

**ALTERNATIVE SERVICE MODELS  
FOR CHILDREN WITH  
SIGNIFICANT BEHAVIORAL CHALLENGES**

**January 28, 2008**

**Prepared by the Division of Developmental Disabilities  
Aging and Disability Services Administration  
Department of Social and Health Services**

**At the request of Governor Christine Gregoire**

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## EXECUTIVE SUMMARY

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The purpose of this report is to identify service models used in other states, which may be effective in supporting families to care for children with significant behavioral issues at home or in local community settings, rather than relying on state institutions to support these children.

Although states organize their service systems and access mechanisms differently, their “service functions” are essentially the same, that is, they offer a similar variety of in-home supports, such as, respite care, personal care, professional services, etc., and typical out of home residential options, including foster care, group care, and institutional care. One service that stands out in this review of other states, however, is the intensive, preventative approach to working with families under stress facing formidable challenges. Priority in those states has been given to providing services that stabilize and empower families to continue to manage the demands of parenting a child with a developmental disability and severe behavioral challenges.

**Cost Comparison:** Under the Oregon Intensive In-Home Services model, the average family is allotted an average of \$3000/month or \$101/day for a wide variety of supports, including, but not limited to behavior consultation/training; in-home daily care, home/vehicle adaptations, monthly out-of-home respite; resource materials, specialized diets when prescribed, transportation, and supervision.

In Washington State “staffed residential” group homes serve children with complex behaviors who are typically too challenging for placement in a foster home. Rates for current placements using proviso funds range from \$296.94 to \$519.15 per day, with an average of \$425 per day. Residential Habilitation Center rates are an average of \$510 per day for ICF/MF care.

### Recommendations:

1. Develop and fund a proposal based on the Oregon “Children’s Intensive In-home Services” (CIIS) model to provide services for families and children with significant behavioral support needs. These children/families need supports that are above and beyond what is typically available for them now.
2. Seek approval for a “Model Home and Community Based Services Waiver” to support this specific population of children with intensive behavioral challenges.
3. Develop a method for identifying children at risk of out-of-home placement and potential institutional placement.
4. For families who have already reached the point of seeking out-of-home placement, develop added capacity for staffed residential homes, including respite beds, using current proviso funds.
5. Explore best practice models for “therapeutic foster care” for children with developmental disabilities.
6. Use data from other states that have had longer implementation histories to project needed growth in an in-home supports waiver.

## INTRODUCTION

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The purpose of this report is to identify service models used in other states, which may be effective in supporting families to care for children with significant behavioral issues at home or in local community settings, rather than relying on state institutions to support these children. In May 2007, the Department of Social and Health Services received a memo from the Office of the Governor expressing concern with “the growing number of institutional placements of children” and directing the Division of Developmental Disabilities (DDD) to explore other alternatives.

Many people, including advocates and families, are concerned that children with developmental disabilities are currently being placed in large institutions, serving primarily adult populations, when families are no longer able to manage or cope with significant challenging behavior(s). Over the last several years, the number of children living in institutions in Washington State has gone from only a few to 35 or more, depending on the number of short-term respite stays at any given time.

Families faced with many pressures may ask for assistance ranging from in-home supports, including respite, to a placement for the child out of the family’s home. DDD developed the Voluntary Placement Program (VPP) in the late 90s to meet the needs of families in distress who needed out-of home placement, but did not wish to relinquish custody of their child. However, the “de facto closure” of VPP, in combination with limited funding for Family Support and new waiver residential placements, has since made it very difficult to offer services in local communities; especially foster home and group home residential placements, forcing families to rely on their only available out-of-home Medicaid entitlement of an Intermediate Care Facility for the Mentally Retarded (ICF-MR) or Residential Habilitation Center (RHC) placement. Community out-of-home services are not similarly entitled.

Even with the institution entitlement, national trends for the last forty years have led away from policies that segregate and isolate children and adults with developmental disabilities. Reliance on institutions as a place for children to grow and develop runs counter to how policy makers believe children should be raised. Services requirements in general direct that children should be provided with a safe, stable environment in which to grow up and a nurturing “caretaker” who is committed to a lifelong relationship with that child, whether it be a foster family, other out-of home arrangement that is best suited to meet the needs of that child at the time, or eventual reunification with the family.

## METHODOLOGY

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Several methods were used to identify services models supporting children and their families in other states. An initial screening of states was conducted including:

- In September 2007 DDD sent out a survey to the State Directors of Developmental Disability programs. Nine responses were received: Georgia, Massachusetts, Minnesota, California, Alabama, New York, Connecticut, Hawaii, and Mississippi.
- Staff conducted a search of the Centers for Medicaid/Medicare website to identify states providing in-home supports for children and families through Home and Community Based Services waivers;
- Recommendations for model programs were obtained from colleagues and best practice experts from across the country.

