



# Florida Statewide Quality Assurance Program

## Family Café June 2013

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## Objectives

1. Provide overview of the surveys and their purpose.
2. Discuss Florida survey data.
3. Discuss strengths and areas of opportunity from survey data for Florida.
4. Provide resources to find ongoing and additional information.



# **National Core Indicators Adult Family and Family/ Guardian Surveys**



# Overview of National Core Indicators (NCI)

- Launched in 1997 as a collaboration between NASDDDS and HSRI
- Currently 34 states and 22 sub-state regions
- Unparalleled 14-year database collects information on over 22,000 individuals and families.
- Survey instruments are updated as desired outcomes of service evolve (e.g., competitive employment now measured).
  - Ideas for changes come from interviewers in the field, NCI team, NASDDDS Research Committee, etc.





## NCI Premise

- National Core Indicators (NCI) is a collaboration of state ID/DD agencies interested in measuring how well public developmental disabilities systems serve and support people.
- Improving performance starts with measuring performance – if you don't measure it, there is no guarantee that it will happen.
- NCI helps states to measure performance:
  - Over time (change from baseline)
  - Against multi-state benchmarks (FL performance compared to other states' performance)



## Florida NCI Data Collection

- In Florida, NCI data are collected by Delmarva 2 ways:
- 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
- Adult Family and Family/Guardian Surveys
  - Mail surveys – separate sample from Adult Consumer Survey



# National Core Indicators Overview: Delmarva's Role

- Pull sample
- Mail Surveys to Participants
- Field Questions from Participants
- Collect survey responses from Participants
- Enter Data from Surveys





# National Core Indicators Survey Overview

## Adult Family Survey

- 18+
- Lives at home
- Receive at least one service in addition to Support Coordination
- Survey mailed out to participant

## Family /Guardian Survey

- 18+
- Lives out of home
- Receive at least one service in addition to Support Coordination
- Survey mailed out to participant



# Florida NCI Data Collection Response Rates

- **Adult Family Surveys:**
  - 2010-11: 1,700 mailed, 471 returned, 28%, 400 valid
  - 2011-12: 373 valid
- **Family/ Guardian Surveys:**
  - 2010-11: 1,100 mailed, 308 returned, 28%, 289 valid
  - 2011-12: 360 valid surveys



## National Core Indicators Overview: Domains

Information  
and Planning

Choice &  
Control

Access &  
Support  
Delivery

Community  
Connections

Satisfaction

Outcomes

## National Core Indicators Overview: Domains

### Information and Planning

**“Families/family members with disabilities have the information and support necessary to plan for their services and supports.”**

### Examples of Questions:

- Do you get enough info to participate in planning?
- SC Respect choices?
- SC tells about public services?
- Did respondent/family member help develop plan?
- Support Plan include all services/supports family member needs?

## National Core Indicators Overview: Domains



**Choice &  
Control**

**“Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.”**

### Examples of Questions:

- Able to contact SC and Providers as needed?
- SC and Providers are available when needed?
- SC and Providers can communicate in preferred language?
- Providers have right training?
- Supports are respectful to family culture?
- Access to services, medications?
- Satisfaction with transition process ?



## National Core Indicators Overview: Domains

**“Families/family members with disabilities get the services and supports they need.”**

A green oval containing the text 'Access & Support Delivery' in white, bold, sans-serif font.

**Access &  
Support  
Delivery**

### Examples of Questions:

- Respondent/Family member choose SC's and Providers?
- Respondent/Family member know how much money is allocated and spent by agency?
- Respondent/Family member have control over how money is spent by agency?



## National Core Indicators Overview: Domains

**“Families/family members use integrated community services and participate in everyday community activities.”**

**Community  
Connections**

### Examples of Questions:

- Family member participates in community?
- Family members has friends outside of staff and family?
- Family member has supports to volunteer in the community?

# National Core Indicators Overview: Domains

## Satisfaction

**“Families/family members with disabilities receive adequate and satisfactory supports.”**

### Examples of Questions:

- Are you familiar with how to file a complaint or grievance?
- If you filed, satisfied with provider response?
- Know how to report abuse or neglect?
- In past year, did you report abuse or neglect?
- If you reported, were authorities responsive?



## National Core Indicators Overview: Domains

### Outcomes

**“Individual and family supports make a positive difference in the lives of families.”**

### Examples of Questions:

- Do services & supports make a positive difference?
- Have services or supports been reduced, suspended, or ended in past year?
- If yes, did service reductions affect family member’s home, relationships, or work?



