

# National Core Indicators Summary of Family Survey Results Fiscal Year 2008

Presented at the June 4, 2009  
RCOC Board of Directors Meeting  
by LeeAnn Christian and Larry Landauer

Last year, RCOC mailed more than 12,000 National Core Indicator surveys to the families we serve. Tonight, I'll be presenting the survey results and Larry will be discussing how the results are being used to make decisions about future directions for RCOC.

The National Core Indicators project generates an enormous amount of information so it's impossible to present it all at once. Tonight, the goal is to review the results that we want to focus our attention on in the near future and again, to communicate to the Board and the community how the data are being or will be used to drive policy and procedural changes at RCOC.

## Brief History of NCI and RCOC Participation

- Collaborative effort between HSRI (Human Services Research Institute) and NASDDDS (National Association of State Directors of Developmental Disabilities Services) that began in 1997
- Purpose: develop nationally recognized performance and outcome indicators that would give state agencies a way to measure their own performance and to see how they compared to other states
- RCOC joined in 2001

First, a brief history of the National Core Indicators project and RCOC's participation in it. NCI started as a joint effort between the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services in 1997 with 7 participating states.

The goal of the project was to develop performance and outcome indicators that would become nationally recognized and to give state developmental disabilities agencies a way to measure their own state's performance over time and to compare their performance to other participating states.

And in fact, they have met their goal as NCI now has benchmarks of performance so that state leaders and policy makers can evaluate their own state's performance.

There are now 31 participating states or regional developmental disabilities systems! We joined the project in Phase IV (FY02) and we just ended our sixth year of data collection. We were the only regional area involved until 2005 when the Regional Bay Project joined NCI. However, they do not fully implement the NCI project as we do.

It's important to note that even though RCOC is a regional system, we are much larger than many of the participating states (e.g., Connecticut, Rhode Island, Washington State). For example, RCOC has more SCs than the whole state of Washington.

There have never been any problems with comparing our data to statewide data because of our size.

## Core Indicators and Data Sources

### ■ Key Indicators

- Level of consumer satisfaction
- Choice and control of daily circumstances
- Types of employment opportunities

### ■ Data Sources

- Consumer Survey
- Family Surveys (4 distinct groups)
  - Adult Family Survey (at home, 18+)
  - Family Guardian Survey (out-of-home, 18+)
  - Children Family Survey (at home, <18)
  - Early Start Survey (birth to 3, RCOC developed)

NCI's core indicators represent about 60 consumer, family, health and safety, and other outcomes. The majority of outcomes relate to consumers (that is, people with developmental disabilities and their families) and revolve around satisfaction, choice, and employment.

These outcomes are important to understanding the overall health of state agencies providing services to individuals with developmental disabilities.

To collect data on all the indicators, NCI developed several surveys.

The primary data sources include:

consumer survey (e.g., focusing on empowerment and choice issues) – these are face to face interviews that take anywhere from 20-60 minutes. Each state is required to randomly sample 400 consumers.

At RCOC, our goal is to conduct surveys with at least 600 randomly selected consumers because that ensures that we have a representative sample from the ≈ 7500 people we serve who are 18+. We will be conducting these surveys again later in the year.

family surveys (e.g., focusing on satisfaction with services and supports) – these are paper and pencil surveys that are mailed to families. Each state is required to mail them to a random sample of 1000 families.

At RCOC, we have decided to interview all families instead of just surveying a random sample. Each year we mail 10,000+ surveys. NCI developed three distinct family surveys: Adult Family – adult child, over 18, living at home; Family Guardian – adult child, over 18, living away from home; Children Family – children 0-18 living at home.

In 2004, we decided to create an Early Start survey so we could tease out potential differences in responding based on the age of the child. As such, we now send Child Family surveys only to families who have children three to 18 living at home and Early Start surveys to families whose children are birth to three.