Through this initial screening, service models in five states were identified for further research including Oregon, Michigan, Colorado, Massachusetts, and Wisconsin. Telephone interviews were conducted with each state along with a review of the state's website information. Staff also traveled to Oregon to meet personally with program managers.

## FINDINGS

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The table in Appendix 5 compares the states of Oregon, Colorado, and Wisconsin, and Massachusetts, including service types, eligibility, waivers, number of children served and cost limits, and services provided. Through follow-up phone calls and website reviews, the staff consultant for this project found a number of reoccurring themes:

- Similar types of services are provided by each state.
- The level of services for children is similar among the states.
- States are serving children with similar levels of significant behavioral issues.
- All five states report the children's intensive in-home services programs are highly successful in supporting families to continue to care for their children in the family home.
- Several states use a behavioral criteria scoring system to determine program eligibility and service level. All elements used in these criteria sets are included in the WA state DDD Assessment.
- Four out of five states provide children's intensive in-home services through a Home and Community Based Services waiver.

### Autism-Specific Waivers:

In March of 2007 the Division of Developmental Disabilities wrote a white paper, "Meeting the Needs of Individuals with Autism" exploring the options available to serve individuals with autism via the home and community-based service waiver program. This review found autism-specific waivers and/or services in the following states:

**Indiana:** Serves up to 300 individuals of any age with autism

- Includes a broad array of services, including
  - Respite

- Therapies
- Residential services
- Day program/supported employment services
- Specialized medical equipment and supplies
- Environmental modifications

**Maryland:** Serves up to 300 individuals with autism spectrum disorder through the end of the semester in which the child turns 21 years of age.

- Administered through the Maryland State Department of Education
- Services include
  - Respite
  - Residential services
  - Day program/supported employment
  - Therapeutic integration
  - Family training
  - Environmental accessibility adaptations

**Massachusetts:** Submitted for approval to the CMS 12/06 and approved 10/07

- Serve up to 80 individuals with autism spectrum disorder up to age eight.
- Services cover intensive in-home behavioral supports.

**Wisconsin:** One waiver has special services for individuals with autism, Asperger's and pervasive developmental disorders up to age 21.

- Services must begin prior to age 8.
- 20-35 hours of face-to-face contacts per week for up to three years.
- Services include a variety of therapeutic approaches than can be implemented with the intent to enhance behavior, communication and social skills.

## **FAMILIES IN STRESS**

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Families don't just decide one day that their child should move into an institution. There are usually many factors that have built up over a period of time that influence a decision of that magnitude. When considered or assessed for acceptance into the Oregon Children's Intensive In-home Services model noted in the table under Findings, a combination of the following behavioral conditions are typically present:

- Supervision and/or intervention required frequently throughout the night,
- Destruction of property in the home,
- Aggressive behavior towards others,
- Self-injurious behaviors resulting in either severe temporary or permanent damage,
- Problems with school attendance,
- Problem behaviors profoundly affecting child and family functioning, such as, frequent screaming, running from caregivers, refusing food or extreme food choices, smearing feces, lack of impulse control, removing clothing, and setting fires,
- Sexualized behaviors,

- Difficulty participating in routine family activities or exhibiting behavior that prevents others from even entering the home,
- Unusual home modifications required in response to behaviors, such as, locks on interior doors, cabinets, and drawers, or safety glass in windows.

In King County, Washington State, the Seattle Children's Home Behavior Support Team (BeST) was created in June 2002 to provide families with an intensive and comprehensive family-centered, in-home approach to help families deal with behavioral and emotional challenges. They serve between 120 to 140 families per year for two to three months of intervention (see Appendix for more detail). In the five and a half years that they have been working with families, they have found the following factors to stand out:

1) Age of child: When children are referred between 11-16 years of age and there are more challenging behavioral issues, and this is the parent's first request for help, it may signify that they have ignored earlier warning signs and thus, may operate more on crisis mode than on preventive mode.

2) Marital Distress: The parents or partners are openly representing that their relationship is distressed, that separation/divorce has been contemplated, or, the staff assessment concludes that there are significant marital problems (e.g., the father is uninvolved in caretaking the child with disabilities and the mother is struggling and upset with the fathers lack of help)

3) Parental Mental Health, Substance Abuse or Capacity issues: When the parent has a chronic mental health condition, has ongoing or recurrent episodes of substance abuse, has limited intellectual functioning, or chronic health problems, any intervention process will require extended lengths and wraparound services to make meaningful changes.

4) "Good Family/Tough Kid": This factor recognizes that some children have conditions that overtax even well-organized, capable parents. Fetal Alcohol Syndrome is a prime example of such a condition for some severely effected children.

