



**NATIONAL CORE
INDICATORS®**
NASDDDS & HSRI

NCI Virtual Annual Meeting: Session 3

September 16, 2020



- Please let everyone know which state you are representing by including the state in your participant name
 - Right click on your video/name and choose “rename”.
 - For example “Dorothy Hiersteiner, MA”
- Please mute to lessen background noise, unless you are speaking
- For questions or comments during the presentation piece of this webinar, either raise your hand in the participant pod or comment in chat box
- Have fun!
- THE SLIDES AND RECORDING WILL BE AVAILABLE TOMORROW ON THE NCI WEBSITE
WWW.NATIONALCOREINDIATORS.ORG

Agenda

- Welcome / Introductions
- OR what they learned from remote survey pilot
- Why are we revising NCI Survey tools now?
 - Overview of NCI 4 year revision cycle
 - Revision Work Plan
 - Hearing from state coordinators
- What do we know about current surveys?
 - Priority Indicator Survey Results from 2019
- BREAKOUT and report back - State Priorities for Revisions
- BREAKOUT and report back - topic specific
 - Community/technology
 - Self-Direction
 - Service Coordination/PCP
 - Family Surveys
- Self-Advocate input into NCI tools
- Wrap Up



NCI Remote Pilot

Notes from the Field

DATE: September 9th, 2020 PRESENTED BY: Alice Longley Miller, MSW, MPH

Interviewing adults with no or limited verbal communication

Challenges in the field

- Training from in person surveys not always applicable to remote interviews
- Increased reliance on proxies
- Impacted on interviewer confidence, especially our experienced team members
- Problems with technology performance/poor internet connection amplified

Lessons Learned in Oregon

Ensuring Response Validity

- New guidance and training
- Role of the systems check
- Coaching interviewers
- Establish communication supports in advance
- Embrace response option: 99
- Importance of detailed pre-survey information



NCI SURVEY REVISION 2020-2021



Why are we here?

NCI has moved to a **four-year revisions cycle for the NCI Surveys** (For DD Systems—including the In-Person Survey, Adult Family Survey, Family Guardian Survey and Child Family Survey).

What does a “four-year revisions cycle for the NCI Surveys” mean for me and my state?

- We will only make substantive changes every fourth year. So the next year of substantive changes will be the 2021-22 data cycle.
- A substantive change is defined as:
 - The addition of questions in the main survey tool (states may still add their state specific questions using NCI’s usual procedure); the removal or restructuring of sections of the survey; wording changes that alter the meaning of the survey questions.

Why are we here?

Why does NCI make revisions on a 4-year cycle?

- States expressed a desire to have a stable tool.
- Creates time to gather meaningful feedback from stakeholders about the functionality of questions.
- Allows for testing of proposed new questions before they're added to the survey.
 - allows for robust psychometric testing and review of select measures for submission.

Why are we here?

WHY REVISE?

Relevant – data collected measure current state priorities and domains based on feedback from users at State DD Agencies

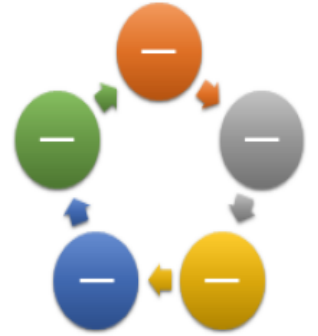
Useable – Data can be used to address state priorities. Information presented in such a way as to ensure use for state DD agencies in their systems, i.e. quality systems.

Feasible – NCI surveys collect data that can be collected in states, and the survey is not cost-prohibitive.

Actionable – States are able to take action with the findings of the NCI survey tools (in aggregate)

Why are we
here today?

4 Year Revisions Cycle



2018-2019 (Current Cycle)

- Data collection year with new Person Centered questions added.
- Review performance of BI elements

2019-2020

- (Summer 2019) Issues/concepts and data on performance of measures for review at NCI annual meeting (summer 2019) and in a communication with NCI states.
- Analyze performance of Person Centered questions and new questions.
- Focus groups with stakeholders to ensure that the survey meets needs
 - states, service recipients, families, researchers, surveyors for data collection, implementation and reporting.

