

Provider Survey: Consumer and Family Representation on Boards of Directors

Phases XI Summary DRAFT Report
FY2008 Data



A Collaboration of the
National Association of State Directors of Developmental Disabilities Services
and the Human Services Research Institute

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Indicators

A handful of NCI states reported information about the representation of consumers and families on provider agencies' boards of directors. Specifically, providers were asked to supply information about: (a) the number of people on the board of directors, (b) the number of voting members, and (c) the number of voting members who are primary consumers or family members of primary consumers.

PRIMARY CONSUMERS are defined as persons with intellectual or other developmental disabilities who are receiving services, not necessarily from the provider that is reporting.

FAMILY MEMBERS include parents, siblings, or other relatives of primary consumers (as defined above).

Concern: The system is sensitive to consumer preferences and demands.

Indicators:

- The proportion of voting members on provider agency boards of directors who are primary consumers.
- The proportion of voting members on provider agency boards of directors who are family members of primary consumers.

Background

In December 1996, the NASDDDS Board of Directors launched the National Core Indicators (NCI). The aim of NCI is to support state developmental disabilities authorities (SDDAs) in developing and implementing performance/outcome indicators and related data collection strategies that will enable them to measure service delivery system performance. The program strives to provide SDDAs with sound tools in support of their efforts to improve system performance and thereby to better serve people with intellectual and other developmental disabilities and their families. The Association's active sponsorship of NCI facilitates states pooling their knowledge, expertise and resources in this endeavor.

NCI Phase I began in January 1997. In August 1997, the Phase I Steering Committee selected a candidate set of 61 performance/outcome indicators in order to test their utility/feasibility. Six states agreed to conduct a field test of these indicators, including administering the consumer and family surveys and compiling other data. Field test data were transmitted to NCI staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

NCI Phase II was launched in January 1999. Phase II data collection wrapped up in June 2000 and set the stage for continuation and further expansion of the project. During Phase II, the Phase I indicators were revised and data collection tools and methods were improved. The revised indicator set consists of 60 performance and outcome indicators. Going forward, NCI

expanded its scope to include services for children with developmental disabilities and their families, continued to develop and refine the indicators, and recruited additional states to participate in the project. Phase II data is considered baseline project data. Technical reports and other selected documents are available online at <http://www.nationalcoreindicators.org>.

Presently, NCI has 29 participating state members, the District of Columbia, plus four sub-state entities (Orange County, CA, Hamilton County OH, Montgomery County, OH, and the Mid East Ohio Regional Council, OH). State participation in NCI is entirely voluntary. For a complete list of NCI states, visit www.nationalcoreindicators.org.

This report summarizes consumer and family representation data collected by states via provider surveys. Since states generally report these data from the preceding year, these figures represent **FY2008 (reported in Phase XI)**.

Introduction

Five states participating in FY2008 collected performance indicator data through provider surveys. These states include: Alabama, Georgia, South Carolina, Washington, and Wyoming. This report summarizes provider survey data related to indicators of consumer and family representation on agency boards of directors. It should also be noted that the boards of directors may include advisory boards as well as governing boards.

The purpose of this report is:

- to summarize the methods used to collect and report provider survey data;
- to present results by state and in aggregate;
- to present results by indicator; and
- to discuss recommendations and observations on how to move forward with the data

The state reports “provider-level” data to the national project, meaning that each line on their spreadsheet represents totals for one provider. Thus, **state by state** results represent the **average figures across all providers** who (1) answered the survey in that state and (2) supplied both the appropriate numerator and denominator for that specific indicator. (Please note that in the data tables below, the N's vary depending on how many providers supplied information for a particular indicator.) **Aggregate** results are computed by using the **totals across all providers who answered the survey in all states**. These non-weighted, absolute values provide the numerator and denominator for the aggregate indicators. **In the tables and charts below, the aggregate results are labeled “TOTAL”.**

Results

Table 1. Consumer and family representation on agency boards of directors. (FY2008)

State	N of Agencies Reporting	Average % of Voting Members who are Consumers	Average % of Voting Members who are Family
AL	46	2.7%	21.4%
GA	24	3.9%	23.6%
SC	33	3.1%	32.9%
WA	128	3.2%	24.3%
WY	6	4.2%	20.8%
TOTAL (aggregate)	237	3.1%	24.3%