5) General Family Disorganization: When the parent's style is unorganized and/or overwhelmed in most aspects of family life, it's unlikely that they can implement the changes necessary to make the positive behavior support plan effective with out a long-term, very involved and coordinated wraparound team that can guide/coach them through the steps.

6) Isolation/ Lack of Natural Supports: This family is cut off or does not have support from extended family, friends, other natural supports (e.g., church or social groups). Catastrophic events, such as a death of one parent, loss of a job or home will likely overtax such parent's ability to cope.

7) Value/ Belief Clash: These parents have cultural, sub-cultural, religious, or other beliefs that run counter to the beliefs that the behaviors can change with the guidance of an outside professional.

When families reach a breaking point, they may feel forced to make choices that they otherwise would not make. In October 2007 DDD asked regional staff to indicate, based on their "professional, clinical judgment", how many families were at risk of asking for institutional care for their children? Case managers responded that they were aware of 36 children who were at risk of imminent institutionalization in a residential habilitation center (RHC) if other community out-of home placement options did not soon become available.

Children with autism spectrum disorders are often viewed as the most challenging in terms of learning, socialization, and maladaptive behaviors. Of the 44 children who have spent time (i.e., respite, short-term and long-term admissions) at Fircrest School since January 2006, 31% have a primary diagnosis of autism. In a few situations families are seeking stabilization of medications or other serious medical conditions; however, typically families are simply unable to cope any longer with their child's behaviors in their home.

## DISCUSSION

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Although states organize their service systems and access mechanisms differently, their "service functions" are essentially the same, that is, they offer a similar variety of in-home supports, such as, respite care, personal care, professional services, etc., and typical out of home residential options, including foster care, group homes, and institutional care. Washington State currently relies on some foster care for children with developmental disabilities and a program called "staffed residential" which is essentially a small group home for up to four children in a home that is licensed through the Children's Administration. Oregon has a residential option called "proctor care" which is a foster home model that is contracted through agencies which recruit, train and wrap services around the particular home and child.

Although a few states have autism-specific waivers, the services within those waivers do not appear to be different from what Washington States offers through its four home and community based waivers (see Appendix for summary of Washington waivers).

One thing that stands out in this review of other states is the intensive, preventative approach to working with families under stress facing formidable challenges. Priority in those states has been given to providing services that stabilize and empower families to continue to cope and manage the demands of parenting a child with a developmental disability and severe behavioral challenges.

Although Washington State has the Individual and Family Services Program (formerly known as Family Support), services are limited in frequency and duration and there is a waiting time as families who have been on the list the longest are assessed for participation in the program. Allocations per client range between \$2000 and \$6000 per year. In the meantime, families who have not had any family support to date or not enough to meet their family's needs, and have faced a lack of community residential options when the VPP program was effectively shut down, are experiencing severe challenges with day to day management, and are closer and closer to turning to the

RHC as their only viable option for immediate and/or long-term support of their child with a disability.

Families are the most central and enduring influence in children's lives. Supporting the families to care for a child with severely challenging behavior and providing them with immediate access to ongoing supports and services during critical periods and times of crisis would help them to discover solutions other than institutionalization.

In addition Washington State has a talented and expert cadre of child service providers currently offering out-of-home placement. These providers are ready to include in-home supports as part of the service they could deliver. Such services may, in time, eliminate the need for the more costly out of home placement.

## **COST BENEFIT**

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In the long run, investing in supports for families and children with severely challenging behavior is a cost-effective investment. Under the Oregon Intensive In-Home Services model, which provides a variety of supports, including, but not limited to behavior consultation/training; in-home daily care, home/vehicle adaptations, monthly out-of-home respite; resource materials, specialized diets when prescribed, transportation, and supervision, the families are allowed to spend an average of \$ 3000/month or \$101 per day.

Staffed residential group homes serve children with complex behaviors who are too challenging for placement in a foster home. Most of the children who are admitted to the RHC and later placed in the community are placed in staffed residential group homes. Although homes may be licensed for up to 6 children, DDD prefers to serve an average of three children per home, and occasionally four. Staffed residential homes offer 24 hour awake staffing and in many cases provide 1 to 1 staffing throughout the day and night. Staffed residential rates are calculated per individual child using a standardized method including, staffing schedules for school days and non-school days, the child's portion of the rent, utilities, food, transportation, and community integration activities. Staffing is by far the largest component of staffed residential program rates. Rates for current placements using proviso funds range from \$296.94 to \$519.15 per day per child, with an average of \$425 per day.

Residential habilitation center rates vary by institution. The rates below are an average, thus a child who requires 1 to 1 or even 2 to 1 staffing would have an individual rate that is considerably higher than the rate shown below. It is difficult to compare staffed residential group home rates with the RHC as RHC rates are not computed per cottage or individual when higher levels of staffing are required.