2020-2021

- (Summer 2020) Draft survey changes reviewed at NCI annual meeting and in a communication with NCI states.
- If needed, cognitive testing (if new questions – or major survey restructure)
- Final tool

2021-2022

- (Summer 2021) Roll out of new survey to all states for survey administration.
- Present draft report templates at annual meeting and in a communication with states.

NASDDDS RESEARCH COMMITTEE

Provide general direction and oversight for the National Core Indicators Program (NCI). Advise the Board and the NCI Project Team, composed of key NASDDDS and HSRI staff, regarding NCI program directions, projects, products and operations.

WORK PLAN: Advisory group

- **This group will be comprised of:**
 - State DD directors
 - A representative with historical perspective on NCI
 - PNS representation
 - Experts on cultural and linguistic competence
 - Quality management experts
- **The advisory group will be responsible for overarching direction of revisions. To that end, this group will:**
 - Advise on revisions to Domains and Indicators (Not specific measures). (IPS, and Family Surveys)
 - Advise on Background Information section revisions

- First meeting: October 2020
- What are indicators?
- What are the ideas that states are grappling with, want to know the outcomes?
- What isn't needed anymore?
- Also present Background Information questions and discuss importance/priorities

Using this info, finalize domains/indicators for 2020-21 revised surveys

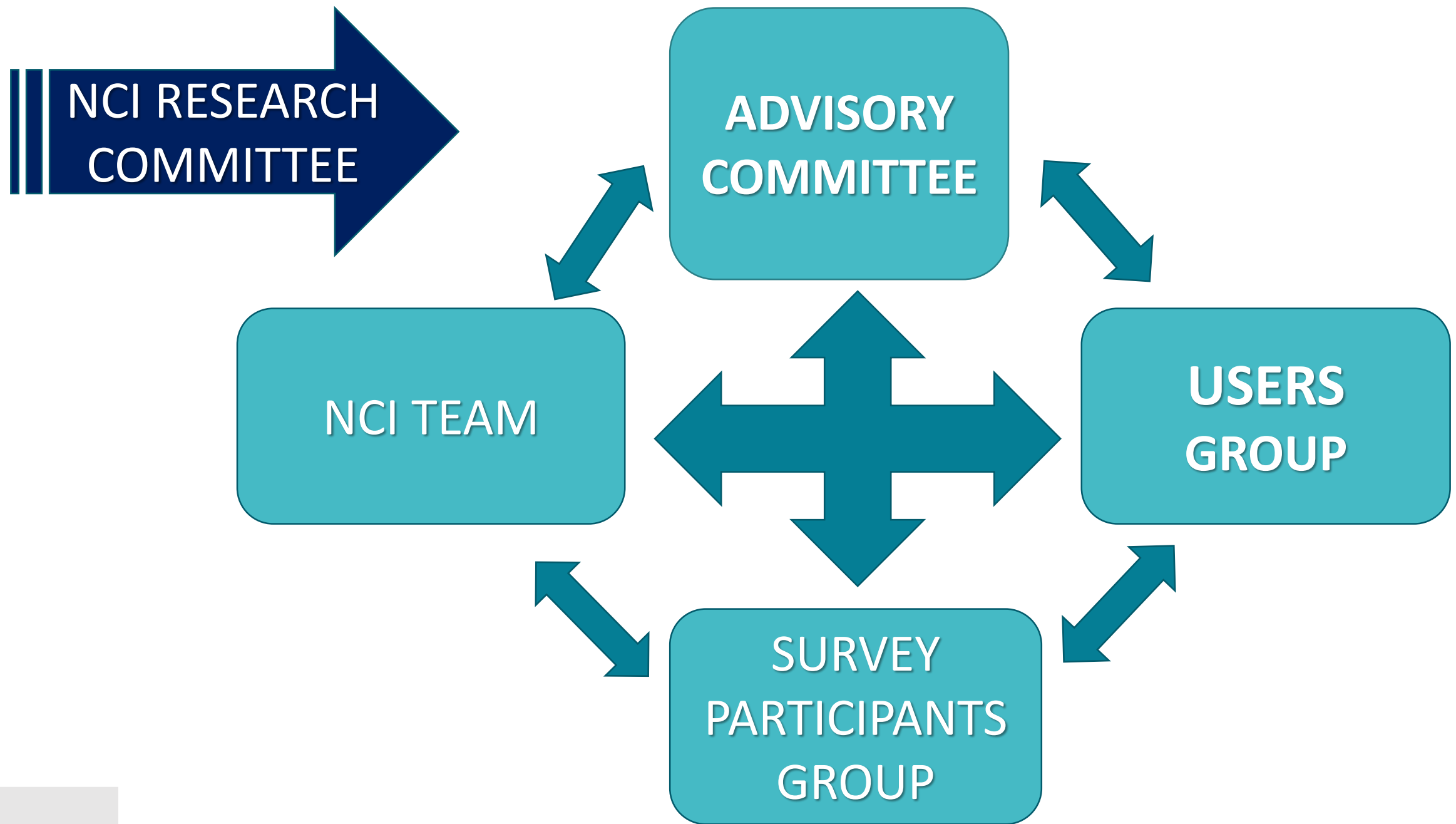
Create drafts of questions

Create indicator/domain crosswalk

WORK PLAN: Topic Specific User Groups

- Each user-group will examine preliminary tool created by NCI team based on Advisory Group feedback on domains and indicators.
- User group will provide feedback on questions and provide insight i.e.:
 - What are examples of tools or questions that they've needed to use outside of NCI to get info they need?
 - What are pressing needs from the field and proposed solutions?
 - Methodological guidance/concerns?
- They will help to revise questions in each **topic** area.
 - Self-Direction
 - Technology
 - Community Inclusion and Engagement
 - Meaningful Day and Employment
 - Person Centered Practices
 - Family Surveys

Start meetings in January, 2021



WORKPLAN: Additional elements

- Seeking to ensure questions address cultural and linguistic considerations (throughout)
- Detailed testing (March-April 2021)
- Incorporating input from people receiving services, families (throughout)

Subdomain: WORK

People have support to find and maintain community integrated employment.

Top 4 Indicators

- The percentage of people who have a goal of integrated employment in their individualized service plan
- The percentage of people who are working-age, do not have a job in the community but would like to have one
- The percentage of people who are working-age and have a paid job in the community
