Everyone Can Self-Direct: Lessons Learned from the NCAPPS Self-Direction Learning Collaborative

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NCAPPS

Welcome to Today's Webinar

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Thank you for joining us to explore lessons learned from the NCAPPS Self-Direction Learning Collaborative.

Today's webinar is sponsored by the National Center on Advancing Person-Centered Practices and Systems (NCAPPS).

NCAPPS is funded by the Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS) and administered by the Human Services Research Institute (HSRI).

NCAPPS webinars are free and open to the public.

The Goal of NCAPPS

To promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan.

Priorities:
- Centering lived experience
- Partnering with advocacy communities
- Disability justice and racial equity
- Cultural humility and competence
- Cross-system collaboration
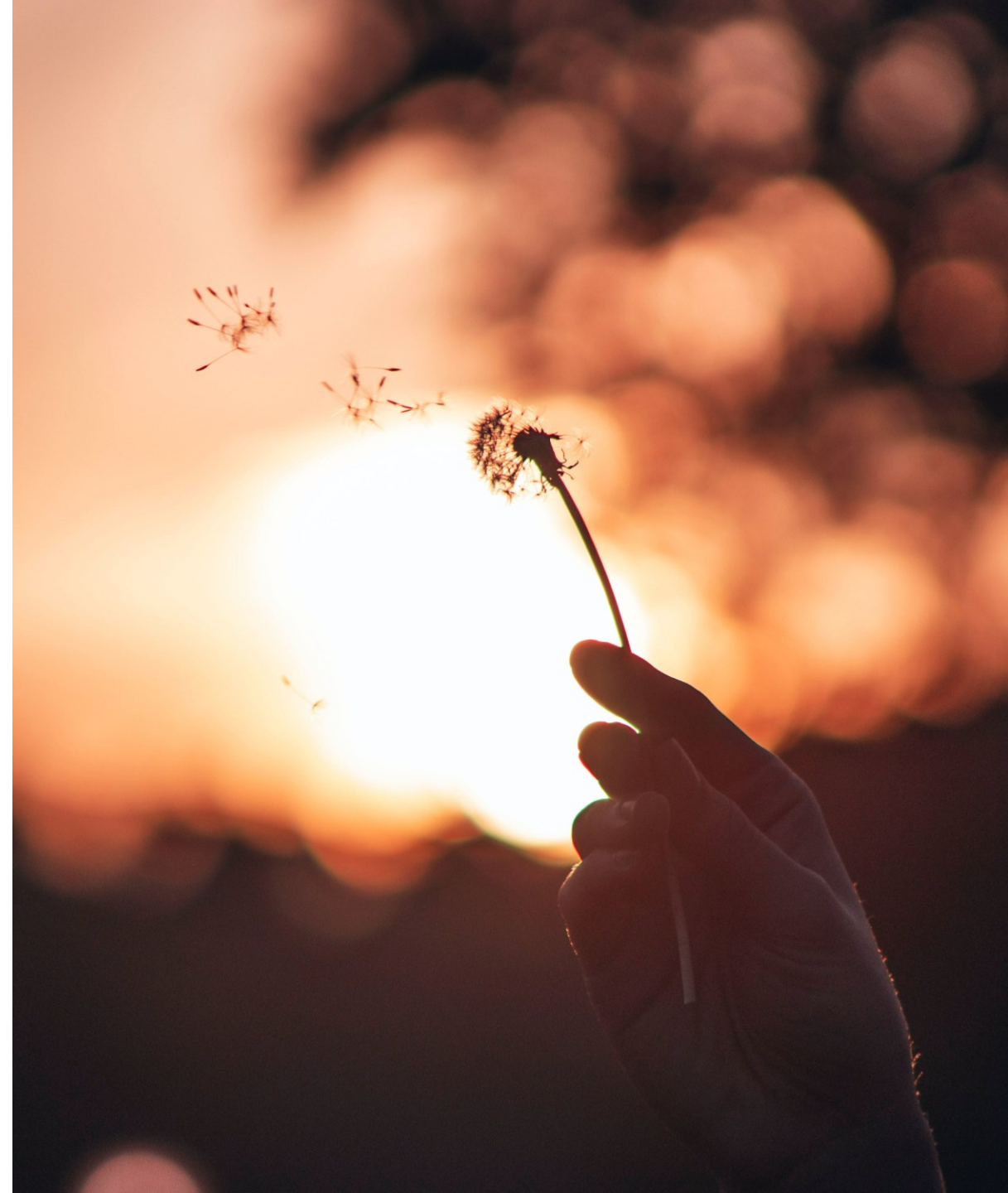
Webbinar Logistics

- Participants will be muted during this webinar. You can use the chat feature in Zoom to ask questions and communicate with the hosts.