### Average RHC Daily Claiming Rates for Fiscal Year 2008:

Fircrest School	\$ 526.81
Rainer School	\$ 500.15
Lakeland Village	\$ 507.93
Yakima School	\$ 506.43

Morgan Center      \$ 535.78

The total average rate for the RHCs combined is \$510.17.

## **RECOMMENDATIONS**

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The Division of Developmental Disabilities recommends the following:

1. Develop and fund a proposal based on the Oregon "Children's Intensive In-home Services" (CIIS) model to provide services for families and children with significant behavioral support needs. These children/families need supports that are above and beyond what is typically available for them now.

2. Seek approval for a "Model Home and Community Based Services Waiver" to support this specific population of children with intensive behavioral challenges.

3. By May 31, 2008 develop a method for identifying children at risk of out-of-home placement and potential institutional placement. Early identification of children/families at risk will assist DDD to intervene effectively and prioritize resources and support children to remain in their family home.

- The DDD assessment tool provides a comprehensive picture of a person's needs and support system.
- Work is underway to identify assessment elements that are most predictive of the risk of out-of-home placement for a child. These elements will be used to develop an algorithm which will be applied to assessments to identify children at highest risk.
- The algorithm will aid in prioritizing the allocation of existing resources and will help determine the level of unmet needs for use in the development of budget requests.

4. For families who have already reached the point of seeking out-of-home placement, develop added capacity for staffed residential homes and respite beds using current proviso funds.

5. Explore best practice models for "therapeutic foster care" for children with developmental disabilities.

6. Use data from other states that have had longer implementation histories to project needed growth in an in-home supports waiver.

## APPENDIX

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CHRISTINE O. GREGOIRE  
Governor



APPENDIX 1

STATE OF WASHINGTON  
OFFICE OF THE GOVERNOR

P.O. Box 40002 • Olympia, Washington 98504-0002 • (360) 753-6780 • [www.governor.wa.gov](http://www.governor.wa.gov)

May 29, 2007

**TO:** Robin Arnold-Williams, Secretary, Department of Social and Health Services

**FROM:** Christine O. Gregoire, Governor *Chris*

**SUBJECT: APPROPRIATE RESIDENTIAL AND EDUCATIONAL PLACEMENTS  
FOR CHILDREN WHO HAVE SIGNIFICANT DEVELOPMENTAL  
DISABILITIES**

Improving outcomes for our state's children is a high priority of mine. As you know, our administration has undertaken a number of initiatives to promote children's appropriate emotional, social, physical and cognitive development. I am concerned about the growing number of institutional placements of children with significant developmental disabilities and the recent reopening of a classroom on the Fircrest campus. I believe these trends run counter to state and federal policies intended to ensure that children who have disabilities are served in the least restrictive settings possible.

I recognize that the needs of some children with developmental disabilities are very challenging and can have a huge impact on their families and at school with their teachers and classroom peers. However, out-of-home residential placements or segregated school placements of children should be considered a last resort. If an out-of-home placement is necessary, a placement in the child's home community close to his or her family, school, and friends is critical. Any institutional placements should be avoided if possible, or be temporary while efforts are made to return the child to her or his home community. Regardless of the placement option, the child should be supported to participate as much as possible in typical activities and the relationship with her or his family and school should be sustained.

I am aware that because Washington participates in the federal Medicaid program, the state must be able to provide "ICF/MR" residential services, such as are offered at our state institutional Residential Habilitation Centers, if a child meets eligibility criteria. I am also aware that cost concerns led the 2001 Legislature to cap the Division of Developmental Disabilities' (DDD) children's Voluntary Placement Program (VPP) which had funded in-home supports for families and non-institutional out-of-home placements. The de facto closure of this program, in combination with limited funding for the DDD Family Support Program and new residential placements through the waiver programs, has limited your department's ability to divert children from institutional placements. However, the significant levels of new funding to expand home and community-based developmental disabilities services included in the 2007-2009 state operating budget is a clear indication that the Legislature and this administration support a policy of providing services to individuals with disabilities in least restrictive settings.



Robin Arnold-Williams  
May 29, 2007  
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I am also aware that some school districts serve disproportionately more of the state's children with significant disabilities than do others and there has been concern regarding the funding mechanisms available to equalize the impact. School districts that have special education expenditures that exceed state and local revenues can apply for additional funding through the special education safety net process. In the 2005-07 biennium, we invested \$19 million to make it easier for districts to access safety net funds by removing a provision that had required districts to maintain the same level of local investment before additional funds would be granted. This year, I worked with the Legislature to secure additional investments for special education which include \$10 million for a new safety net category for districts located in communities that draw a large number of families in need of special education services, and \$65 million in additional special education funding that will flow to school districts. Clearly the intent here is to support local school districts in meeting the educational needs of children with disabilities.