## 2008 Family Survey Results

- Response Rates range from 20-28% which is generally accepted as reliable in producing results that represent the targeted populations
- Consumer Characteristics – generally unchanged over the history of family surveys except for:
  - Average age for adult surveys was 43 years – in earlier years it was 32 years
  - Increasing trend in autism
- Respondent Characteristics – generally unchanged over the history of family surveys. Major point for RCOC:
  - 61% of family members with adult children living home are 55 years or older (14% 75+)

Before delving into the results themselves, here's some background and demographic information.

### Response Rate

Of the more than 12,000 NCI surveys sent last year, more than 2700 usable surveys were returned so our overall response rate was 22.5%. The range of response rates based on survey type and primary language ranged from 20% (CFS) – 28% (GFS).

Our response rates are generally accepted as reliable in producing results that we can have confidence in – in other words, we can be confident that these results are representative of the general population of the families we serve.

### Regarding Consumer Characteristics...

Each family member who completes a survey is asked to provide information about their family member with a disability. In general, the age, gender, disability, primary language and ethnicity of the family members with disabilities has been about the same since 2002 with two exceptions:

- \* The average age of adult consumers was 43 years old for the past few years, but prior to that it was 32 years old. (current avg. is 36 with min 18 max 90)
- \* There has been an increasing trend across years in the percent of family members who reportedly have a diagnosis of autism, which is in line with the increasing trend we are seeing across the state and at RCOC (currently 24%).

### Regarding Respondent Characteristics...

Each family member who completes a survey is also asked to provide some general information about themselves. In general, age, income, health status and other variables have remained relatively unchanged over the years. However, it is important to note that 61% of family members with adult children living at home are 55 years or older and 14% of those are 75 years or older. This is important information to have as we work with aging parents about what the future holds for their adult children who are still living at home.

## RCOC Report Card

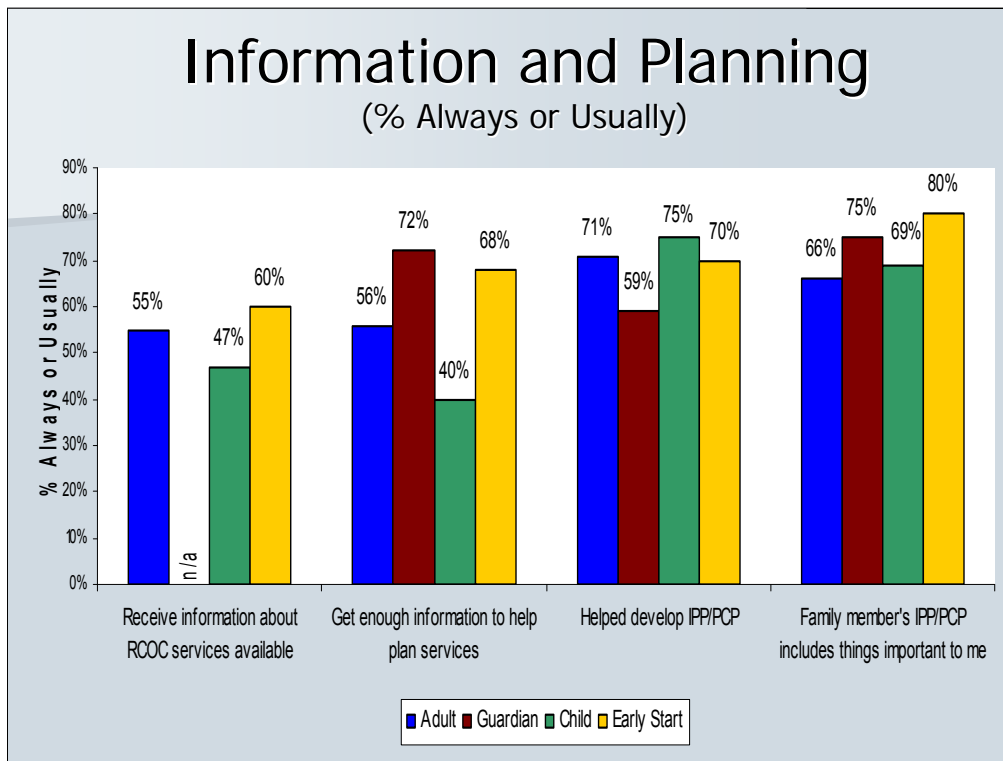
Survey Type	Compared to	Information and Planning	Access and Delivery	Community Connection	Satisfaction and Outcomes
Adult	RCOC Previous	=	=	↓	-5% =
	<i>FY08 Overall State Average</i>	=	=	↓	-4% =
Guardian	RCOC Previous	=	=	=	=
	<i>FY08 Overall State Average</i>	=	=	↓	-7% =
Child	RCOC Previous	↑ +3-11%	=	=	=
	<i>FY08 Overall State Average</i>	=	=	↓	-5% =
Early Start	RCOC Previous	=	=	=	=