- Towards the end of the webinar, panelists will have an opportunity to respond to questions that have been entered into chat.

- The webinar will be live captioned in English and live interpreted in Spanish.
    - 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 haciendo 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.

- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.

Feedback and Follow-Up

- Follow-up questions and feedback about the webinar can be addressed to ncapps@hsri.org. This email address is not monitored during the webinar.

- NCAPPS webinars are not officially approved for Continuing Education Units (CEUs). However, we do provide a confirmation of attendance in case an organization wishes to use participation in our webinars to grant credit for internal requirements. Zoom will automatically send attendees a confirmation of attendance one day after the webinar.

- All registrants will receive a link to the webinar recording and other materials such as slides and resources one day after the webinar.

- NCAPPS webinars and associated materials such as plain language summaries and transcripts are archived on the NCAPPS website at https://ncapps.acl.gov/.

Who's Here?

"In what role(s) do you self-identify? Select all that apply."

1. Person with a disability/person who uses long-term services and supports
2. Family member/loved one of a person who uses long-term services and supports
3. Self-advocate/advocate
4. Peer specialist/peer mentor
5. Social worker, counselor, or care manager
6. Researcher/analyst
7. Community or faith-based service provider organization employee
8. Government employee (federal, state, tribal, or municipal)

Meet Our Panelists

What is Self-Direction?

- According to [Applied 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. When a person self-directs, they decide how, when, and from whom their services and supports will be delivered. As a model, self-direction prioritizes participant choice, control, and flexibility. This contrasts with 'traditional' services received from an agency, where the agency controls most aspects of service delivery, including who will provide the service. In self-direction, the participant selects and trains their own staff, develops their staff's schedules, and sets their own standards for how their services will be delivered.

SELF-DIRECTION IS PERSON-CENTERED

Benefits of Self-Direction

1

During the pandemic, many individuals and families chose to self-direct their services to cope with closures of out-of-home programs or workplaces or to overcome staffing shortages.

2

There is a workforce crisis across human services and self-direction offers the possibility of tapping into a non-traditional workforce (e.g., friends, neighbors, family members).

3

Self-direction makes it possible to individually tailor services and supports rather employing a one size fits all approach and therefore has the potential of being more cost-effective.

4

Self-direction helps participants build decision-making skills and a support system in line with their goals and aspirations.

HOWEVER…

Based on data from the National Core Indicators 20-21 In-Person Survey, only 18% of respondents are self-directing

Further – the numbers of people self-directing by state ranged from 1% to 55%

THEREFORE…

The NCAPPS team determined that there is a need for a national effort to expand the quality and availability of self-direction as a person-centered option available to a wide range of potential participants. To reach this goal, we created a broad-based Learning Collaborative.

NCAPPS Self-Direction Learning Collaborative

- From April 2022 to September 2023, the NCAPPS Self-Direction Learning Collaborative brought together teams from across the country and experts to learn from each other as they worked to improve self-direction
  - 22 teams from 16 states participated (200+ participants)
  - Teams include state representatives, community advocates, people with lived experience of self-directing, and family members

