# Empowering Choice: Exploring Self-Direction Experiences and Outcomes among National Core Indicators Respondents


Human Services Research Institute

National Association of State Directors of Developmental Disabilities Services

ADvancing States

Applied Self-Direction

State of Wisconsin


# Speakers

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National Association of State Directors of Developmental Disabilities Services

ADVANCING STATES

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# Webinar logistics

- Participants will be muted during this webinar. Please use the Q&A feature in Zoom to ask questions and communicate via chat with the hosts.
- Toward the end of the webinar, panelists will have an opportunity to respond to questions that have been entered in the Q&A.
- The webinar will be live captioned in English and live interpreted in Spanish and ASL.
  - Live English captions can be accessed by clicking the “CC” button at the bottom of your Zoom screen
  - Live Spanish interpretation can be accessed by clicking the “interpretation” button at the bottom of your Zoom screen (world icon). Once in the Spanish channel, please silence the original audio
  - Se puede acceder a la interpretación en español en vivo hacienda clic en el botón “interpretation” en la parte inferior de la pantalla de Zoom (icono del mundo). Una vez en el canal español, por favor silencie el audio original.
- Due to a recent Zoom update, full accessibility (including ASL interpretation) may not work if you are joining with a mobile device, and slides can no longer be viewed simultaneously via phone or tablet. Swipe on your mobile device to find the ASL interpreter if you need to.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.
- The webinar will be recorded and posted to YouTube at a later date, and slides will be available on our website.

# Sarah Taub

Sarah Taub was the National Core Indicators Director until 2013 when her life what cut short by an aggressive cancer.

Her sense of mission and purpose was an essential part of the growth of NCI to the prominence it has today.

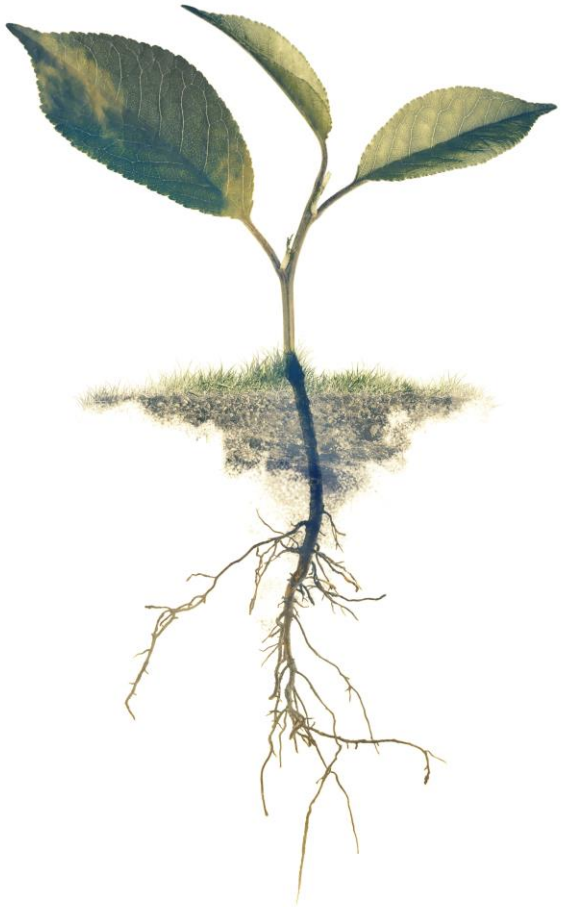
She was a fierce advocate for people with disabilities, and for their representation at all levels in the work we do. She never let us forget the people behind the numbers.

# Webinar Objectives

- **Increase knowledge about self-direction** and the experience of self-direction
- **Share best practices** around supporting people who are self-directing and expanding the use of self-direction
- **Demonstrate what NCI data show** regarding the characteristics of people self-directing and their outcomes
- **Identify areas where additional data collection** on self-direction is needed

# Polls: Who's in the audience?
# How would you rate your knowledge of self-direction?

# Self-Direction: Overview and History



# Traditional service delivery vs. Self-direction

## Traditional Model

- Public funds go to a provider
- Services driven by case manager and provider

## Self-direction Model

- Public funds go to an individual's service budget
- Services driven by individual to spend on staff, goods, and services

# The Promise of Self-Direction: Empowering Choice

- Self-direction is part of the larger **human right to self-determination** that asserts all people should have control to make choices about their own lives
- Self-direction reflects the promise of self-determination by putting the **power in the hands of people needing supports** to design and purchase services and supports that most closely aligns with their exercise of self-determination.

# Self-Direction Timeline

**1953:** Attendant Care program began in California for polio survivors

**Early 1980s:** States like MA and CA develop self-directed attendant care for people with physical disabilities

**1995**: Cash and Counseling initiated by ASPE and supported by RWJF

**1997:** RWJF launches self-direction pilots for people with IDD in 19 states

**2003:** Self-direction becomes a service option for multiple groups through HCBS waivers

**2023:** 260 self-direction programs across the country serving a total of 1,520,267 individuals

# Variations in State Approaches to Self-Direction

- Service Brokerage/Case Management – Some states use traditional state case managers, some states contract with private non-profits service brokerage agencies
- Independent Facilitation – Some states allow participants to purchase "personal agents" whose services may or not be deducted from their budgets
- Supports Menu – States vary in the services, supports, and goods and services that people can purchase with their individual budgets
- Populations Served – States vary in the types of groups that have the opportunity to self-direct
- Funding Authorities – States use a range of funding authorities to support self-direction including 1915c, k, and I; Older Americans Act, and state general fund. Veterans can self-direct through Veteran Directed Care

# Applied Self-Direction

- Mission-driven organization advancing self-direction across the U.S. since 2015
- A national hub providing technical assistance, training, and community-building
- Stakeholders served include State Agencies, FMS providers, MCOs, Participant & Advocacy Groups, Support Brokers, and more

**www.appliedselfdirection.com**

# Background & Context

**Purpose of the Self-Direction National Inventory**

- To provide an overview of all publicly funded self-directed LTSS nationwide

**History of the Inventory**

- Previous Inventories were completed in 2011, 2013, 2016, & 2019

**What is notable about 2023?**

- The first Inventory conducted since the COVID pandemic emerged in 2020
- Coincided with a huge wave of new interest in self-direction at the participant and program level
- While the number of people self-directing has grown in every Inventory, there was a sharper rate of enrollment growth in 2023
- States were now implementing more new programs and program expansions than at any point in the previous decade

# Methods

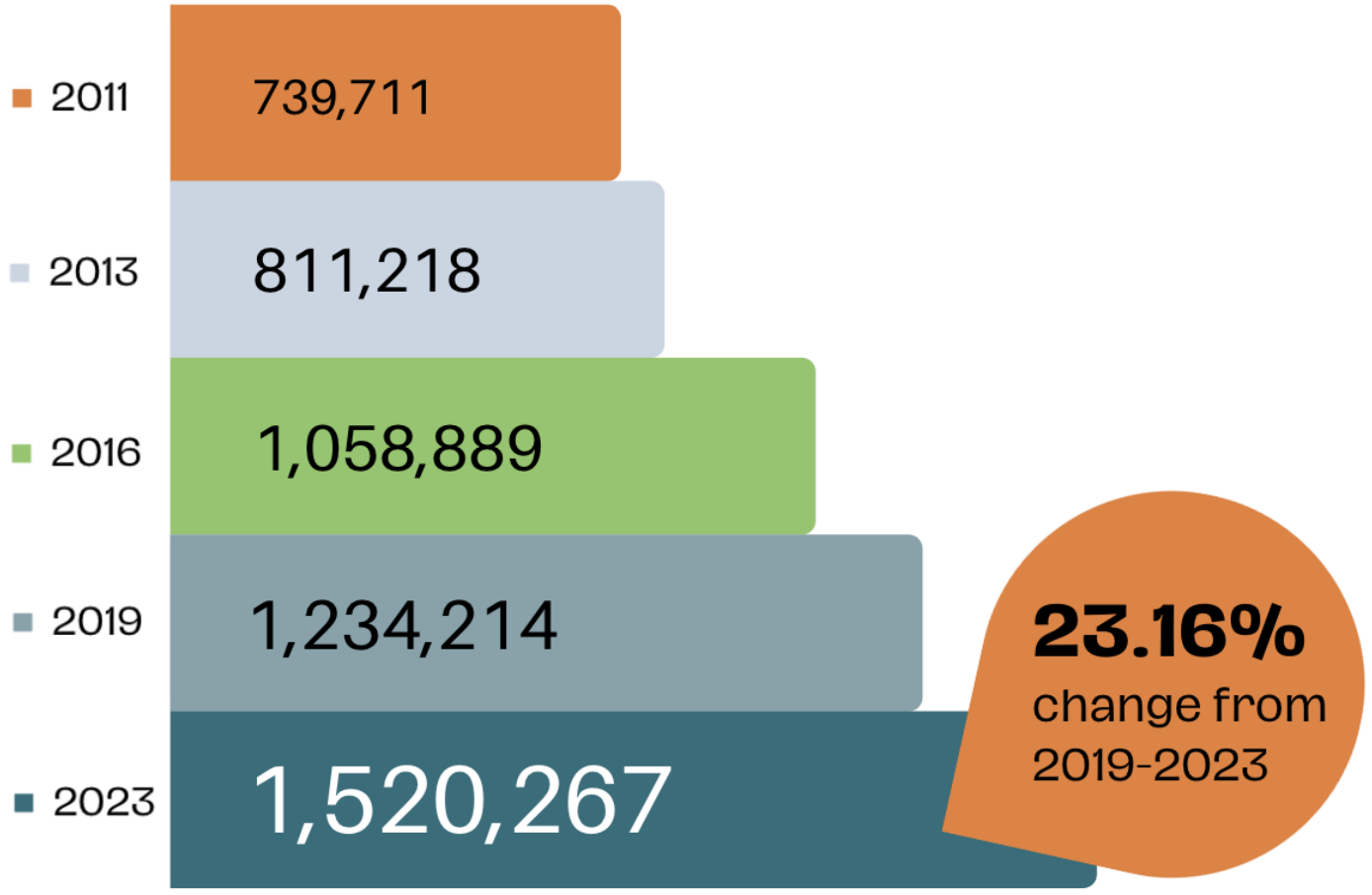
- Program data were collected from October 2022 through February 2023
- Data collection process included the following steps:

1. Comprehensive review of publicly available information via state Medicaid waiver applications, Medicaid state plan documentation, and state websites across all 50 states and DC.
2. Conducted 65 interviews with state staff from 43 states and had correspondence with administrators in every state.
3. In a few cases when enrollment data was not available from state administrators, program data was provided by FMS entities or we used enrollment estimates from Medicaid documentation
4. Enrollment findings were shared with ASD state and FMS members for final review

