



Human Services
Research Institute

NATIONAL CORE INDICATOR FAMILY MEMBER & GUARDIAN SURVEY INFORMATION

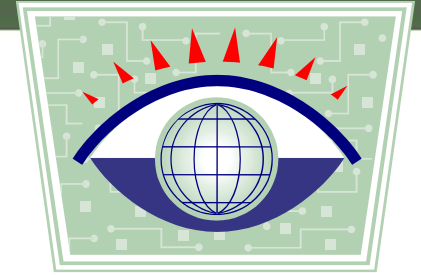
Florida Statewide Quality Council Meeting
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Overview of NCI

NATIONAL CORE INDICATORS

- Launched in 1997 as a collaboration between NASDDDS and HSRI, National Core Indicators (NCI) is a collaboration of state ID/DD agencies measuring how well public developmental disabilities systems serve and support people.
- Improving performance starts with measuring it – if you don't measure it, there is no guarantee that it will happen. NCI helps states measure performance over time against their own state benchmarks as well as against other states' benchmarks.
- 34 states and 22 sub-state regions have a 14-year database on over 22,000 individuals and families. Survey instruments are updated as desired outcomes of service evolve (e.g., competitive employment now measured).



NCI VISION

- Influence national and state policy
- Improve practice at the state, local and provider level
- Inform strategic planning and priority setting at state and national levels
- Include the voices of people with intellectual and developmental disabilities and their families in the conversation about quality and outcomes

Florida NCI Data Collection

In Florida, NCI data are collected by Delmarva 2 ways:

1. Adult Consumer Survey

- In-person conversation with a sample of adults receiving services to gather information about their experiences
- Keyed to important person-centered outcomes that measure system-level indicators

2. Adult Family and Family/Guardian Surveys

- Mail surveys are separate samples from Adult Consumer Survey
- Adult Family Survey to families with adult with ID/DD living with family
- Family/Guardian Survey to families with adult with ID/DD living outside their home

What are the NCI Core Indicators (e.g., Performance Measures)?

Outcomes for Adults Receiving Services:

- Employment
- Community Inclusion
- Choice and Decision-making
- Relationships

System Performance:

- Service Coordination
- Staff Turnover
- Incidents and Mortality



What are the NCI Core Indicators?

Outcomes for Families and Guardians:

- Information and Planning
- Choice & Control
- Access & Support Delivery
- Community Connections
- Family Involvement
- Satisfaction
- Impact of Services