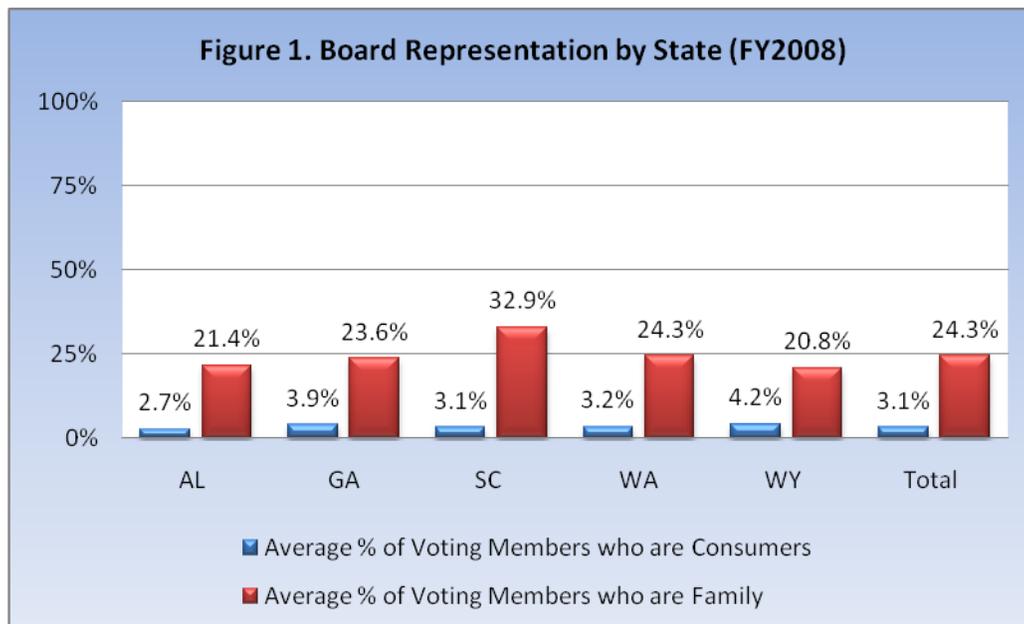
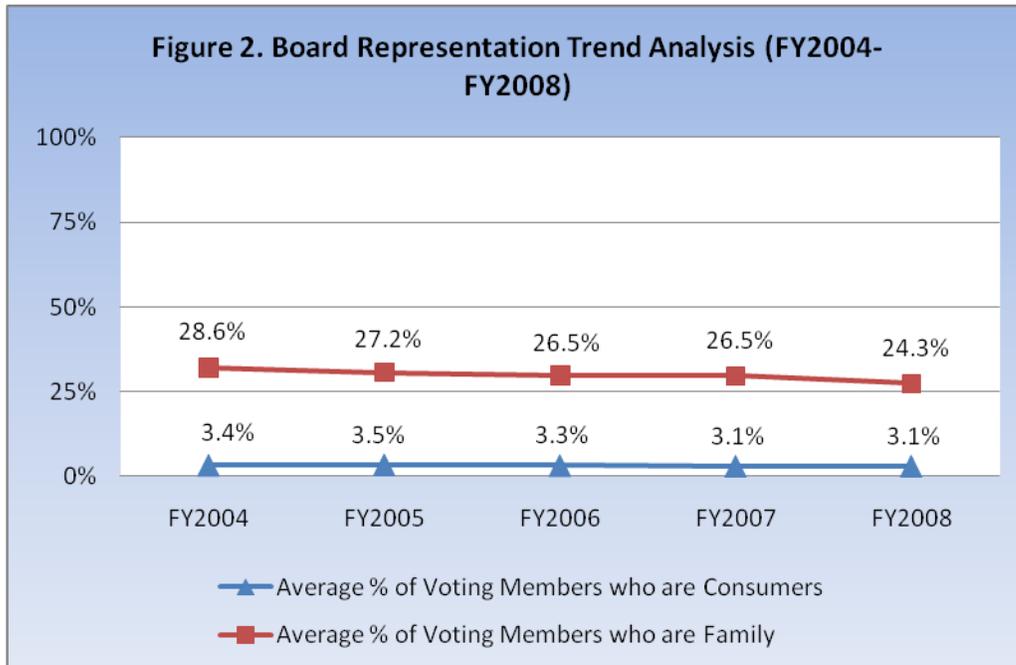


Figure 2 shows the Board Representation numbers over the last *five* years of NCI Data. As you can see, the numbers have stayed relatively constant during this time.



Findings

While the information presented here may be useful for individual states, cross-state comparisons are difficult to make due to the differences in numbers of provider agencies across states (for example, 54% of providers reporting in FY2008 are from Washington State). Additionally, because of the small number of NCI states participating and the variance of states that do participate from year to year, we strongly urge caution before using the results for overall year-to-year comparisons.

That being said, here are some findings from FY08:

- The percentage of voting board members who were consumers ranged by state from 2.7%-4.2%.
- The percentage of voting board members who were family of consumers ranged by state from 20.8%-32.9%.
- There was not one state that had a majority of total voting board members who were consumers or family. South Carolina was the closest with 36% of total voting members being consumers or family of consumers.

- Since FY2004, the trend for both consumers and family being voting board members has been stagnant, both only fluctuating by no more than a few percentage points.

Recommendations/Observations

Data collected by individual states for the purposes of NCI is intended to be useful for performance monitoring and strategic planning. However, the utility of the information is limited when only a small number of states report on specific indicators. It is further limited when one of the states (e.g., Washington) is over-represented, accounting for the majority of total providers reporting.

Given the sparse amount of data collected on Board Representation, we recommend suspending reporting on these indicators. Going forward we propose developing new performance indicators that address how state agencies facilitate and support the participation of individuals and families in system improvement.

Although the data are limited, the results do suggest that inclusion of individuals and families as voting members on boards is an area that could use improvement. Some resources were identified as helpful documents:

- A guide developed by Green Mountain Self-Advocates and the ARC of Vermont that gives tips and suggestions on how to include self-advocates as board members. The document can be accessed below:

<http://www.ddas.vermont.gov/ddas-publications/publications-gmsa/publications-gmsa-documents/get-on-board-2003>

- Additionally, the NCI website, www.nationalcoreindicators.org, has resource suggestions on how to explain to self-advocates what a board of directors is and why it is important to get involved. Go to the “Reports” page and click under “Consumer Workbook.”