- Of people who have a paid job in the community, the average number of months they have been working at their job

Subdomain: CHOICE AND DECISION

People make choices about their lives and are actively engaged in planning their services and supports.

Top 4 Indicators

- The percentage of people who make choices about daily schedule
- The percentage of people who make choice about paid community job
- The percentage of people who make choices about where they live
- The percentage of people who reported they chose or were aware they could request to change their case manager/service coordinator

Subdomain: COMMUNITY INCLUSION

People participate in activities in their communities and have opportunities to do things that they enjoy in the community

Top 4 Indicators

- The percentage of people regularly participate in everyday integrated activities in their communities
- The percentage of people who do things in their communities that they like to do as often as they want
- The percentage of people who have enough things they like to do at home
- The percentage of people who report they are supported to learn new things

Subdomain: RELATIONSHIPS

People have friends and relationships and are able to maintain their friendships and relationships

Top 4 Indicators

- The percentage of people who often feel lonely
- The percentage of people who have friends and caring relationships with people other than support staff
- The percentage of people who are able to see their families and friends if they want
- The percentage of people who can go on a date if they want to

Subdomain: SATISFACTION

People have friends and relationships and are able to maintain their friendships and relationships

Top 4 Indicators

- The percentage of people who are satisfied with their job
- The percentage of people who report that they would like to live somewhere else
- The percentage of people who have a paid community job who would like to work somewhere else
- The percentage of people who are satisfied with where they live

Subdomain: SELF-DIRECTION

People participate in directing their own supports and services

Top 4 Indicators

- The percentage of people who are currently using a self-directed supports option (this can include those who self-direct any portion of their supports or services)
 - make decisions or have input in making decisions for how budget for services is used
 - who receive information about their budget/services that is easy to understand
 - who report they can make changes to their budget/services if they need to

Subdomain: HEALTH

People secure recommended health services.

Top 4 Indicators

- The percentage of people who have had a complete annual physical exam in the past year
- The percentage of people who have had routine dental exam in the past year
- The percentage of people reported as having a primary care doctor
- The percentage of people who have had a flu vaccination within the past 12 months

Subdomain: MEDICATION

Medications are used effectively and appropriately.