To be consistent with federal and state policies that prioritize the provision of services to children with disabilities in least restrictive settings, I am directing you to do the following to reverse the trend of placing children in institutional settings or in segregated schools:

1. Take steps within the budget authority granted to reduce reliance on institutional placements for children and ensure that children are supported to live with their families or as close to them as possible.
2. Work with school superintendents and the Office of the Superintendent of Public Instruction to ensure that Individual Education Plans (IEPs) for any children placed in institutional settings conform to federal IDEA requirements for an education in the least restrictive setting. Given our efforts to strengthen special education funding mechanisms, it should be very unusual for any child to receive his or her education on an institutional campus.
3. Identify alternative service models, including those used in other states, that might be effective in supporting families to care for children with significant needs at home or in placing children in less restrictive out-of-home community placements rather than in institutional settings. Given the earlier concerns expressed by the Legislature regarding program costs, please include a cost-benefit component in this analysis.

Thank you for your ongoing efforts to promote better outcomes for children and to stabilize our home and community-based system of services for individuals with developmental disabilities and their families.

**APPENDIX 2**  
State of Washington  
Department of Social & Health Services  
Division of Developmental Disabilities

**Children's Services State Survey**

The State of Washington, Division of Developmental Disabilities (DDD) is interested in learning what other states are doing to support families to care for children with developmental disabilities and significant behavioral needs at home or, if necessary, in community out-of-home placements. Our Governor has asked DDD to identify alternative service models that might be effective here in Washington. Please help us learn about what you are doing in your state by answering the following questions.

Please return this survey by October 12, 2007.

**WHAT STATE DO YOU REPRESENT?**

“Left click” on the yes or no box to indicate your answer below. If “yes”, please also describe your program and provide an estimate of its cost.

**1. WHICH OF THE FOLLOWING SERVICES/SUPPORTS DO YOU PROVIDE FAMILIES TO CARE FOR CHILDREN WITH SIGNIFICANT BEHAVIORAL SUPPORT NEEDS AT HOME?**

**a. Do you provide in-home respite care?**  Yes  No

a. Description/Comments:

If yes, amount spent per year:

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**b. Do you provide out-of-home respite care?**  Yes  No

b. Description/Comments:

If yes, amount spent per person/year:

Type of settings (i.e., short-term foster home stay)

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**c. Do you provide Interventions for problem behaviors (For example, unpredictable sleep schedule, aggression, self-injurious behaviors, property destruction, PICA, inappropriate sexual behavior, etc.)?**  Yes  No

c. Description/Comments:

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d. Do you provide in-home crisis response teams?

Yes  No

d. Description/Comments:

If yes, describe service limits:

Financial:

Days/Hours

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e. Do you provide "other services" for children?

Yes  No

e. Description/Comments:

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**2. IF LIVING AT HOME IS NO LONGER WORKING OUT FOR THE CHILD AND/OR FAMILY, WHAT TYPE OF RESIDENTIAL OUT-OF-HOME PLACEMENT OPTIONS DO YOU PROVIDE?**

a. Foster homes?

Yes  No

a. Description/Comments:

If "yes", are parents required to relinquish custody when there has been no neglect or abuse?

-----

b. Licensed community-based group settings for children?

Yes  No

b. Description/Comments:

If "yes", average size per type of setting:

Staffing model per type of setting:

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c. State-operated institutions?

Yes  No

No

c. Description/Comments:

If "yes", how large?

-----

c. Other residential models?

Yes  No

c. Description/Comments:

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**3. DO YOU HAVE A HOME AND COMMUNITY BASED WAIVER STRICTLY FOR CHILDREN'S SERVICES?**  Yes

No

If yes, describe:

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**4. DO YOU HAVE A HOME AND COMMUNITY BASED WAIVER STRICTLY FOR CHILDREN WITH AUTISM?**  Yes

No

If yes, describe:

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**5. HAVE YOU HEARD OF MODEL PROGRAMS IN OTHER STATES OR COUNTRIES THAT DO A GOOD JOB OF SERVING CHILDREN WITH SIGNIFICANT BEHAVIORAL CHALLENGES?**

Yes  No

If yes, describe:

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**6. PLEASE PROVIDE THE URL FOR ANY WEB SITE(S) THAT WOULD PROVIDE US WITH ADDITIONAL INFORMATION ABOUT YOUR PROGRAMS/SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES?**

Please return this survey by October 5, 2007 to:

Gaye Jensen, Voluntary Placement Program Manager  
DSHS/DDD  
[jensegf@dshs.wa.gov](mailto:jensegf@dshs.wa.gov)  
Mailstop: 45310  
Lacey, Washington 98503-5310

