



**NATIONAL CORE
INDICATORS®**
NASDDDS & HSRI

National Core Indicators®

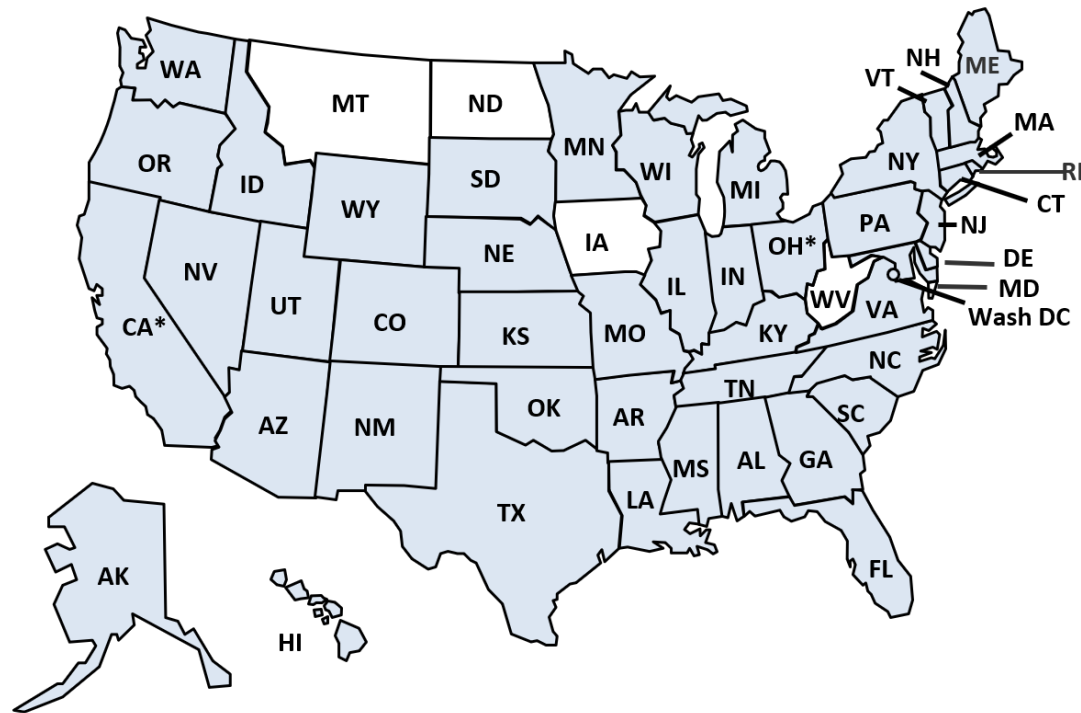
Florida Quality Council

October 2020

NCI Overview

State and national perspective

NCI Purpose

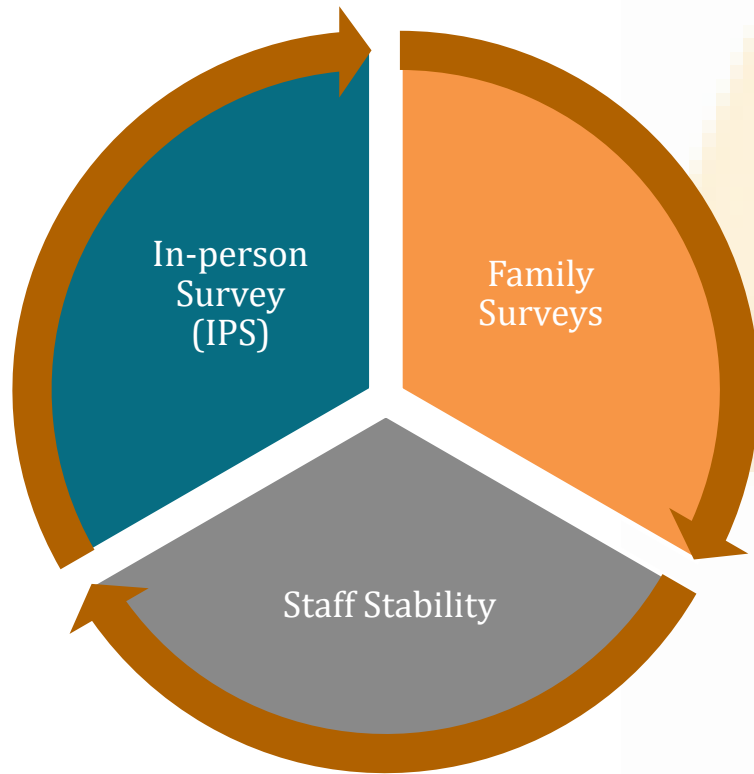


NCI is a *national* initiative that:

- Established a nationally recognized set of performance and outcome indicators for DD service systems
- Uses valid and reliable data collection methods & tools
- Report state comparisons and national benchmarks of system-level performance

You play a crucial role in collecting this information that is ultimately used to make people's services, and lives, better.

