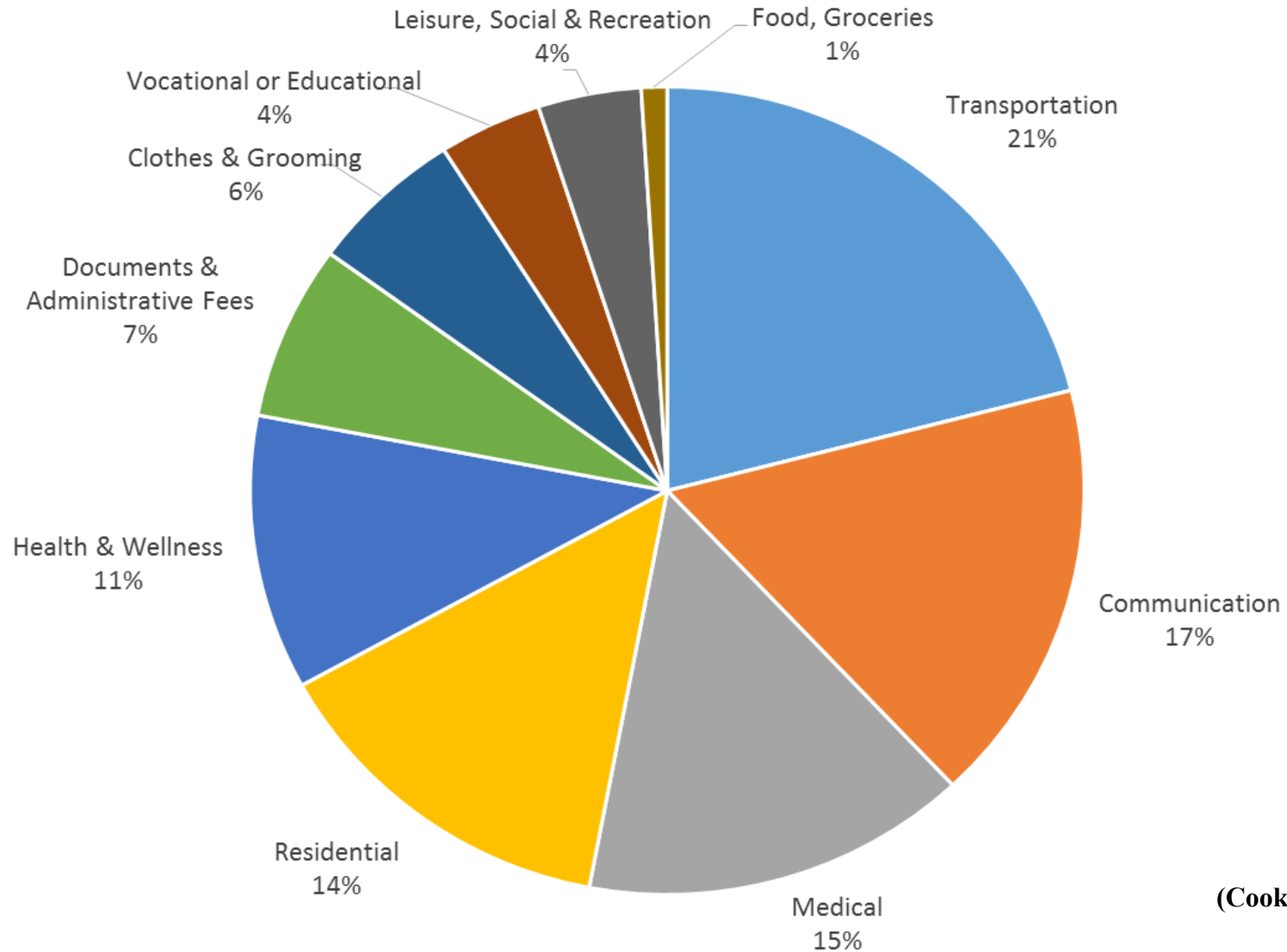
* random regression analysis, time x outcome interactions p < .05

(Cook, 2019)