Learning Collaborative State Representation
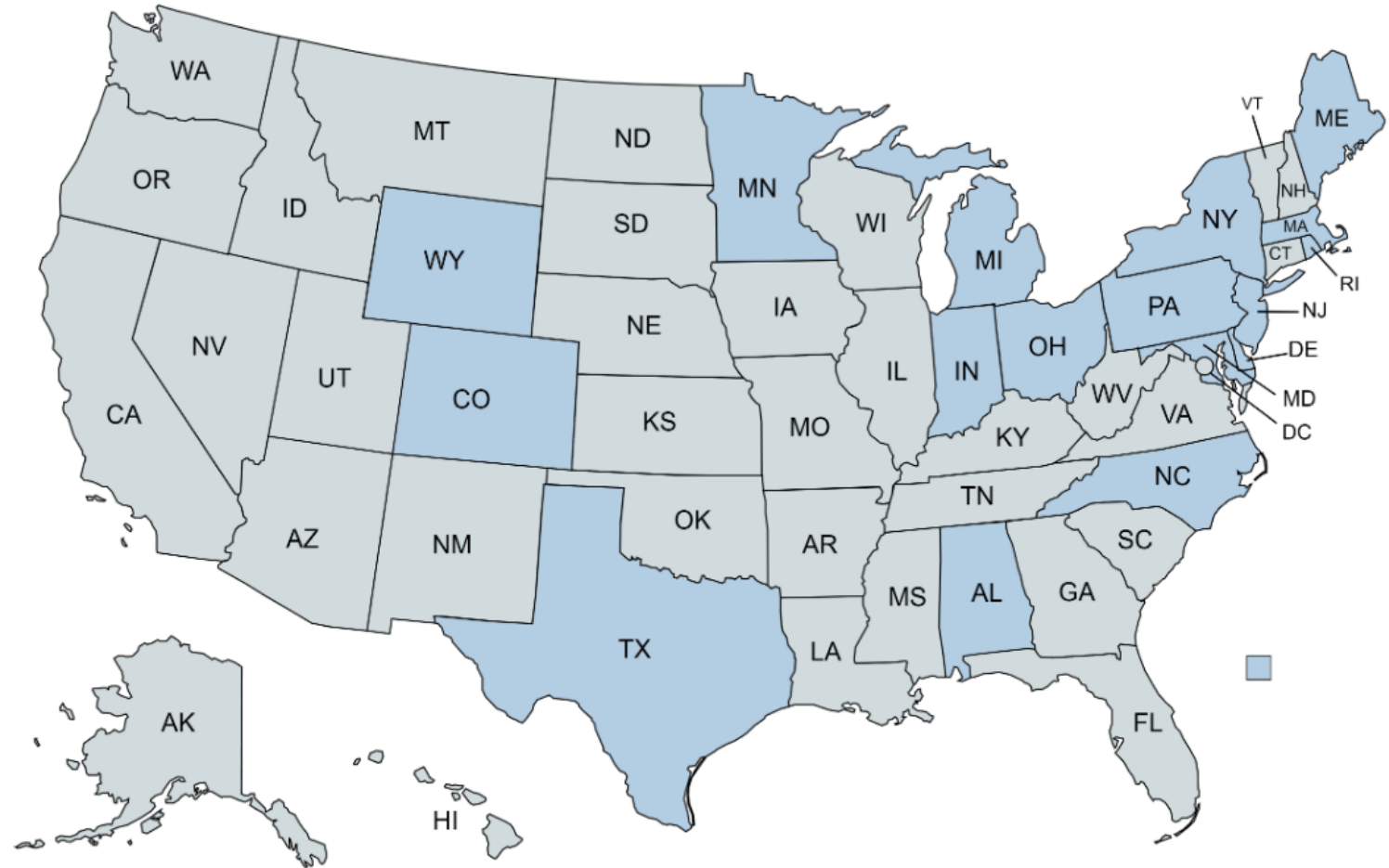
Questions for the Audience

What are some challenges to enhancing and expanding self-direction? Any success stories you would like to share?

If you could wave a magic wand, what would you wish for to "fix" self-direction?

What Were We Trying to Accomplish?

The Learning Collaborative wanted to enhance the availability, quality, and access to self-direction by:

- Disseminating information regarding self-direction, its benefits and how it works
- Developing self-direction policies and procedures that are equitable, transparent, flexible, and easily understood and implemented
- Enhancing infrastructure to support self-direction
- Recruiting and training Direct Support Professionals (DSPs), support brokers, and peer mentors to support self-direction

Reaching the Summit

Team Colorado

NCAPPS
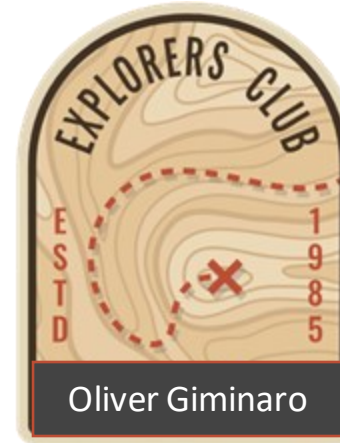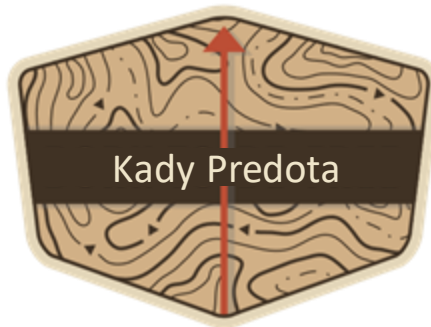
Our Primary Drivers

Reaching the Summit

Secondary Drivers (Strategies)
- Develop culturally appropriate outreach strategies to educate a variety of participants & family members about self-direction.
- Educate state & local public managers about self-direction values.
- Create accessible guides & supports for participants & families.
- Ensure case managers are prepared to embrace self-direction.

Primary Driver
Driver One: Disseminate information regarding self-direction, its benefits and how it works.

