Our presenters

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THE spark
INITIATIVE
a creative catalyst for change

OUR PURPOSE and FOCUS

LIVING A SELF DETERMINED LIFE

HUMAN Dignity

The Spark Initiative:
a creative catalyst for change

Consortium

- Developed, underwritten and hosted by Optum

- Brings together leaders in government, nonprofit and private sectors to "spark" new thinking on major national issues confronting state Medicaid and human services agencies

- In addition to Optum, the Spark team is represented by 25 organizations to collectively develop a variety of resources for the public

Focus

- Launched in 2016 with a focus on the justice-involved population

- In 2017, the initiative focused on the I/DD population with a goal to define and drive a unified national effort to better serve people with disabilities primarily through changes in the service delivery system

Benefits

- *To state and public constituents, including specific populations:* a supportive coalition providing resources and innovation for productive change

- *To Optum:* understand voice of the customer, influence product innovation and market advancement

- *For everyone:* making the health system work better for everyone

Spark Initiative Members

ACL — Administration for Community Living

The Arc — For people with intellectual and developmental disabilities

NACDD — National Association of Councils on Developmental Disabilities

Quality Trust for Individuals with Disabilities

Alliance BEHAVIORAL HEALTHCARE

CQL | The Council on Quality and Leadership

NATIONAL COUNCIL FOR BEHAVIORAL HEALTH — Community Services Group

RCPA — REHABILITATION & COMMUNITY PROVIDERS ASSOCIATION

aaidd — American Association on Intellectual and Developmental Disabilities

HOPE HOUSE FOUNDATION

The National Leadership Consortium on Developmental Disabilities — University of Delaware

UNIVERSITY OF MINNESOTA — rtc on community living

ANCOR — American Network of Community Options and Resources

Human Services Research Institute — HSRI

OPEN MINDS

VAYAHEALTH

The Arc: Arizona

Community Resource Associates

University of Mass. Boston, Institute for Community Inclusion

Michigan Department of Health and Human Services, The Behavioral Health and Developmental Disabilities Administration (BHDDA)

National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)

National Association for Rural Mental Health (NARMH)

People First of Nevada

SPARK! I/DD work groups

	① Shared framework Foundation for work of groups 2, 3 and 4	**② Provider barriers**	**③ Outcomes and performance**	**④ Education**
Audience	I/DD community	I/DD providers and I/DD system	Policy makers, legislators, state authorities	General public
Deliverable	White paper exploring what self-determination should look like for the disabled	Summary report from a nationwide provider survey to understand how individualized support is delivered today and what barriers exist for improvement	• Online self-assessment tool for local/state I/DD authorities to guide them to self-directed resources and best practices • White paper recommending ways programs can change to better support individuals with disabilities to lead a self-determined life	National campaign toolbox to help break down barriers and educate the public on how to best interact with people with disabilities in ways that enable them greater self-determination and independence
Status	Developing outline; authored by representatives of Human Research Services Institute	National quantitative online survey in market April 21 through May 25, 2018	• Collecting models for analysis • Target completion: Q3 2018	Direction for creative and campaign strategy finalized April 2018 Target completion: Q4 2018 (toolbox, promotional plan with industry partners)
Engagement	White paper distribution via Spark organizations, industry conferences and national campaign toolbox	Report dissemination via Spark organizations, industry conferences, and national campaign toolbox	Promotion of deliverables via Spark organizations and industry speaker circuit; POV on needed policy changes	National *Presume Competence* awareness campaign

Working group participants:

- **Nancy Weiss**, National Leadership Consortium on Developmental Disabilities

- **Richard Edley**, Rehabilitation and Community Providers Association

- **Susan Blue**, National Council of Behavioral Health/Community Services Group

- **Mike Hammond**, Optum

Researchers:

- **Caitlin Bailey,** PhD ABD, Director of Research and Evaluation, National Leadership Consortium on Developmental Disabilities, University of Delaware

- **Cory Gilden,** M.Ed., Graduate Research Assistant, National Leadership Consortium on Developmental Disabilities, Department of Human Development and Family Studies, University of Delaware.

Self-Directed Services

Adults with I/DD have control of:

People who receive these services do not need to live alone but they must have control over their own lives with the supports they want/need to be successful.

Budget and Spending

Living Situation

Agency and People who Facilitate Services

Interests and Goals

Schedule

Work

THE SELF-DETERMINATION MOVEMENT

A Distinction of Terms

Self Directed Services *(from Centers for Medicare and Medicaid Services)*

Service Users "have the responsibility for managing all aspects of service delivery in a person-centered planning process. Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided…Participants may also have decision-making authority over how the Medicaid funds in a budget are spent."

Self Determination *(American Association on Intellectual and Developmental Disabilities)*

