

The 2021 Self-Direction Virtual Conference Series

#SDseries2021



Bridging the Gap Between Academia and Practice: A Conversation with Researchers in Self-Direction

Self-Direction Virtual Conference Series

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STANFORD/VANDERBILT STUDY OF FAMILY CAREGIVING AMONG SELF-DIRECTED MEDICAID LTSS RECIPIENTS



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BIG QUESTION: WHAT IS THE EFFECT OF SELF- DIRECTION ON HEALTH AND SOCIAL OUTCOMES?

- **Approach #1: Compare outcomes of self-directing individuals to outcomes of those not self-directing**
 - *Pros & Cons:* Flexible, allows for a wide range of research questions and (qualitative or quantitative) study designs, but ensuring “apples to apples” comparisons can be hard if those who opt to self-direct are different than those who don’t
 - We can control for differences in income or basic demographics, but it’s tough to control for factors that are hard to observe, such as “extended family support” or “self-advocacy skills”
- **Approach #2: Randomized controlled trial**
 - *Pros & Cons:* The research “gold standard,” but requires tremendous stakeholder cooperation, can raise ethical issues
- **Approach #3: Natural experiment**
 - *Pros & Cons:* Comparing outcomes before and after an inflection point (legal or policy change that affected ease or availability of self-directing services) can make comparisons more “apples to apples,” but finding good inflection points in the real world can be challenging

OUR APPROACH: A NATURAL EXPERIMENT (APPROACH #3)

- ***What's the research question?***
 - We're focusing on the demand for and effects of **family caregiving** in self-direction
- ***What's the "inflection point"?***
 - We have two inflection points, both of which were caused by the Covid-19 pandemic:
 - Labor shortages (many non-familial caregivers stopped coming to work)
 - Regulatory changes (many states loosened restrictions on family caregiving for Medicaid beneficiaries)
- ***How will we carry out the study?***
 - Collaboration between our research teams, a large managed care organization (MCO), and ASD
 - We'll collect detailed data (including on use of family caregivers) from before and after the pandemic on self-directed Medicaid populations in states that did, and did not, expand scope of family caregiving
 - We'll compare differences in outcomes between different "treatment" groups & "control" groups

Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Lurie Institute
for Disability Policy

IMPACT OF COVID-19 ON MEDICAID BENEFICIARIES RECEIVING HOME AND COMMUNITY-BASED SERVICES

Community Living Policy Center

MICHAEL ATKINS, JOE CALDWELL,
SANDY HO

Background for Research Study



Examined the experiences of people who self-direct their Home & Community Based Services



