Washington State Core Indicators Workgroup Recommendations Report

Washington State
Developmental Disabilities Council
July 2006

Introduction

The Developmental Disabilities Council convened a workgroup of family members of children with developmental disabilities and community providers to review the results of the Children's Core Indicators Survey conducted in Washington State in 2005. The Core Indicators survey is a national study that assesses performance and outcome indicators for state developmental disabilities service systems. Washington State Core Indicators survey participants were selected from the caseload of the Division of Developmental Disabilities and focuses on children receiving services and living in their family's home.

The workgroup met three times during April, May and June of 2006. The report reviewed by the committee was *Child Family Survey Final Report, December 2005 (Phase VII)*. More information about the report is located in Appendix A.

Using the data from the 2005 and previous surveys, the workgroup developed systems change recommendations for presentation to the Developmental Disabilities Council and the Division of Developmental Disabilities

The workgroup made recommendations for all five quality indicators of the survey:

- Information and planning
- Access to and delivery of services and supports
- Choice and control
- Community connections
- Outcomes and satisfaction with services and supports

The workgroup also provided additional general comments (see page 8).

Information and Planning

1. Access to information

We recommend improving families' access to information about DDD services and other public benefits in ways that are easy to understand. (5.0)

This recommendation is based on the following observations:

Families aren't getting the information they need

- Washington State is doing worse than our previous years and other states/counties in getting information to families. 33.8% of families report getting little or no information about services and supports that are available to their child and family. System information is not organized and accessible. (Question 1)
- When families get information, more than half (54%) do not understand at least some of the information they receive. (Question 2)

Families aren't getting information about public benefits available to them

- 52.4% of respondents say they are not getting information about public benefits that are available to them. (Question 10)

2. Child Development Information

We recommend UCEDD work with all professionals on increasing families' access to information about their child's development. (5.0)

This recommendation is based on the following observations:

Families aren't getting information about their child's development

- 44% of families not informed about their child's development (Question 3)

3. Case Manager Training

We recommend the Division continue to support Case Resource Managers through training, especially in helping families understand their choices, and respecting family opinions. (3.7)

This recommendation is based on the following observations:

Case manager effectiveness

- The numbers of families who report the staff that assist them are not generally effective increased from 8.2% in 2003 to 13.6% in 2005. (Question 12)

Staff respect for families' choices and opinions

- More families are reporting that staff that assist them seldom or never respect their choices and opinions (from 6.7% in 2001 to 12.3% in 2005). (Questions 8 and 9)

Access and Delivery of Services and Supports

4. Need for Increased Resources

We recommend getting additional funding to meet the needs of families receiving services and to meet the needs of the unserved. The Division should make sure services are allocated in a fair and equitable manner throughout the state. (5.0)

This recommendation is based on the following observations:

Not enough services and supports when needed

- There are not enough resources to meet the needs. 17% of families report that they never get the services and supports they need, up from 12.1% in 2003. 44.8% of families get some of what they need. (Question 15)
- There is an increase in the number of families that report that the services and supports offered never meet their needs. (14.5% in 2003 versus 20.0% in 2005. (Question 16)
- The number of families that state supports are rarely or never available when their family needs them has increased from 16.8% in 2003 to 25.1% in 2005. (Question 17)

5. Emergency Assistance

We recommend the Division improve its response to families in crisis and work actively to prevent crisis. (4.0)

This recommendation is based on the following observations:

Assistance in crisis situations:

- 42.5% of families report not getting help they needed in a crisis. Up from 37.7% in 2003. Also, approximately 50% of respondents reported having an emergency or crisis in the last year.

6. Access to equipment and adaptive technology

We recommend increasing families' access to information about acquiring special equipment and assistive technology. (3.6)

This recommendation is based on the following observation:

Access to special equipment and accommodations decreasing

- The number of families who report their child seldom or never has access to the special equipment or accommodations he/she needs has increased from 18.9% in 2003 to 31.9% in 2005. (Question 23)

7. Access to medical and dental services

We recommend monitoring families' access to medical and dental services.