People with disabilities have the right to become "contributing, valued and respected members of their communities and live lives of their own choosing"
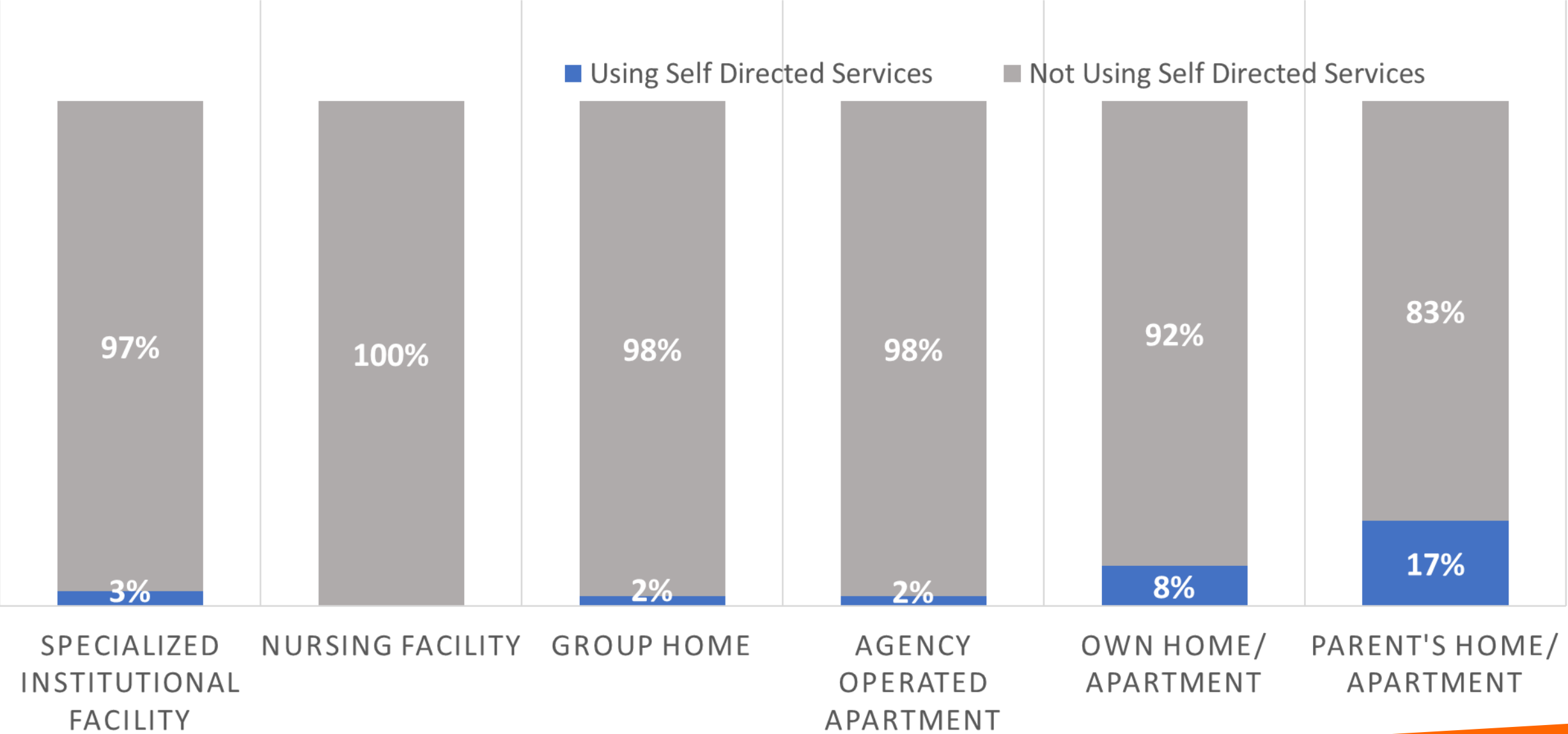
Person Centered Services *(National Association of State Directors of Developmental Disabilities Services)*

Person Centered Services provide "ways of planning, providing and organizing services rooted in listening to what people want and helping them live in their communities based on their choices"

Use of Self Directed Services

Use of Self Directed Services

Use of Self Directed Services

Legend: ■ Using Self Directed Services ■ Not Using Self Directed Services

Category	Not Using Self Directed Services	Using Self Directed Services
SPECIALIZED INSTITUTIONAL FACILITY	97%	3%
NURSING FACILITY	100%	
GROUP HOME	98%	2%
AGENCY OPERATED APARTMENT	98%	2%
OWN HOME/ APARTMENT	92%	8%
PARENT'S HOME/ APARTMENT	83%	17%

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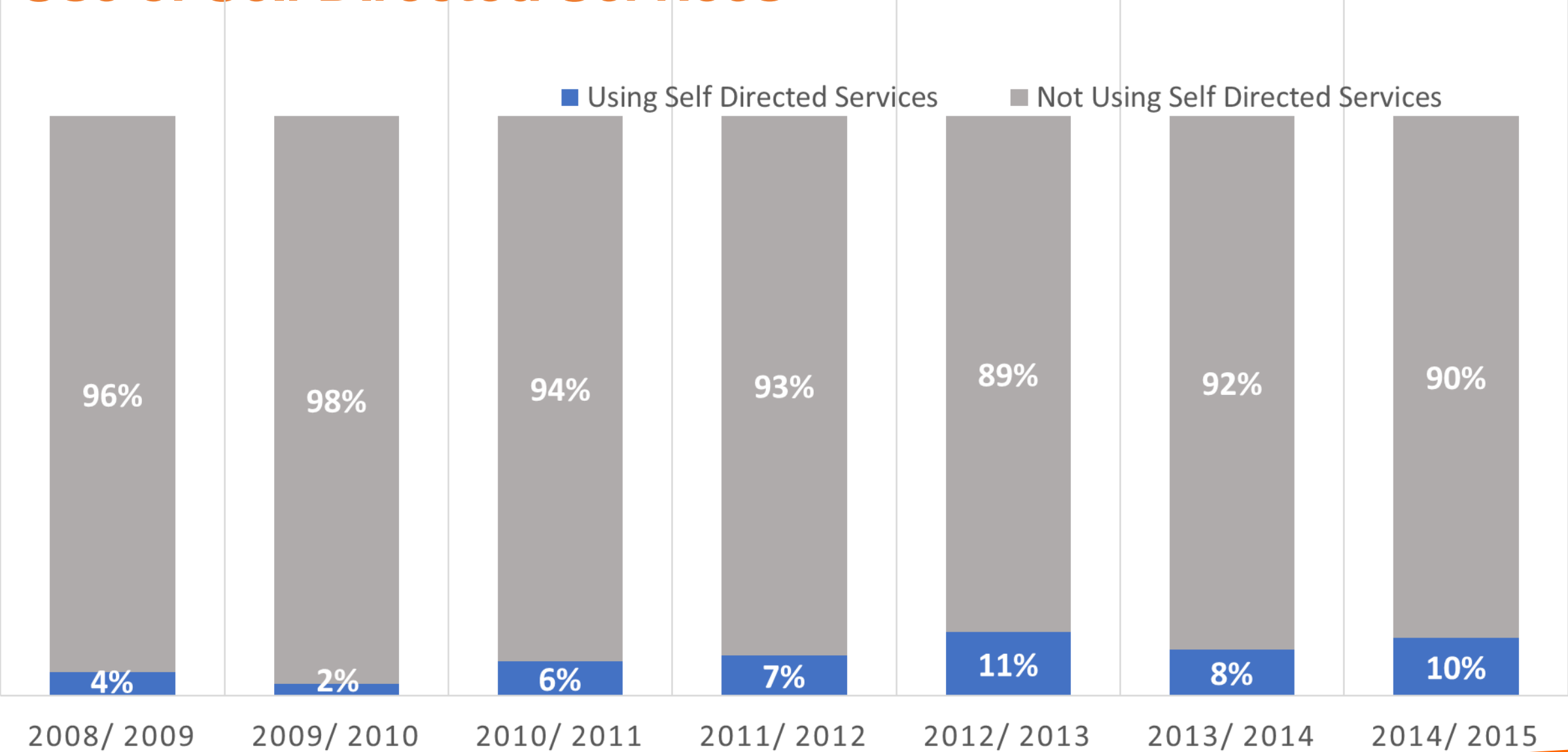
January 2018
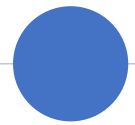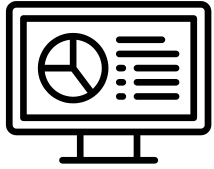
Spark! Designs Initial Survey
Survey Development