NCI Survey Tools



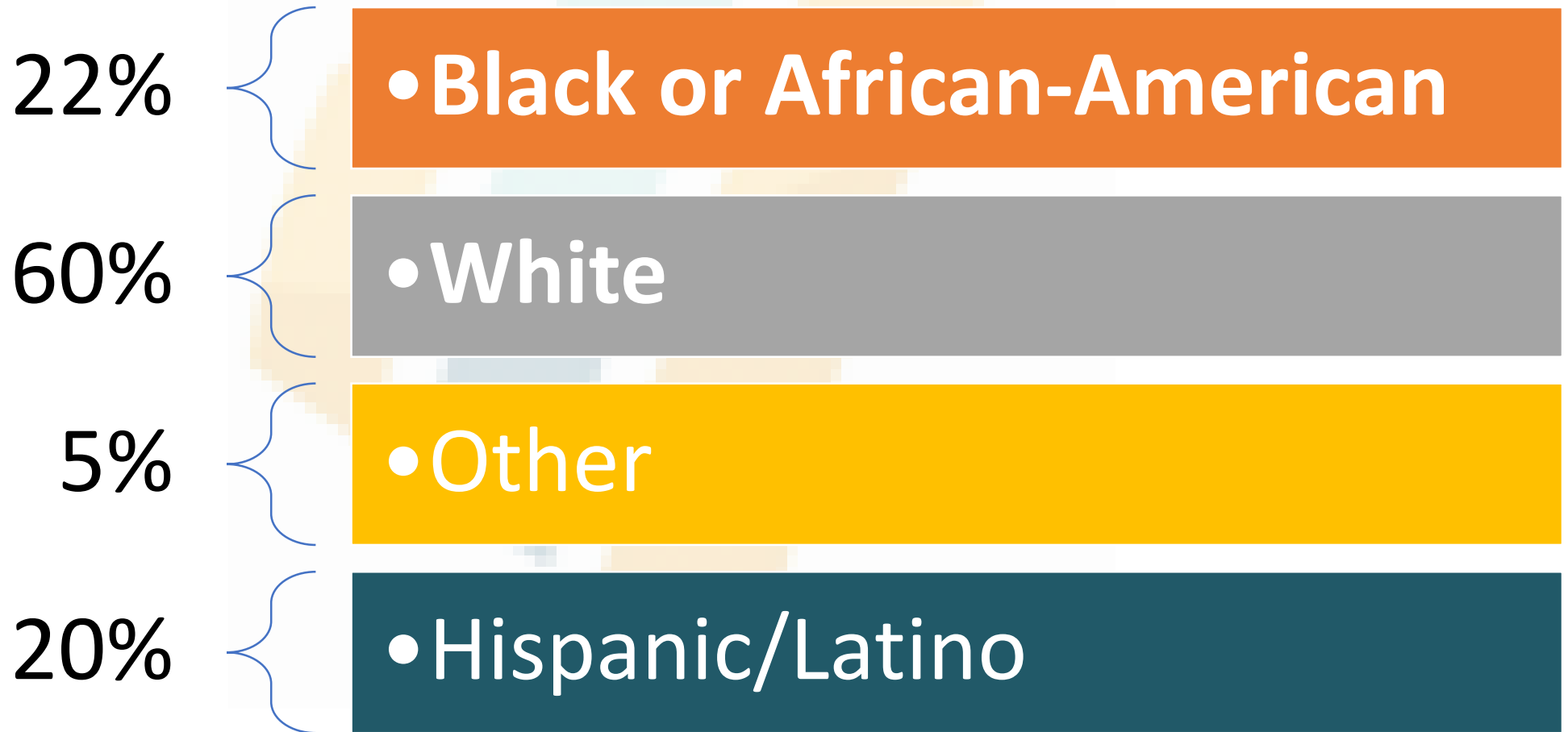
Adult Family Survey

- Respondents are typically family members and/or guardians of adults who have I/DD and receive at least one service in addition to case management from the state DD service system.
- The respondent lives with the adult receiving services.
- Florida collected **488** surveys.