Traditional service expenditures over 2 years by all study subjects (N= 216, mean = $2,324 per person per year)

Medications 49%
Psychiatric Rehabilitation 13%
Inpatient 10%
Med Management 8%
Emergency 6%
Counseling 4%
Substance 4%
Residential 2%
Diagnostic 1%
Case 1%
Peer 1%
Skills 1%

(Cook, 2021)

Non-traditional expenditures over 2 years by SDC subjects
(N=114, mean = $673 per person per year)

Leisure, Social & Recreation 4%

Food, Groceries 1%

Vocational or Educational 4%

Transportation 21%

Clothes & Grooming 6%

Documents & Administrative Fees 7%

Health & Wellness 11%
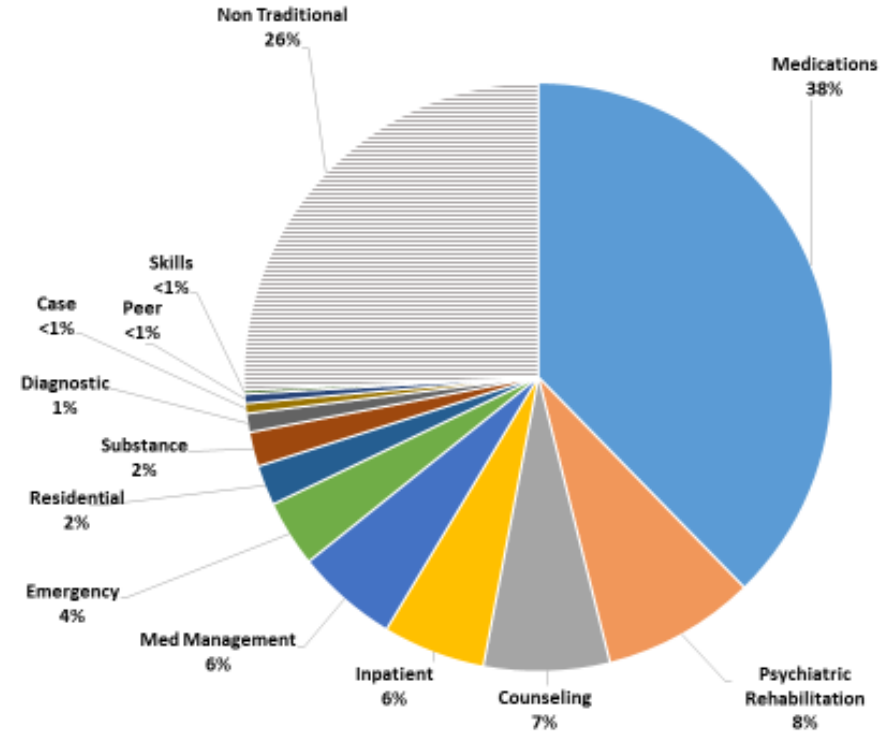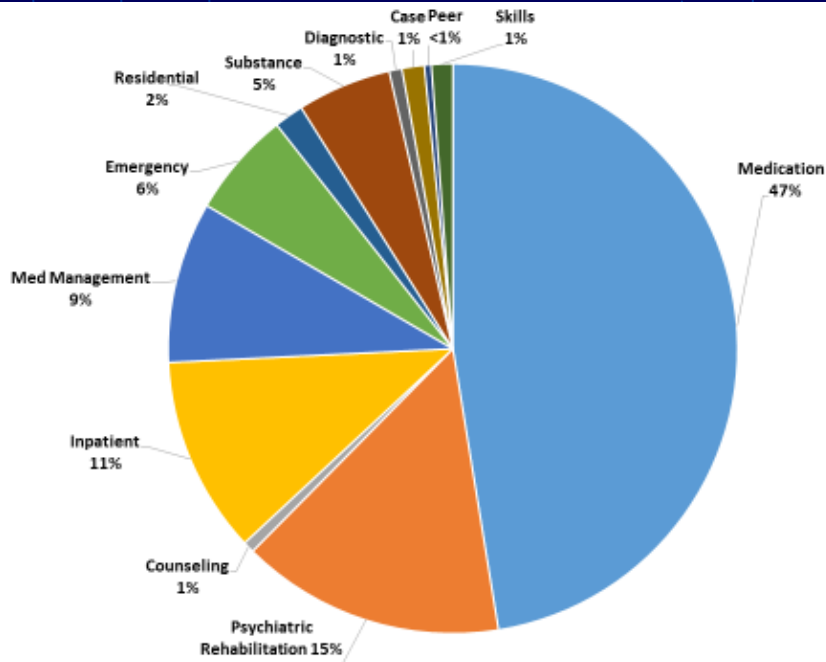
Residential 14%