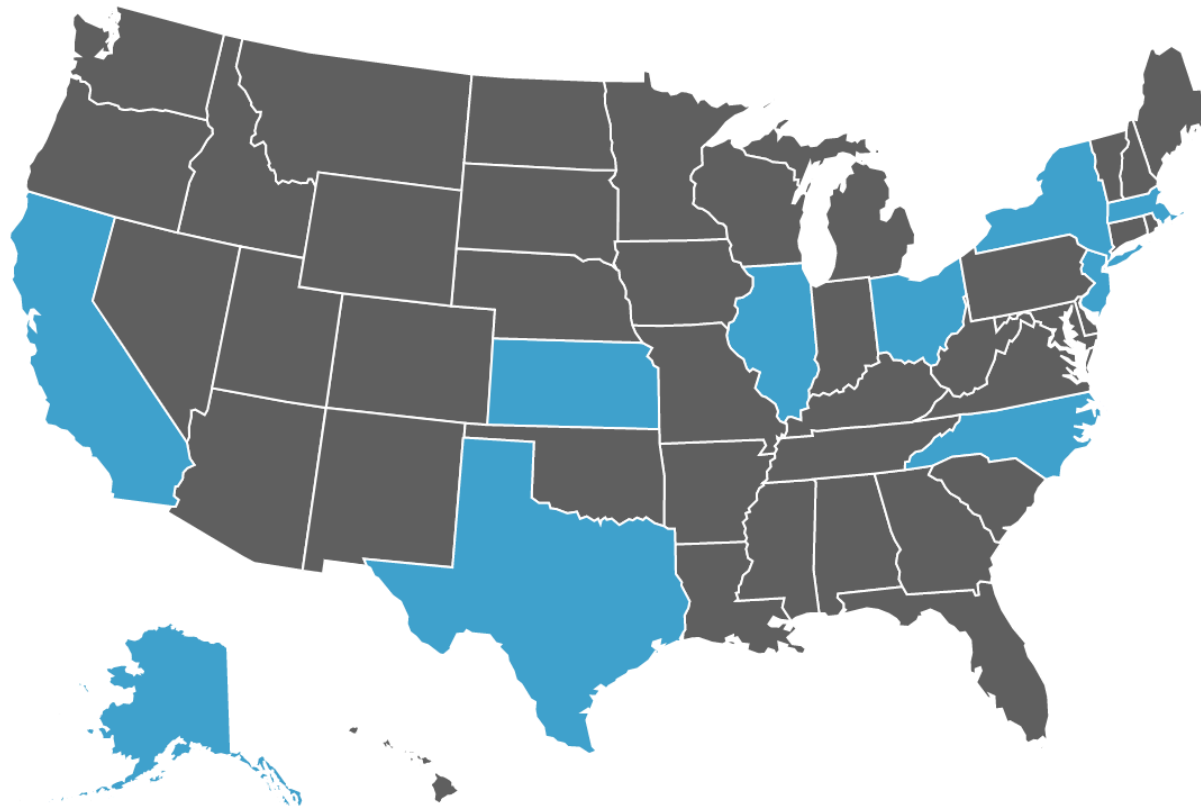
- access to direct care workers

- access to PPE



- social connection to others

Research Participants



- **40 participants**
- **10 states**
- **over 40% of participants identify as a person of color**

Initial Findings



- Access to direct care workers



- Role of self-direction



- Maintaining safety



- Social connection

One participant on his experience during COVID:

“I chose my mom because we already live together. She knows me inside and out. I felt like it would be more difficult to hire someone new and have to take the risk of them coming in and I don’t know where they’ve been the day before or who they’ve been around. With my health, I can’t take that chance. So, if I’m around my mom 24/7 and she’s already here, then it makes more sense to hire her if she wanted to, and she did.”