Top Indicators

- The percentage of people who take medication for behavior challenges and have a behavior plan
- The percentage of people taking medications for mood, anxiety, and/or psychotic disorders and the number of medications taken for this purpose
- The percentage of people taking medications for behavior challenges , and the number of medications taken for this purpose

Subdomain: RIGHTS & RESPECT

People receive the same respect and protections as others in the community

Top 4 Indicators

- The percentage of people indicating that staff treat them with respect
- The percentage of people who can lock their bedroom
- The percentage of people who report that others let them know when entering home/bedroom
- The percentage of people who have a key to their residence

Subdomain: SAFETY

People feel safe

Top Indicators

- The percentage of people who report they feel afraid in their home, neighborhood, transport, workplace, day program/ at other daily activity and/or other places
- The percentage of people who report having someone to go to for help when they feel afraid

Subdomain: WELLNESS

People maintain healthy habits

Top Indicators

- The percentage of people who maintain healthy habits in areas such as tobacco use
- The percentage of people who maintain healthy habits in such areas as BMI
- The percentage of people who maintain healthy habits in such areas as physical activity

Subdomain: ACCESS

Services and supports of quality are readily available

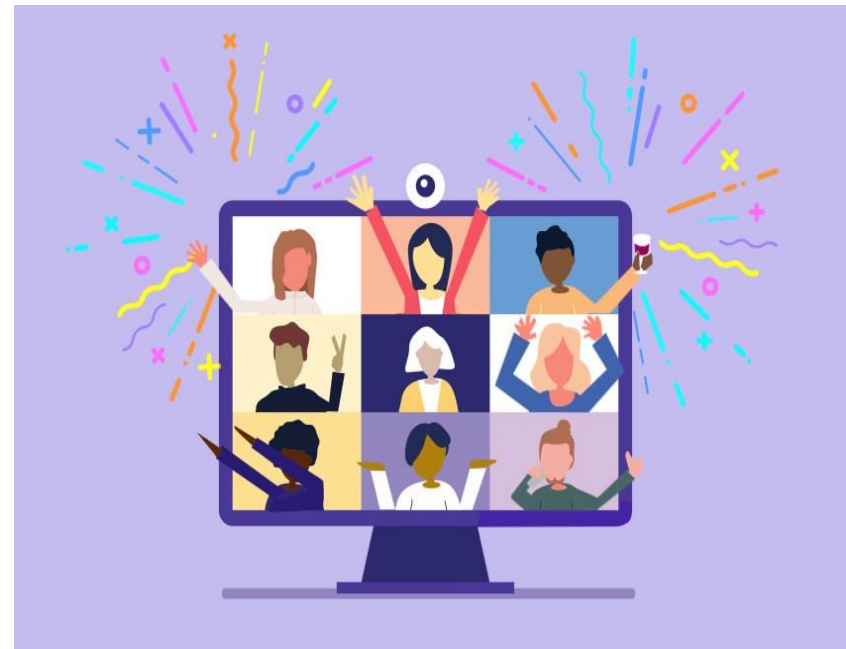
Top Indicators

- The percentage of people who reporting having a way to get places they need to go
- The percentage of people who report having a way to get places when they want to go somewhere
- The percentage of people who feel their support staff have the right training to meet their needs
- The percentage of people who need additional services and supports

Breakout Session 1

What results would you like to see from the survey revision process?

- ✓ Domains/Indicators
 - Relevant to 2020 and future
- ✓ Results from Data
 - Collecting data that allows states to see information in the way that is important to states