# Self-Direction Enrollment (1/2)

**Self-direction enrollment increased by 23% from 2019 to 2023**

- 1,520,267 people self-directing nationwide
- By comparison, enrollment grew by 17% from 2016 to 2019



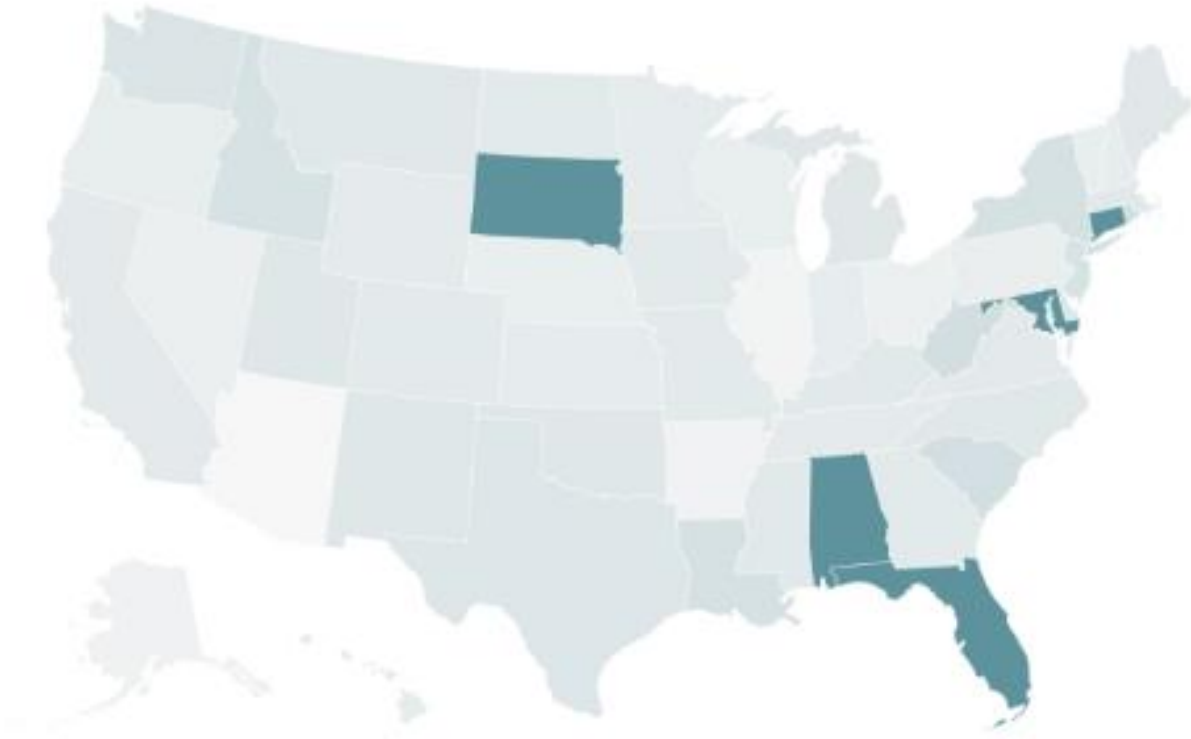
# Self-Direction Enrollment (2/2)

**State-by-state self-direction enrollment**

- Most states (44) reported an increase in SD enrollment
- A few states (7) reported a decrease
- California continues to account for a significant share (48%) of total national enrollment, but this percentage continues to trend downward since 2011

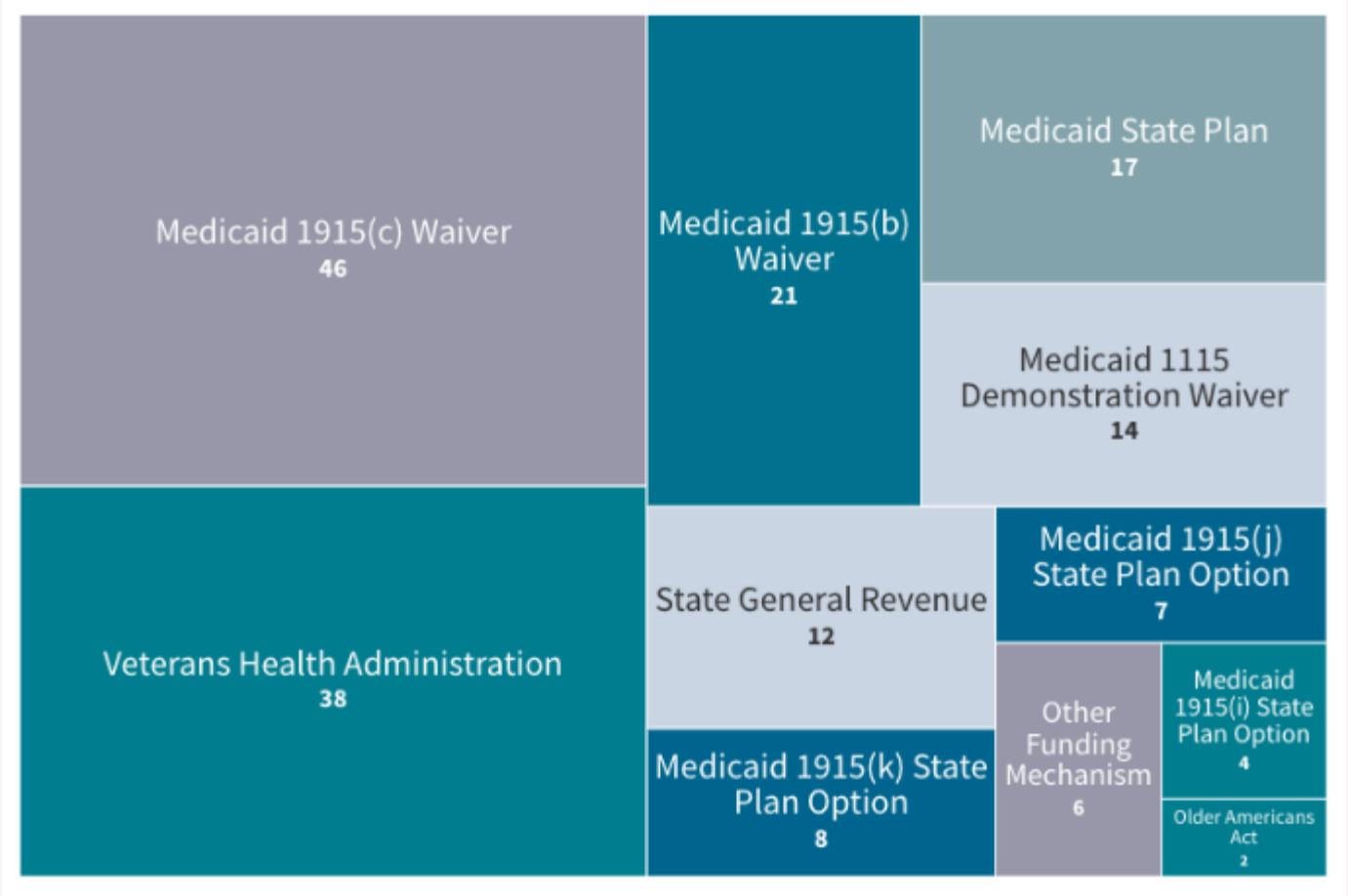
**Notably, six states have more than doubled self-direction enrollment since 2019**

- Alabama
- Connecticut
- District of Columbia
- Florida
- Maryland
- South Dakota



# Self-Direction Funding Sources

The Medicaid 1915(c) waiver is the most frequently used funding source for self-direction, and the adoption of additional Medicaid authorities is growing.



# Spotlight on Veteran-Directed Care (1/2)

The Enrollment in Veteran Directed Care (VDC) has increased significantly.

‘19

**2,353**

33 Veterans per site

**157%**
change from 2019-2023

‘22

**6,041**

88 Veterans per site

# Spotlight on Veteran-Directed Care (2/2)

**Opportunities for major growth:**

- The Veterans Health Administration has committed to expanding VDC to every Veterans Affairs Medical Center (VAMC) by the end of fiscal year 2026
- Elizabeth Dole Home and Community-Based Services for Veterans and Caregivers Act was signed into law on January 2, 2025

# Availability of Self-Direction by Population

- Almost all states provide at least one Medicaid-funded self-direction offering for adults over age 65, adults with physical disabilities, and adults with intellectual and developmental disabilities.
  - Self-direction is less widely available for other populations (e.g., people with behavioral health needs; children who are medically fragile)
  - In general, though, states are signaling more interest in expanding self-directed options to these populations