Medical 15%

Communication 17%

(Cook, 2021)

Total Service Expenditures Over 2 Years
No sig difference between study conditions

Control (n=102, $560,246)

SDC (n=114, $597,326)

(Cook, 2019)

Cost Results Summary

Overall Budget Neutrality

- *no difference* between SDC & control condition on total costs

Some cost savings

- SDC group more likely to have *zero cost* than controls for 6 service types & less likely for 1 service type

- SDC group had *lower costs* of 4 service types & higher on 1 type among users of those services

(Cook, 2019)

SDC Participant Satisfaction Survey

➢ 90% rated the program as good or excellent

➢ 97% would recommend the program to a friend

➢ 87% were very or somewhat satisfied with their broker

➢ Compared to before entering SDC, people felt the services purchased through SDC were
  - ➢ Better   74%
  - ➢ About the same   19%
  - ➢ Worse   7%

(Cook, 2019)

What We Learned

- SDC model achieved superior client outcomes for no greater expenditures than the traditional service delivery system.

- Re: specific services, SDC more often had zero costs & had lower costs for some services

- SDC participants did not forgo traditional services such as psychiatric medication or psychotherapy

(Cook, 2019)

What We Learned – cont.

- Instances of fraud or misuse of funds were rare.

- People with psychiatric disability developed recovery plans, budgets, & spent money responsibly & effectively on both traditional & non-traditional services.

(Cook, 2019)

Self-Directed Care implementation manual

Self-Directed Care Implementation Manual:
A Comprehensive Mental Health Program Guide

Judith A. Cook
Laurie Curtis
Jessica A. Jonikas
Carolyn Russell
Nancy Fudge

http://bit.ly/2lsPu3v

(Cook, 2019)

Manual Chapters

- Chapter 1: What is Self-Directed Care?
- Chapter 2: Getting Started
- Chapter 3: Being Participant Driven
- Chapter 4: SDC Program Structure
- Chapter 5: Self-Directed Life Planning
- Chapter 6: Budgeting & Purchasing
- Chapter 7: Recruitment, Eligibility, & Enrollment
- Chapter 8: SDC Support Brokers
- Chapter 9: SDC Program Evaluation & Fidelity

(Cook, 2019)

References

Foster L, Brown R, Phillips B, Schore J, & Carlson BL. (2003). Improving the quality of Medicaid personal assistance through consumer direction. *Health Affairs, 23*(3), W3-W162.

Cook JA Russell C, Grey DD, & Jonikas JA. (2008). A self-directed care model for mental health recovery. *Psychiatric Services, 59*(6), 600-602.

Cook JA, Shore S. et al., (2010). Participatory action research to establish self-directed care for mental health recovery in Texas. *Psychiatric Rehabilitation Journal, 34*(2), 137–144.

Cook JA, Shore S, Burke-Miller JK et al., (2019). Mental health self-directed care financing: efficacy in improving outcomes and controlling costs for adults with serious mental illness. *Psychiatric Services*, 70(3), 191-201.

Contact Information

Judith A. Cook, PhD

University of Illinois at Chicago

Department of Psychiatry

1601 W. Taylor St. M/C 912

Chicago, IL 60612

312-355-3921; jcook@uic.edu

www.center4healthandsdc.org/

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My Voice My Choice:
Mental Health Self-Direction in Texas

Dena Stoner, Director, Innovation Strategy, IDD/BHS, Health and Human Services Commission

May 2021

Sponsor Acknowledgment

MONEY FOLLOWS THE PERSON

"This presentation was developed under grant CFDA 93.791 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal Government."