With the research team of the National Leadership Consortium on Developmental Disabilities at the University of Delaware
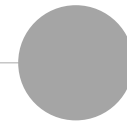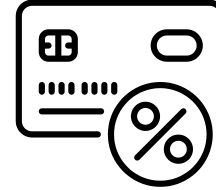
March 2018

Refining the Survey
Pilot Survey

Sent to 25 hand-selected professionals who work with adults with I/DD
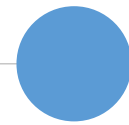
April 2018

Nationwide
Survey Dissemination

Across the U.S. through the listservs, websites and social media of national organizations, by direct email, in welcome bags at national conferences
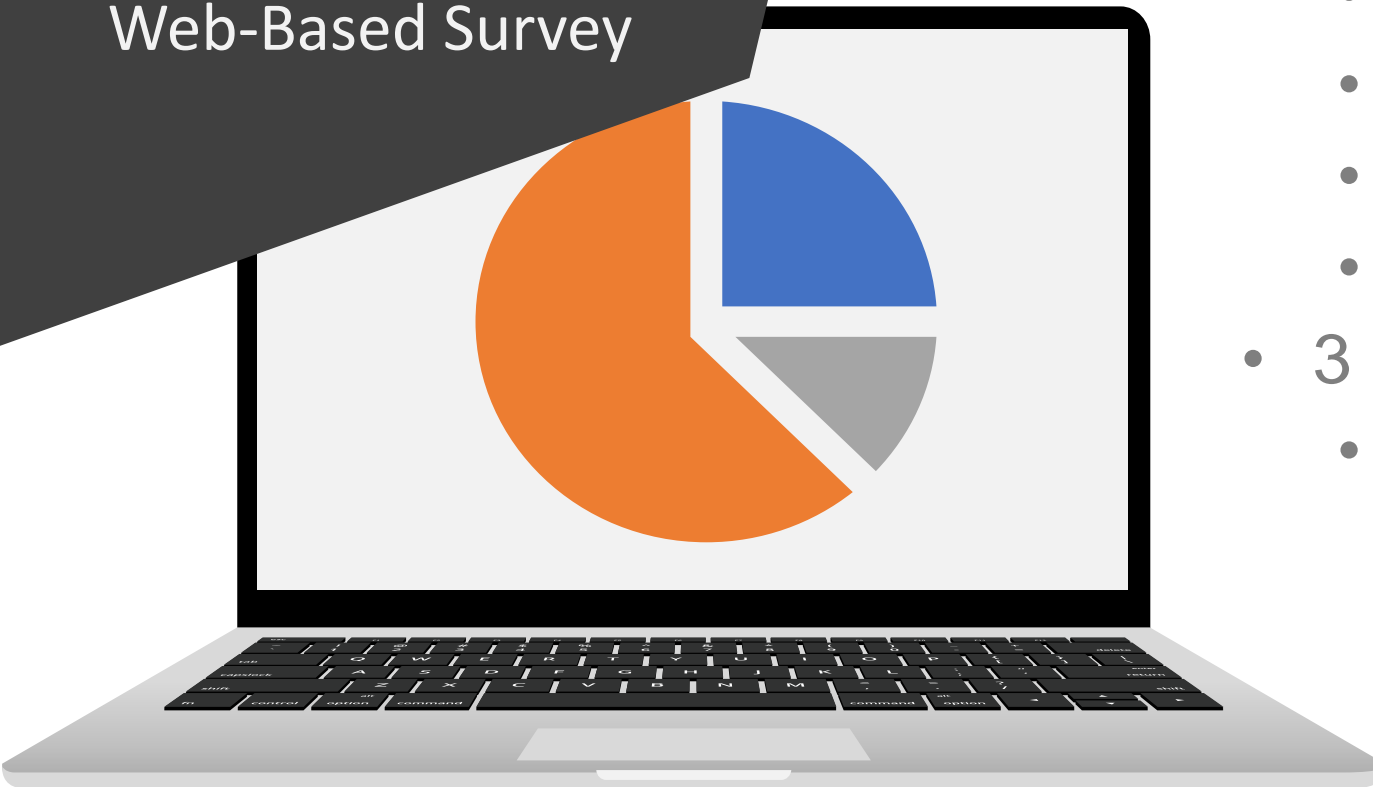
July 2018