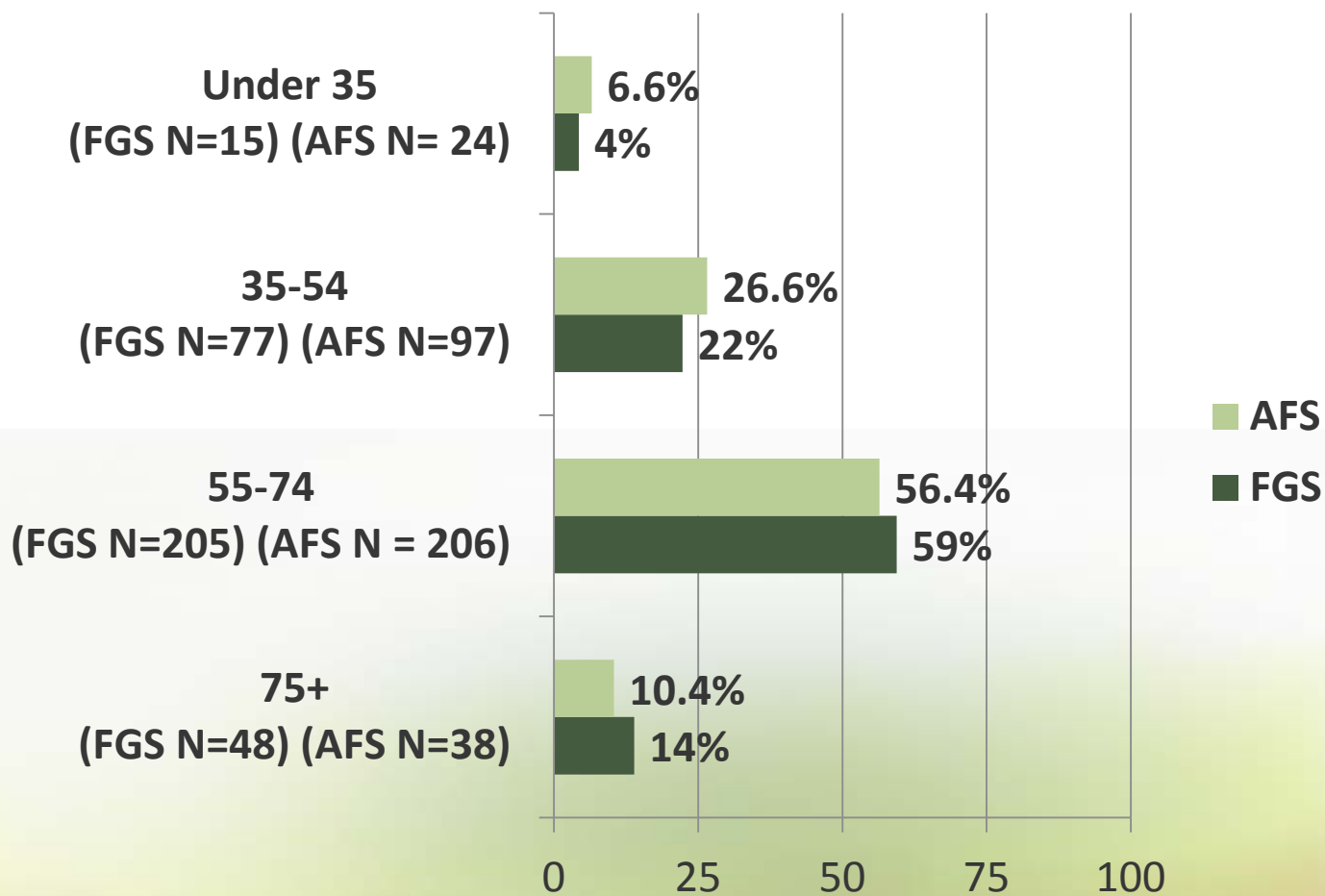


Florida NCI Information for Quality Improvement

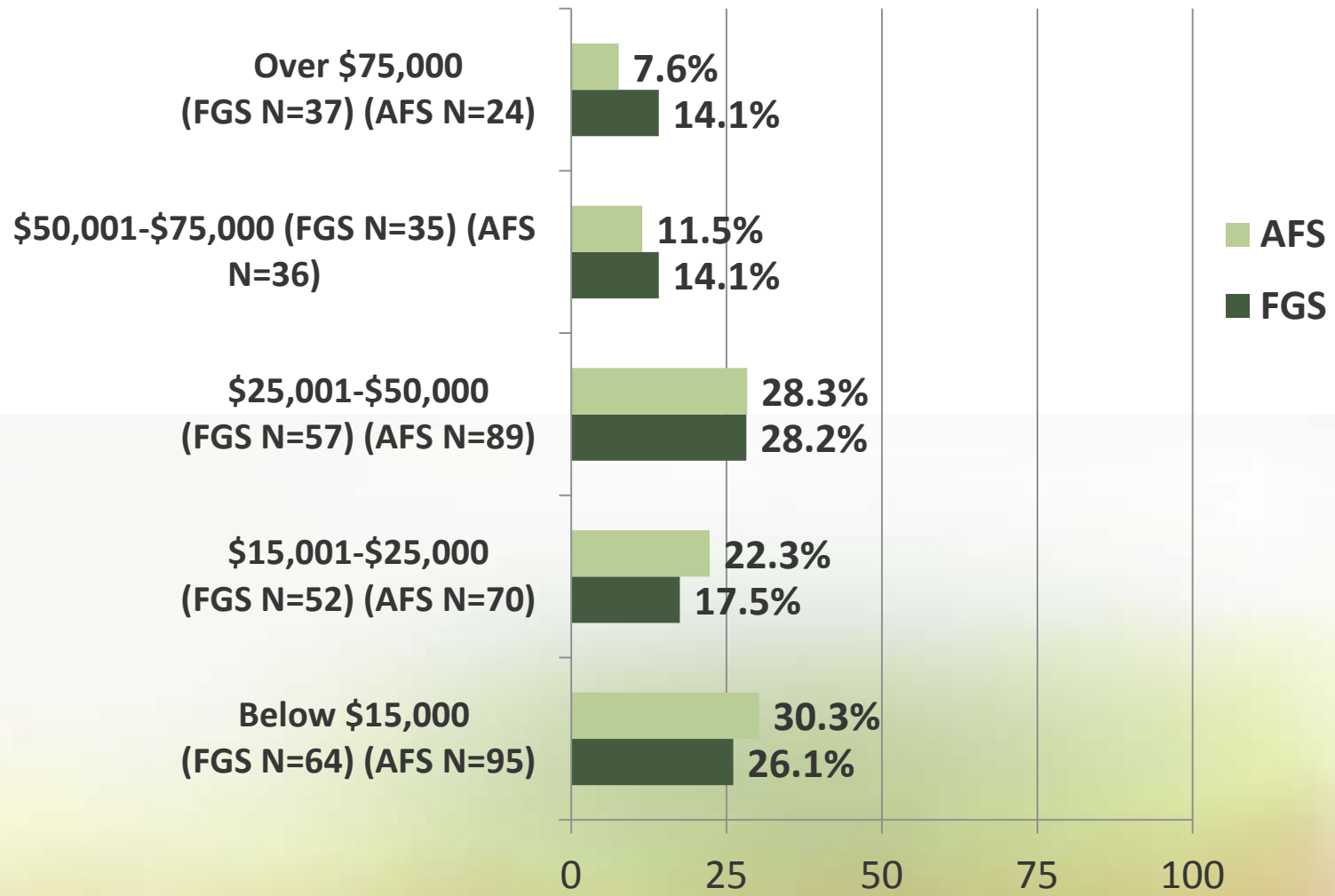
Quantitative demographic data presented from 2011-12 Adult Family and Family/Guardian Surveys. Other quantitative data presented from 2010-11 Adult Family and Family/Guardian Surveys

Qualitative data presented from 2010-11 and 2011-12 Adult Family and Family/Guardian Surveys