Specific Goals & Aims

Self-Direction Welcome Kits (CDASS & IHSS)

ACCOMPLISHED

UNDERWAY

FUTURE

Data gathering and analysis

Community partners targeted outreach

Case Manager Cafes

Community Educational Workshops

Data Our Team Used to Measure Progress

▼ **HOW WE MEASURED PROGRESS**
Increased use of self direction programs (CDASS and IHSS) get data from Financial Management Service (FMS) providers and Health Care Policy and Financing (HCPF)
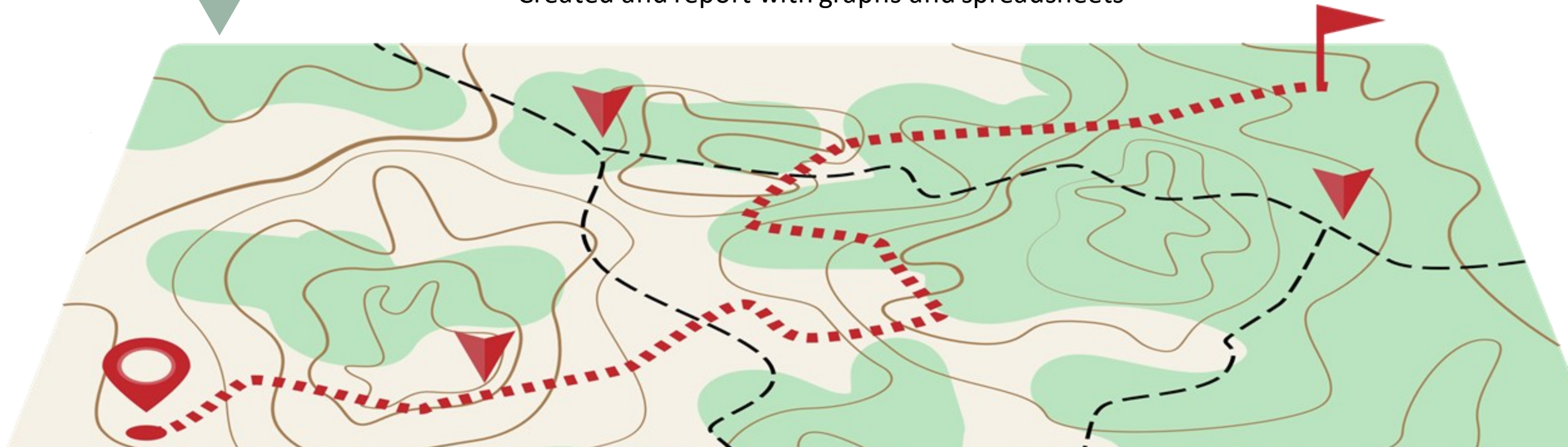
▼ **BASELINE DATA AND CURRENT DATA**
Data from Financial Management Service (FMS) providers and Health Care Policy and Financing (HCPF)

▼ **INPUT, PROCESS, & OUTCOME MEASURES**
Created and report with graphs and spreadsheets

DIVING INTO THE DATA

Data Highlights - identifying pinch-points and how to best address them.

- Department data by county
- Members by county
- CDASS & IHSS growth
- Case management caseload
- Attendant (Caregiver) numbers
- Allocation Averages

How did the data drive our initiatives?

- Self-Direction utilization is disproportionate throughout the state.
- Initial thought: a lack of available resources about self-direction.
- Reality: Not a lack of resources, it's a lack of awareness and understanding of self-direction and HCBS.

Methods

What we did that worked well…

Data Collection

Participant Direction has been well established in Colorado for 20+ years.

Review Current Materials

Locate where it is housed, how it is disseminated and who has access.

Outreach

Original hypothesis was it was a lack of available resources. It was lack of understanding and basic knowledge of Participant Direction

What we tried, but later changed…..

Pivoted from two drivers (Driver 1 and Driver 4) to just Driver 1

Lessons Learned

⋀ COMMIT TO THE LAST LEG ⋀
Implementation can be scary but be bold & confident. Change comes from action.

⟨⟩ CHECK-IN ⟨⟩
Communicate your capacity & take breaks if needed. Remember, effective change takes time.

⚒ GATHER SUPPORTS ⚒
Identify who can help & how. Bringing them in early will ease the lift & spread news quicker.

☼ CHART THE COURSE ☼
Collect & assess data to map out what you want & need to accomplish. Be pragmatic!

Aspirations for the Future

Work will continue by seeking out a contractor to develop our Welcome Kit.

Maintain gains by continuing data collection & analysis, strengthening & expanding our network, & streamlining current materials.

We want to continue strengthening our network & increasing stakeholder presence.