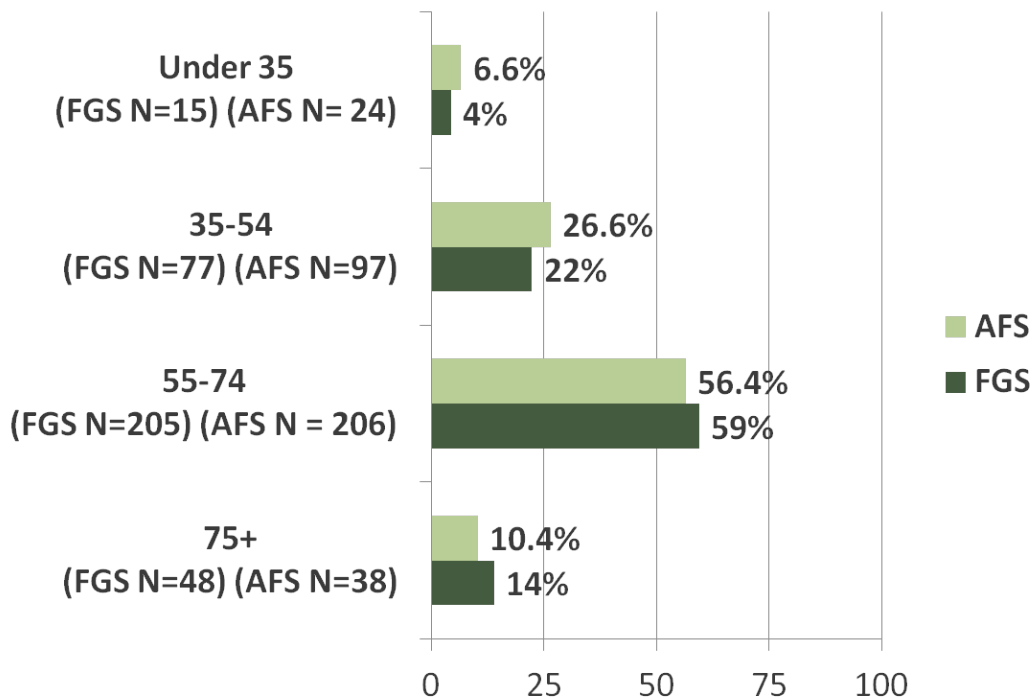
# Mid Session

## Questions?



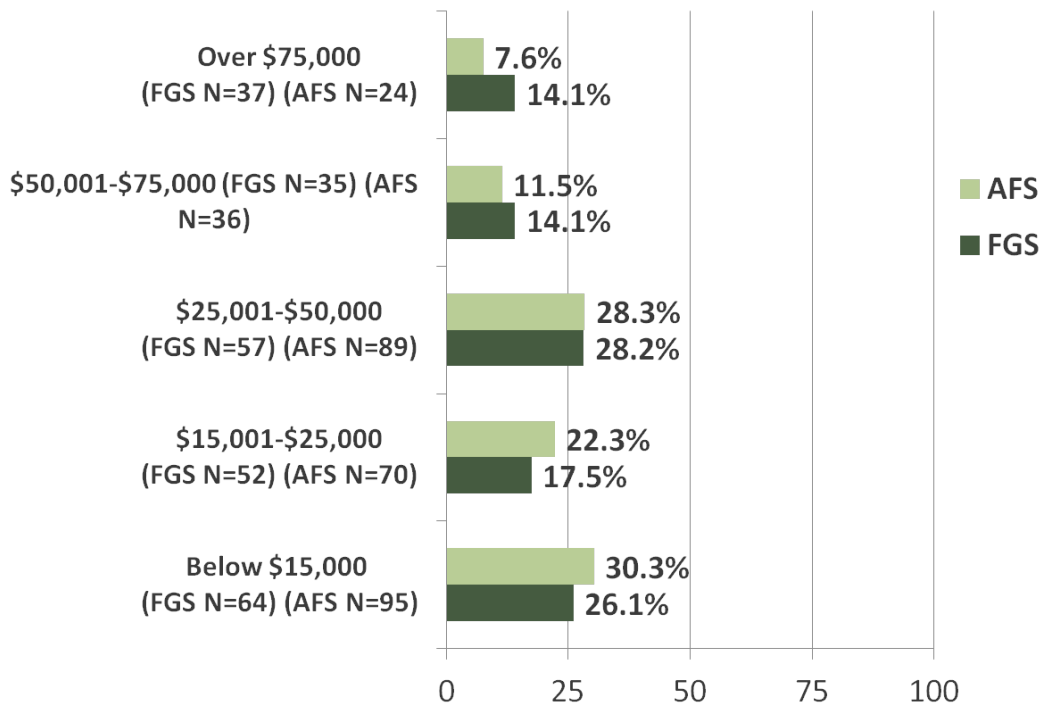
# Demographic Data

## Age of Respondent



# Demographic Data

## Household Income

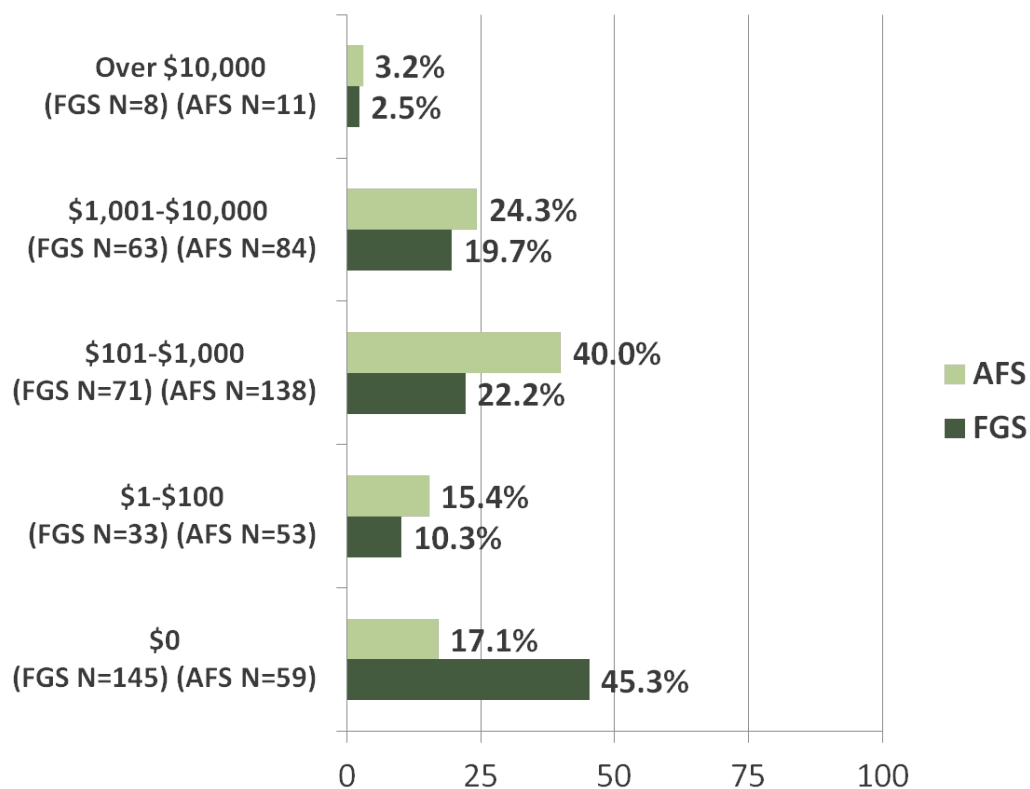




# Services received

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 Expenses





## 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.” 24





## Choice and Control: AFS & FGS

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

“Give families more choices in support providers, and let them know the amount of money available for the family member. Give them choices on what the money can be used for.”



## 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

“I haven't had help with (individual) in 4 months. I'm 78, he is 52 and it's hard for me to handle him . He is going downhill; he can't do things he used to do. So get us some good help.”

“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."

"More day options for adults, day programs, job training, ongoing social speech groups, therapy after they leave the school district"



# Satisfaction with Services and Supports: AFS & FGS

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



## Satisfaction Services & 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

"Agency almost always sent people who were acceptable and blended with our family. Since the severe budget cuts, it is much harder for the agency to find people willing to work for lowered wages."

"Agencies need to be held accountable when they fail to provide adequate services for people with intellectual disabilities - especially when those services are paid for with government funding."





## 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**

“We are pleased that our son has the services and supports that he has. They help him lead a good life and be a good person and citizen in the community. These services do the job they were intended for and help him be more independent.”

“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**