This recommendation is based on the following observations:
Decreasing access to health services

- Children having access to health services decreased from 91.8% in 2001 to 86.3% in 2005. Washington had the lowest score of "always or usually" responses on this question. (Question 24)
- There is pretty good access to dental services. Only 6% of families report that their child seldom or never has access to dental services. (Question 25)

8. Support workers

We recommend the Home Care Quality Authority monitor the impact of personal support staffing changes on families. (4.0)

This recommendation is based on the following observations:
Support staff experience:

- Almost half of families (43.6%) reported that frequent changes in support staff were seldom or never a problem. (Question 27)
- 88% of respondents stated that support staff is generally courteous and respectful. (Question 28)

Choice and Control

9. Client choice

We recommend increasing families' choice of providers, services & supports. (3.6)

This recommendation is based on the following observations:

Choice of services and supports

- Washington State is above the national average in ability to choose the agencies and provider who work with their family (79.2% were able to always, usually or sometimes able to choose the agencies or providers who work with their family. (Question 29)
- More families report they are always or usually able to choose the support workers who work with their family in 2005 (44.9%) than 2003 (38.5%). (Question 30)
- An increasing percentage of families (70.6% in 2005 compared to 67.4% in 2003) want to have control and/or input over the hiring and management of their support workers. (Question 32)

10. Information about Spending for Services

We recommend the Division provide families with information about how much money is being spent on their child and increase families' involvement in deciding how the money is spent. (4.6)

This recommendation is based on the following observations:

- The number of families who report they seldom or never know how much money is spent on their child with a developmental disability has increased from 57% in 2003 to 62.3% in 2005. (Question 33)
- The number of families reporting they always or usually get to decide how the money is spent has decreased from 39.4% in 2003 to 28.8% in 2005. The number reporting they seldom or never get to decide how this money is spent has increased from 29.6% in 2003 to 43.4% in 2005. (Question 34)

Community Connections

11. Access to Community

We recommend increasing families' supports to have their children spend time with other children without disabilities in social settings outside of school. (5.0)

This recommendation is based on the following observations:

Access to community

- The number of families reporting that their child seldom or never participates in community activities has increased from 40.7% in 2001 to 46.5% in 2005. (Question 38)
- The number of families who report that staff help them use typical supports in the community help connect them to these supports has decreased from 22.4% in 2001 to 16.3% in 2005. (Question 35)

Participating in activities with children without disabilities

- 13.9% of families report that their child seldom or never spends time with children who do not have developmental disabilities. (Question 39)
- The question doesn't ask what type of participation kids with DD are having with children without DD. If the survey is only counting school, it is not enough. (Question 39)

Outcomes and Satisfaction with Services

12. Information about Grievance Procedures

We recommend the Division continue to collaborate with organizations to educate families about families' rights, the DDD complaint process, and DDD fair hearing process. (4.0)

This recommendation is based on the following observations:

- The number of families reporting they are not familiar with the complaint or grievance process is still too high – almost 60%. (Question 41)
- Satisfaction levels with those who have had grievances/complaints appear to be similar to the 2003 levels. (Question 42)

13. Supports Make A Difference in Families Lives

We recommend funding family support services for families on the wait list. Income data supports how important this is to families. (4.8)

This recommendation is based on the following observations:

- A high percentage of families feel supports have made a positive difference in the life of their family (62.0% report always or usually, 32.5% report sometimes). (Question 43)
- The majority of families report that family supports have improved the ability to care for their child. Washington's score is better than the average on this question. (Question 44)
- The majority of families report that family supports have helped them to keep their child at home. (Question 45)