Texas Medicaid Context

- Primarily a capitated managed care system.

- STAR+PLUS:

  ‣ Is the state's managed care program for adults who are aging or have disabilities.

  ‣ Includes health, behavioral health, and long-term services and supports.

  ‣ Members have complex conditions.

  ‣ Provides an environment conducive to integration of services and innovation.

Mental Health Self-Direction

- Provides the individual with more choice and control over purchasing services and supports through:
  - ▸ Personal (expanded) budget authority;
  - ▸ Person-centered recovery planning process; and
  - ▸ Information and assistance (advisors, fiscal intermediaries).
- Funds may be used for:
  - ▸ In-network outpatient mental health services;
  - ▸ Out-of-network outpatient mental health services; and
  - ▸ Non-traditional goods and services.
- Purchases must be related to recovery goals.

My Voice My Choice

- Tested principles of mental health self direction in the integrated Medicaid managed care system.

- Enrolled adult managed care members with serious mental illness (SMI) on a population basis (without targeting a specific subset such as those at a certain level of care).

- Two year randomized pragmatic trial in central Texas (Travis) managed care service delivery area.

- Informed by previous scientific research in the state mental health system, which demonstrated better recovery outcomes at no greater cost than traditional services (Dallas SDC Pilot).

Texas Partners

- **State HHS** – Direction, Oversight
- **Stakeholder advisory committee** – Design, Oversight, Review
- **Medicaid managed care organizations (MCOs)** – Financed self-directed services
- **UT Health San Antonio** – Recovery advisors
- **Texas Institute for Excellence in Mental Health Services (TIEMH)** – Independent evaluation
- **Texas A&M Public Policy Research Institute (PPRI)** – Participant recruitment & surveys

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Persons with Lived Experience

MVMC Project Design and Implementation	SDC Toolkit	PCRP Toolkit
SDC Stakeholder Committee	Review and feedback	Review and feedback

Outcomes Evaluated

- Physical and mental quality of life
- Potentially preventable events
- Service use
- Activation measures
- Satisfaction with healthcare
- Satisfaction with social participation
- Social determinants (education, transportation, employment, housing, food)
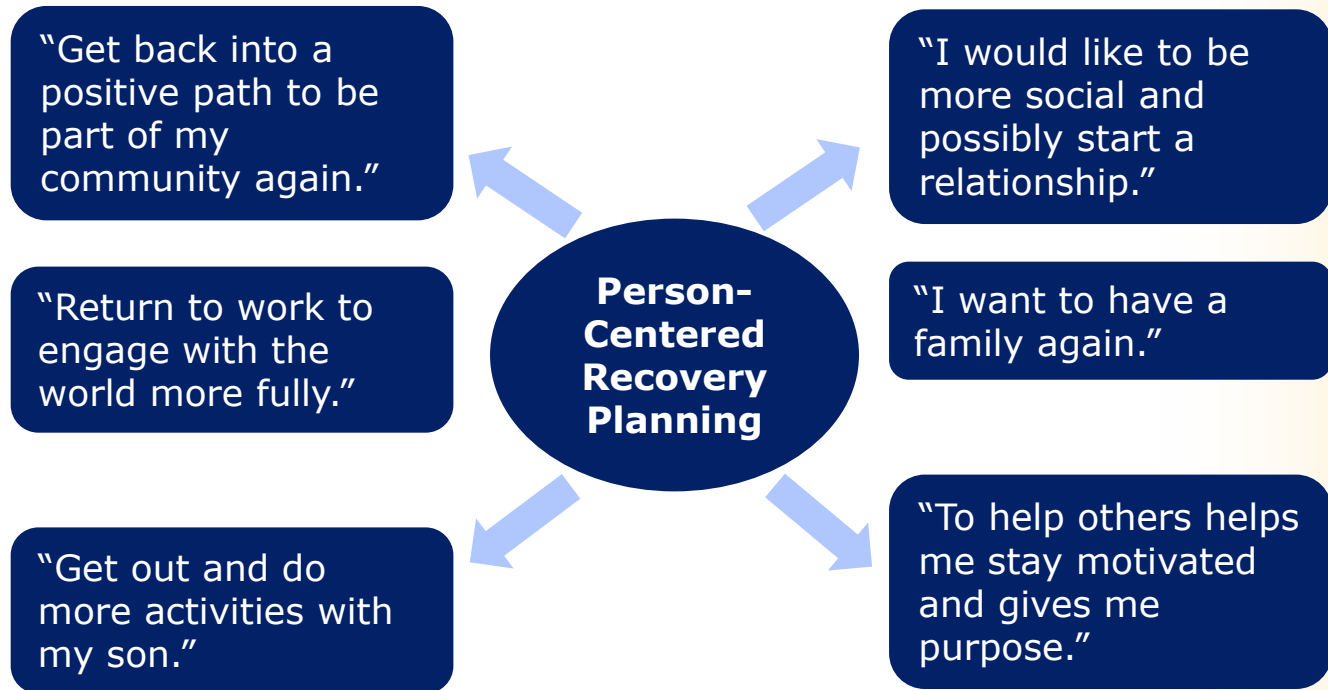- Recovery goal progress