Phone: (360) 725-3403  
E-mail:

FAX: (360) 407-0955

*Thank you very much for taking time to help us with this survey.*

Name of Your State's Program:

Your Name:

Telephone:

E-mail:

## APPENDIX 3

### **Integrating PBS and Mental Health Approaches for Comprehensive Family-Centered Intervention**

Gene McConnachie, Division of Developmental Disabilities/ Washington State Dept. of Social & Health Services,  
Terry Coleman, Sharon Remaize, Ken Alexander, Angelina Novak, Behavior Support Team (BeST), Seattle Children's Home,  
Irma Hill, King County Division of Developmental Disabilities  
Seattle, WA

Presented at the 3<sup>rd</sup> *International Conference on Positive Behavior Support: Expanding the World of PBS: Science, Values, and Vision*  
Reno, NV March 24, 2006

#### Abstract

Family stresses are often high when children with developmental disabilities exhibit challenging behaviors. Parents have difficulty finding natural and social services supports to assist them, and often have difficult relationships with their school. These parents may have to deal with suspensions or expulsions and are not usually informed of their child's rights under IDEA. They have difficulty finding mental health services, when needed, that provide services appropriately tailored to the child's and families unique needs. A lack of respite services can heighten the parent's sense of burnout and it is not unusual to encounter families under chronic crisis conditions in their home.

These clinical observations have been supported by published surveys and literature reviews that show that these families have multiple and complex needs that are not often met in a coordinated or comprehensive fashion. Compared to families without children with developmental disabilities, these families are more likely to be headed by single-parents, be at or below the federal poverty level, and have one or both parents under- or unemployed. Marital strife and divorce rates are also more prevalent than in the general population. This is not to discount the incredible strengths and knowledge that these families may possess. However, when family stressors are high and personal and social service resources are hard to muster, any family can struggle to maintain a positive home life.

In those cases, standard didactic or prescriptive approaches to training parents in behavioral intervention skills often fail to produce socially relevant changes in family functioning. Instead, families need a broad array of supports in addition to training in PBS and it's procedures to address the spectrum of issues in their family ecology. George Singer and colleagues have termed this broader approach adding "supportive contextual interventions" such as supportive counseling, marital therapy, parent to parent support, and training in problem solving approaches. We also stress taking an advocacy role with the schools and social service systems to gain needed resources to help the family meet their needs.

The Behavior Support Team (BeST) provides families with an intensive and comprehensive approach to intervention that is designed to be family-centered. We began seeing families in June of 2002 on a budget of \$250,000 per annum. This program is funded by a partnership between Region 4 of the State of Washington's Division of Developmental Disabilities, and King County's Division of Developmental Disabilities. These services are free to all families with children aged 3-17 enrolled for DD services in our county.

### **Development of the BeST**

The program model was developed after holding several stakeholder focus groups with parents, parent advocates, and DD and mental health professionals. The first and last author then summarized that feedback and the needs identified in reviews of the literature in a Request for Proposals that was announced in late 2001. That RFP listed several key requirements of the new contractor, including:

- Quick Response to Referral: The BeST clinician will be in the families home beginning assessment and crisis response within three days of receiving the parents request for services;
- Assessment and intervention will take place in natural settings; home, school, daycares, etc.;
- The BeST clinician will join with and/or help form a "wraparound" team so that they can promote coordinated assessment and intervention efforts. The clinician will help advocate for the family with social services, schools, and other agencies;
- The core approach to the challenging behavior will be PBS, based on a functional assessment of those behaviors;
- Assessments of family conflict and mental health issues will occur concurrently, and supportive counseling will be integrated into the intervention process;
- A parent support group will be offered;
- Services will be intensive, but time-limited to 8-12 weeks.
- Parent satisfaction with services will be measured, and results reported to the funding agencies, and used for quality improvement.

### **Implementation of the Model**

The Behavior Support Team blends three different practice modalities to deliver effective behavioral health services to children and families. The unique blend consists of the following:

**Positive Behavior Support** begins by addressing problem behavior in a family context. It is an assessment model that helps families understand and cope with the fundamental shifts that disability brings to the family ecology. The BeST clinician leads the family and others involved through the functional assessment process to develop a consensus on the antecedents and setting events that predict the challenging behaviors, and hypotheses as to the function of those behaviors. The parents come to understand the impact that the various environments have on their children and how change within those environments will promote positive change in the behavior of the child, and therefore improve the quality of life for all in the family. A written PBS plan is developed with the parents (and often, teachers) that fits the family's needs and capabilities. Then the clinician helps the family implement and refine the PBS procedures.

