



Self-Determination: Are We There Yet?

A Brief Status Report from the US and
Beyond

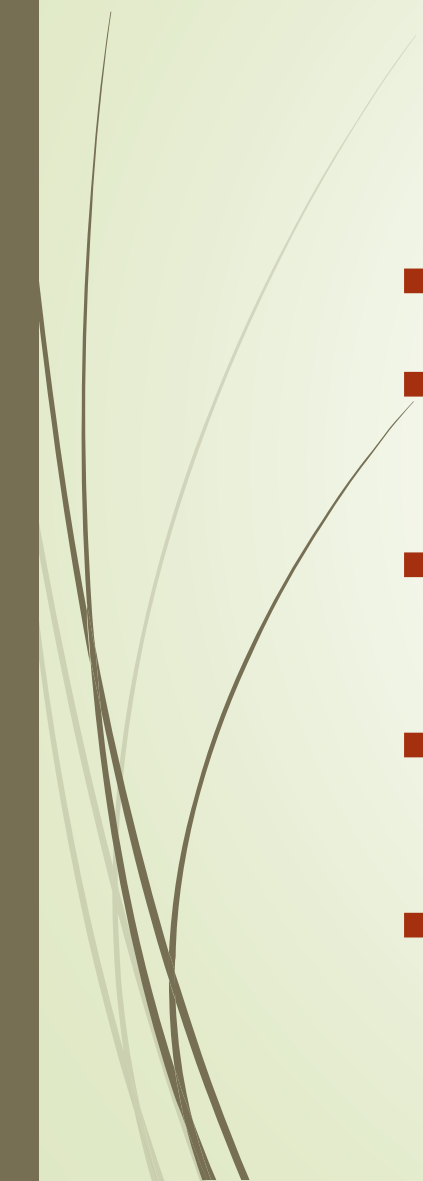


Sarah Taub NCI Webinar Series
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What Will We Cover

- Review of key concepts
 - Brief history of self-determination in the U.S. and early results
 - Review of NCI data and what it tells us about people who self-direct
 - Discussion of self-determination at the state level and internationally
 - Recommendations going forward
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What Is Self-Determination?

People plan their own lives, make their own decisions, determine how resources are spent for their supports, plan & choose their own supports (formal and informal), and take responsibility for the decisions made.

Freedom

Authority

Supports

Responsibility

It is About Changing Systems...

- **Shifting authority** for decision making to the individual.
- **Changing the way supports are funded** to give people direct control over dollars.
- **Changing the role** of service providers, case managers and support staff.
- **Putting the person into the center** of the relationship between the state and provider organization.

Antecedents Include...

- Family support programs
- Personal assistance programs
- Employment voucher innovations (Ticket to Work)
- Cash and counseling (1996-2013) programs



Robert Wood Johnson Demonstration Sites (1995-2001)

Arizona
Connecticut
Florida
Hawaii
Iowa
Kansas
Maryland
Massachusetts
Michigan
Minnesota

New Hampshire
Ohio
Oregon
Pennsylvania
Texas
Utah
Vermont
Washington
Wisconsin





RWJ Evaluation Findings

- ▶ **Flexibility breeds flexibility**--A system that encourages self-determination must be flexible enough to accommodate a variety of life choices (e.g., budgeting, contracting, etc.)
- ▶ **Let all flowers. . .** Self-determination requires agile procurement systems to accommodate the purchase of services and supports from a wider number of sources than typically is the case in specialized service systems.
- ▶ **Self Determination is not a rehearsal** – Leaders of successful initiatives did not treat self-determination as a "project" but rather embedded the approach throughout the system.



RWJ Evaluation Findings



- ▶ **Supporting the Supporters** -- Across the country, the ability to lead a self-determined life was significantly influenced by the availability of direct support professionals.
- ▶ **Leadership Counts** -- Leadership at the state and local level and the presence of innovation and momentum within a state were key elements in the success of the self-determination initiative.
- ▶ **Keep it Simple** -- Dealing with the mechanical elements of consumer budget management and employee administration can be extremely complex.



RWJ Evaluation Findings

- **Build It and They Will Come** -- To simplify the process of self-determination, it will be necessary in some states to significantly alter the "architecture" of how public agencies allocate, disperse and track funds.
- **It's All Relative** -- The lesson here is that we should not confuse decision-making over the substance of one's life with decision-making over backroom operations.
- **Managing Case Management** -- The nexus of self-determination is the brokerage function. It was at this point in most states/sites that the greatest stress was experienced.

Self-Advocates Said That Self Determination Means That. . .

- I am a person like all people: My life is my own.
- I make my own choices
- I am the boss of my own life.
- I make my decisions in my own life.



Self-Advocates Said They Saw Some Problems in Implementation

- There are problems with the doing
- People don't know what self determination is
- Caseworkers don't allow people to make their own decisions.
- Agencies say they believe in self-determination but then don't want to give up the money (or the power)
- Agencies don't want to get us the supports we want
- Professionals or staff not talking directly to us... talking to others instead of us.



The Fundamental Issues From the RWJ Evaluation

► **Technical**

Can we figure out ways to make the structure work in a technical sense?

► **Political**

Do we have the will to make changes to the flow of money?

Can we abandon program (slot) driven approaches?


Can we move from supply centered to demand centered systems?