“As elderly parents we could not keep our son at home if he lost his day program. It gives us a chance to do the things necessary to give him a safe and happy home. The continual threats of budget cuts to day programs are a nagging stress inducer that families like ours do not need!!!”

“Every time we have a cut on (individual named) services we suffer tremendously.”



## Adult Family Surveys and Florida Written Comment Trends/Concerns:

- Education about Support Planning process
- Budgets
- Access to resources
- Access to transportation
- Access to therapies
- Concerns about aging caregivers and futures planning



## Family/ Guardian Surveys and Florida Written Comment Trends/Concerns:

- Budgets
- Access to resources, educational opportunities
- Access to transportation
- Access to therapies
- Desire more communication/responsiveness from supports
- Turnover of supports



## What Have We Learned

- Florida has a higher percentage of older caregivers
- Transition services not viewed as effective
- Generally positive views of SC's and Providers
- Abuse, Neglect, and Exploitation remain a concern
- Lack of access to all services including mental health and dental



## Resources and Source Documents

- Human Services Research Institute (HSRI):  
[www.hsri.org](http://www.hsri.org)
- National Core Indicators (NCI):  
<http://www.nationalcoreindicators.org/>
- Delmarva Foundation for Medical Care:  
[www.dfmc-florida.org](http://www.dfmc-florida.org)



## Resources

Agency for Persons with Disabilities  
(APD): <http://apd.myflorida.com/>

Agency for Healthcare Administration  
(AHCA): <http://ahca.myflorida.com/>



# Please Complete the Training Evaluation

All Review Tools & Procedures are posted to  
Delmarva's Florida website

[www.dfmc-florida.org](http://www.dfmc-florida.org)

Thank You!!!





# Questions?





## Contact Us

### Delmarva Foundation

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## List of Abbreviations

AFS – Adult Family Survey

AHCA- Agency for Health Care Administration

APD- Agency for Persons with Disabilities

CMS – Centers for Medicare and Medicaid

AFS – Adult Family Survey

FGS – Family/Guardian Survey

HCBS – Home and Community Based Services

HSRI – Human Services Research Institute

NCI – National Core Indicators

SC- Support Coordinator