BREAKOUT REPORT OUT

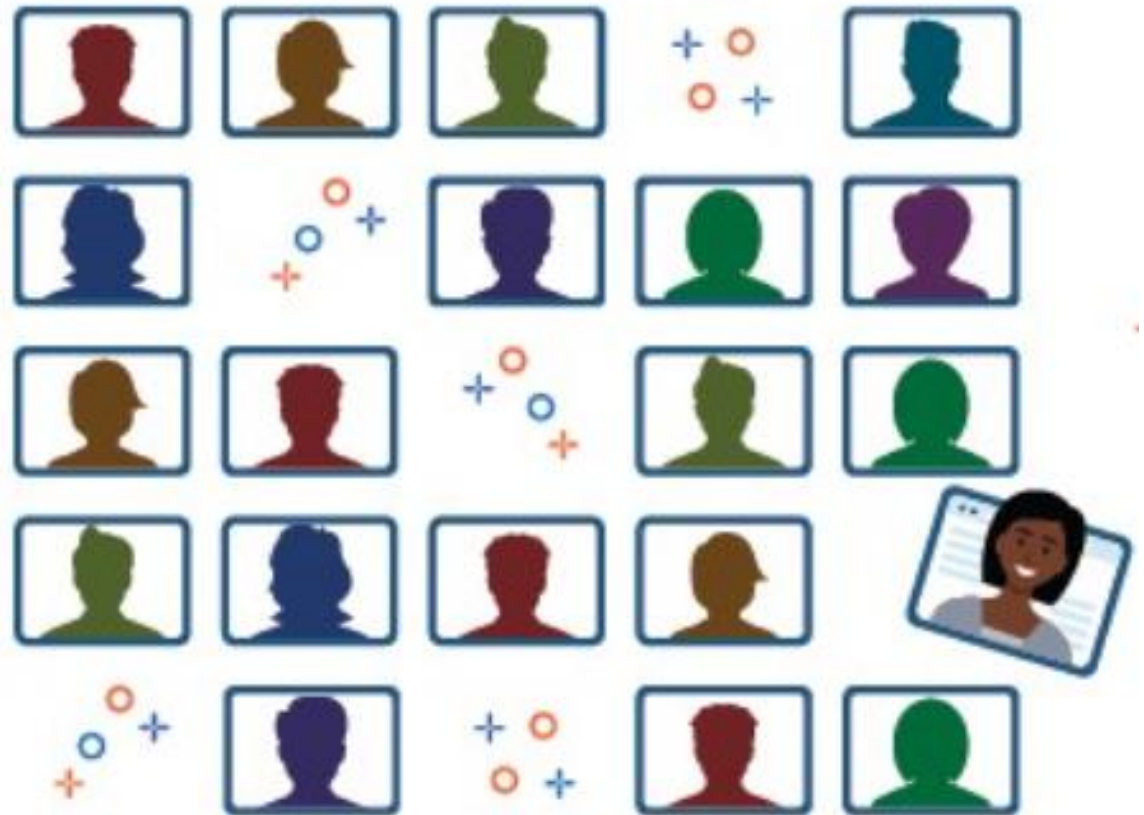
Break-outs!

You will be assigned to one of the following 3 Domain-Specific topic discussions:

1. **Community / Technology**
2. **Self Direction**
3. **Service Coordination/Person Centered Planning**

In each Breakout Room, NCI staff will facilitate and show topic specific slide

1. Review and discuss Subdomain Specific Considerations on topic specific slide
2. Given your state perspective, review and discuss the extent to which indicators align with value statement



Community / Technology

Considering Community...

- Update indicators to increase meaningfulness of frequency of community participation
- Assure indicators are relevant to current definitions of community (2020 definition of community) ex. Post office, bank, shopping

Technology

- Plan to add technology questions: developed with 2 states.
- Focus on technology in people's lives
- Create meaningful indicators for tech questions

BREAKOUT SESSION 2: Community Inclusion, Participation and Leisure

Community Inclusion, participation and leisure	People participate in activities in their community and have opportunities to do things that they enjoy in the community	The percentage of people who report regularly participating in everyday integrated activities in their communities
		NOT INCLUDED IN THIS DOMAIN: The percentage of people who report satisfaction with their level of participation in various community activities The percentage of people who report that they would like to be involved in more groups in their community
		The percentage of people who report doing things in their communities that they like to do, as often as they want
		The percentage of people who have enough things that they like to do at home
		The percentage of people who are supported to learn new things
		Community inclusion Existing composite includes response to [How many times did you go shopping in the past month?; How many times did you go running errands in the past month?; How many times did you go for entertainment in the past month?]

Technology Questions (sample)

MO- 21 Do you currently use any specialized technology supports (such as technology that may help you communicate or get around your home)?

If you currently do not use technology supports, why? (Tech not needed ; Lack of knowledge about technology options to support me ; Technology not available in my area (i.e. lack of vendors); Lack of funding for initial purchase

If yes to MO-21, what types of technology supports are you using?