Age of Respondent



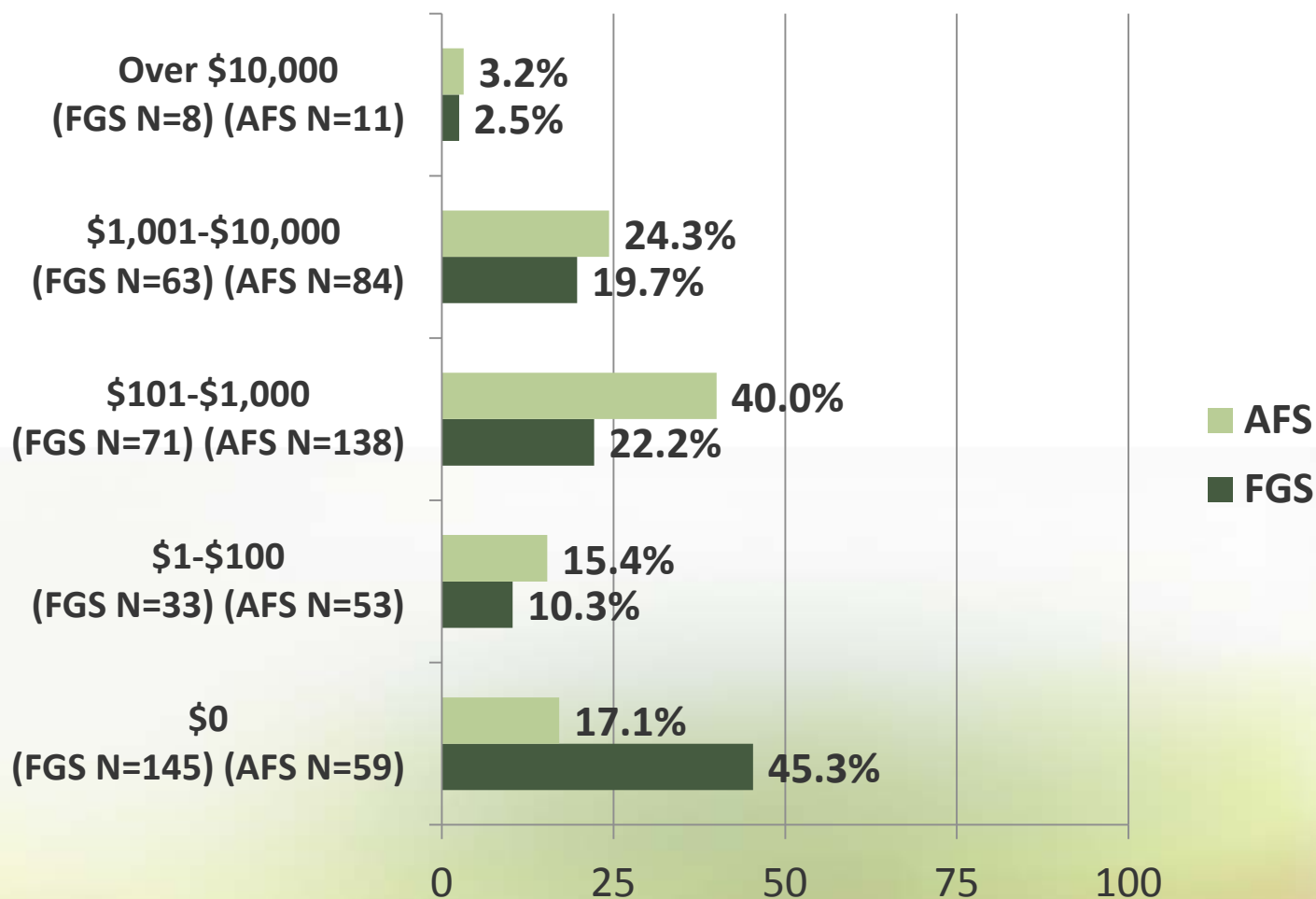
Household Income



Services Received

Survey Type	Day Program (unpaid)	Day Program (paid)	Vocational Training	Community Employment (unpaid)	Community Employment (paid)	Paid In Home Services	At home (by choice)	At Home (due to lack of services)
FGS	11%	52%	8%	0%	7%	7%	0%	2%
AFS	18%	34%	5%	6%	11%	22%	15%	7%

Out of Pocket Support Expenses



What do families and guardians have to say about changing times and State resources?

What quality improvement initiatives does the Florida Quality Council see in this data?



Information & Planning: AFS & FGS

Question	AFS*	FGS*
Enough information to be involved in developing plan services	71%	87%
Support Coordinator is generally knowledgeable	89%	98%
Service plan includes services & supports important to family	95%	93%
Received information about individual's rights	95%	87%
*Percent "yes" or combining "always" and "usually"		

Information & Planning: Themes Across 2 Years



Most Satisfied

- ✓ Support Coordinators
- ✓ Out of home day services
- ✓ CDC+

“Our case manager makes sure our family’s opinions and decisions are important and taken into consideration when making the planning.”

“I am satisfied with all the CDC+ program and orientation/help I receive from my coordinator.”



Least Satisfied

- ✓ Stop funding cuts!
- ✓ Support Coordinator more responsive, accurate information, longer tenure
- ✓ More services, especially dental

“There is always warnings and harassment with regard to services being cut from APD and around the news. This is very stressful.”

“Better communication from support coordinator to provide more feedback and better explanation of services, resources, etc.” “To be informed -- have a support coordinator for more than 4 months.”