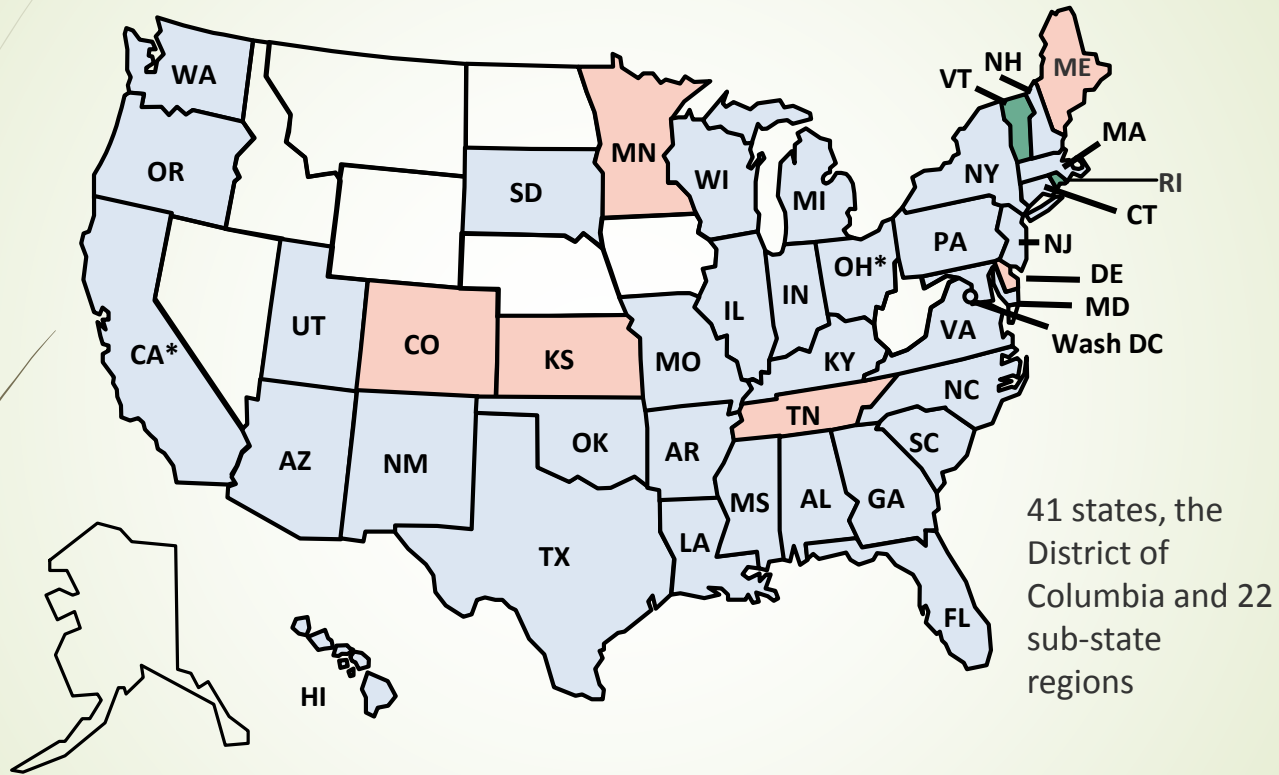
What Do NCI Data Tell Us About People Who Self- Direct?



WHAT IS NATIONAL CORE INDICATORS?

- Multi-state collaboration of state DD agencies
 - Measures performance of public systems for people with intellectual and developmental disabilities
 - Assessment of performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
 - Launched in 1997 in 13 participating states
 - Supported by participating states
 - NASDDDS – HSRI Collaboration
- 

NCI State Participation 2014-15



State contract awarded in 2014-15 through AIDD funding
 CA*- Includes 21 Regional Centers
 OH*- Also includes the Mid-East Ohio Regional Council



NCI is a Person-Centered Tool that Provides Information on:

- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare



WHAT IS NCI?

► **Adult Consumer Survey**

- ✓ In-person conversation with a sample of at least 400 adults receiving services to gather information about their experiences
- ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.

► **Adult Family, Child Family, and Family/Guardian Surveys –**

- ✓ administered by mail to a separate sample from Adult Consumer Survey

► Other NCI system level data: **Staff Stability**



Measuring Self-Determination:

Participant Characteristics and Outcomes



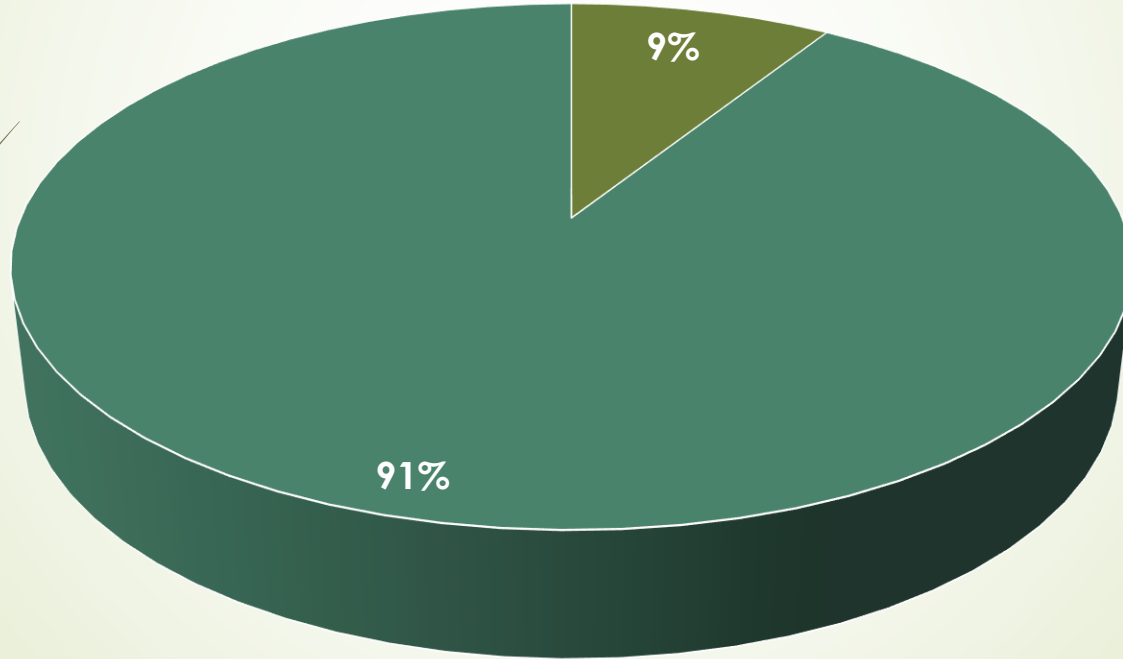
Methods, Measures and Sample:

- ▶ Findings from 2013-14 data collection cycle
- ▶ Based on Background Information Section of the survey
- ▶ Filter: Is this person currently using a self-directed supports option?
 - ▶ “Self-directed” or “participant directed” supports options offer individuals (and their representatives, including family members) the opportunity to manage some or all of their services. They may hire and fire their own support workers and/or control how their budget is spent.
 - ▶ No – 13,781
 - ▶ Yes – 1,276
 - ▶ Don't Know (coded as missing)
 - ▶ Total number of individuals for whom “yes” or “no” responses were entered: 15,057

Unless otherwise indicated, NCI Average=average of cases (not average of state averages)