A goal is to attend state resource fair to connect with other agencies & community members.
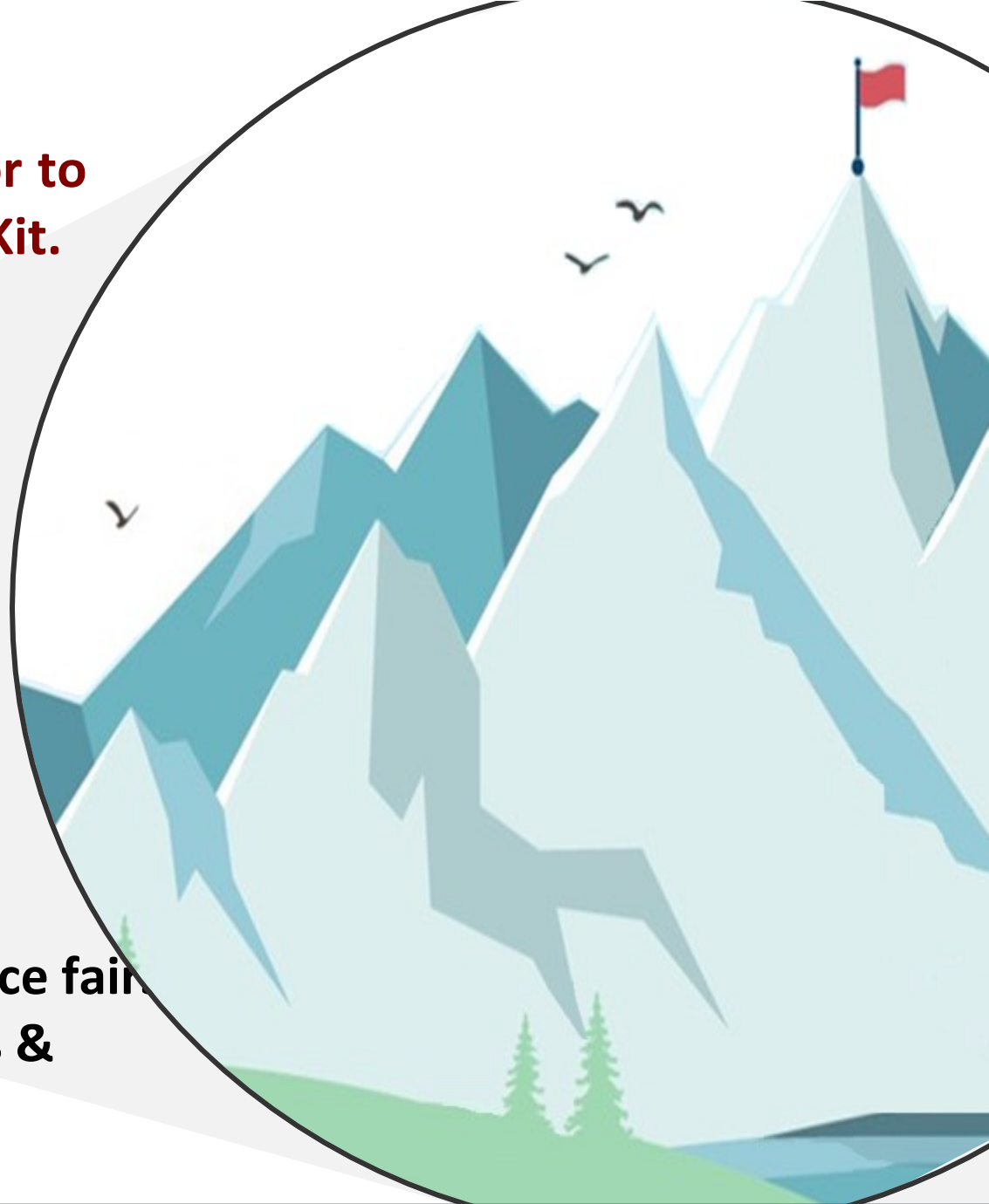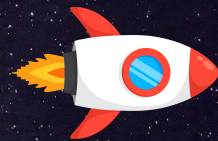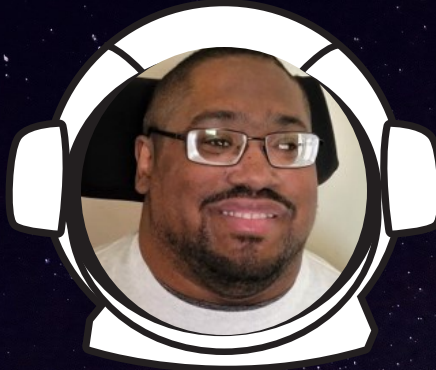
Thank You!

"A new frontier (for Ohio) lies not beyond the planets, but within each one of us."