# Impact of the COVID Pandemic

**The pandemic accelerated the expansion of self-direction nationwide**

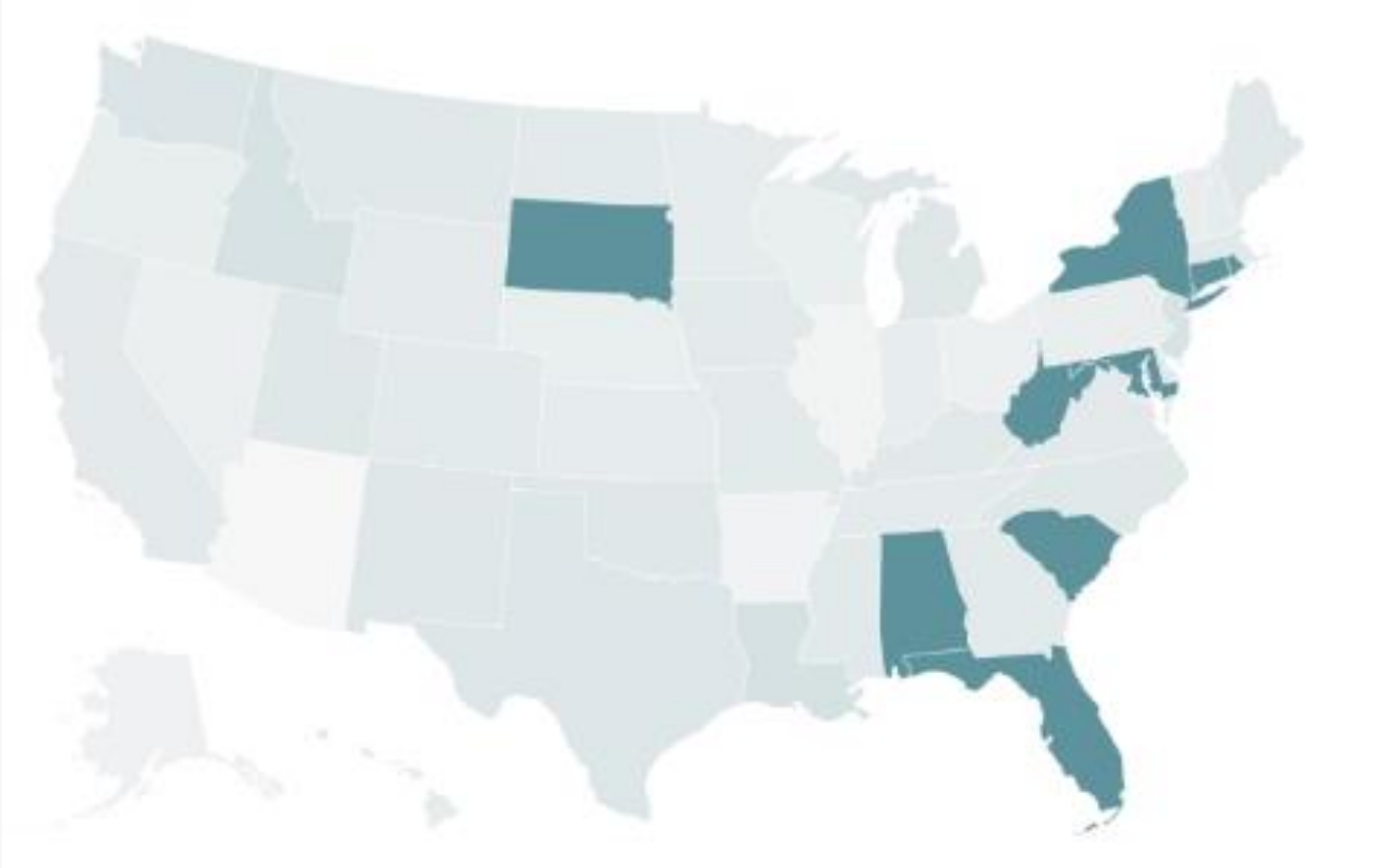
A majority of states created a **temporary emergency option via Appendix K** to allow legally responsible individuals, such as spouses and parents of minor children, to serve as paid caregivers, in addition to other options to expand family caregiving.

States reported that **self-direction was critical in filling a void** left by the widespread closure of day services across the country.

The pandemic **galvanized federal investment** in Medicaid, and particularly HCBS

# Importance of Budget Authority

States that demonstrated the greatest growth in Medicaid-funded enrollment tend to offer budget authority, in addition to employer authority



# More Sophisticated Funding Structures

- As self-direction is made more widely available, it is becoming more deeply embedded within a complex array of Medicaid authorities.
  - States are now including self-direction as an option within an ever-greater number of Medicaid authorities
  - Depending on the state, participants may self-direct through multiple programs (e.g., a 1915(c) waiver and state plan personal care) at once
  - Participants are increasingly given the option to select their preferred mix of traditional and self-directed services.

# Self-Direction Workforce

**Impact of workforce shortages on self-direction**

- Several states reported that self-direction mitigated workforce shortages, though in many states self-direction was impacted by the direct care workforce crisis.

**Recommendations for Future Research**

- The impact of increased wages and benefits
- The impact of paid family caregiving
- The impact of budget authority

**More Data is Needed**

- Requirements in FMS contracts to collect key data and metrics on the self-direction workforce

# Interviews with state administrators suggest more research is needed to examine:

How worsening workforce shortages have impacted reliance on self-direction and family caregiving

How self-direction can scale to support historically marginalized and underserved communities

Levels of unmet need among people who self-direct vs. people who use traditional services

Whether EVV and/or cumbersome enrollment processes have been driving factors on enrollment in states reporting a decline

# What do NCI Data Reveal?

## A national look at self-direction outcomes

# National Core Indicators (NCI)

NCI tools collect data on performance and quality of life indicators directly from:

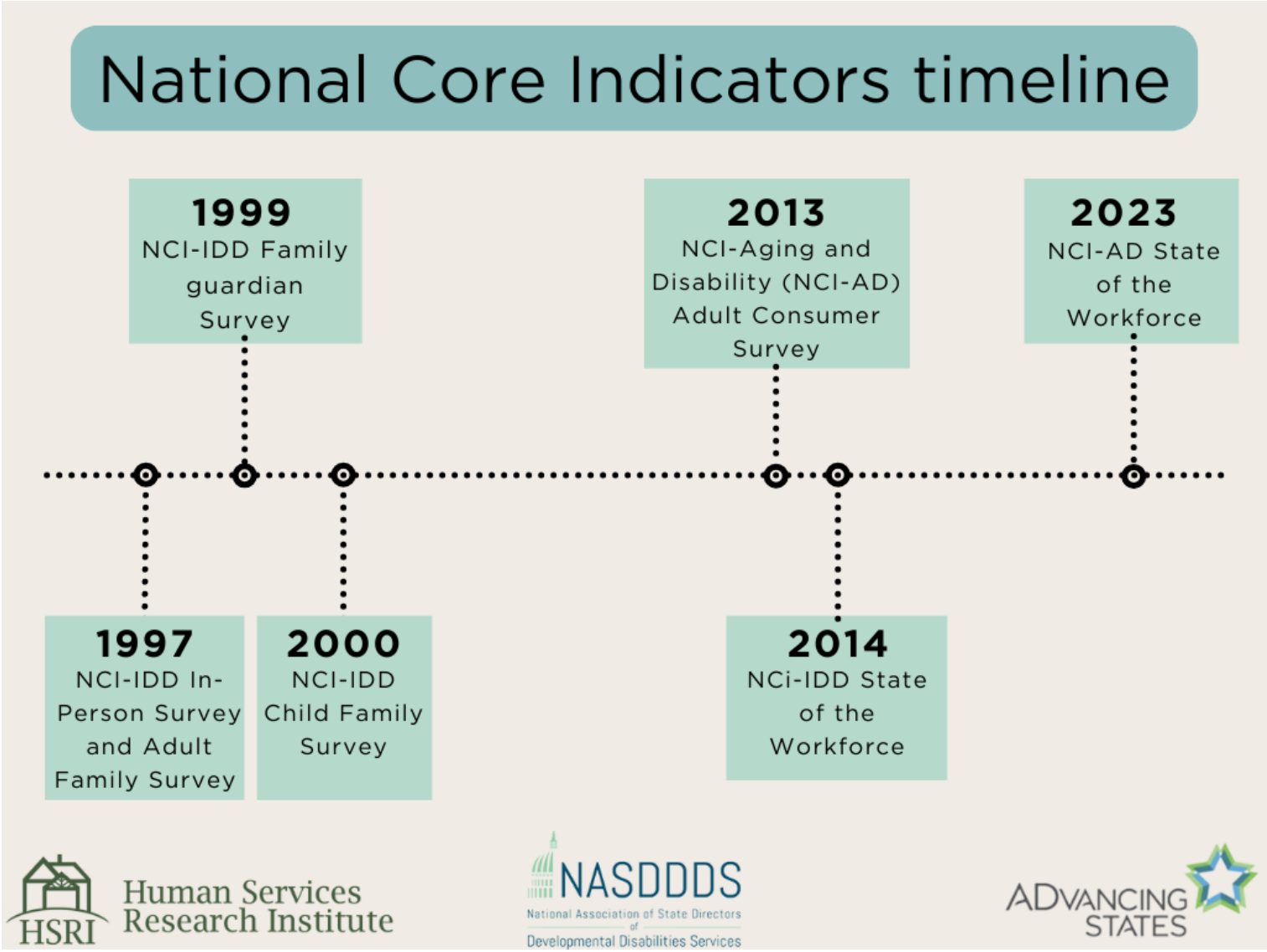
(1) people who use disability and/or aging services systems;

(2) families; and

(3) those who deliver services

Participating states:

- NCI-IDD IPS and Family Surveys: 48
- NCI-AD: 26
- State of the Workforce: 30 states for the NCI-IDD SoTW, and 5 states for NCI-AD SoTW



# Goals of NCI

Establish a **nationally recognized set of performance and outcome indicators** for aging & disability (including IDD) service systems

Use **valid and reliable** data collection methods & statistical techniques to capture information directly for people who use services

Report individual state results and **national benchmarks** of indicators of system-level performance

# NCI-IDD In-Person Survey (IPS) and NCI-AD Adult Consumer Survey

***Sampling:*** **States design their samples with guidance from HSRI. Final samples must reach threshold of 95% confidence level and 5% margin of error based on sample frame.**

***Inclusion criteria:***

- AD: Person receiving one "active service" at least twice a week
- IDD: Person receiving at least one service in addition to case management

***Consent:*** **Surveyors follow state specific consent requirements**

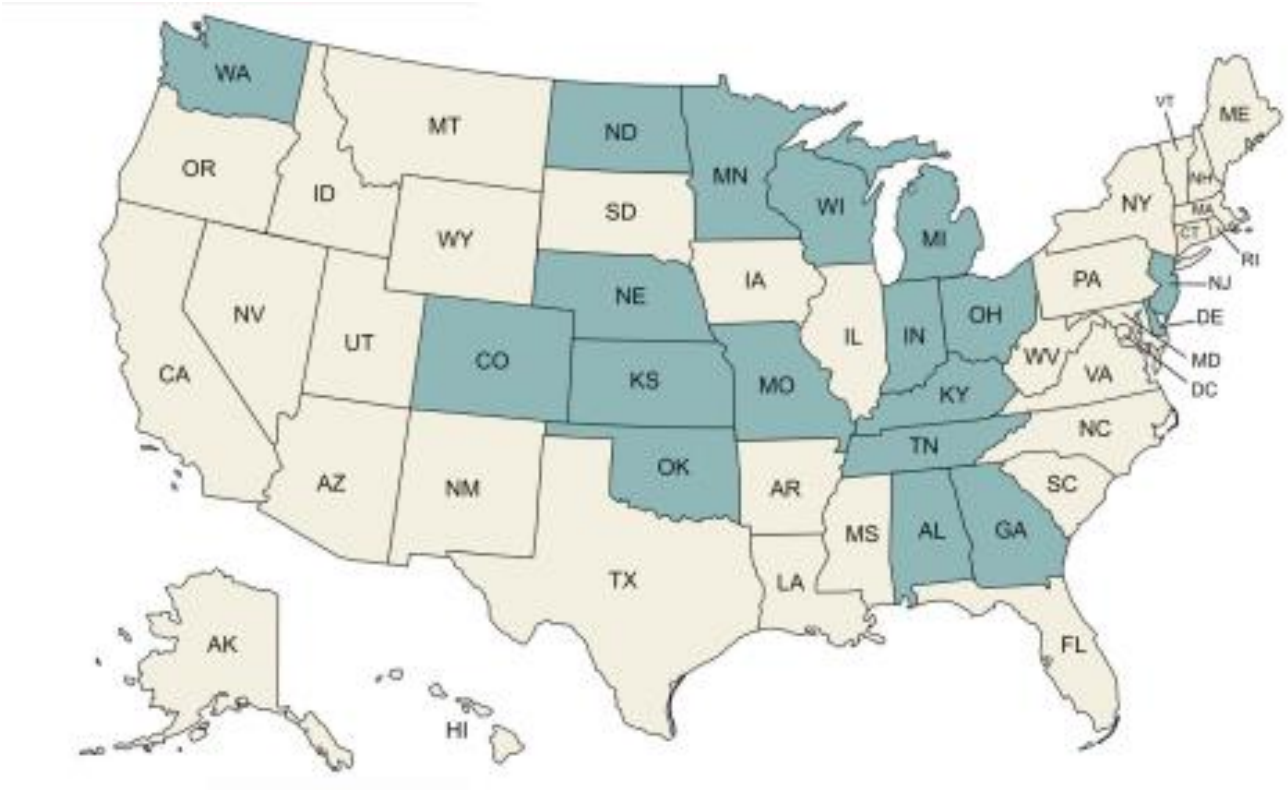
- Those who are surveyed are informed that their services will not be impacted directly by their responses