Review the following categories. Which best describes the technology supports (assistive or remote supports) you use? Self-Made (Any type of adaptation or modification that you made or came up with) ; Applications (“Apps” that may be used on a cell phone, tablet, or computer); Equipment (medication systems, readers, talk boards, etc.); Other electronic or “smart” technology or software

Does your form of technology support require an internet connection?

If you need specialized technology (such as Apps or equipment), how is it funded?

During your plan meeting, did your case support coordinator tell you about other technology supports that might help you in your daily life?

If you receive technology supports from the Division and the technology came from or was set up by a service provider, did you have choice of technology provider?

Do you feel that technology supports have increased your quality of life? (Do you feel that technology supports have made your life better?)(Participation in community activities ; Building and maintaining relationships; Increased independence in performing daily activities; Independent manipulation/control of environment; Decreased need for support staff; Improved health ; Feel safer when alone; other

Have technology supports decreased your need for support staff?

Have you received enough training on how to use your current technology supports?

Are the current technology supports meeting your needs?

If no or maybe, why are the technology supports not meeting your needs?

Self- Direction

- Clarify definitions of what is and is not self-direction eg. Only waiver appendix E or formal Medicaid specific self-directed waiver programs? Only FMS, employer of record, etc?
- Clarify self direction as a *mechanism that can be used to manage own supports*. Clarify distinction between choice/self-determination/self-direction
- **Background information should indicate if person self-directs which informs self-direction domain) (states who do not have self-directions would not complete self-direction questions)
- Ensure indicators are updated to reflect current practice

BREAKOUT SESSION 2: Self-Direction

Self-Direction	People participate in directing their own supports and services	Please note, participation in a self-directed supports option (for the purposes of NCI) is determined by the use of budget authority and/or employer authority models. Items indicated with an asterisk (*) note items that may be answered by the proxy in his/her own perspective, if he/she supports the person receiving services to use the self-directed supports option.
		The percentage of people reported to be using a self-directed supports option
		The percentage of people reported to be using a self-directed supports option who report that they participate in decisions about how service budget is used
		The percentage of people reported to be using a self-directed supports option who report that they hire or manage staff*
		The percentage of people reported to be using a self-directed supports option who report having enough help in deciding how to use their individual budget/services*
		The percentage of people reported to be using a self-directed supports option who report that they can make changes to their budget/services if they need to*
		The percentage of people reported to be using a self-directed supports option who report they receive information about the balance of their supports budget*
		The percentage of people reported to be using a self-directed supports option who report that they receive information about their budget/services that is easy to understand*

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Service Coordination/ Person Centered Planning

- Are the value statements and indicators aligned . Do they need to be realigned?
- New expectations of case management that are not captured in indicators?
- Track satisfaction with timeliness and responsiveness



BREAKOUT SESSION 2: Service Coordination

Service coordination	Service coordinators are accessible and responsive to people. The service plan is responsive to people's goals and needs. People participate in the service planning process.	The percentage of people who report having met or spoken with their service coordinators
		The percentage of people who report that their case manager/service coordinators ask them what they want
		The percentage of people who report that they can contact their case manager/service coordinator when wanted
		The percentage of people who report that their staff come and leave when they are supposed to
		The percentage of people who report having taken part in their last service planning meeting (or had the option to take part but chose not to)
		The percentage of people who report having understood what was being talked about at the last service planning meeting
		The percentage of people who report having been able to choose what services were included in their service plan
		The percentage of people whose service plan included things that are important to them
		The percentage of people who report that the service planning meeting included people they wanted to be there
		The percentage of people who report that they remember what is in their service plan
		The percentage of people who report having discussed learning new things in their service planning meeting
		The percentage of people who report that their service plan includes things that are important to them
		The percentage of people who report that they know whom to ask if they want to change services
		The percentage of people who report that they want to increase independence in functional skills (ADLs) who are reported to have a related goal in their service plan
		The percentage of people who report that they want a job who are reported to have a related goal in their service plan



BREAKOUT REPORT OUT

People Who Participate in Surveys

- Strategies used currently to gain input and feedback into state specific NCI IPS questions/indicators
- Existing structures in states used to gather feedback/input from people with I/DD for general program