Survey Closed
Data Collection Complete

I/DD Provider Survey on
Self-Directed
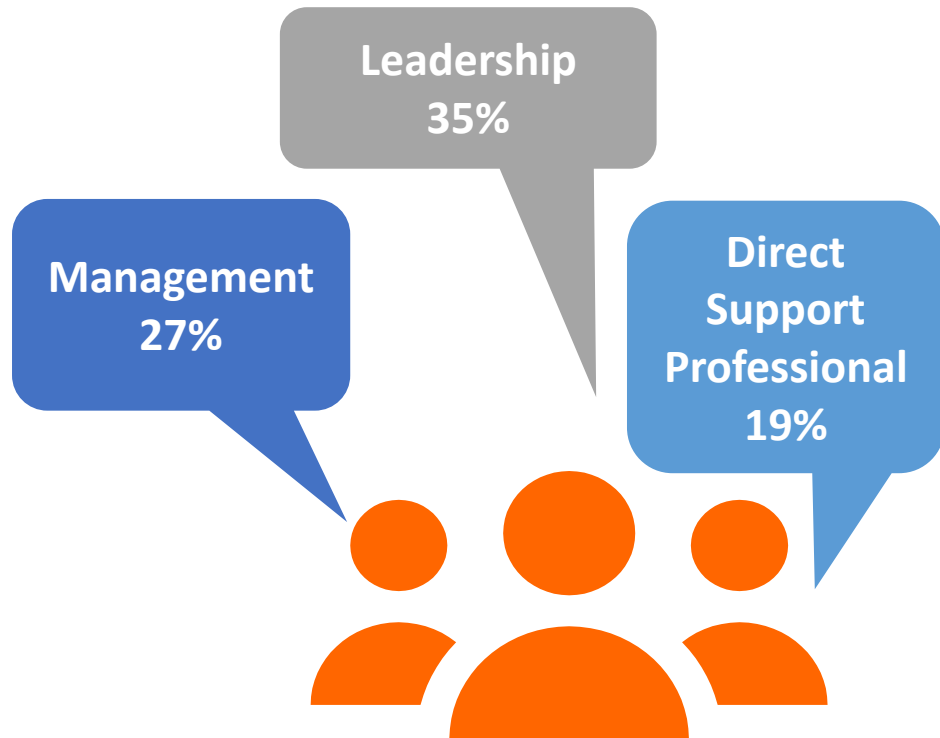## Services and Supports

Web-Based Survey

- About 45 Multiple Choice Questions
  - Barriers to Self-Direction
  - Facilitators to Self-Direction
  - Agency Practices of Self-Direction
  - Values about Self-Direction
  - Demographic Information
- 3 Short Answer Response Sections
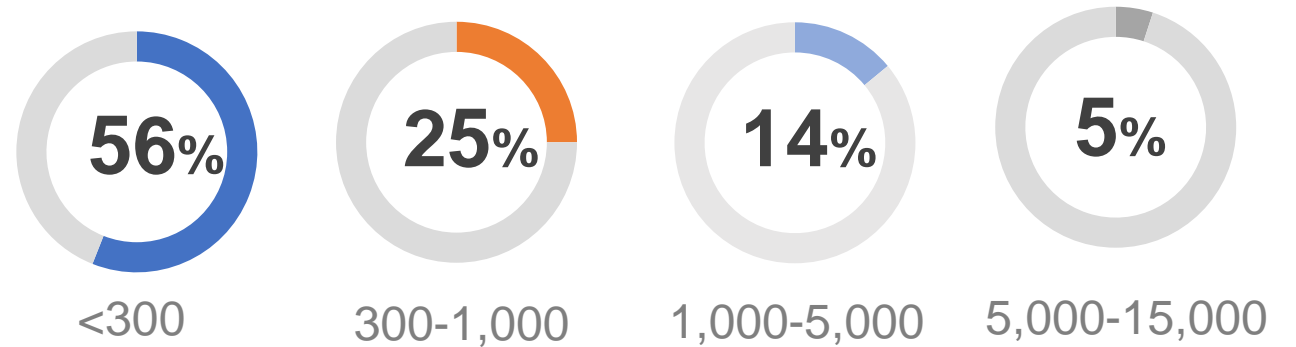 - Clarify/Explain Answers

Survey Respondents

Position at Agency

Management 27%

Leadership 35%

Direct Support Professional 19%

19% Administrative or Other Staff

People Served by Agency

56% <300

25% 300-1,000

14% 1,000-5,000

5% 5,000-15,000

✔ **475 Respondents**
From 37 states

✔ **70% Private, Not-for-Profit Agencies**
Others from private for-profit or state/city/county run,