Why these data are important

- NCI data collected will provide states with important pre-, during, and post-COVID service system and quality of life outcomes
- Data presented are based on the National Core Indicators COVID-19 Bulletin #5: Data from the Adult Family Survey; recommendations come directly from Bulletin
- The Bulletin emphasizes that [research](#) has shown:
 - The impact of COVID has been felt especially strongly by those who are not white and who have lower incomes.
 - Family caregivers compared to non-caregivers during the pandemic are especially vulnerable to isolation, anxiety and depression, exhaustion, food insecurity and financial distress

Race and ethnicity of family member receiving services



Age and Health of Respondents

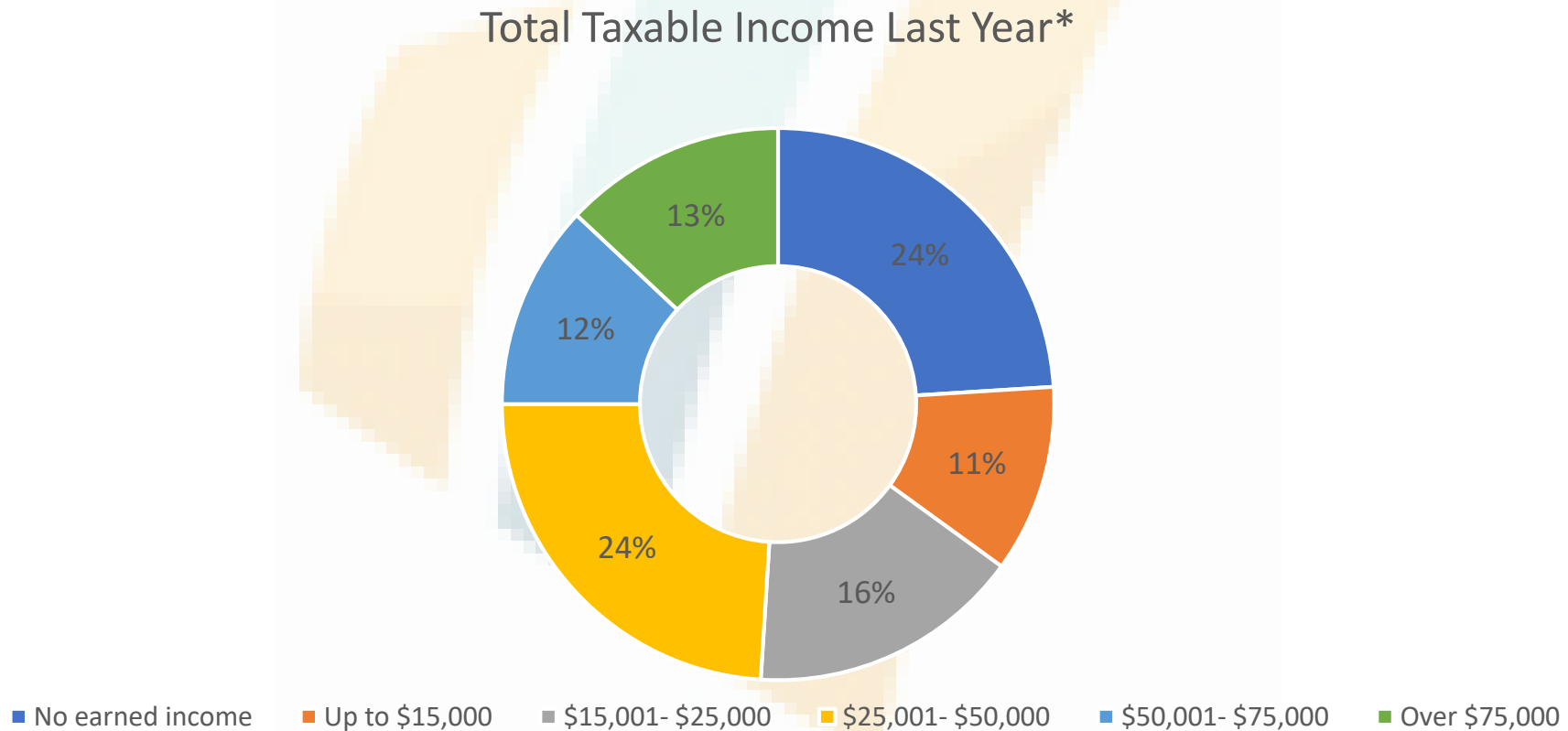
Nearly **80%** of respondents are **55 and older**.