Sample

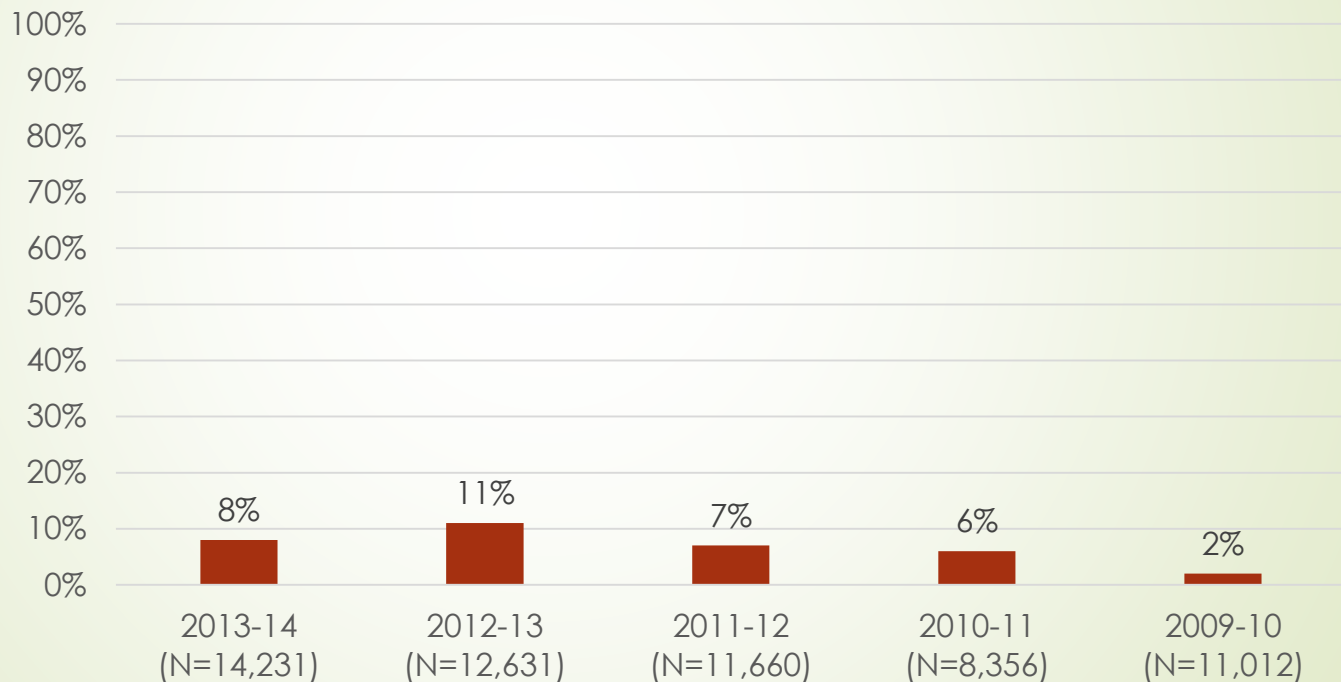
Currently Uses a Self-Directed Supports Option



- Uses self-directed supports option
- Doesn't use a self-directed supports option

Percentage Using a Self-Directed Supports Option

From the background information section



National Core Indicators (NCI)

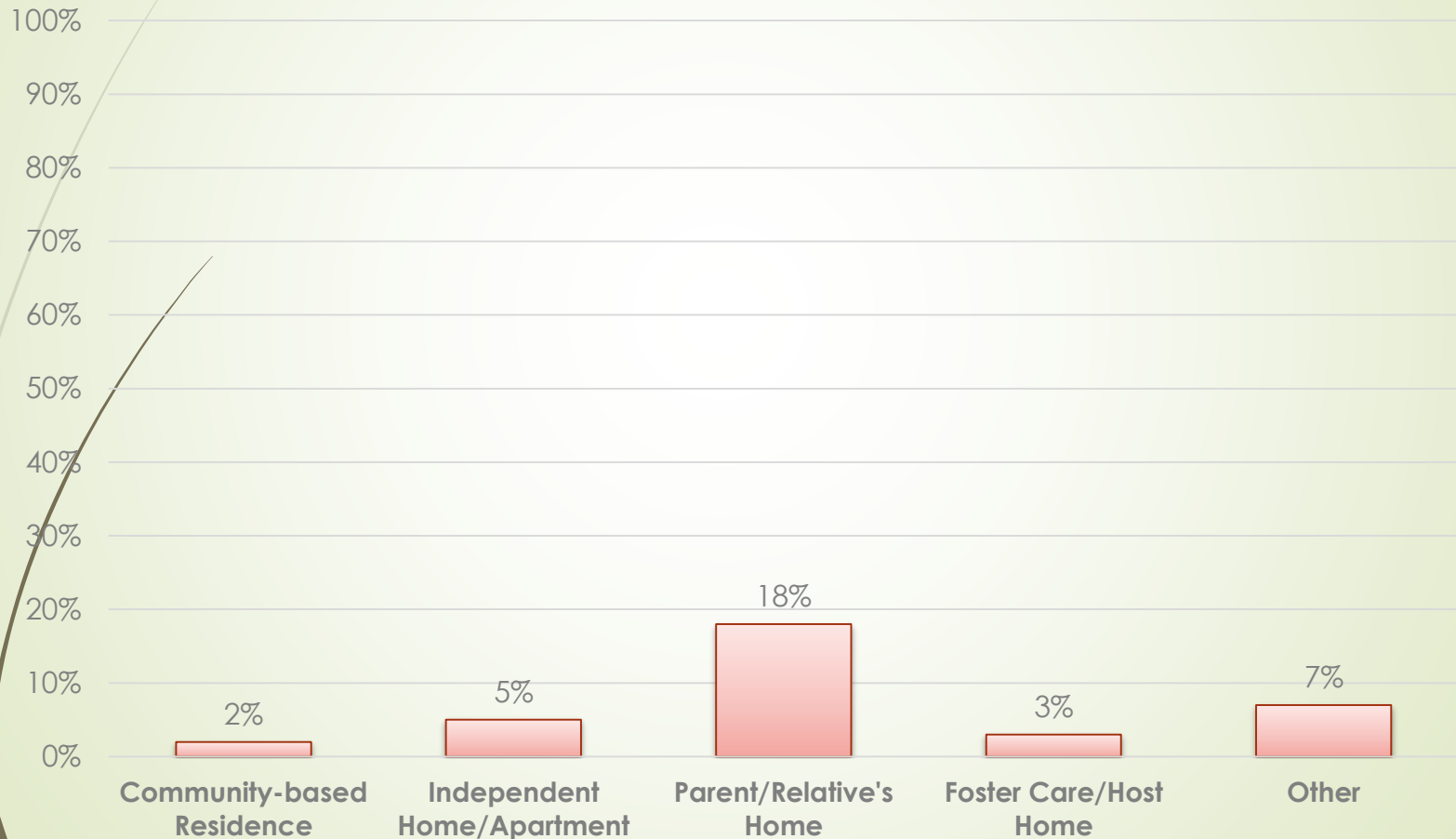
These percentages are the average of state averages

Finding

- Respondents who self direct differ significantly from those who do not use such supports in where they live and their satisfaction with their living situation as well as what they do during the day.