***Surveyor training:*** **All surveyors complete standardized training. IPS uses peer-surveyors as well.**

***Survey features:***

- May be conducted in-person or remotely
- Includes detailed Background Information section that primarily comes from existing records
- Surveys are available in multiple languages
- Questions may be rephrased or reworded
- Allows for use of proxy for select questions

# 2022-2023 NCI-AD Sample




**15,455 total respondents**

**18 states**

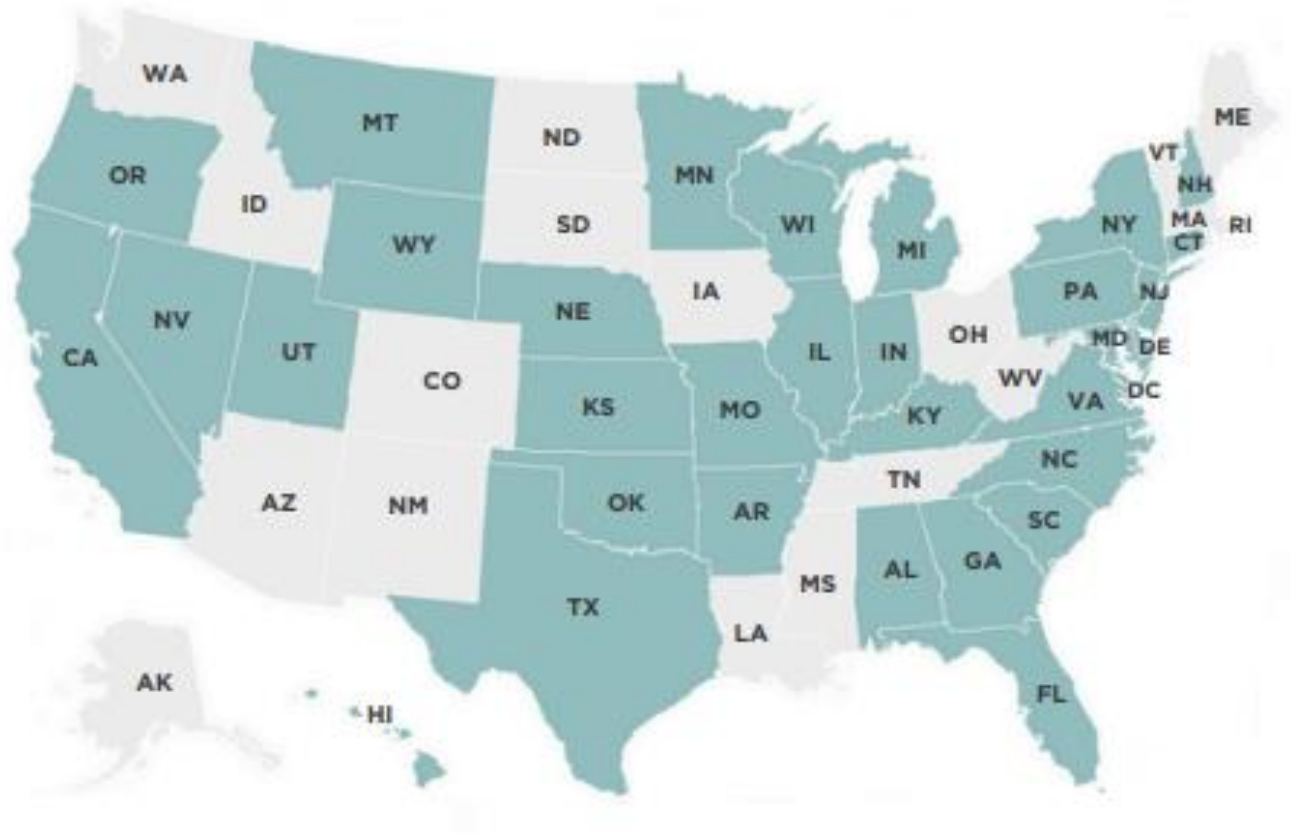
- **34% male**
- **Average age: 67**
- **Race/ethnicity**
  - *65% White; 24% Black; 4% Latino*
- **Diagnosis**
  - *6% ID; 11% TBI; 14% Alzheimer's/Dementia; 63% Physical Disability*

# 2022-2023 NCI-IDD Sample

**25,424** total respondents

33 states

- 60% male
- Average age 40
- Race/ethnicity
  - *63% White; 17% Black; 14% Latino*
- Diagnosis
  - *84% ID; 31% ASD*



# Using NCI data for advocacy: The exit ramp

NCI data can reveal patterns and trends, but it doesn't necessarily tell you:

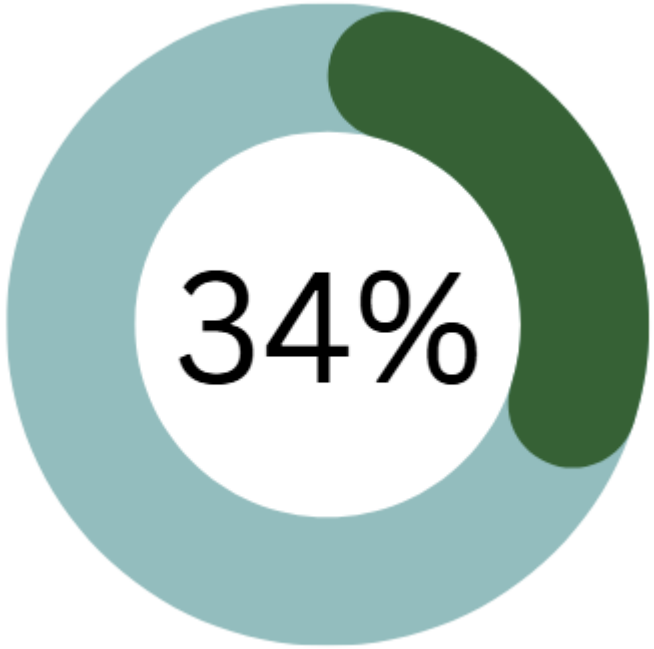
- The root cause(s)
- The right solution(s)

NCI data should be used to start a conversation about the possible root causes of patterns to be sure to consider the various solutions to improve systems.

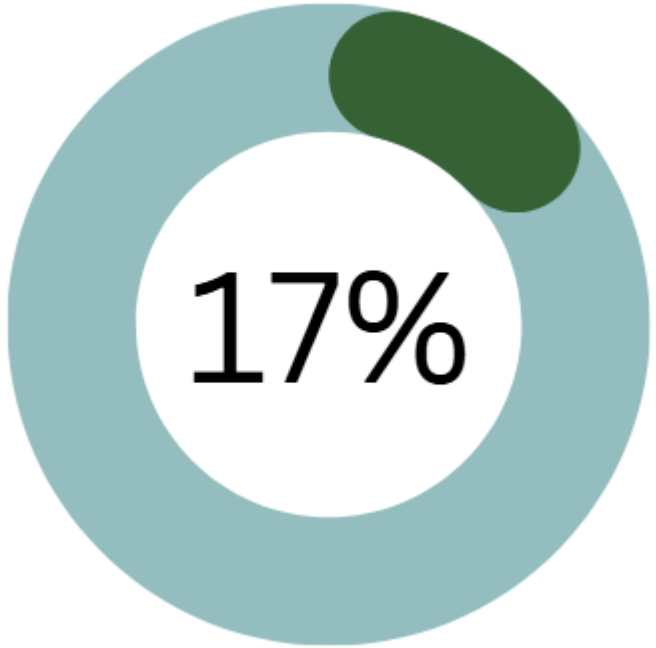
# Who uses self-directed supports?