✔ **83% Both Individual and Congregate Services**
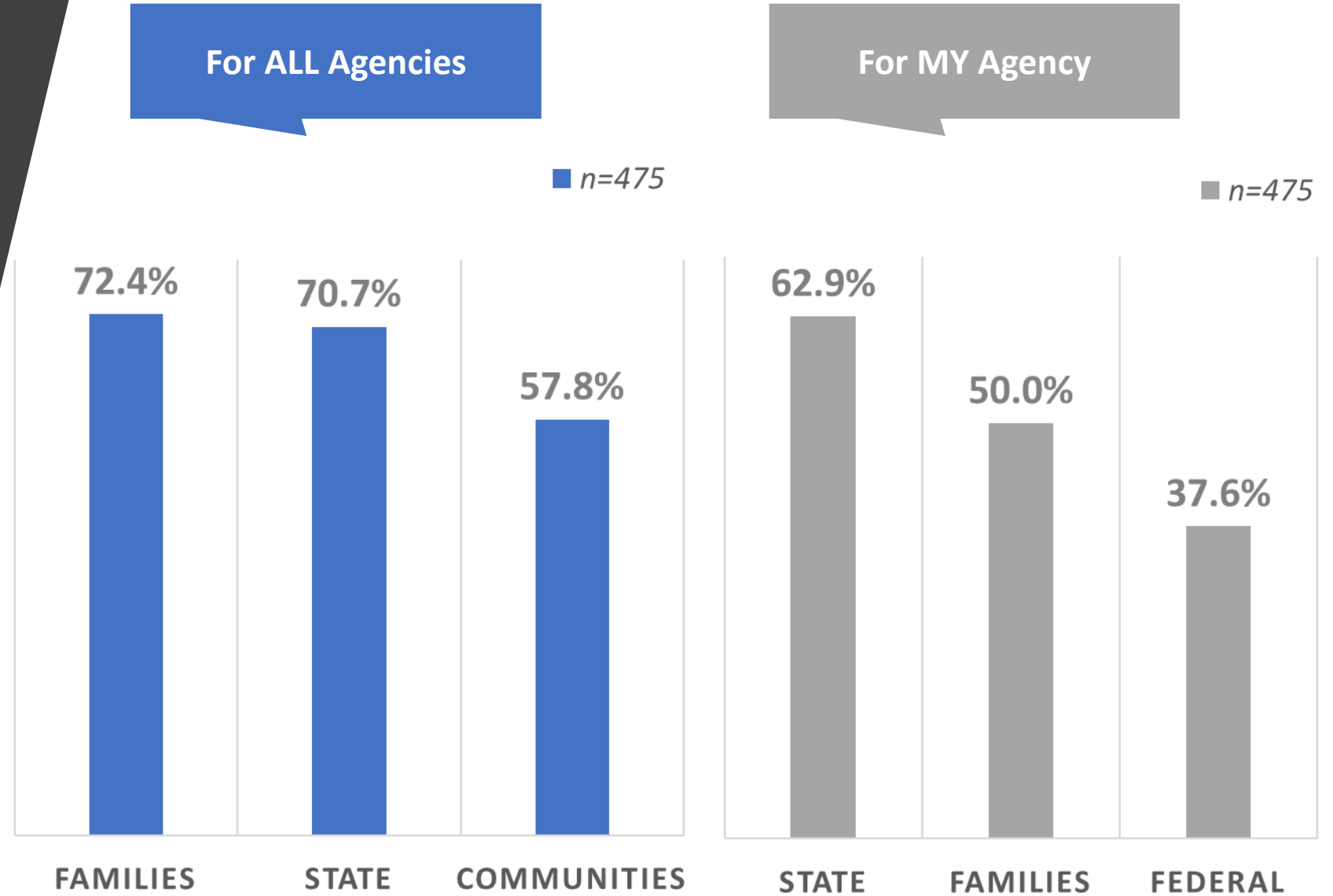Including center and community based programs, vocational programs, and residential programs

What are the Factors to consider?

- **Federal** policies, regulations, funding and service definitions
- **State** policies, regulations, funding and service definitions
- **Managed care organizations'** policies, structures and practices
- **Community** systems, opportunities and attitudes
- **Board of directors'** attitudes, traditions and leadership
- **Service coordination/ case management** attitudes and processes
- **Provider agency** policies, structures and practices
- **Provider agency** leadership or staff attitudes, beliefs and skills
- **Family** attitudes, knowledge and involvement
- **People who receive support**—their attitudes, ability and opportunity

What are the Barriers to self-direction?

Top 3 Responses

For ALL Agencies ■ *n=475*

For MY Agency ■ *n=475*

72.4% — FAMILIES
70.7% — STATE
57.8% — COMMUNITIES

62.9% — STATE
50.0% — FAMILIES
37.6% — FEDERAL

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What are the Most Impactful barriers?