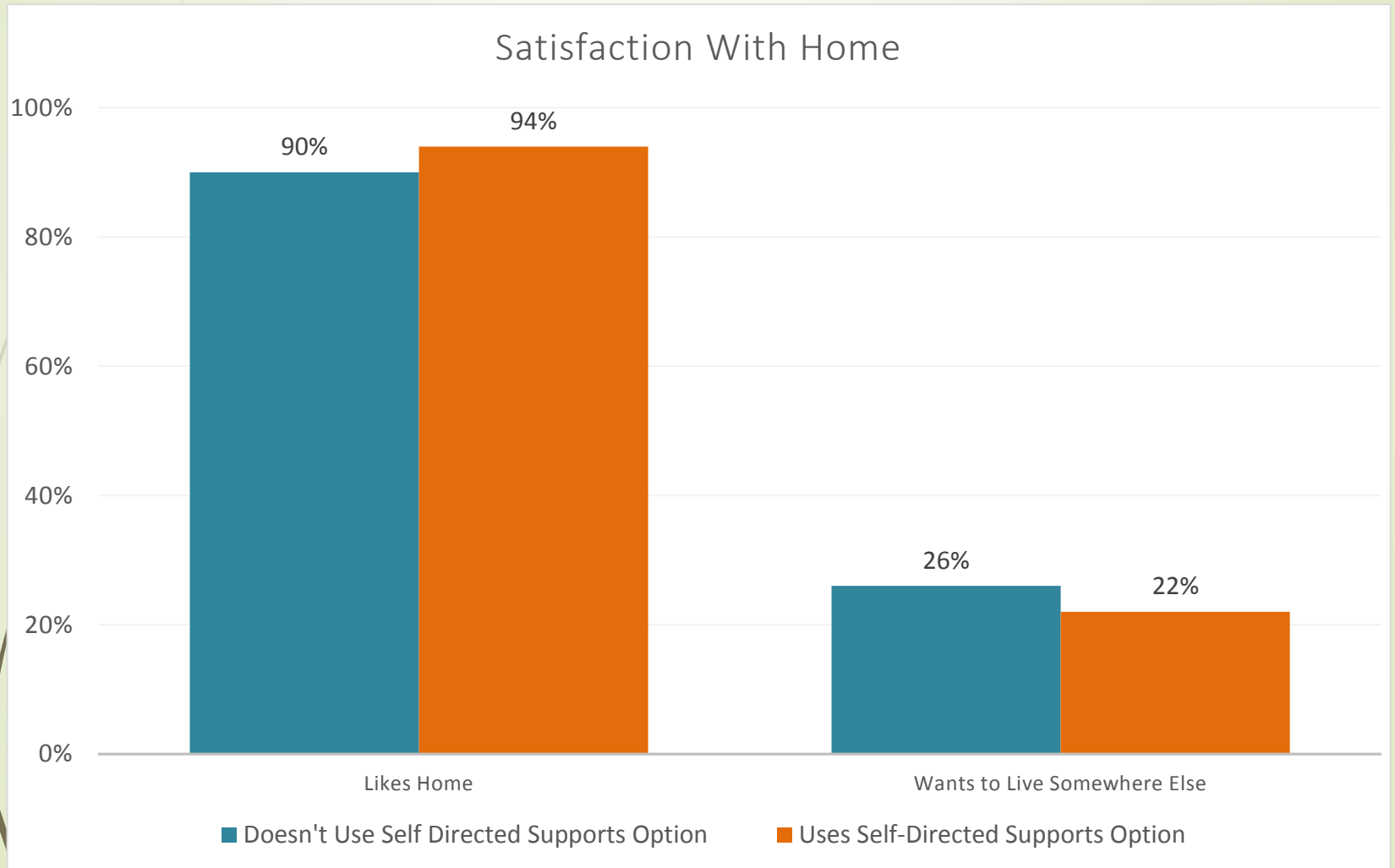
Proportion of People Using Self-Directed Option by Residence Type



Where People Who Are Using A Self Directed Supports Option Live

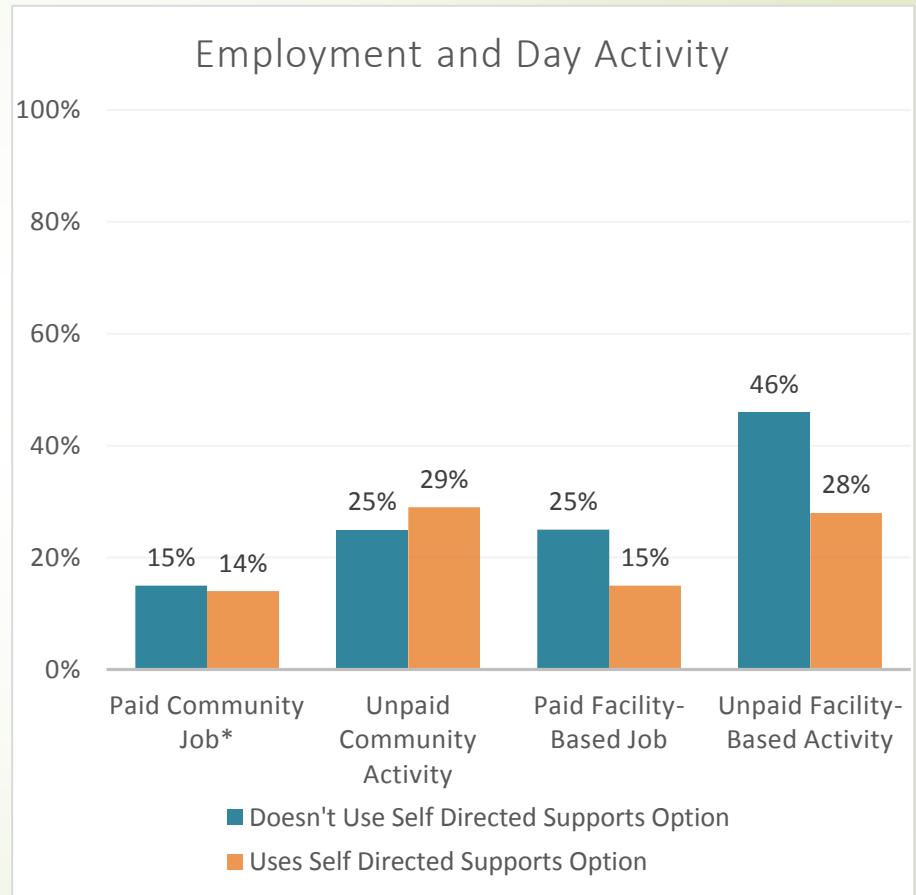
	Institution	Community-based	Independent home/apt	Parents/relatives	Foster care/host home	other
Of those not using self directed supports option...	4%	34%	20%	32%	7%	3%
Of those using self directed supports option....	0%	6%	12%	77%	2%	3%

Home



Work and Day Activity

- Respondents who used self-directed supports options were:
 - ✓ less likely to spend their days in facility-based jobs/activities
 - ✓ more likely to participate in unpaid community activities