Other General Comments

Demographics

Race Ethnicity of Child (%)[1]	**2001**	**2003**	**2005**	**WA 2000 Census**
	n=834	n=508	n=478	
White	76.5%	77.4%	80.0%	81.8%
Black	6.2%	5.2%	8.6%	3.2%
Asian	6.0%[2]	6.0%	3.6%	5.5%
Hawaiian/Pacific Islander		1.5%	.2%	.4%
American Indian/Alaska Native	4.4%	4.7%	4.5%	1.6%
Mixed race	7.3%	5.8%	6.2%	3.6%
Other/Unknown	1.5%	1.3%	2.1%	3.9%
Hispanic/Latino	8.5%	7.3%	8.6%	7.5%

1. *The ethnic composition of the surveyed population and the state's general population are roughly similar. The one exception to this is the Asian population in the survey, which is slightly less than the state's Asian population.*

Survey Household income	**2001**	**2003**	**2005**	**WA- US Census**
	n=740	n=443	n=404	2000
Below $15,000	21.1%	24.2%	27.2%	8.0%
$15,001-$25,000	18.5%	15.3%	21.5%	9.1%
$25,001-$50,000	23.1%	30.2%	26.7%	28.4%
$50,001-$75,000	26.2%	19.9%	15.1%	24.5%
Over $75,000	11.1%	10.4%	9.4%	30.1%

2. *The number of families who are living at or near the poverty level is increasing. In the 2005 survey, almost 50% of the families had incomes of $25,000 or below. This is especially significant when compared to the income of the general populations.*

[1] Respondents were able to select more than one ethnic category, if applicable
[2] Asian/Pacific Islander were one category in the 2001 survey

General comments

1. *Some of the survey terminology was confusing to the panel members, and could be confusing to those completing the survey*

2. *Luck, family income, and "system savvy" shouldn't play such a large role in determining which families get services.*

3. *Funding for special equipment and assistive technology is crucial – it increases life choices, improves quality of life and reduces long-term costs.*

4. *We recommend the Division recognize and support Case Resource Managers that are courteous and helpful to families in planning and figuring out what they need.*

5. *We recommend families be supported in continuing to use families, friends or neighbors to provide support when they so desire.*

Appendix A: Reviewed Material & Panel Composition

In developing their recommendations, the panel reviewed the data collected through surveys done in Washington State under the National Core Indicator's Project. More detailed information and copies of the report are available at the National Core Indicators website: http://www.hsri.org/nci/index.asp?id=reports.

States/Regional Center Participating in Children's Core Indicators Surveys

Arizona
California, Regional Center of Orange County
Connecticut
Washington
Wyoming

Scoring Process

A number follows each recommendation. This number represents the average scored level of importance assigned to the recommendation by the workgroup. The scoring range went from "1" (I don't want this recommendation) to "5" (this recommendation is a 'must have').

In scoring each recommendation, the group used the following criteria:

1. How well does the draft recommendation work to increase families' abilities to make informed decision?
2. How well does the draft recommendation work to increase families' abilities to make informed decision?
3. How well does the draft recommendation emphasize preventing crisis (proactive versus reactive)?
4. How well does the draft recommendation move to maintain/improve the health of the family unit?
5. How well does the draft recommendation enable children to stay in home placement?
6. How well does the draft recommendation improve inclusion in the community?
7. How well does the draft recommendation provide a way to serve more families more effectively?
8. How well does the draft recommendation improve communication between families and between community/state agencies?

Workgroup Members

Audrey Adams	Family Member	King County
Ryan Callaway	Family Member	Yakima County
Arlene Curry	Family Member	Grays Harbor County
Dee Dee Garman	Family Member	Grays Harbor County
Leticia Gonzales	Family Member	Yakima County
Denny Hasko	Service Provider	King County
Kama Hunter	Service Provider	Pierce County
Kate Jackson	Family Member	Spokane County
Pamela Klein-Farrow	Family Member	King County
Terry Villalovoz	Family Member	Spokane County
Judy Westsik	Family Member	Benton County

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