Before getting into the details, this report card was developed to give you a bigger picture view of how RCOC's 2008 survey results compare to our results in previous years and to the 2008 overall state averages. The table is divided by survey type (i.e., adult, guardian) and by four of the core indicator domain areas (i.e., Information and Planning, Access and Delivery of Service).

A large copy of this report card is in your packet so you can have it as a point of reference as I go through the rest of the presentation.

Of course, what stands out here is the Community Connections domain. We have struggled over the years in this area and have continually had results that are lower than the other states and for the adult survey this year, lower than our results in previous years. In general, there has been a 5-7% deviation between our results and the state averages in the area of Community Connections.

In the Information and Planning domain we saw improvement in our Child Survey results in 2008 where we saw a 3-11% improvement in some of the responses. This is especially good news because families with children 3-18 are the least satisfied group, not just for RCOC, but across the nation so we are excited to see the improvement.



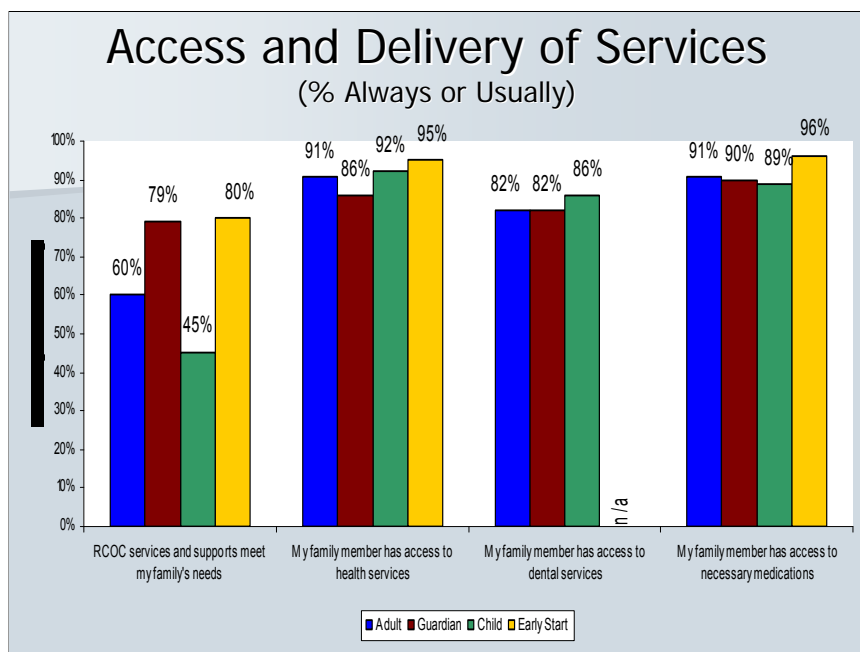
In the Information and Planning Domain, one of the core indicators of interest is:

The proportion of families who report they are informed about the array of existing and potential services available and they have the information needed to skillfully plan for their family member's services and supports.

Results for the first two questions have been relatively stable across years. It seems that some of this is a result of a continuing perception that we hide information from families. We are always making efforts to change that perception.