**Intensive Family Preservation Services** is strategic and goal oriented family-based service. It focuses on the family as the target of the intervention with an emphasis on strengthening and empowering the family as a unit. It cooperates with both formal and informal systems and strives to enhance the family member's sense of control over their life. The goal of the intervention is to overcome problems by strengthening all components of the family.

**Traditional Mental Health Services** are provided to all individuals in the family with special attention given to the child with developmental disabilities. The therapists are all trained mental health providers. When children exhibit signs of distress that cannot be explained by the mere presence of the disability then it is imperative to explore the possibility of adjustment or other mental health issues. Many of these children are undiagnosed for such disorders as anxiety, depression, ADHD and PTSD. Because all of their symptoms are attributed to their developmental disability they may not get appropriate psychological treatment, or if needed, medication. In addition, the linkages between the worlds of Developmental Disability and Mental Health are often poor. The BeST clinicians facilitate those linkages in several ways.

The Behavior Support Team believes that by blending PBS, Intensive Family Preservation Services, and Mental Health Services and by relying on the expertise of the family, significant improvements will result that help families survive the current crises and will strengthen the family unit. In combining these three models, the Behavior Support Team follows a five stage process of clinical practice that occurs during the 8-12 week intervention. These aren't necessarily sequential steps, but are overlapping. The goals of these clinical processes are: Stage 1: Joining/ Relationship Building; Stage 2: Developing Shared Perspective of problems and solutions; Stage 3: Assessment Processes (PBS and Family System/mental health functioning); Stage 4: Share Assessments and Plans: build consensus for hypotheses and interventions; Stage 5: Implement and Revise plans to insure good contextual fit and effectiveness.

### Description of Children and Families Served- 2005

#### Client Demographics (N= 123 ; 2005 data)

	<b>Percent of Children/Families</b>
Identified child is Male	68
Single Parent Family	35
Parents need language interpreters	9
<i>Ethnicity--</i>	
<i>White/Caucasian</i>	52
<i>Mexican/Mexican American/ Hispanic/Other Spanish</i>	18
<i>African American</i>	10
<i>Asian</i>	10
Median Age of Identified Child (bi-modal)	4, 10
Child has more than one developmental or mental health diagnosis	37
On psychotropic medications at intake	51

#### Rank Orders Based on Parent Report (2005)- Most common to least:

Rank	Presenting Problems	Rank	Primary Developmental Disability
1	Aggression	1	Autism/ PDD/ Aspergers
2	Tantrums	2	Developmental Delay (< 6 yrs)
3	Non-compliance	3	Mental Retardation
4	School Issues	4	Genetic/Chromosomal anomalies
4	Self-Harm	5	Down Syndrome
6	Elopement	6	Cerebral Palsy
7	Sleep problems		
7	Toileting problems		
7	Sexual problems		

#### Discussion

There are natural similarities between the PBS model and the Family Systems mental health approaches for supporting families whose children have behavioral challenges. Both models have ecological perspectives, seeing the child as part of a larger family system and the family as part of a larger community, and that these micro and macro systems are interconnected. The “Wraparound” treatment model developed from Family Systems Therapy perspectives, and is analogous to how PBS encourages stakeholder teams and person-centered planning to guide comprehensive interventions. Both stress “Strengths-based” and “family-centered” values.

While the BeST model presented here is only one possible approach to providing comprehensive family-centered supports, we offer it as a model program, and seek your consideration and feedback. Combining PBS with the Family Systems mental health approach appears to be unique and we believe our model would be valuable in other communities. We are constantly trying to evolve it to be more effective and responsive to families needs. We do not have experimental data on its effectiveness, but have garnered impressive results in reported parent satisfaction (See table below) and a very positive reputation in our community.

*Limitations of our model:* Due to the high demand and relatively small number of staff of the BeST we made a decision early to make this a short-term and more crisis-oriented intervention model, and to only serve children between 3-17. We’ve had requests to serve 2-year olds and those in the 18-20 year age range still living with their families, where these same services would be very appropriate. The model of 8-12 weeks of service may not provide enough supports to some families, though we’ve let BeST be somewhat flexible in extending their services. We don’t have the staff to be open 24-7, so it is not a true crisis service. If we do get the chance to increase our staff and budget, we envision offering groups for social skills and for sibs, more day and short-term overnight respite, having a “Flex-fund” to help families with essential needs that are not available through the categorical funding streams of social service agencies, and having the BeST clinicians offer more consultation and training to our local mental health providers, who often shy away from trying to help these families due to their lack of knowledge and competencies.