*Not significant difference

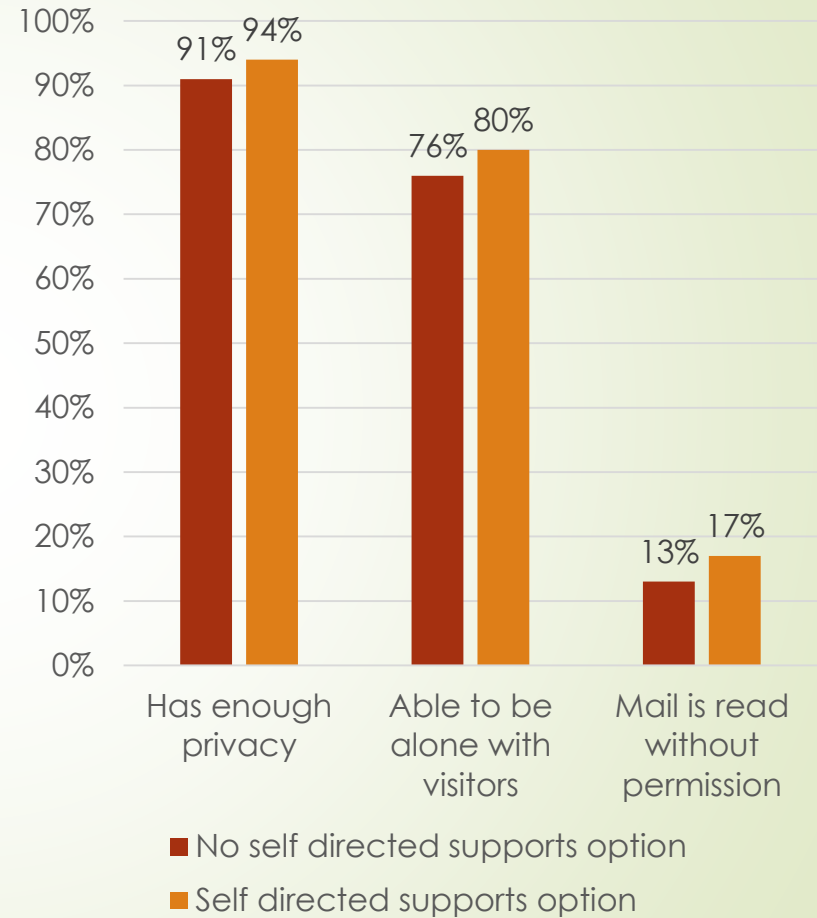
Finding

- Respondents who use self directed supports option were significantly more likely to report having enough privacy at home, and being able to be alone with visitors
- Respondents who use self directed supports option were significantly more likely to report that their mail was read without their permission



Rights and Respect

- Respondents who use self-directed supports option reported higher rates of:
 - Having enough privacy
 - Being able to be alone with visitors
- Respondents who use self-directed supports option reported higher rates of:
 - Mail being read without permission.



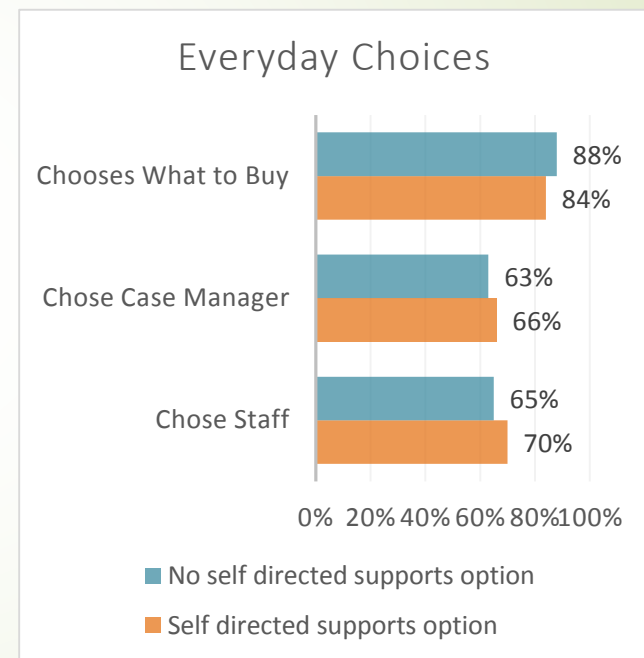
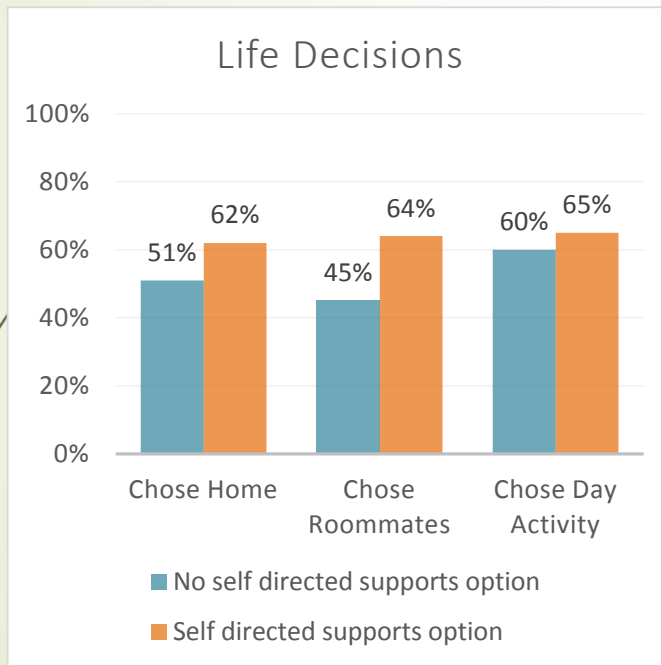
Finding

- Respondents who use self directed supports option have significantly more autonomy in everyday choices and life decisions and reported more close relationships.
- Respondents who use self directed supports option were significantly less likely to report that they have input in what to buy with their money.



Choice

Respondent had at least some input in the following choices:

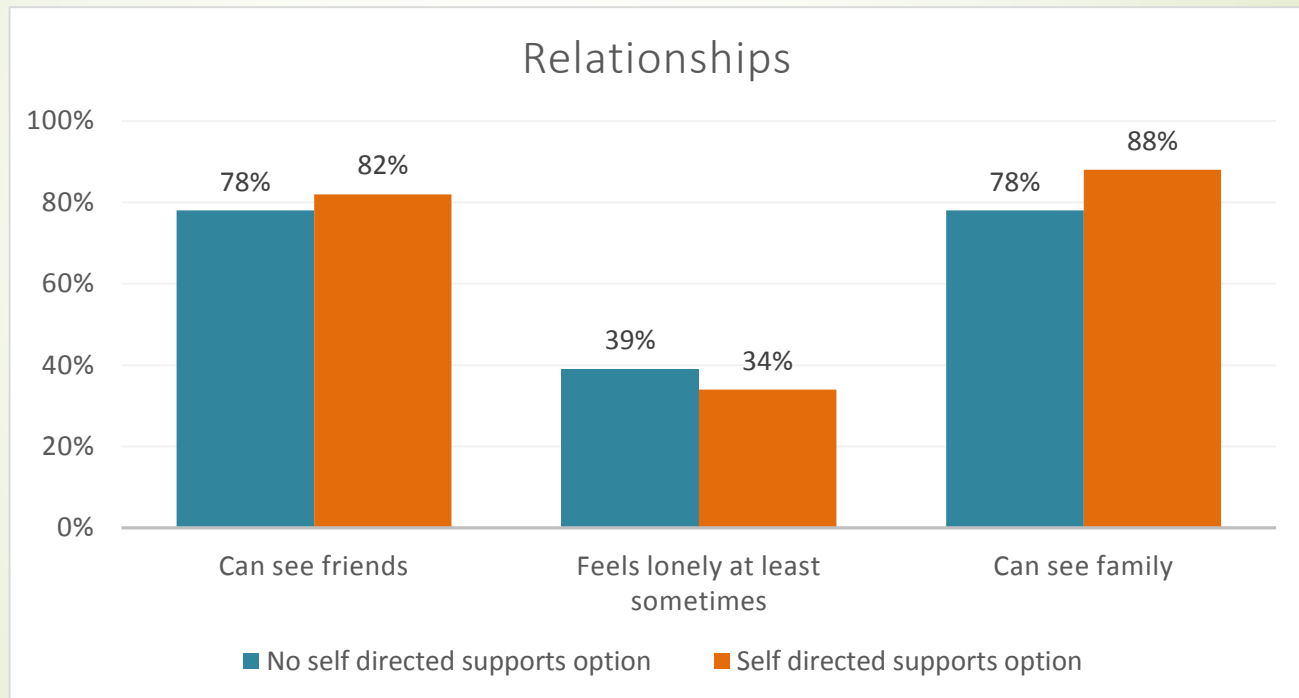


Finding

- ▶ People who use self directed supports option are significantly more likely to report being able to see friends and family and significantly less likely to report feeling lonely sometimes or more often.