*Keep in mind that they represent those who responded “always or usually”. There is also a “sometimes” response which, depending on the question, was chosen by 25-35% of families for these questions. When you add those two responses together, you are talking about 70-90% of the respondents. In other words, a low percentage of respondents are saying No to these questions.*

As you can see, the CFS has the lowest response on several of the questions, but even so, some of these responses are the best ever with increases of 5-11% from past years for “helped develop IPP” and the “IPP includes things important to me”.



Now we move to the area of Access and Delivery of Services.

The core indicator of interest here is the proportion of eligible families who report having access to an adequate array of services and supports.

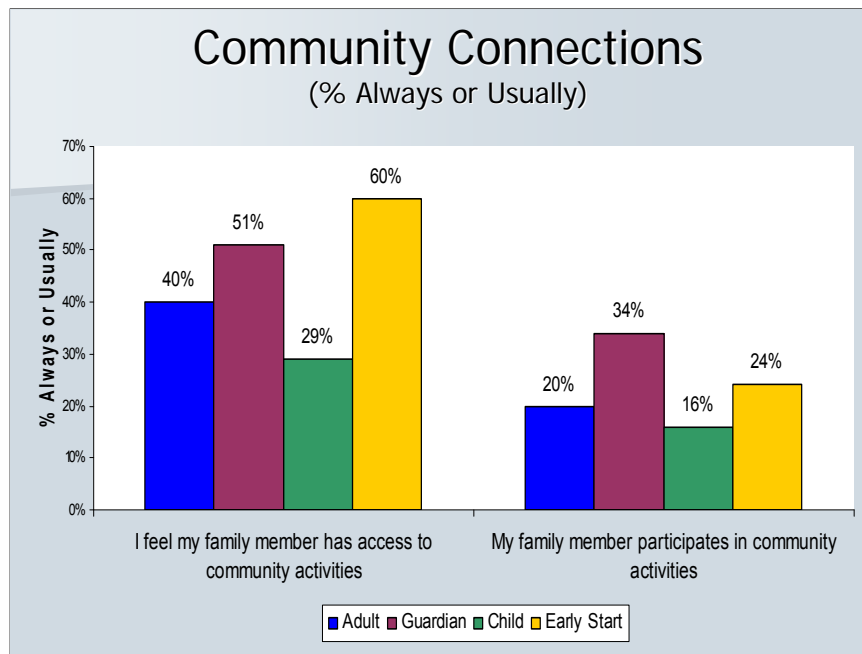
There is a lot of variability across surveys with regard to whether families report that RCOC services and supports meet their families needs. As before, we see the CFS being much lower than the rest, but another 40% did say “some of the time”. These results are typical of years past and are in line with the overall state average.

Over the years, we along with many other states have speculated about the reasons for this. Regional centers are not the primary source of support for families with school-aged children – the school system is. As a secondary source of support, it might just be that we, and other state systems, are not viewed as the entity that meets most of the families’ needs. That said, over the past few years, we have worked on improving our services in the areas of respite, after school care and behavioral services for school-aged children, and we did see a 5% increase in the always/usually responses to this question in 2008.

Although we would certainly like to see improvement in this area, given the current fiscal climate, it’s probably unrealistic to think that there will be significant improvement in the next year or two. However, we will continue to work with our Service Coordinators on identifying needed services at IPP meetings and will continue to help families advocate for appropriate educational services.

I also want to let you know that we did analyze the data to see if there was a correlation between a child’s diagnosis and whether or not the family reported that services and supports met their needs. There was not a correlation meaning that responses to that question were not influenced by the diagnosis of the child. [For all disability groups, about 76-80% of families said always/usually or sometimes and 8-15% said seldom or never.]

As far as access to health and dental services and medications – we’ve seen upward trends in these numbers over the years. Not a huge trend, but at least it’s consistently going in the right direction.