Access and Service Delivery: AFS & FGS

Question	AFS*	FGS*
Contact workers when need to?	93%	91%
Contact Support Coordinator when needed?	93%	94%
Do services change when needs change?	80%	80%
Is there consistency in support workers?	89%	74%
Dental services?	Not in survey	67% (below NCI average)
*Percent “yes” or combining “always” and “usually”		

Access & Service Delivery: Themes Across 2 Years



Most Satisfied

- ✓ Having services (in home personal care & companion services, out of home day programs & volunteer work)
- ✓ Support Coordinator

“Now more respite services available, which I did not ever use before. Recently had knee surgery, so was very thankful for the help of a caring respite worker.”



Least Satisfied

- ✓ Dental care
- ✓ Stop budget cuts!
- ✓ Additional respite, both in home and center based

“BUDGET!! It is very upsetting that my child cannot attend the day program even though it has been approved due to the budget being ‘frozen’!”

“Medicaid will not pay for sedated dental care which he requires.”

Choice and Control: AFS & FGS

Question	AFS*	FGS*
Family member choose agency or providers that provides support?	55%	51%
If so, more than one service provider choice?	89%	90%
Choose individual workers that support him/her?	53% (above NCI average)	47% (above NCI average)
Know how much money is spent by APD on supports & services?	59% (above NCI average)	91%
*Percent “yes” combining “always” and “usually”		

Choice and Control: Themes Across 2 Years



Most Satisfied

- ✓ Use of funds & options to choose among services & providers / CDC+
- ✓ Support Coordinator

“I’m on CDC. Happy being able to employ family members that I trust. Would not just pick someone from a list.”

“Consumer directed care allows us to spend money on services where needed!”

“Availability of support coordinator is essential to allow for choice and control as much as possible with funding limits.”



Least Satisfied

- ✓ Dental care -transportation, dental visits, sedation, dentists closer to home
- ✓ Stop budget cuts!
- ✓ More respite – in home & center based

“BUDGET!! It is very upsetting that my child cannot attend the day program even though it has been approved due to the budget being ‘frozen’!”;

“Medicaid will not pay for sedated dental care which he requires.”

Community Connections: AFS & FGS

Question	AFS*	FGS*
Enough support to volunteer/work in community (e.g., support workers, community resources)?	58%	69%
Do either the Support Coordinator or support workers help connect family member to community activities?	50%	69%
*Percent “yes” combining “always” and “usually”		

Community Connections: Themes Across 2 Years



Most Satisfied

- ✓ Community connections are available to access range of activities whether via family or in home support staff or facility staff

“She volunteers 4 days a week at the hospital and provides lots of worthwhile services to others.”

“I’m very satisfied that the general community is very receptive and tolerant of people with disabilities.”



Least Satisfied

- ✓ More recreation and social activities
- ✓ More services/hours (PCA, companion, augmentative communication, adult day).

“Not enough resources for support coordinators to assist us in getting enough and the right services for our family member. Feel they are very limited in what is available to them.”

“Until 9/2010, he was funded for and attended adult day training program at (name). However the staff in his room did little if anything other than have the ‘consumers’ watch DVDs. After several years of this, our son began to refuse to go....”

Satisfaction with Services and Supports: AFS & FGS

Question	AFS*	FGS*
Are you familiar with how to file a complaint or grievance?	70%	71%
If you filed, satisfied with provider response?	86%	84%
Know how to report abuse or neglect?	87%	80%
In past year, did you report abuse or neglect?	4%	17%
If you reported, were authorities responsive?	N too small	100%
*Percent “yes” combining “always” and “usually”		

Satisfaction Services and Supports: Themes Across 2 Years



Most Satisfied

- ✓ Quality of staff
- ✓ Support Coordinator

“My son has grown and matured a great deal due to (companion’s name).”

“My brother has a life with the day program; he has a sense of independence with transportation provided and he feels loved and a part of a special group.”



Least Satisfied

- ✓ Stop budget cuts! Need more hours of services
- ✓ Support Coordinator

“My brother needs to be in a home where he can be supervised. He tried to cook something before I got home from work and set a paper plate on fire; luckily he did get it to the sink. He also got in his medicine, I didn’t know what or how much he had taken.”