# The use of self-directed supports among NCI respondents is limited and impacted by sample design

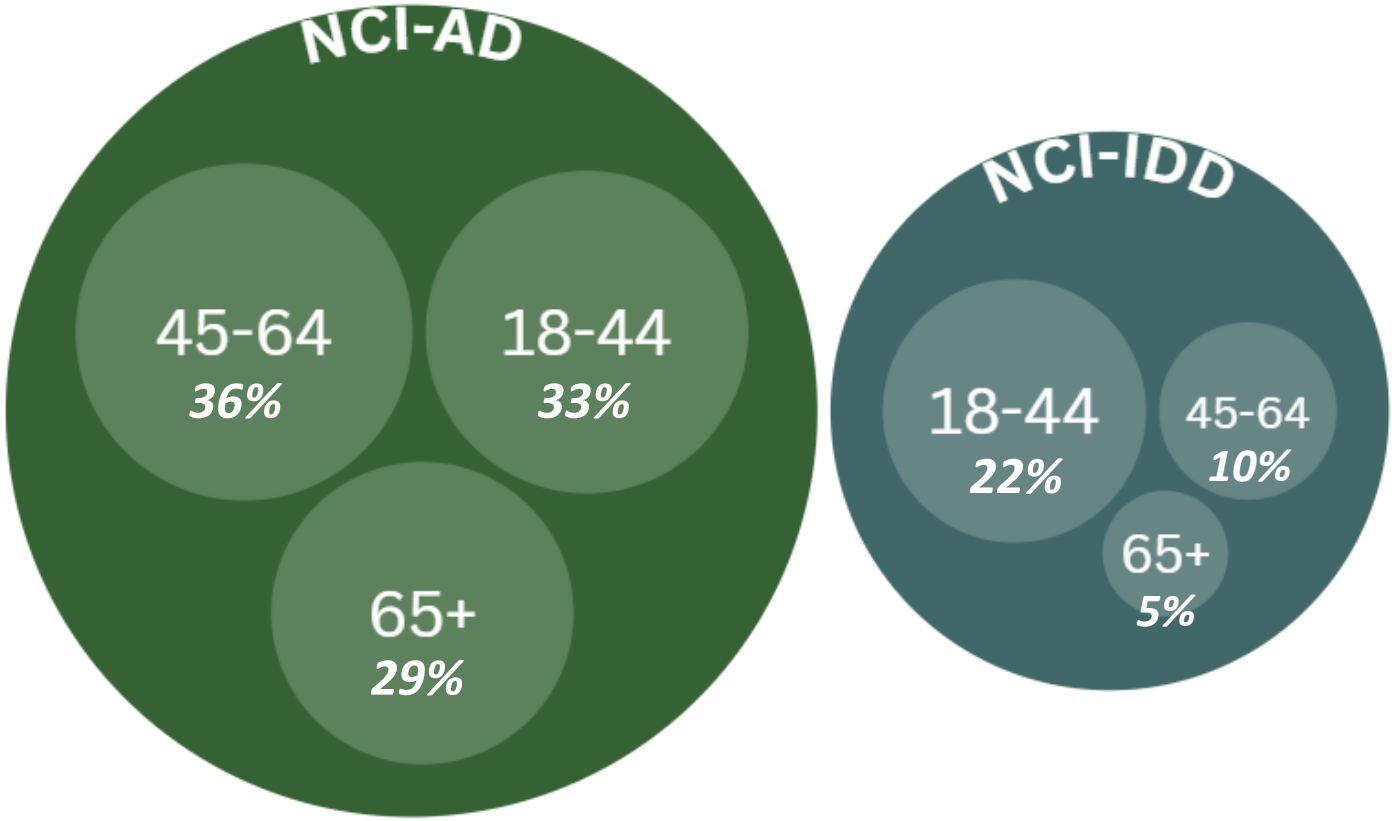
**About 1 in 3 NCI-AD respondents use self-directed supports**




**Fewer than 1 in 5 NCI-IDD respondents use self-directed supports**



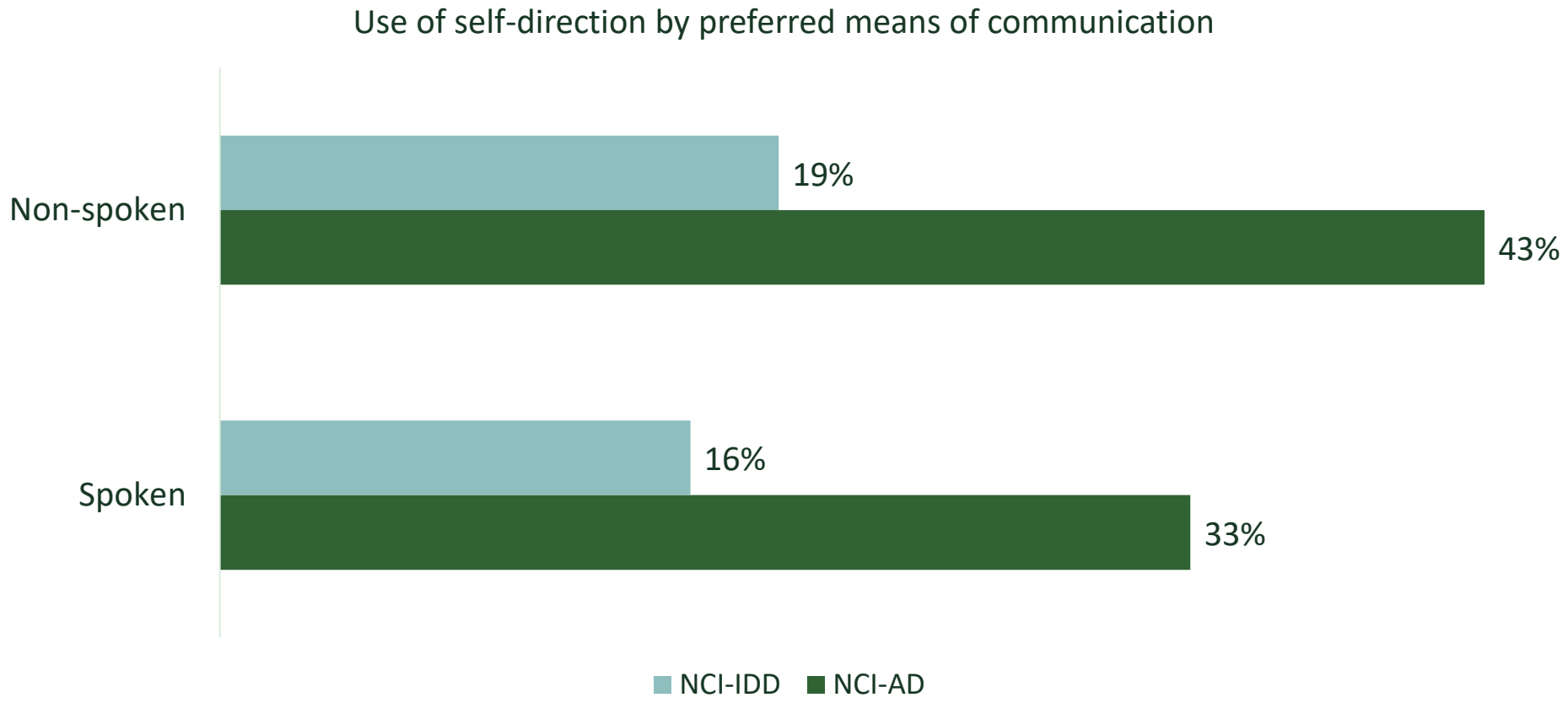
# Demographics of People Who Use Self-Directed Supports: Age



# Demographics of People Who Use Self-Directed Supports: Race and Ethnicity

| Race/Ethnicity | NCI-AD 2022-23 | NCI-IDD 2022-23 |
|---|---|---|
| American Indian/Alaska Native | 44% | 22% |
| Asian | 46% | 16% |
| Black | 32% | 12% |
| Pacific Islander | 41% | 20% |
| White | 33% | 19% |
| Hispanic | 40% | 9% |
| Other | 20% | 16% |

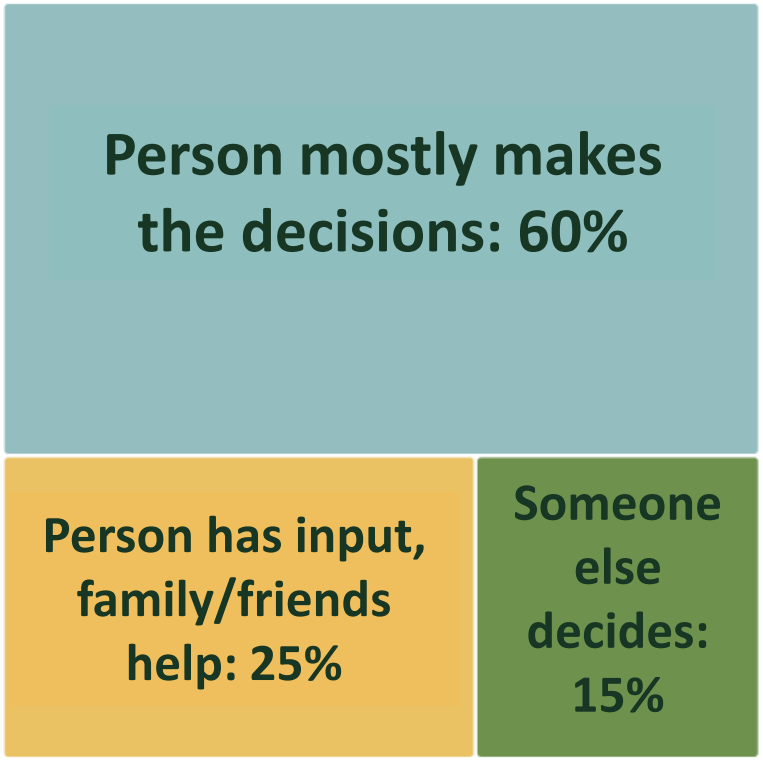
# Those who prefer non-spoken means of communication have higher rates of self-direction in both the NCI-AD and NCI-IDD



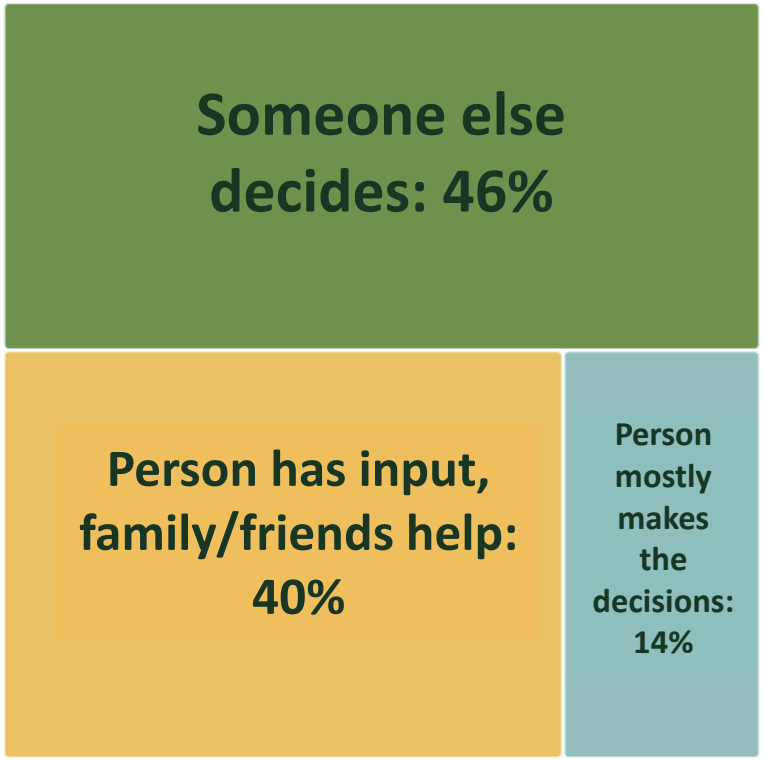
# What is the experience of self-direction?