In the area of Community Connections, the main indicator of interest is whether family members participate in integrated activities in their communities.

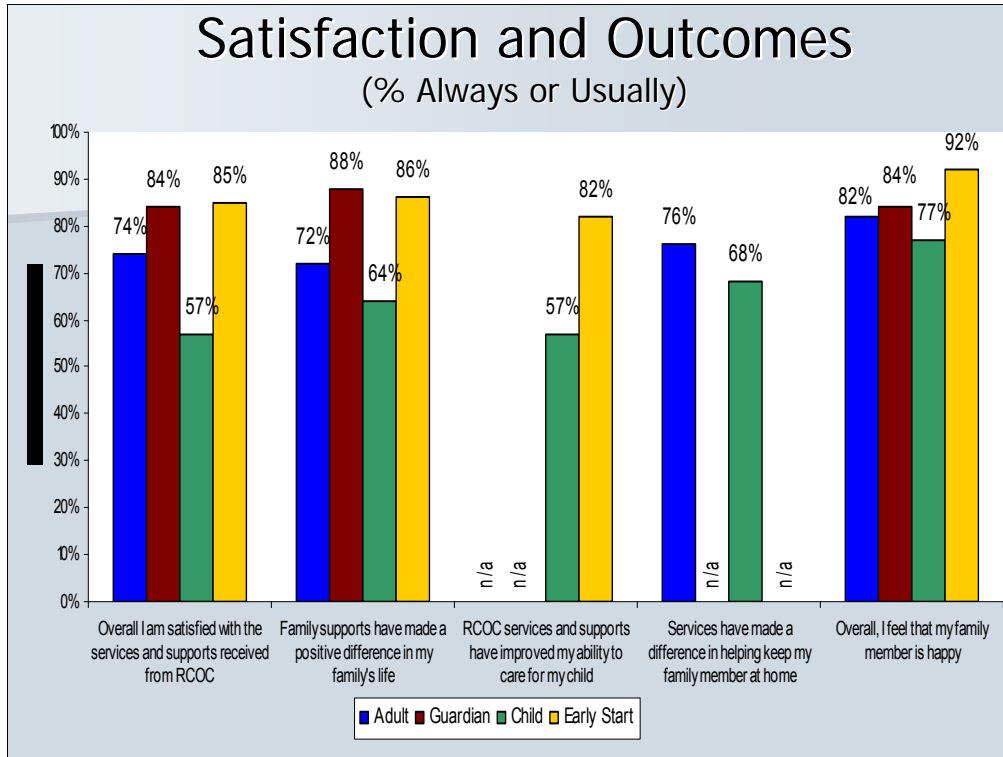
This slide addresses access to and participation in community activities

As the report card indicates, we have been consistently below average compared with other states on all family surveys in this area and we saw an overall 5% decline in the adult surveys compared to our own data in past years. Each year we have added questions that will help us find out more from families about what barriers exist and whether RCOC can or should assist in some of the areas, but still it's been a struggle to impact change.

As is typical, the CFS have the lowest of all for both of these questions.

As far as access to activities – an additional 24-39% said that their family members sometimes had access and 13-24% said they seldom or never had access.

Regarding participation in community activities, a much lower percentage of family members reportedly participate in community activities even though they have access. With an additional 26%-38% more saying their family members participate sometimes and 29-50% saying they seldom or never participate.



One of the most important core indicators of all - the proportion of families who feel that services and supports have helped their family member and family.

In general, these results are similar to previous years with the exception of a 10% increase from FY06 in the GFS results for the first question and a 5% increase for the CFS results for the second question.