Relationships

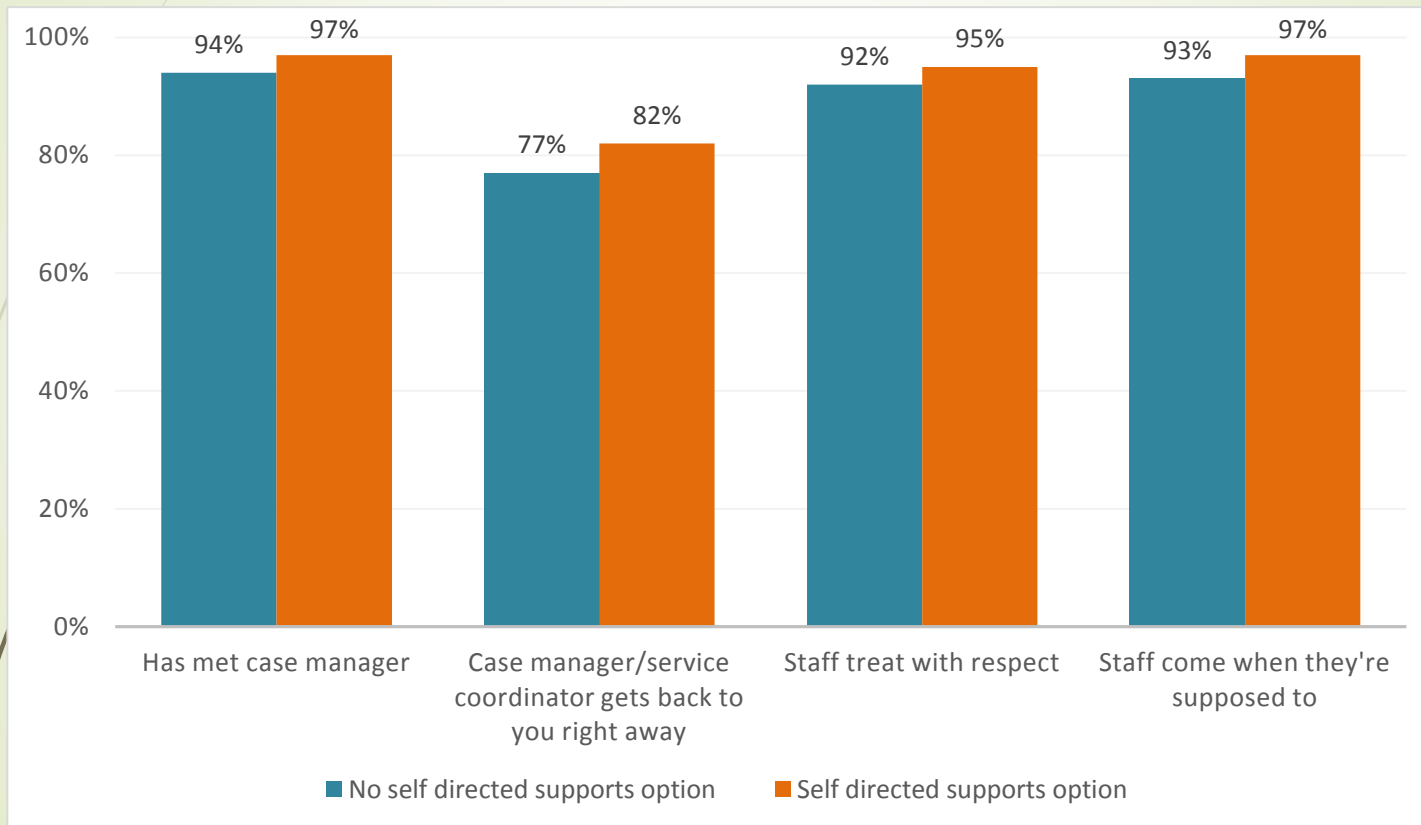


Finding

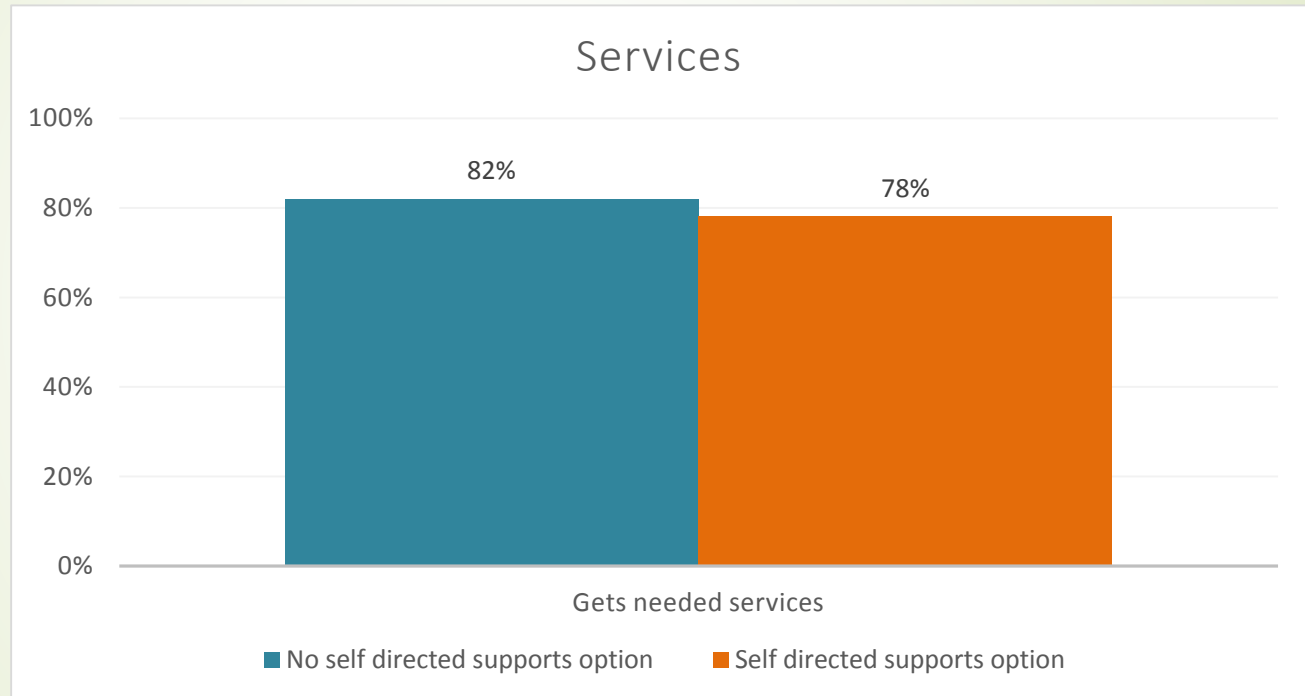
- ▶ Respondents who use self directed supports option were significantly more likely to report having met their case manager, that their case manager gets back to them right away, that their staff treats them with respect and that their staff come when they're supposed to.
- ▶ However, respondents who use self directed supports option were significantly less likely to report that they receive needed services.



Staff



Services



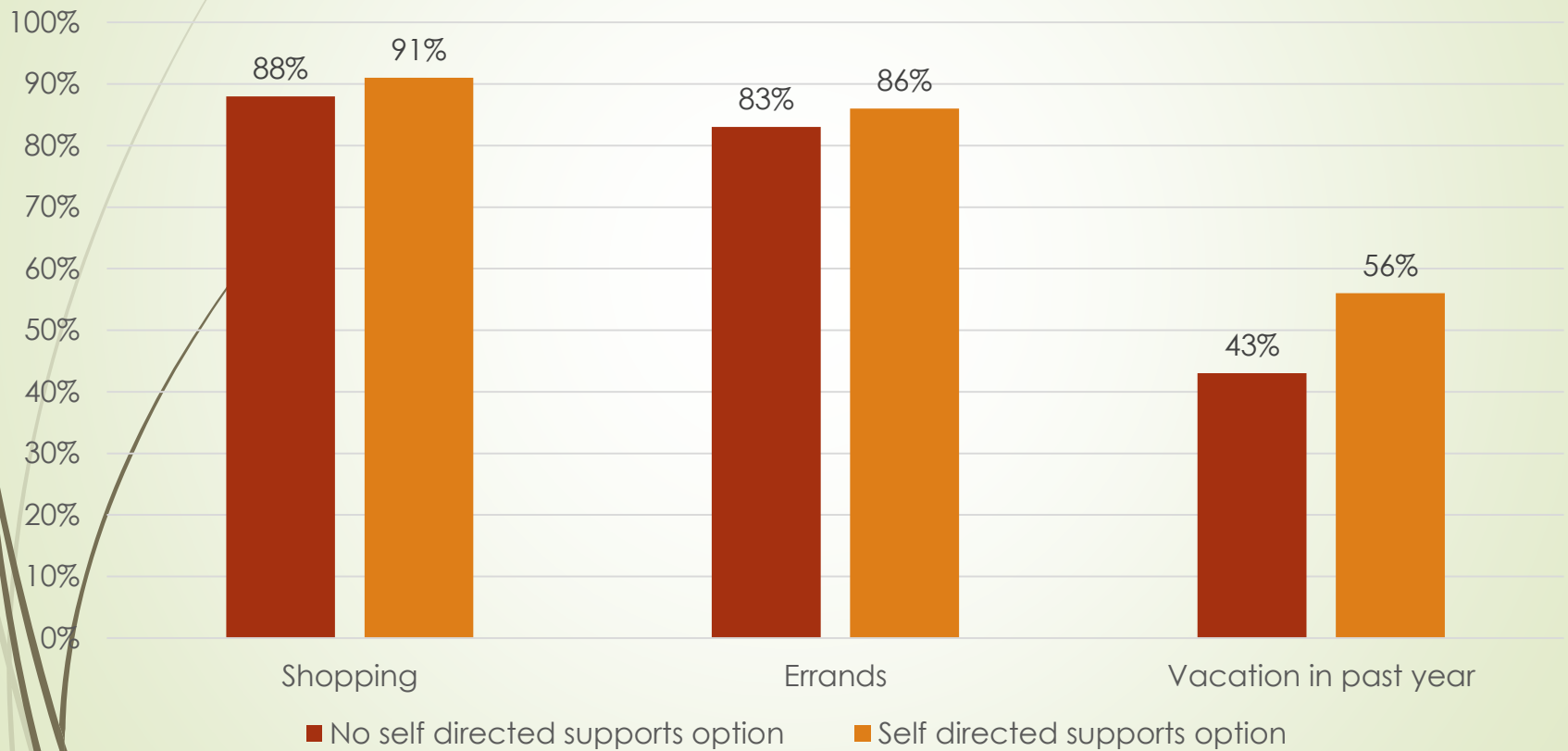
Finding

- ▶ Respondents who use self directed supports option were more likely to go shopping or on errands in the past month and go on vacation in the past year.