- **21%** of all respondents were **75 and older**.

Almost **half** were in **fairly good** (40%) or **poor** (6%) health



51% reported a household income of \$25,000 or less



*Self reported data. Income does not include state/federal benefits such as SSI, SSDI, etc. Nineteen percent (19%) of respondents chose not to answer this question.

2020 HHS Poverty Guidelines for a household of four is an income of \$26,200



Behavior Support

Level of support family member receiving services needed for self-injurious, disruptive, or destructive behavior:

- **16%** Extensive
- **29%** Some
- **55%** None

Crisis, emergency and respite

Respondents reported they:

60%

Received crisis services
when needed

89%

Discussed how to handle
emergencies related their
family member's care at
the last planning meeting

27%

Could always use respite
services when needed

Crisis support during COVID

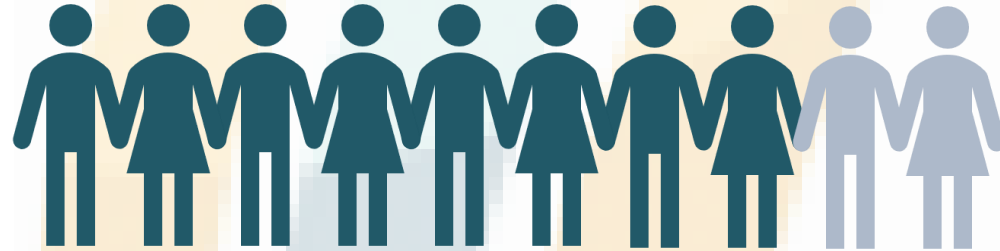
- During the pandemic, the use of telehealth has been introduced. To make telehealth useful to families who are unable to secure in-home crisis services, clinical staff will need to train families on how to use the technology, do an individualized assessment, and ensure that practitioners are trained on how to use this milieu to support families to implement specific interventions. They also need to develop the protocols/procedures to execute these services via telehealth.

Crisis support during COVID

- In the absence of traditional crisis services, families should have access to crisis lines including peer support lines, text crisis lines, crisis phone lines. To monitor the well-being of families and family members with IDD, it will be important for case managers to do frequent remote check-ins.
- Families coping with family members in crisis needs also need support for stress, anxiety and other mental health concerns. The American Psychological Association provides a range of strategies to relief stress and anxiety for caretaking families.