Pierre Trudeau

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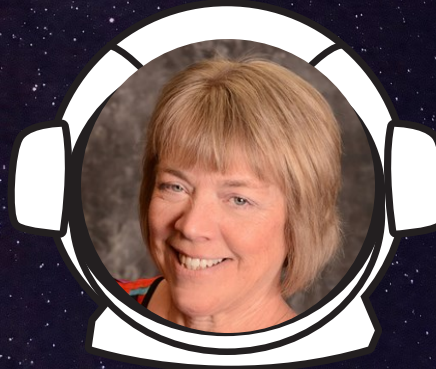
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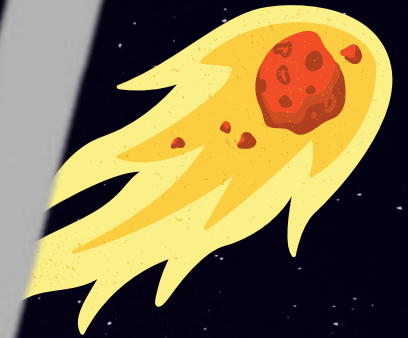
CHALLENGES TO PROGRESS:

- Took on too much too fast
- New FMS
- New Self-Directed transportation
- 3 new self directed services in 1 waiver
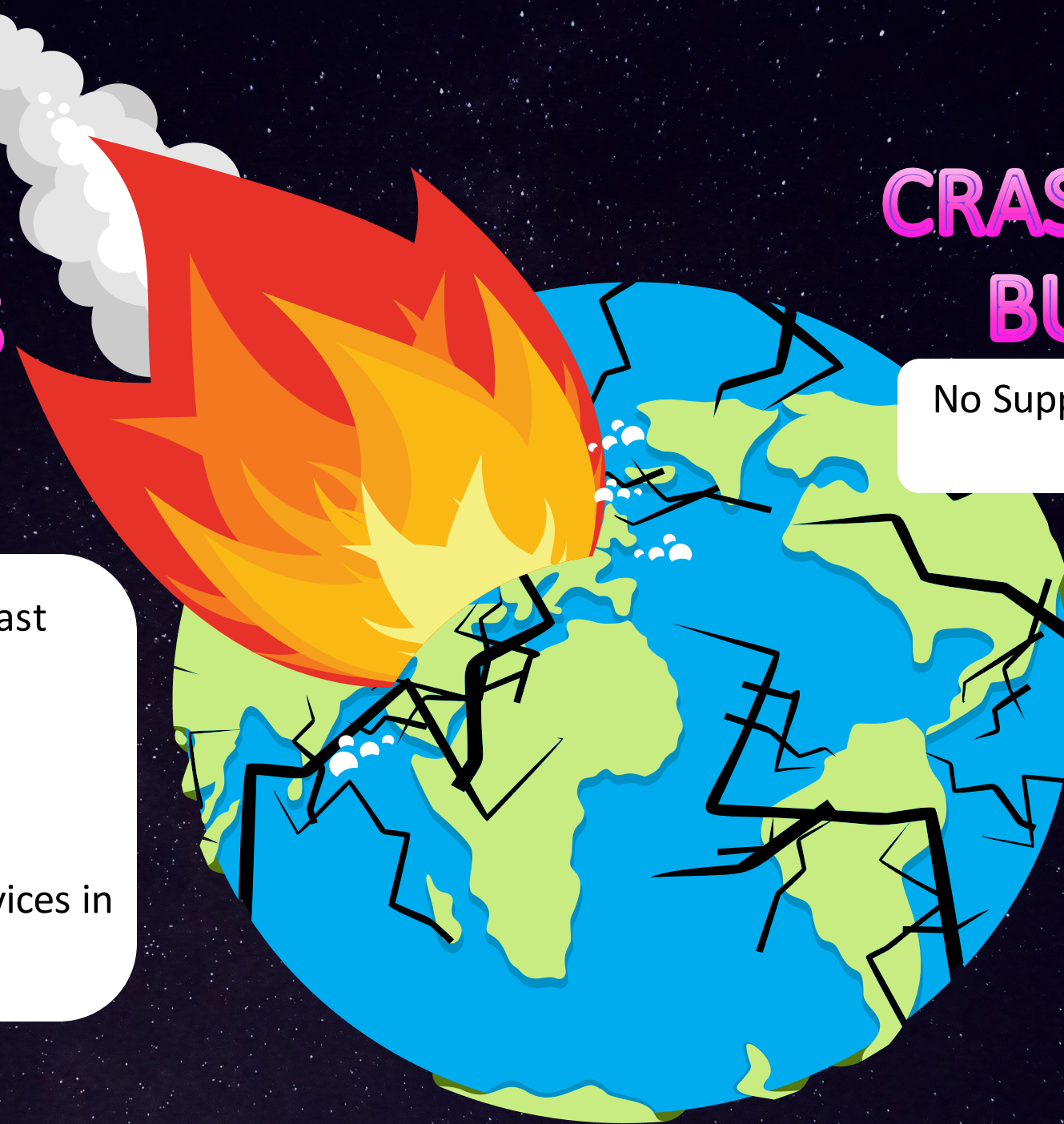
CRASH AND BURN:

No Support for Support Broker

BLASTING OFF
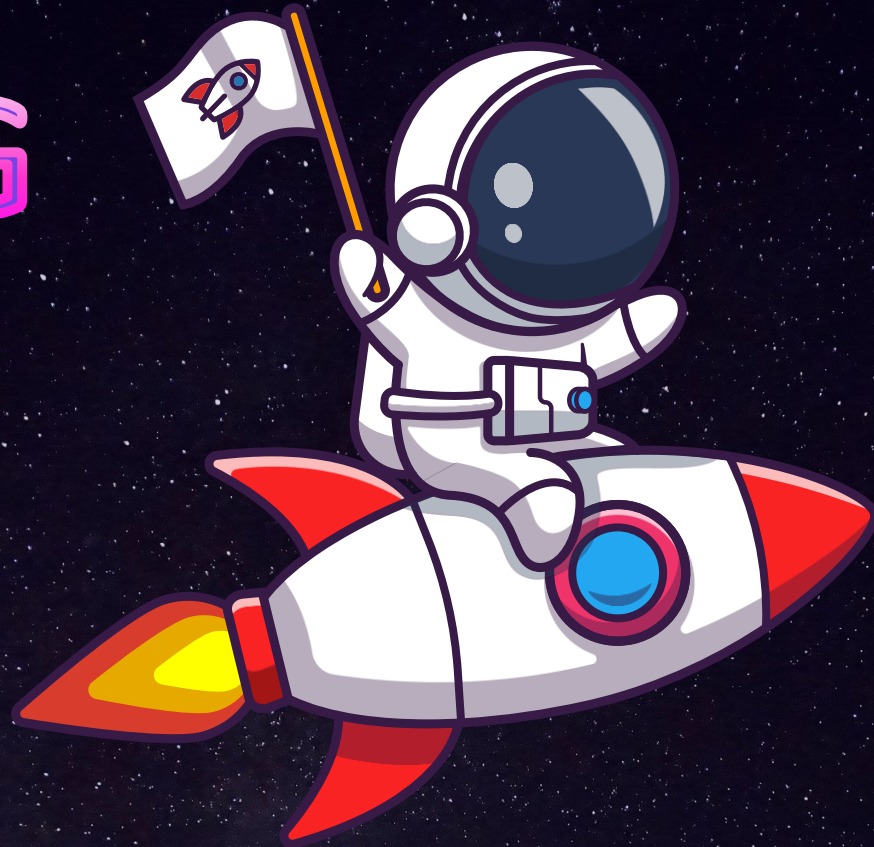
TOWARD THE FUTURE!

Budget Authority

Employer Authority

Grow the network

Support Broker

Simplify Provider Cert.

Keep the Team

"A new frontier (for Ohio) lies not beyond the planets, but within each one of us." -- Pierre Trudeau

New NCAPPS Resource: *A Guide for Developing Strategic Objectives to Expand Self-Direction*

- The Guide offers a road map to strategic targets that are linked to the key drivers of a robust self-direction option within public programs. It lays out a series of decision points beginning with the selection of overarching goal(s) to pursue, aspects of the goal to tackle, and actions steps to pursue.

- The road map is based on the Self-Direction Learning Collaborative Change Package.

How to Use the Strategic Objectives Template

1. Consult with people receiving services, family members and others regarding the conduct of self-direction in the state

2. Conduct an environmental scan to identify gaps and areas for improvement including political and financial feasibility

3. Select One or More Strategies

4. Chose a Secondary Strategy

5. Identify Action Steps

6. Create a Measurement Strategy

PRIMARY STRATEGIES

- Disseminate information regarding self-direction, its benefits and how it works.

- Develop self-direction policies and procedures that are equitable, transparent, flexible, and easily understood and implemented.

- Enhance infrastructure to support self-direction.

- Recruit and train Direct Support Professionals, support brokers, and peer mentors to support self-direction.