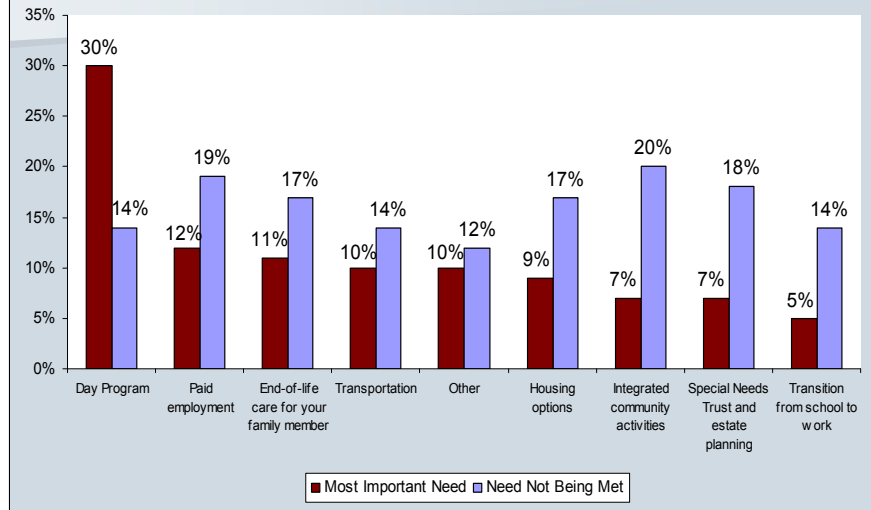
For most of these questions, another 10-30% of families responded “some of the time”.

It is certainly great to see that RCOG supports have made a positive difference in a majority of family’s lives.

And finally, most families report that their family member is happy overall.

## Adult – Unmet Needs and Priorities

Which of the following service needs are currently not being met for your family member and which one is most important to you?



The next four slides show the results of two new questions that we added to the surveys in 2008. The first question asked families which service needs were not being met and they could check all that applied from a list and add others. The follow up question asked the families to select the one most important need that they had.

Given the current and proposed cuts to the regional center system, this is probably the most important data we gathered last year because it tells us about unmet needs and more importantly, tells us which services are viewed as most critical to families.

This graph shows results for AFS. The RED bars indicate the most important service needs listed by the families.

A clear standout here was day program at 30% while the rest range tightly from 5-12%.

12% paid employment

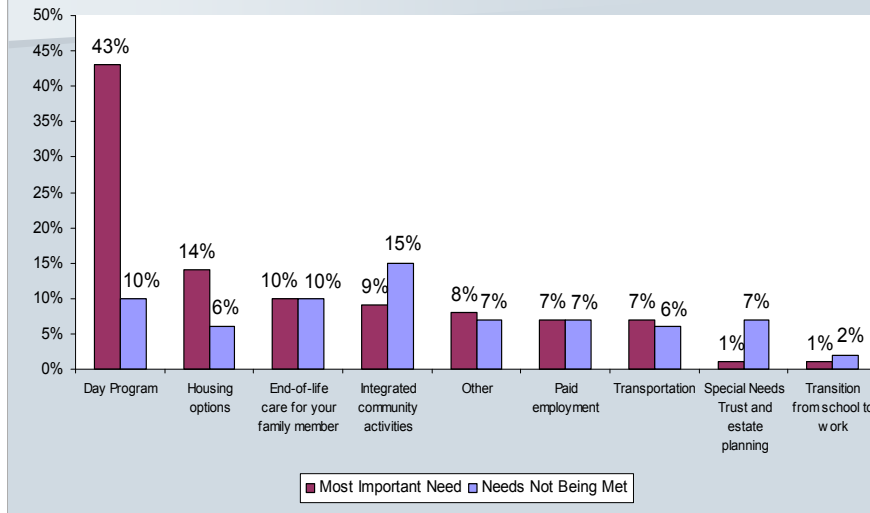
11% end of life care for their family member

\*\*I do want to point out that this does not mean that 30% of families said their family member didn't have a day program – just that is was the most important need they had.

Since we just discussed access and participation in community activities, I one to point out one other thing on this graph. That is that these families listed integrated community activities as the top unmet need (20%), but when asked to indicate the service that was a priority, that was near the bottom of the list at 7%.

## Guardian – Unmet Needs and Priorities

Which of the following service needs are currently not being met for your family member and which one is most important to you?