# Not all people who use self-directed supports make the decisions about the services that are self-directed

## NCI-AD




## NCI-IDD



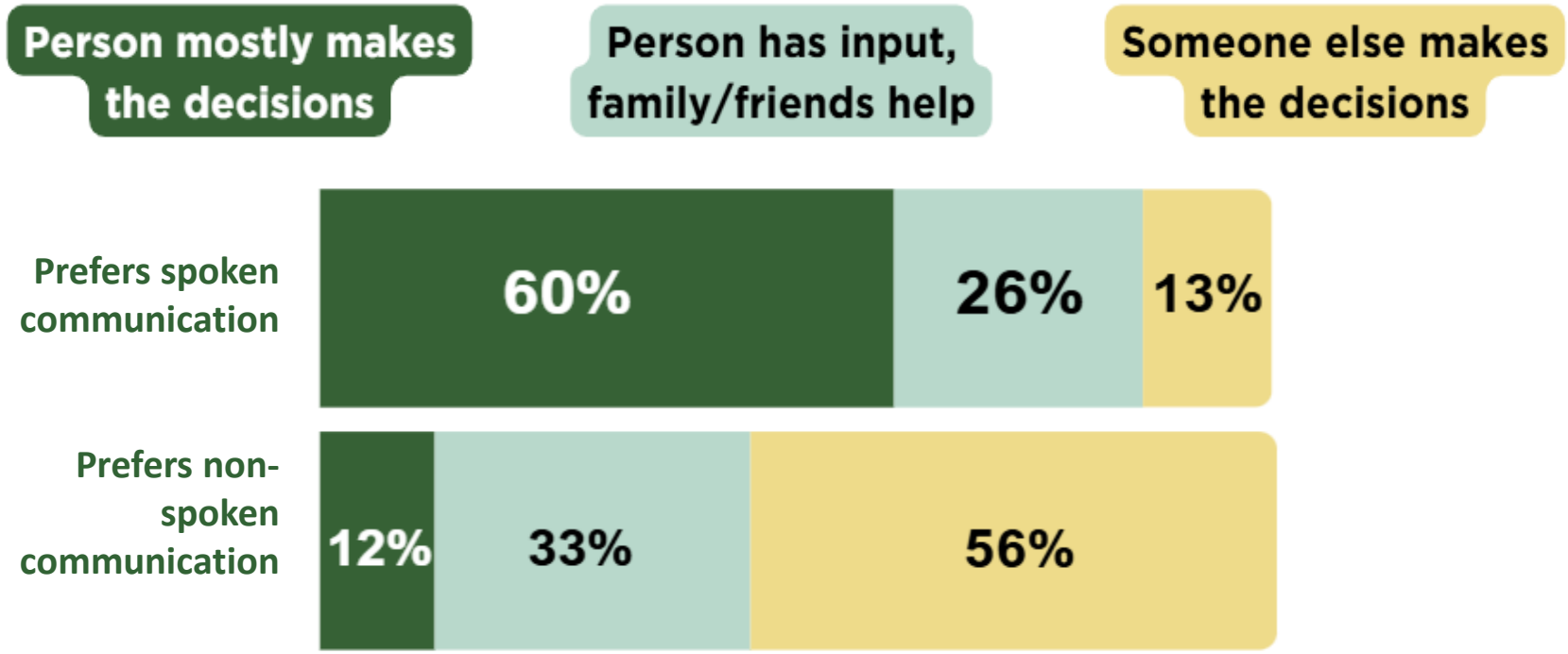
# NCI Respondents Experiences with Self-Directed Supports

| | NCI-AD 2022-23 | NCI-IDD 2022-23 |
|---|---|---|
| Person has enough help deciding how to direct their services | **94%** | **85%** |
| Person can make changes to the services and support they self-directed if needed | **94%** | **90%** |
| Person has amount of control they want with the services they self-direct | **91%** | **84%** |
| The services and supports the person wants to self-direct are always available | **78%** | **65%** |
| The person needs help with at least one part of self-direction (e.g., getting staff paid, finding or keeping staff, managing benefits for staff) | **34%** | **49%** |

# People who prefer non-spoken means of communication are less likely to make or have input on self-direction decisions

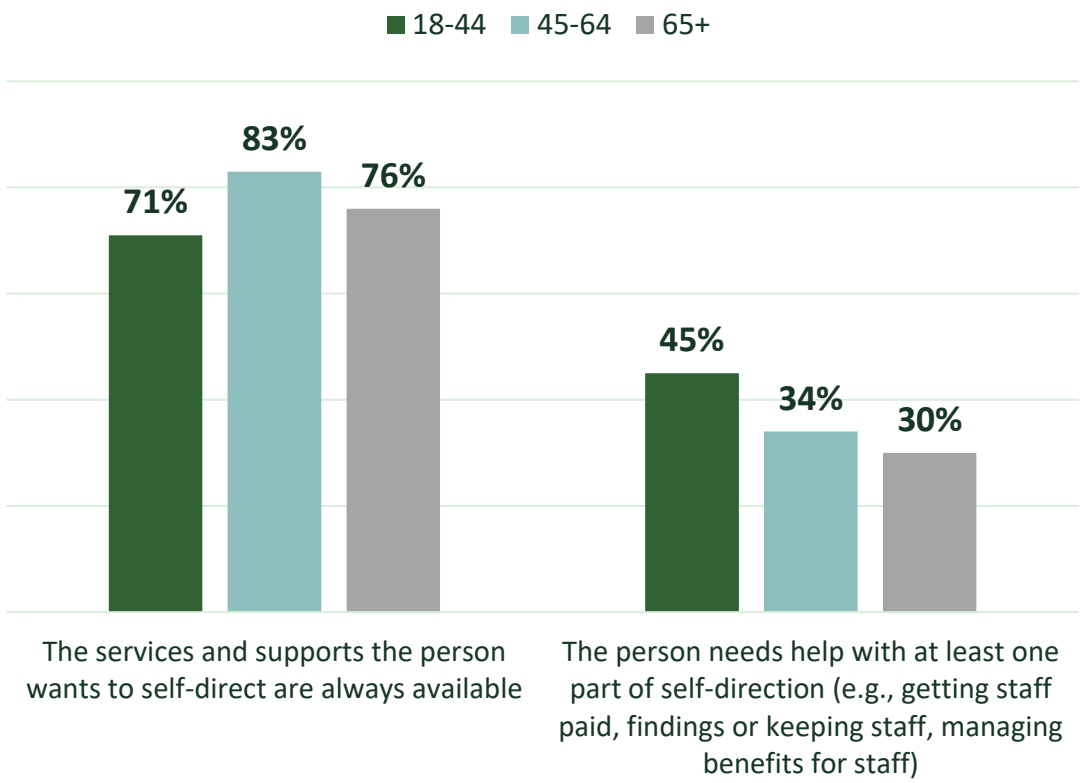
- We see **significant differences for both the NCI-AD and NCI-IDD population** on several self-direction experience measures related to choice and decision-making
- People who use sign language, gestures, or communication devices may use family, friends, and staff to help interpret their communication. There are still many people who prefer non-spoken means of communication who report that someone else makes decisions for them.
- To ensure that people who prefer non-spoken means of communication have the same opportunities to make choices about their services, additional supports may be needed to facilitate decision-making. For example:
    - Staff training
    - Person-centered service planning meeting requirements

# Experience of self-direction by preferred means of communication among NCI-AD respondents

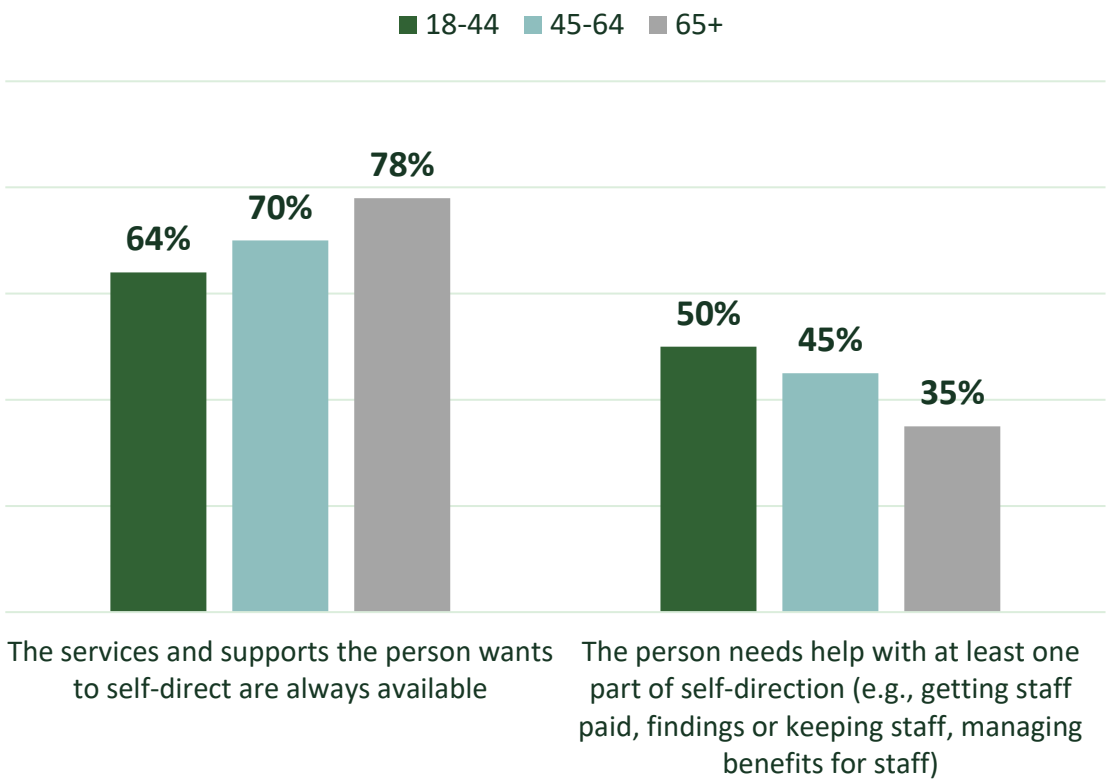


# Experience of self-direction by age group

## NCI-AD




## NCI-IDD



# Self-Direction in Wisconsin

Christian Moran and Alicia Boehme
Wisconsin Division of Medicaid Services
January 29, 2025

# Overview

Today we will cover:

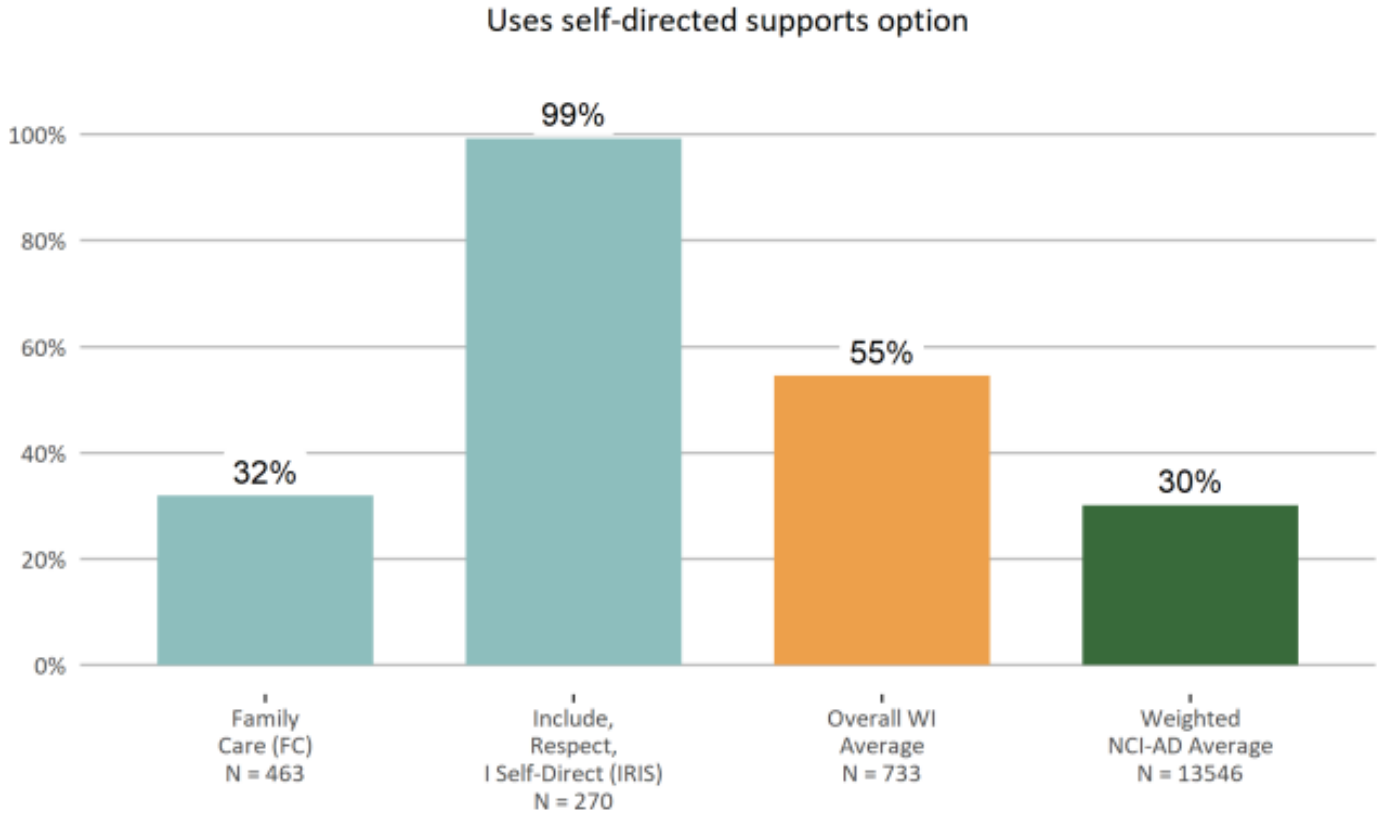
1. Wisconsin long-term care waiver program landscape
2. IRIS self-direction program overview
3. How Medicaid collaborates with participants, families, advocates, providers and partners
4. Opportunities to improve growth and access to quality
5. In hindsight

# WI LTC Waiver Enrollment

**Family Care = 53,070**
- I/DD= 24,559
- Physical Disability = 8,872
- Older Adults = 19,729

**IRIS = 26,923**
- I/DD= 10,800
- Physical Disability = 9,633
- Older Adults = 6,490

**Partnership = 3,362**
- I/DD= 1,093
- Physical Disability = 991
- Older Adults = 1,278




2022-23 NCI AD Report

# IRIS Program Overview

- History
  - Include, Respect, I Self-Direct
  - July 1, 2008
  - Program for 18+

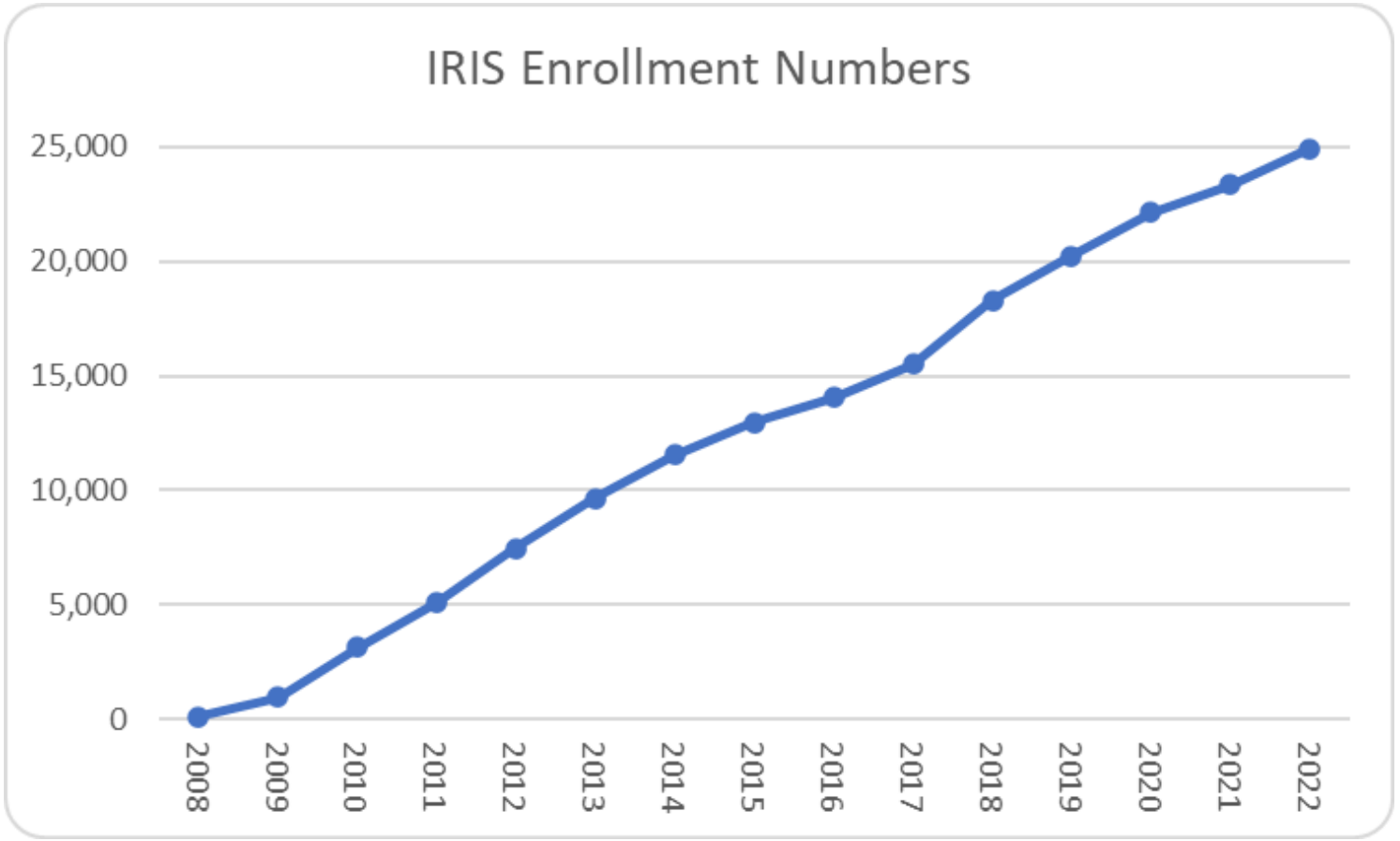
- Current Facts
  - Enrollment: 27,000
  - Budget: ~ $1 Billion

# IRIS Benefit Package

Includes services such as:

- Vocational
- Transportation
- Supportive home care
- Personal care
- Medical equipment and supplies
- Counseling and therapeutic