Top 3 Responses

Most Impactful

■ *n=475*

	STATE	FEDERAL	FAMILY
	32.1%	16.7%	16.1%
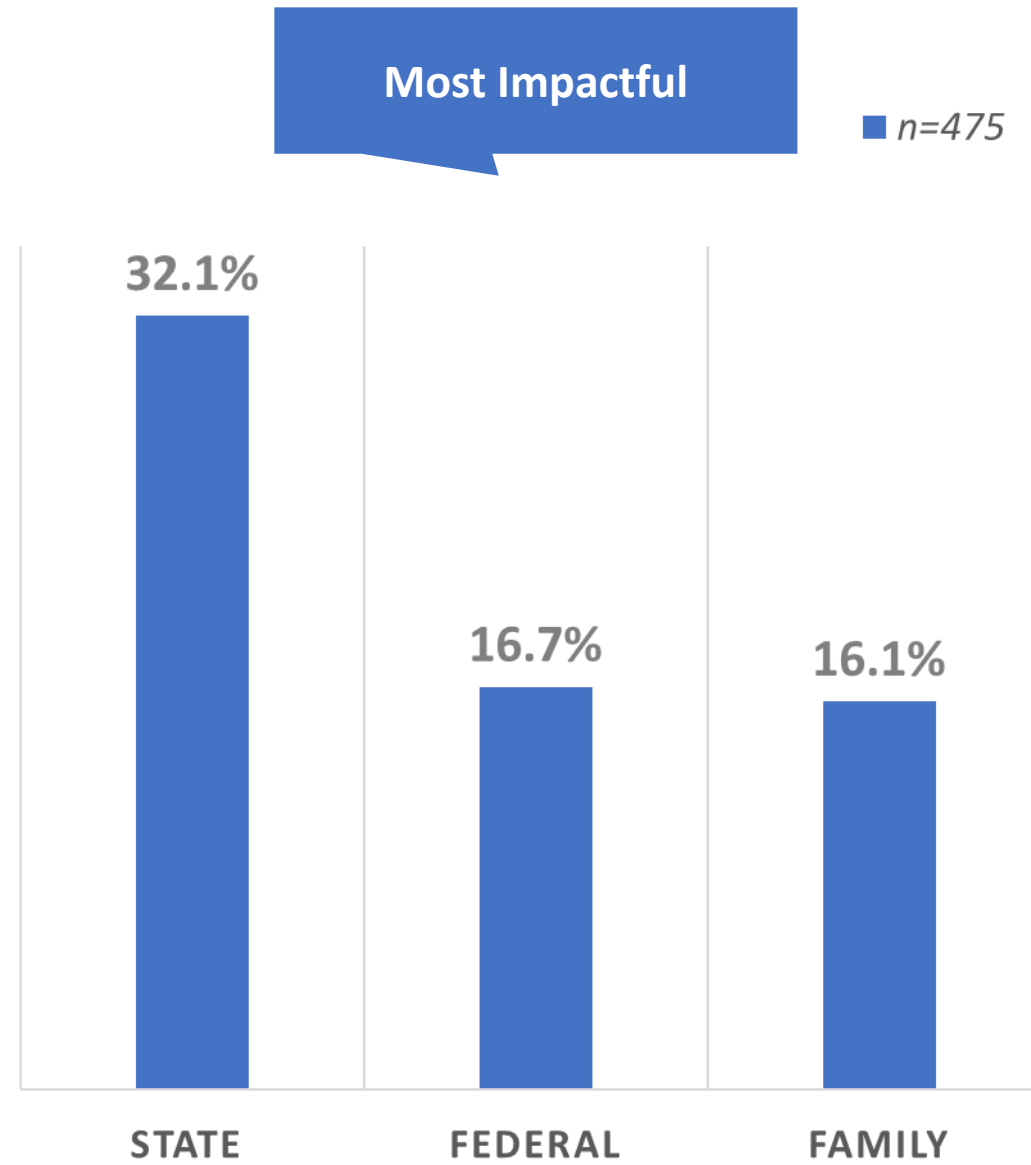
If you had a
Magic Wand
which would you fix?

Top 3 Responses

What would you fix?

Board of directors' attitudes, tradition and leadership **1%**

Managed care organizations' policies, structures and practices **2%**

Provider agency policies, structures and practices **2%**

People who receive support: attitudes, abilities and opportunity **5%**

Service coordination/case mgmt attitudes and processes **5%**

Provider agency leadership or staff attitudes, beliefs and skills **9%**

Family attitudes, knowledge and involvement **11%**

1 **39%** State policies, regulations funding and service definitions

2 **14%** Federal policies, regulations funding and service definitions

3 **12%** Community systems, opportunities and attitudes

"Funding plays a big part in allowing people to do what, how, when they want to do things. It effects how much staff/support hours they have and what activities they can afford to do. If an individual lives in a house with a roommate with one staff member on shift and they plan on going to the park for coffee, and then one person changes their mind at the last minute, the staff are stuck because there isn't the funding to have two staff at the house. Funding also effects how we hire and retain good DSPs. If their wage is just the minimum all that get hired are new people into the work force or young 18-year-old college kids looking for a short-term job not a career."

"State policies create an administrative burden and risk: documentation and tracking of service delivery overwhelms providers and the risk of adverse and retrospective audit findings to the ill-defined standards for Medicaid reimbursement is high."