TEXAS
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Participant Recovery Goals

"Get back into a positive path to be part of my community again."

"Return to work to engage with the world more fully."

"Get out and do more activities with my son."

Person-Centered Recovery Planning

"I would like to be more social and possibly start a relationship."

"I want to have a family again."

"To help others helps me stay motivated and gives me purpose."

Findings

- Positive outcomes for a broad range of participants.

- Improved mental and physical well-being.

- Increased confidence, self-esteem, hope, motivation, and sense of purpose.

- Participants improved over time and, in comparison with, the control group on:
  - Mental health (SF 12-MCS);
  - Active participation in mental health care (PAM-MH); and
  - Social participation and activities (SSRA).

- No reliable differences in physical health scores.

- Cost neutral - no greater Medicaid utilization costs, consistent with Dallas study.

Recovery Advisors

The collaborative relationship between participants and Recovery Advisors enabled people to:

- Define their goals;

- Develop person-centered plans;

- Purchase good and services to support their plans; and

- Achieve positive outcomes (e.g., improved mental health, social and mental health engagement).

Potential

- Increased active participation in mental health may result in cost savings over time.

- Research suggests that every point increase in active participation could potentially result in a:
  - ▸ 2 percent decrease in hospitalization; and
  - ▸ 2 percent increase in medication use.

- A Medicaid benefit, which would provide SDC over a longer time period than the study, could have a greater impact on recovery outcomes

Some Considerations

- Defining clear program / purchasing policies

- Involving people with lived experience

- Developing infrastructure to support MH SDC

Options

- Texas is exploring how mental health self direction might be incorporated into Medicaid in the future.

- There are various ways that states might consider including Mental Health SDC in Medicaid. Some ideas include:

  ▸ Under HCBS State Plan or 1115 waiver authority;
  ▸ As an MCO quality improvement program;
  ▸ As an MCO value-added benefit; and /or
  ▸ As a value-based purchasing strategy.

Thank you

Dena Stoner

dena.stoner@hhs.texas.gov

More to Come!

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is a jointly funded (CMS/ACL) Technical Assistance center dedicated to the work of person-centered practices in all its forms.

NCAPPS is planning a learning collaborative focused on self-direction in the coming year as part of a series called *Beyond Compliance* which will support states to further develop their systems once compliance with the HCBS settings rule is established.

NCAPPS can provide technical assistance on self-direction through NCAPPS TA and applications will be available in the early summer.

People can sign up for the NCAPPS mailing list by sending an email with "subscribe" in the subject line to ncapps@hsri.org.

Questions?

Feedback

Please complete a brief survey to help ACL monitor the quality and effectiveness of our presentations.

Please use the survey link:

https://www.surveymonkey.com/r/5ZPTQ3G

WE WELCOME YOUR FEEDBACK!