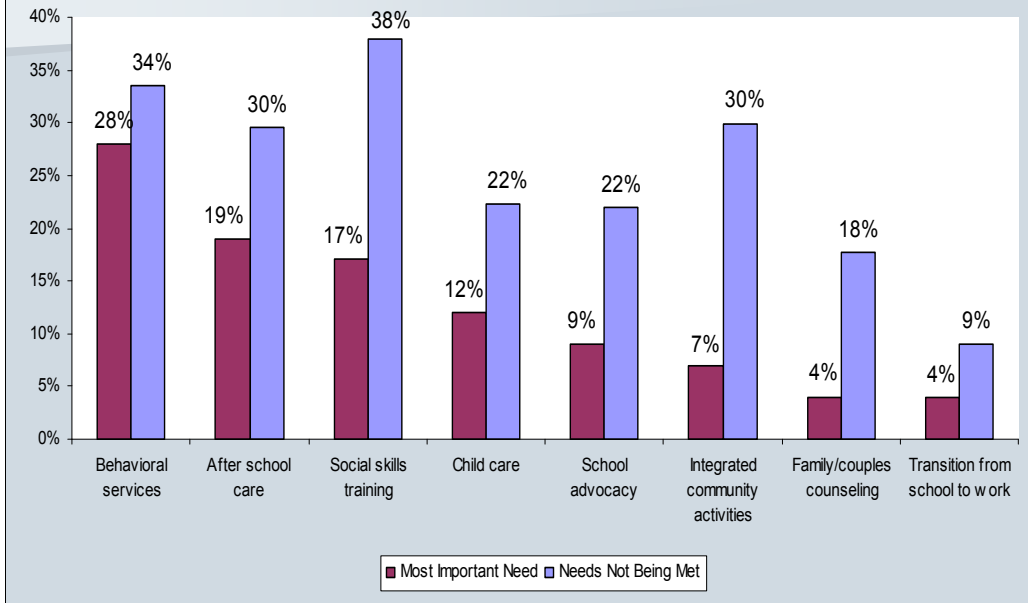
Here are the results for GFS.

Even more of a stand out for the guardian survey is day program with 43% of families reporting it as the most important need. As with the AFS, there really aren't other standouts with the other areas ranging from 1-14% - housing being at 14%.

And similarly, integrated community activities was listed as the top unmet need (15%), but again was not a priority in the follow up question (9%).

## Child – Unmet Needs and Priorities

Which of the following service needs are currently not being met for your family member and which one is most important to you?



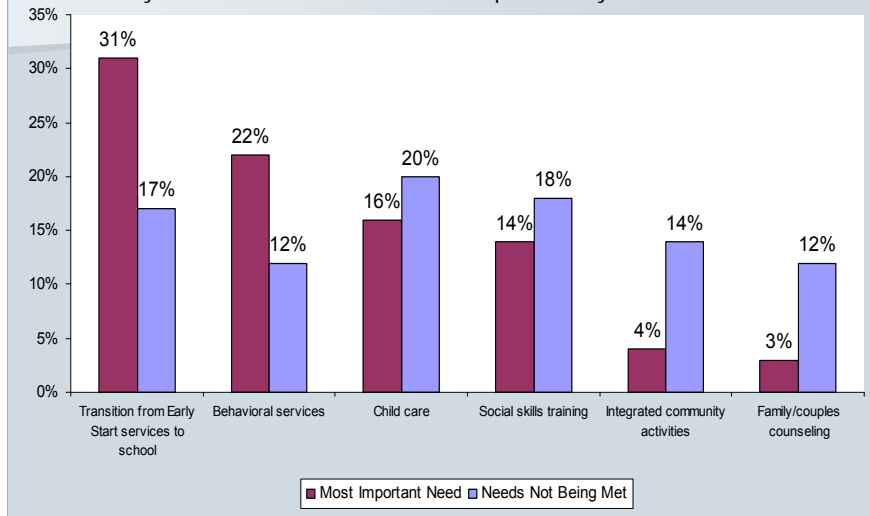
Here are the results for CFS

Families with children 3-18 ranked behavioral services (28%), after school care (19%) and social skills training (17%) as the most important needs for their family members.