Access to Services

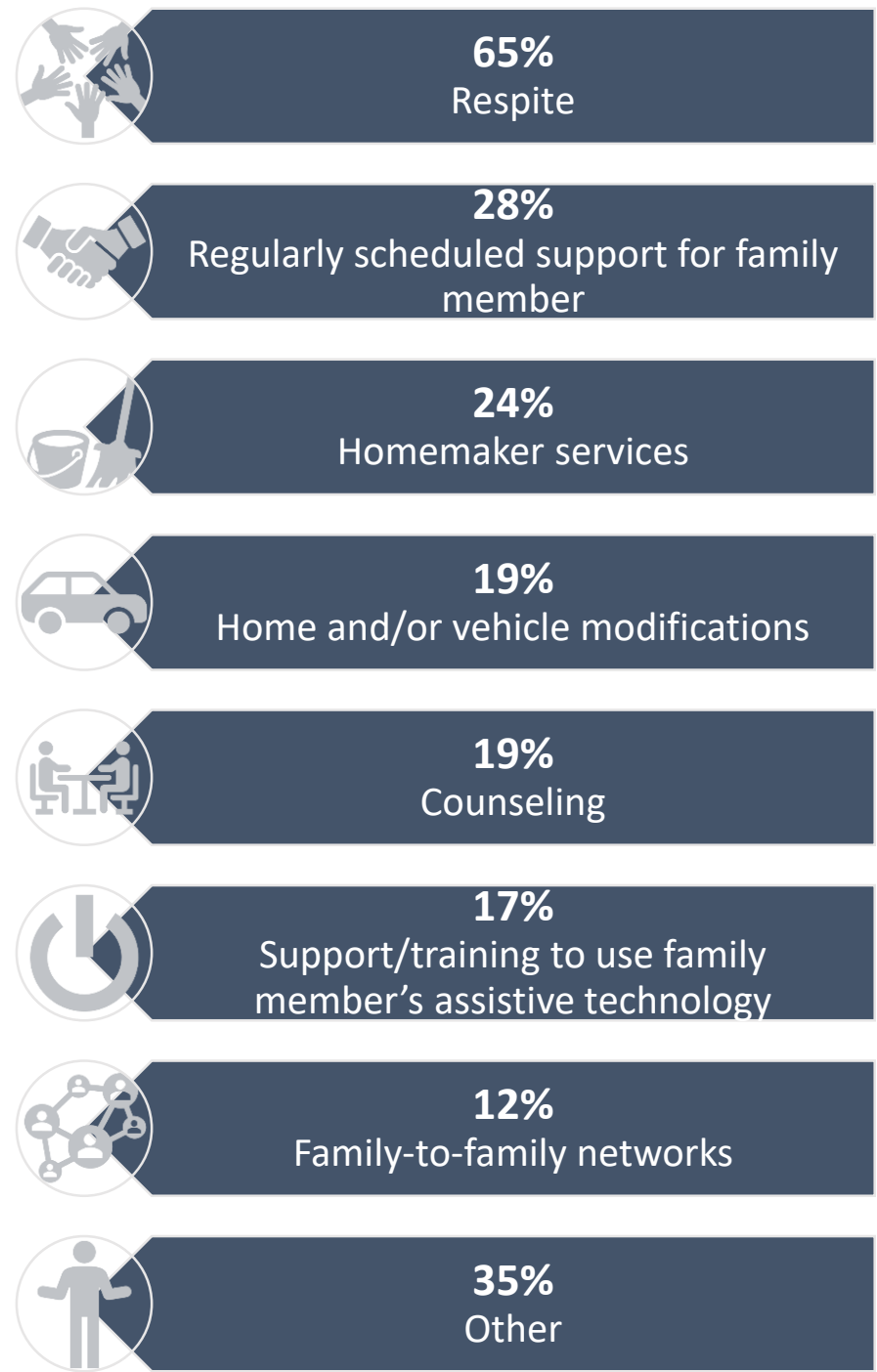
80% of respondents reported they have access to needed services



Respondents whose family member required some or extensive behavior support were less likely to have access to needed support

- **83%** no support needed
- **76%** some or extensive support needed

What additional supports are needed...



Services and supports during COVID

- Many day programs have “deconstructed” their day programs and have found ways to engage adults with disabilities in their own homes. Families should be made aware of these alternative programs and how to gain access.
- Returning to the first principles of family support is particularly important during this pandemic including that families have the information they need, are given choices and control over the supports they need, and that their expertise regarding the needs of their family member is recognized. The American Association on Intellectual and Developmental Disabilities and the Arc joint position paper lays out a comprehensive list of the foundations of family support.

Services and supports during COVID

- Given disruptions in services and supports, one way to minimize the impact is to give families more control and flexibility. [Self-direction is an option that provides families with more control by giving them the ability to manage a budget and hire staff.](#) Self-direction can increase the family's independence and expand their options.
- States have responded to the unique burdens placed on families during this pandemic by getting CMS approval to pay family members to provide care and support. Prior to the pandemic, 36% of families reported that a family member was paid to provide support to their family member [The Centers for Medicare and Medicaid Services – through the Appendix K procedure \(which allows for temporary discontinuance of waiver provisions\) allowed states to amend their waivers to include payments directly to family members.](#)

82%
reported their family
member took part in
community activities

What makes it hard for family members to take part in
community activities...



17%
Cost



12%
Lack of
transportation



11%
Stigma



10%
Lack of support staff



Community Resources and Networks

- **76%**
Reported there are resources in the community the family can use that is not provided by the DD agency
- **18%**
Took part in family-family networks

Staying connected during COVID

- States can make information available to families regarding support groups, local disability advocacy organizations, community organizations and other groups that can provide information and personal support, advice, and reassurance.
- It is also important that siblings of people with disabilities can reach out to other siblings for information, advice, and support. States can make available through their websites and other dissemination strategies local and state sibling networks.
- Publicly funded family supports centers and services are particularly important during this period given their mission to provide information, funding, and training to families with family members with disabilities. State IDD agencies should make sure that information regarding these services is readily available and accessible to families state-wide.



THANK YOU!!