"Our state has a one size fits all. They state person-centered over and over, but there is none. The definitions and trainings are the same for every provider. They have not really come up with a program that is person-centered in any sense of the word. The service definitions and training are the same for provider agencies and we just have to follow along. We are just not the same. Policies should reflect the agency and the differences."
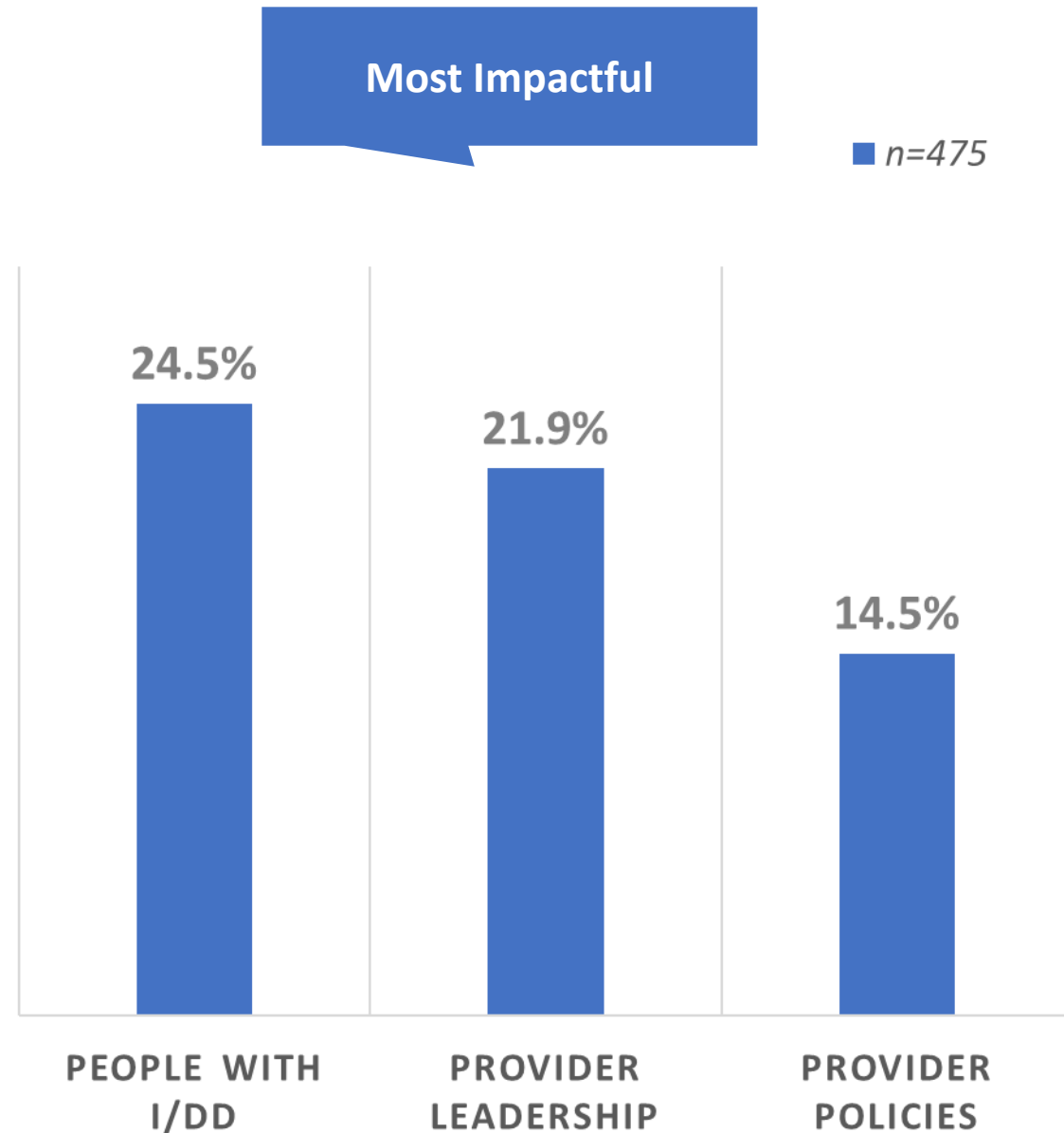
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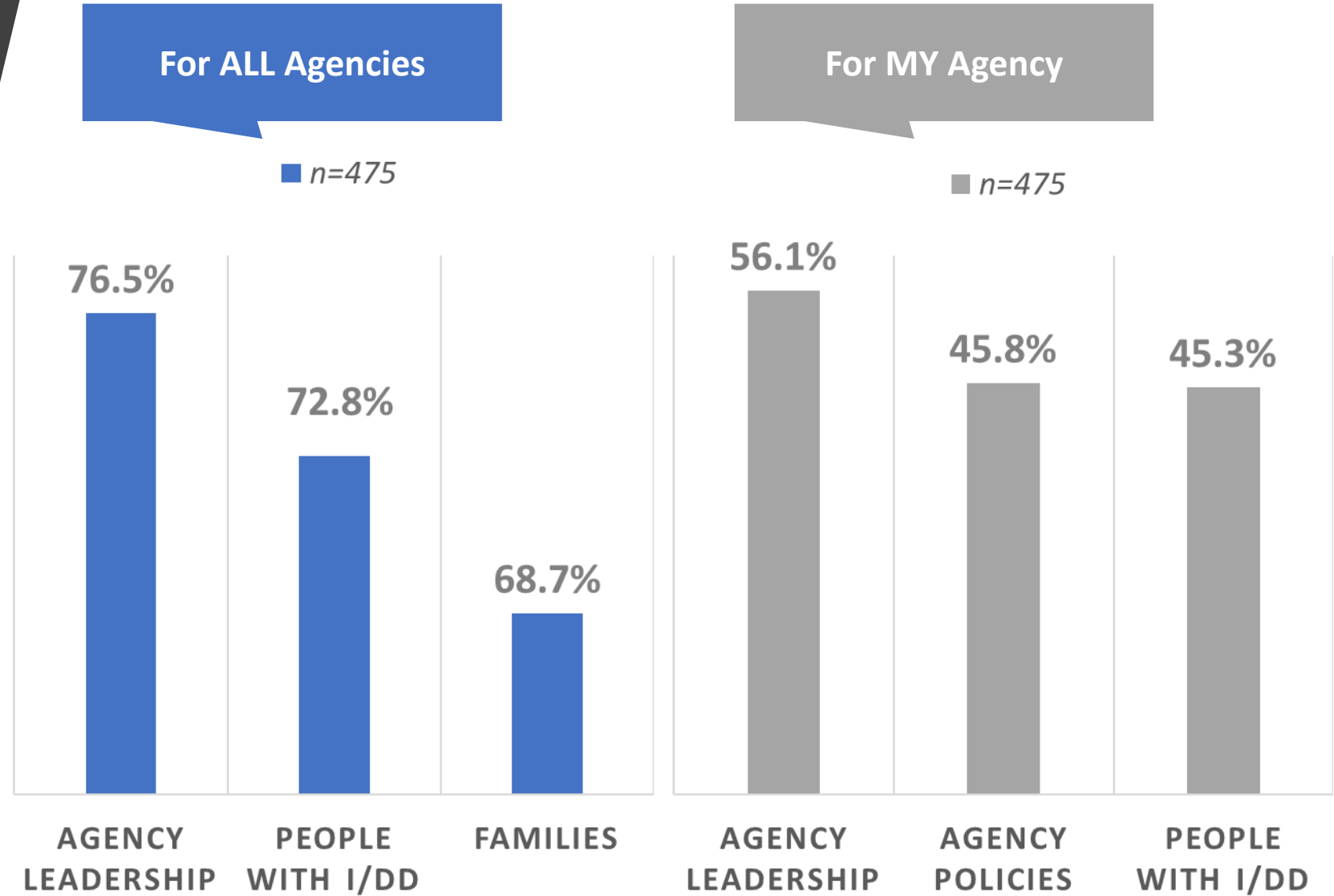
What are the
Most Impactful
facilitators?