Bridging the Gap Between Academia and Practice

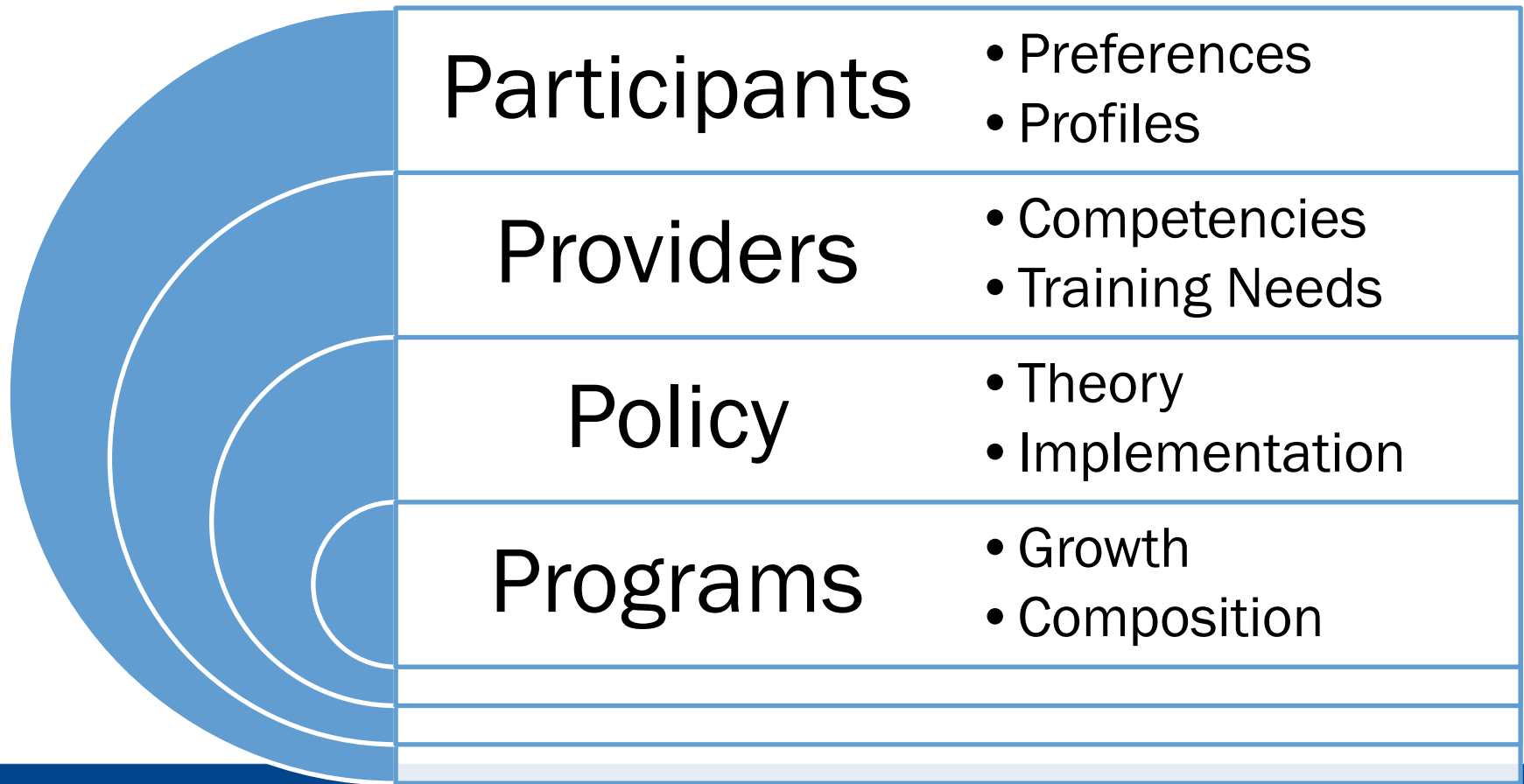
Research on self-direction

Mark Sciegaj, M.P.H., Ph.D.

Professor of Health Policy and Administration

Penn State University

The four “Ps” of my research on self-direction



Further reading

- **Participants**

- Sciegaj, M., Capitman, J. A., & Kyriacou, C. K. (2004). Consumer-directed community care: race/ethnicity and individual differences in preferences for control. *The Gerontologist*, 44(4), 489-99.

- **Providers**

- Hooyman, N., Sciegaj, M., & Diez, V. (2014). Aging Network Workforce Competencies in Person-Centered Approaches and Self-Directed Services Delivery Options. Gero-Ed Center, Council for Social Work Education.
- Sciegaj, M., Hooyman, N., Mahoney, K., & DeLuca, C. (2018) The times they are a-changing: Self-directed long-term services and supports and gerontological social work, *Journal of Gerontological Social Work*, DOI: 10.1080/01634372.2018.1439852



Further reading

- **Policy**

- Hooyman, N., Mahoney, K., & Sciegaj, M. (2016). Theories that Guide Consumer-Directed/Person-Centered Initiatives in Practice. *Handbook of Theories on Aging*. New York: Springer Publishing.
- Sciegaj, M., Crisp, S., Edwards-Orr, M., & DeLuca, C. (2016). Three Emerging Themes From Implementing Self-Directed Long-Term Service and Support Programs Under Managed Care. *Public Policy & Aging Report*, 26(4), 134-137.

- **Programs**

- Sciegaj, M., Mahoney, K., Schwartz, A., Simon-Rusinowicz, L., Loughlin, D., & Selkow, I. (2016). An Inventory of Publicly Funded Participant-Directed Long-Term Services and Supports Programs in the United States. *Journal of Disability Policy Studies*.



Research from the Financial Management Services (FMS) Perspective

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Holly Carmichael, GT Independence

Questions?

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