# IRIS Program Growth



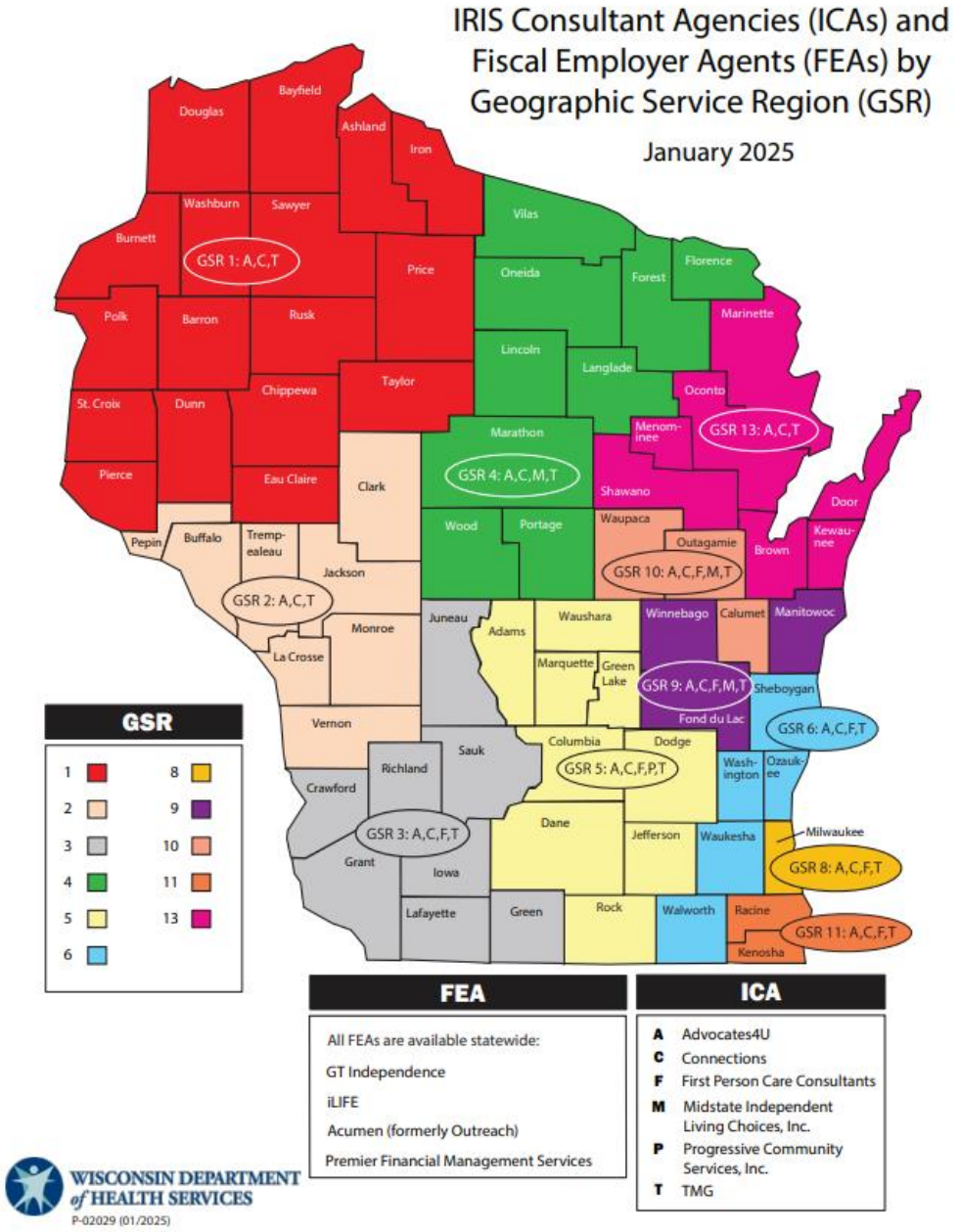

IRIS
Include, Respect,
I Self-Direct

# Partner Agencies

IRIS fiscal employer agencies (FEA) help participants choose and manage the workers they hire.

IRIS consultant agencies (ICA) help participants manage their own care and handle day-to-day program operations.

IRIS self-directed personal care agency (SDPC) allows participants to hire, train, and oversee their personal care workers.



# IRIS Advisory Committee

Responsible for providing advice and input on:

- Proposed changes to program policies, contracts and federal waivers
- Implementation of program operations and infrastructure
- Reports such as NCI and state-led participant satisfaction surveys

Committee members include participants, family members, and providers and advocacy groups representing the needs and interests of the three target groups served by the program (I/DD, Physical Disability, Older Adult)

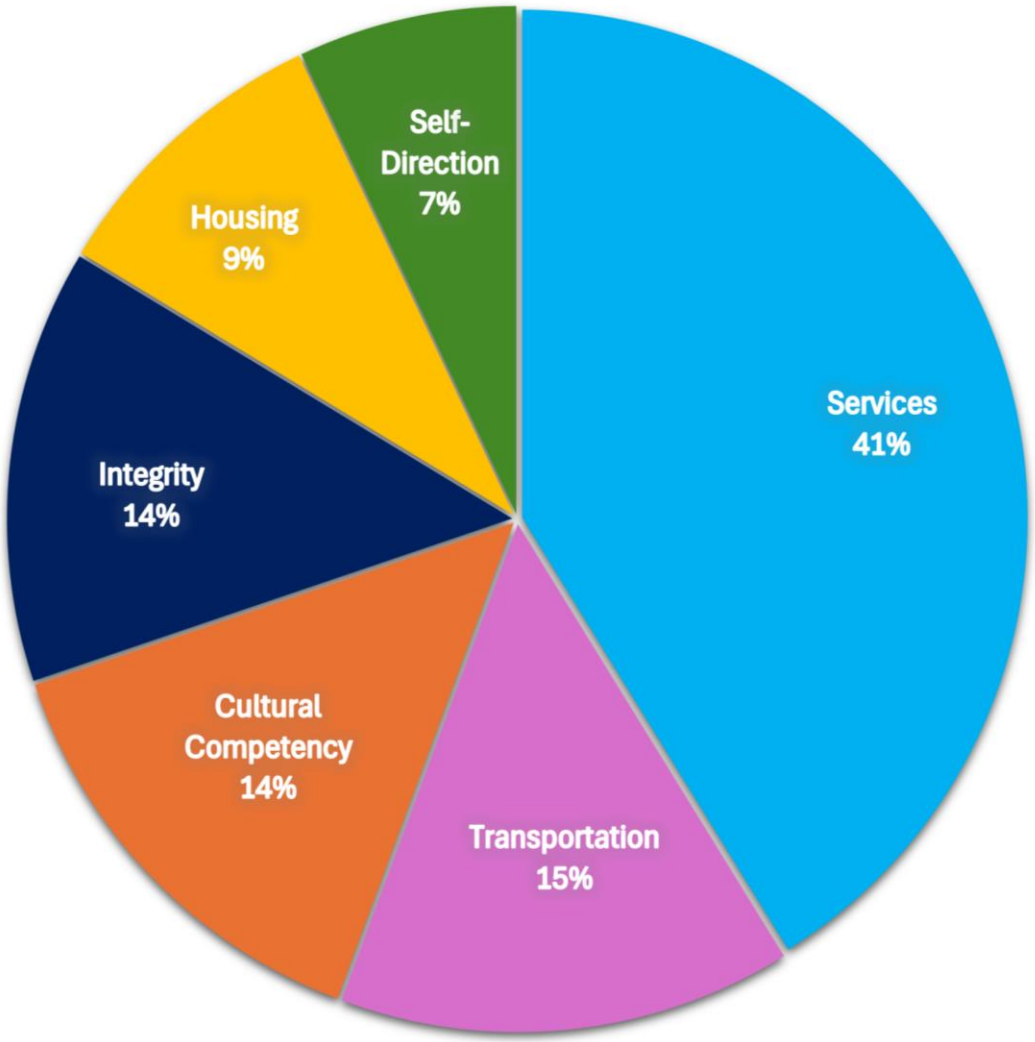
# IRIS Waiver Renewal

- We must renew the 1915(c) HCBS waiver every five years.
- This is a chance for us to make the IRIS program better between 2026 and 2031.
- We can improve policy, services, and other things that can make the programs better for participants.

# IRIS Waiver Renewal Outreach

| What | Who | When |
|---|---|---|
| **Survey**<br><br>(Available in English, Spanish, and Hmong with accessibility features) | • Participants<br>• Family, Friends, and Caregivers<br>• Providers<br>• Advocates<br>• ICA/FEA staff<br>• Other Partners | • July 9, 2024 - August 2, 2024 |
| **Targeted Outreach** | • IRIS Advisory Committee<br>• Tribal Health Directors | • July 23, 2024<br>• November 13, 2024 |
| **Public Input Sessions** | • All partners<br>• Open to the public | • July 30, 2024 (Evening)<br>• July 31, 2024 (Day) |

# IRIS Feedback Themes




- Six major themes surfaced in survey, public input sessions, and other outreach.
- Many of the themes are complex issues with multiple causes.
- While we can't fix them all through the waiver renewal, we're committed to addressing these issues.
- We'll use this feedback to find more ways to improve the program.

https://www.dhs.wisconsin.gov/iris/waiver-renewal.htm

# Theme #1: Services

Providing access to necessary services empowers individuals to live more independently.

Equitable access to services helps bridge gaps in care and support.

From a provider perspective, a community needs assessment and clear information on how to access information on covered services, which would be beneficial to aid in the development of services that will support the needs of the community.

-ADRC Staff

# Theme #2: Transportation

Lack of transportation is a major barrier to accessing the community and needed services.

Participants, families, and support people desire more reliable, accessible, flexible, and convenient transportation options.

> Transportation assistance is lacking for me. I get money for public transit, but that's it. If I needed to go somewhere I couldn't access by bus, my only good option is to ask my caregiver to drive me. This puts more stress on my caregiver since I can only access this through him.
>
> -IRIS Participant

# NCI data example

**Table 26. Has transportation to do the things they want outside of home**

*Proxy respondents were allowed for this question*

| Program | Yes | Maybe | No | N |
|---|---|---|---|---|
| Family Care (FC) | 80% | 8% | 12% | 591 |
| Include, Respect, I Self-Direct (IRIS) | 86% | 6% | 8% | 371 |
| **Overall WI Average** | **82%** | **8%** | **10%** | **962** |
| **Weighted NCI-AD Average** | **68%** | **16%** | **16%** | **14,095** |

2022-23 NCI AD Report -- Wisconsin

**Has transportation to do the things they want outside of home**

| | Yes | Sometimes | No |
|---|---|---|---|
| **Overall WI Average** | 76% | 17% | 8% |
| • *Uses self-directed supports*<br>• *Doesn't use self-directed supports* | *71%*<br>---<br>*76%* | *19%*<br>---<br>*16%* | *10%*<br>---<br>*8%* |
| **Weighted NCI-IDD Average** | 80% | 17% | 4% |

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# Theme #3: Cultural Competency

Match participants with providers who can relate to their culture, background and values. If that is not possible, consider annual diversity trainings and practical ways to be inclusive.

-IRIS Caregiver and Provider

- Explore additional services to support cultural differences and minimize barriers to care.

Consider a resource for culturally competent services to ensure that care is tailored to the diverse needs of individuals.

We could use more cultural/language-specific day service opportunities, especially for the elderly. There are few adult daycare programs for Hmong or Spanish-speaking participants.

-Family Member or Friend

# Theme #4: Integrity

Assess for when the IRIS member is no longer able to self-direct. There seem to be a lot of folks on the program who can't advocate for their own best interest.

-Other Partner

There are individuals on IRIS that should have an alternate decision maker. There are times when IRIS is not appropriate or the participants are not safe or when the alternate decision maker's decisions are not in the best interest of the person.

-IRIS Caregiver and Provider

A program with strong integrity guarantees that resources are used effectively and responsibly, which ensures participants receive the services and supports needed to achieve their long-term care outcomes.

# Theme #5: Housing

Participants request more assistance with finding affordable, safe, and accessible housing.

There are a limited number of housing options for adults with disabilities to maintain the quality of life they are accustomed to when living at home with parents/loved ones. It would be great to invest/expand partnerships between organizations that offer housing vouchers so there are more resources to provide affordable quality housing options.

-IRIS Participant

# In Hindsight

What do we know now that we wish we knew when the IRIS program started 16 years ago?

# Self-Direction Takeaways and Future Directions

- Use of self-directed supports continues to expand
- It is important to ensure that all populations have the same opportunity to find information about and access self-direction
- As self-direction expands, we need to measure and monitor the quality of self-direction
- Continued research will be needed to explore more deeply the associations between use of self-direction and community living outcomes

Human Services Research Institute

*Improving systems. Changing lives.*

# About Us

- We are a 501(c)(3) nonprofit organization founded in 1976
- We craft community-based, person-driven solutions across service systems.
- We gather research using a collaborative, inclusive, and participatory model.