Credit: Medisked

Strategy 1: Disseminate information regarding self-direction, its benefits, and how it works

Secondary Strategy	Description	Rank Order 1-high priority; 5-low priority
Develop an outreach strategy to educate participants and families regarding self-direction	Information about self-direction opportunities must be broadly available. Such information should be available in a range of formats and languages to ensure accessibility for all potential participants regardless of race, ethnicity, income level or place of residence. To spread the word, people who enjoy the benefits of self-direction are the best ambassadors.	
Educate state and local public managers regarding the values of self-direction	It is public managers at the state and local level who have the responsibility to develop policies and procedures for self-direction. To ensure that those policies and procedures embody the values of choice and self-determination, it is important that these managers are introduced to, embrace, and understand the benefits of self-direction.	
Create accessible guides and supports to participants and families	Policies and procedures surrounding self-direction must be transparent and accessible to people with disabilities and their families. Materials describing the process should be culturally sensitive, written in plain language, and publicly available. People need to be aware of the components of self-direction such as the nature of the planning process, participant responsibilities, how to work with an agency with choice, how to access information and assistance and/or how to work with the fiscal intermediary.	

Strategy 1: Disseminate information regarding self-direction, its benefits, and how it works

Secondary Strategy	Action Steps/ Rank Order 1-high priority; 5-low priority
Develop an outreach strategy to educate participants and families regarding self-direction	• Create culturally appropriate videos and written materials that highlight participant experiences with self-direction, in multiple language formats _____ • Engage organizations and groups including state legislators, Aging and Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs), Centers for Independent Living (CILs), and Public Education Early Intervention and Transition Programs through presentations and materials about self-direction_____ • Identify priority target groups (e.g., young adults making transition to adulthood, people with autism, etc.) _____ • Identify self-direction participants who can serve as "ambassadors" to a range of constituencies and who help to champion self-direction_____ • Train self-direction ambassadors on existing policies and procedures and work with them to create talking points to share with participants, families, case managers and providers_____ • Create a publicly available and accessible website to house outreach material_____
Educate state and local public managers regarding the values of self-direction	• Develop trainings for managers that compare and contrast the benefits/outcomes of self-direction to conventional services/and supports _____ • Emphasize that anyone can self-direct with individually tailored supports_____ • Address misconceptions about self-direction (e.g., potential for fraud) _____ • Ensure managers seek public input and learn from the experiences of participants_____
Create accessible guides and supports to participants and families	• Create plain language guides accessible to self-directing participants and families that include step-by-step directions _____ • Translate materials into commonly spoken languages that are culturally competent and that reflect cultural practices of target populations _____ • Provide guides and directions on an easy-to-navigate, publicly accessible website _____ • For those who need more support, provide support through independent facilitators _____
Ensure case managers are prepared to embrace self-direction	• Survey case managers to determine their level of familiarity with benefits of self-direction and solicit their input on obstacles to self-direction (e.g., caseload size, complexity, etc.) _____ • Conduct trainings with case managers underscoring that self-direction is a priority _____ • Create a learning community for case managers to grow and enhance their approach to administering self-direction programs_____

Table: Examples teams can refer to when identifying their action steps and measures.

Example Strategies	Example Action Step	Example Output	Example Measures
Strategy 1: Disseminate information regarding self-direction, its benefits and how it works **Secondary Strategy: Create accessible guides and supports to participants and families**	Translate materials into commonly spoken languages that are culturally competent and that reflect cultural practices of target populations	The team brings informational self-direction materials (webpage and video) before diverse groups representing the cultural/racial/ethnic make-up of the state and modifies them to incorporate culturally relevant self-direction concepts, examples, and language. The team also translates the modified materials into the languages most commonly used in the state.	• Percent of people newly self-directing who say they have reviewed the materials. • Percent of calls, e-mails, or other communications received related to self-direction in alternate languages (the team expects an increase in outreach in selected languages). • Percent of people self-directing by identified cultural/racial/ethnic or linguistic group who report that the guide was a helpful explanation of the process. • Percent of participants by cultural/racial/ethnic or linguistic group that start self-direction following the introduction of modified materials (the team expects increases in targeted groups). • Percent of support brokers who report that people are better prepared to participate in self-direction when they have viewed the materials.

Questions?

Real-Time Evaluation Questions

- Please take a moment to respond to these six evaluation questions to help us deliver high-quality NCAPPS webinars.

- If you have suggestions on how we might improve NCAPPS webinars, or if you have ideas or requests for future webinar topics, please send us a note at NCAPPS@hsri.org

Real-Time Evaluation Questions (cont.)

1. Overall, how would you rate the quality of this webinar?

2. How well did the webinar meet your expectations?

3. Do you think the webinar was too long, too short, or about right?

4. How likely are you to use this information in your work or day-to-day activities?

5. How likely are you to share the recording of this webinar or the PDF slides with colleagues, people you provide services to, or friends?

6. How could future webinars be improved?

Thank You.