Outcomes: AFS & FGS

Question	AFS*	FGS*
Do services & supports make a positive difference?	97%	100% (FL only state 100%)
Have services or supports been reduced, suspended, or ended in past year?	46%	42%
If yes, did service reductions affect family member's home, relationships, or work?	75%	60%
*Percent "yes"		

Outcomes: Themes Across 2 Years



Most Satisfied

- ✓ Relieved to be receiving services

“To most people, my son is just another number & the services he receives are not necessary since he lives with family. If it wasn’t for the help we receive, he would not have the quality of life he has, and we his family, would not be able to have him live at home where he is most happy. To reduce or do away with these services would be a great disservice to a wonderful person.”

“Ms. (name) lives a very full life as normally as possible which I attribute fully to her support coordinator, (name).”



Least Satisfied

- ✓ Service reductions; living with threat of budget cuts & uncertain planning for future
- ✓ Dental care

“Stop trying to reduce budget based on past usage. This makes it impossible to plan, is arbitrary & has nothing to do with real needs of clients.”

“Behavior supports should be provided in a proactive way and sustained. Come in only when individual is out of control does NOT help sustain positive outcomes. Focus on PBS BEFORE reaches crisis stage!”

Federal and State Emphasis on Quality Improvement

- Centers for Medicare and Medicaid Services (CMS) expects states to remediate individual situations but also to respond to trends in the data.
- In reviewing evidence, CMS looks to see if continuing compliance issues are identified through quality improvement initiatives.
- CMS expects States operating home and community based waiver programs to reviews trends, report how quality improvement strategies are developed, and the ways strategies are evaluated for effectiveness. Having a review of NCI data by the Statewide Quality Council is one strategy.



Florida Family and Guardian Survey Data

Areas for Quality Improvement Projects

“Will this survey help anything?”



Data Spotlight

- **Demographics:** Large and growing number of people live with families. Significant percent are poor elders using in home and out of home services. Elder caregivers may need services themselves (67% AFS and 73% FGS are 55 years of age and older). Few adults with ID/DD are working though substantial percent use day services. If day services were redirected to fund work supports, these individuals could contribute more to their families' out of pocket expenses.
- **Information and Planning:** More information could be useful. Support Coordinator makes or breaks family member/guardian experience. Responsive and caring ,even when services reduced, matters.
- **Choice and Control:** Only half families and guardians have choice of agency or of individual providers. Many in home families don't know how much money is spent for services. Once familiar with CDC+, program is highly valued.
- **Access and Delivery of Services:** 20% report services don't change when a persons' needs change. Dental care is not available or insufficient for many people dependent on Medicaid.

Data Spotlight

Community Connections: Substantially more direct paid supports and Support Coordinator assistance are reported necessary to realize.

Satisfaction with Services and Supports: 30% of families and guardians do not know how to file a complaint or grievance. A substantive percent also do not know how to report abuse or neglect.

Outcomes/ Impact of Services: When people are receiving paid services, it has a positive impact on their lives. Almost half of these families and guardians experienced service reductions/suspensions/ or terminations in preceding year; and most of them note that this affected their lives.

Most family members and guardians are extremely thankful and appreciative of supports and services – especially if they have a responsive and caring Support Coordinator who sticks around. Satisfaction and appreciation is high too if they have enough information to use CDC+ program and choose own staff and services.

National Core Indicators (NCI) Resources

- Link to NCI website:
<http://www.nationalcoreindicators.org/indicators/>
- Link to NCI National Adult Family Survey Reports:
http://www.nationalcoreindicators.org/upload/core-indicators/2010-11_AFS_Final_Report.pdf
- Link to NCI National Family Guardian Survey Reports:
http://www.nationalcoreindicators.org/upload/core-indicators/2010-11_FGS_Final_Report.pdf
- Link to Florida Adult Consumer Survey Reports:
<http://www.nationalcoreindicators.org/indicators/>



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