Community Inclusion

Community inclusion in past month

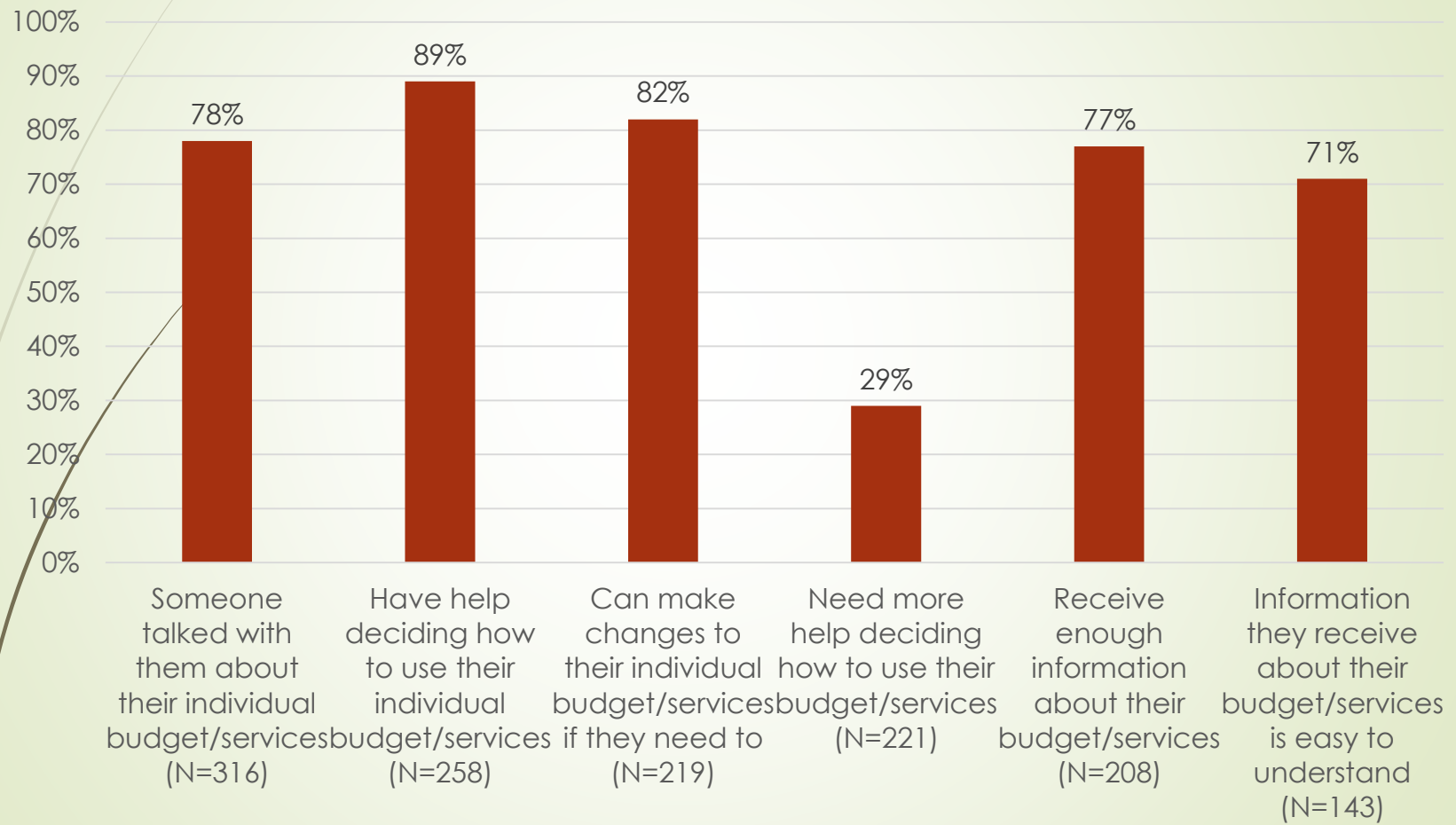


Finding

- ▶ Respondents who commented on the support they receive to self-direct indicate that more help, training and information is needed



Self Determination Section: Section I (no proxy)



Data only analyzed for those respondents who were reported to be using a self-directed supports option in the BI section. States with less than 20 respondents for this section were not included in the NCI average. These percentages are the average of state averages.

Finding

- ▶ Self advocates are voicing concerns about self determination that we heard almost 20 years ago





Notes from a Recent Self-Advocate Discussion of Self-Determination

- Training is needed for service coordinators so they can explain self-direction
- It is not the place of the service coordinator to decide whether self-determination is right for us
- Some service coordinators don't want to do self-determination because it's too complicated
- Need for materials in simple language about self-determination and about budgeting
- Family and other team members should not overshadow the wishes of the individual
- Need to know how to find individuals to work with us



Examples of Self Determination From Other States and Internationally

- Australia
- Scotland
- U.S.

Old System in Australia Compared to the New Individual Choice System

Current State	The NDIS
Individuals receive services from Government and non-government providers	The role of the individual is to exercise choice and control to purchase services that will best meet their needs
Funding envelope currently primarily only captures specialist disability support services	The purchasing of services from non-specialist disability support providers will be within the scope of some reference support packages
The breadth and depth of services is determined by Government	The breadth and depth of services will be driven by market forces and their capacity for participants and suppliers to learn and evolve
A service model with heavy Government intervention	A complex service model with an evidence-based set of tailored intervention approaches that can be applied proportionately to underpin the stability and continuity of the market and ensure that there are adequate opportunities for agents within the market to learn and evolve



Social Care Act in Scotland



- ▶ The Social Care (Self-Directed Support) (Scotland) Act 2013 is an Act of the Scottish Parliament that ensures that local authorities offer self-directed support to anyone who requires support services, including unpaid carers who require support to help them maintain their caring role.
- ▶ Covers all individuals – people with intellectual and developmental disabilities, physical disabilities, people with behavioral health challenges and elders
- ▶ **Duty to have regard to the general principles of collaboration, informed choice and involvement as part of the assessment and the provision of support** (this duty applies with respect to adults, children/families, adult carers and young carers)

Four Options in the Act

The 2013 Act imposes a new duty on the authority to provide 4 options to all adults, children and carers eligible for support or provided with services. The options are intended to support the flexibility and creativity allowed under the social welfare and wellbeing duties relating to both adults and children.

- Option 1: A direct payment
- Option 2: Directing the available support: this option should provide greater transparency and control for the supported person without the requirement to take this support as a direct payment
- Option 3, Services arranged for the person by the authority – this is where the authority arranges any services on the person's behalf.
- Option 4, A mix of the first 3 options for different aspects of the person's support.

JOIN



**Self Directed
Support
In Scotland**

States that Have Made Some Progress on Self Direction

- Wisconsin
- Oregon
- Connecticut
- Ohio
- New Jersey
- Idaho (for kids)
- Georgia has a lot of families that self-direct (but very few individuals)

Some Tentative Lessons



- ▶ Do not make participants pay for support brokering out of their service budget unless all budgets include an increase to cover the costs
- ▶ Separate support brokering and case management—support brokering is a direct hands-on service focused on supporting self-direction, case management carries much broader responsibilities
- ▶ It is fine to include “traditional” services under *budget authority*—but not “true” self-direction. You cannot self-direct provider controlled service, nor can you really self-direct professionals such as nurses, PTs, etc.—they set their own treatment plans and direct their own work...

Some Tentative Lessons

- Do not have more than two fiscal intermediaries and do not offer FI as a waiver service as you do not want freedom of choice nor multiple FIs—it should be an administrative functions – with new labor regulations, may only want one
- Provide continual education on what it means to self direct to participants, families, support brokers, administrative staff
- Make sure that self-direction is available to people with less education and income and time to master the complexities
- **Listen to self-advocates and families!!!!!!**



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