Top 3 Responses

Most Impactful

■ *n=475*

24.5%	21.9%	14.5%
PEOPLE WITH I/DD	PROVIDER LEADERSHIP	PROVIDER POLICIES

How do you rate your agency's

Desire & Capacity

to deliver self-directed services?

On a Scale of 0-10

■ Agency Capacity
■ Agency Desire

Rating	Agency Capacity	Agency Desire
0	1	0
1	6	3
2	17	5
3	23	7
4	31	11
5	44	20
6	39	15
7	61	36
8	51	54
9	34	40
10	112	229
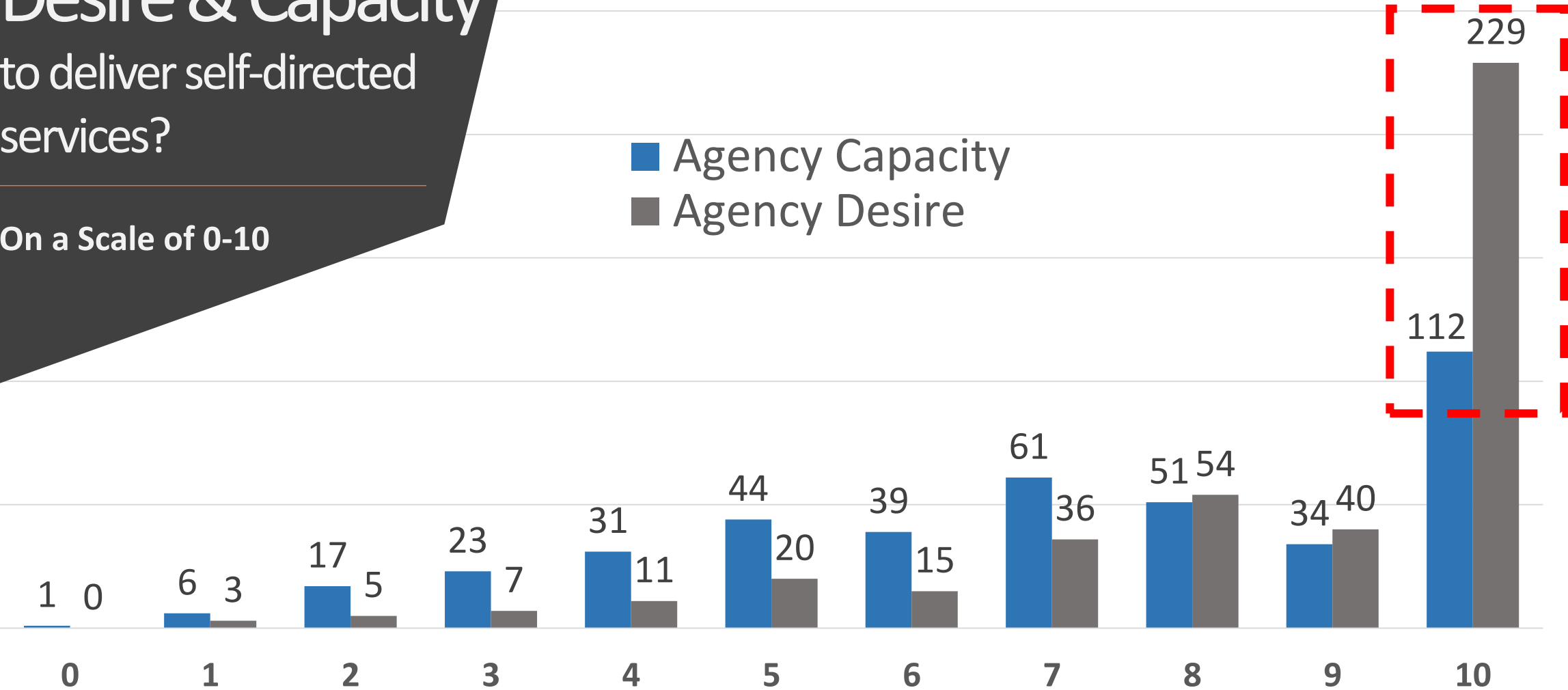
What are your agency
Practices
of self-direction?

Self-direction principles and language included in agency materials

Agency provides tools and supports for staff

Agency provides tools and supports for people with I/DD

What are your Values about self-direction?

People at the agency who are supportive of self-directed services and supports

Individual values regarding self-direction for adults with I/DD

Implications for Federal and State Policymakers and Managed Care Organizations

Incentivize self-directed services and supports

Make sure policies, regulations, funding structure and service definitions enable self-directed services

Provide technical assistance and support to agencies that are interested in transitioning to self-directed services.

Implications for Provider Agencies

Learn from agencies that have successfully transformed and fully implement self directed services

Embed principles of self direction into written and unwritten agency policies, practices and training

Adopt leadership and management philosophies that align with principles of self-direction

Make sure employee's beliefs and attitudes align with self-direction

Implications for Families and People with I/DD

Learn from people with disabilities and families who have successfully transitioned to self-directed services

Leverage the power and influence of families and people with I/DD to make self-direction a reality

What's Next?

1. Continue to disseminate and promote Survey findings

2. Learn from agencies that have successfully transformed and fully implemented self directed services

3. Work to develop and prioritize solutions to address barriers and other provider concerns

Discussion

Thank You!

For more information, contact

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