Consistent with the AFS and GFS results, integrated community activities, which was listed as one of the top unmet needs (30%), dropped closer to the bottom (7%) when families were asked to choose the most important need they had.

## Early Start – Unmet Needs and Priorities

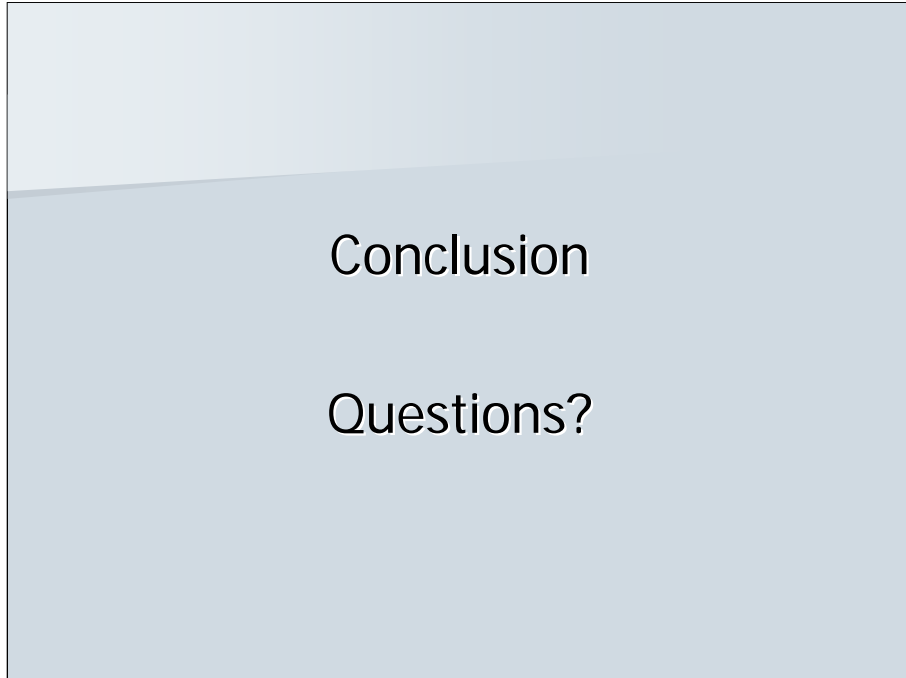
Which of the following service needs are currently not being met for your family member and which one is most important to you?



Finally, the last graph shows the results for Early Start families.

Most critical to families who have children under 3 years old is the transition to school (31%), behavioral services (22%) and child care (16%).

At this time, given that Early Start is a grossly underfunded mandated (that is – the state spends \$400M and only gets \$50M in federal dollars for the program), the resources we can put into this are limited. However, based on these results, we will continue developing and enhancing our relationships with school districts so the transition to school process for the children turning three is as smooth as possible.



These results show us that when families are asked to prioritize, they seem to select services that are most likely to impact their family life on a daily basis.

For families with adult children, it means that they have a day program.

For families with school-aged children, it means that their children's behavioral issues are addressed and that they have a safe and reliable place to go after school.

Although families identified other areas of needs – for example, integrated community activities – when asked to prioritize – they seem to go back to the basics – and that is, what is critical to keeping their family life running smoothly.

In these tough times, the NCI survey information can tell us what services are most valuable to the people we serve and to their families.

RCOC may not have a lot of influence over the some of the cuts that are and will continue coming our way, but at a minimum, we can listen to our families and advocate for the services that are a priority for them when we are part of discussions with ARCA and our local legislative delegation.

The information that we gather from NCI is critical because as a regional center, we want to advocate for the preservation of services that are most valuable to our families.