**Parent Satisfaction Survey Results—2005 N= 67**

<b>Questions</b>	<b>Percent Positive Response</b>	<b>Percent Negative Response</b>
How Helpful were the BeST services?	<b>84 %</b> “Helpful” or “Very Helpful”	<b>3%</b> “Not Helpful” or “Made Worse”
Since initial meeting with BeST, how has your child been?	<b>78%</b> “Better” or Much Better	<b>12%</b> “Worse” or “Much Worse”
How satisfied were you overall with the services provided by BeST?	<b>91 %</b> “Mostly” or “Very Satisfied”	<b>5 %</b> “Somewhat” to “Very Dissatisfied”
Would you recommend these services to others?	<b>96%</b> “Probably” or “Definitely Yes”	<b>3 %</b> “Probably” or “Definitely Not”

*We dedicate this presentation to Sandy McAuliff, M.S.W, who was one of the creative forces behind the development and success of the BeST and a tireless advocate for children and families of all stripes. 1946-2005.*

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## Appendix 4

### Washington State DDD HOME AND COMMUNITY-BASED SERVICES WAIVERS

The Division of Developmental Disabilities manages four home and community-based services Medicaid waivers.

Medicaid home and community-based services waivers allow states to deliver long-term care services in community settings and to collect federal Medicaid dollars for the cost of those services. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings.

The four waivers offer packages of services that vary based on the needs of the population targeted to be served by each waiver. The services covered under each waiver (and any applicable expenditure limits) are listed below.

Current data indicate the DDD has approximately 1,935 individuals on the active caseload with a diagnosis of autism. Approximately 820 of these individuals are served on one of the four DDD HCBS Waivers.

#### **WAC 388-845-0205 Basic Waiver Services.**

<b>BASIC WAIVER</b>	<b>SERVICES</b>	<b>YEARLY LIMIT</b>
	<b>AGGREGATE SERVICES:</b> Behavior management and consultation Community guide Environmental accessibility adaptations Occupational therapy Physical therapy Specialized medical equipment/supplies Specialized psychiatric services Speech, hearing and language services Staff/family consultation and training Transportation	May not exceed \$1454 per year on any combination of these services
	<b>EMPLOYMENT/DAY PROGRAM SERVICES:</b> Community access Person-to-person Prevocational services Supported employment	May not exceed \$6631 per year
	Sexual Deviancy Evaluation	Limits are determined by DDD
	Respite care	Limits are determined by the DDD assessment
	Personal care	Limits are determined by the DDD assessment

BASIC WAIVER	SERVICES	YEARLY LIMIT
	MENTAL HEALTH STABILIZATION SERVICES: Behavior management and consultation Mental health crisis diversion bed services Skilled nursing Specialized psychiatric services	Limits are determined by a mental health professional or DDD
	Emergency assistance is only for aggregate services and/or employment/day program services contained in the Basic waiver	\$6000 per year; Preauthorization required

**WAC 388-845-0210 Basic Plus Waiver Services.**

BASIC PLUS WAIVER	SERVICES	YEARLY LIMIT
	AGGREGATE SERVICES: Behavior management and consultation Community guide Environmental accessibility adaptations Occupational therapy Physical therapy Skilled nursing Specialized medical equipment/supplies Specialized psychiatric services Speech, hearing and language services Staff/family consultation and training Transportation	May not exceed \$6192 per year on any combination of these services
	EMPLOYMENT/DAY PROGRAM SERVICES: Community access Person-to-person Prevocational services Supported employment	May not exceed \$9691 per year
	Adult foster care (adult family home) Adult residential care (boarding home)	Determined per department rate structure
	MENTAL HEALTH STABILIZATION SERVICES: Behavior management and consultation Mental health crisis diversion bed services Skilled nursing Specialized psychiatric services	Limits determined by a mental health professional or DDD
	Personal care	Limits determined by the DDD assessment

<b>BASIC PLUS WAIVER</b>	<b>SERVICES</b>	<b>YEARLY LIMIT</b>
	Respite care	Limits are determined by the DDD assessment
	Sexual Deviancy Evaluation	Limits are determined by DDD
	Emergency assistance is only for aggregate services and/or employment/day program services contained in the Basic Plus waiver	\$6000 per year; Preauthorization required

**WAC 388-845-0215 Core Waiver Services.**

<b>CORE WAIVER</b>	<b>SERVICES</b>	<b>YEARLY LIMIT</b>
	Behavior management and consultation Community guide Community transition Environmental accessibility adaptations Occupational therapy Respite care Sexual deviancy evaluation Skilled nursing Specialized medical equipment/supplies Specialized psychiatric services Speech, hearing and language services Staff/family consultation and training Transportation	Determined by the Plan of Care or Individual support plan, not to exceed the average cost of an ICF/MR for any combination of services
	Residential habilitation	
	Community access Person-to-person Prevocational services Supported employment	
	<b>MENTAL HEALTH STABILIZATION SERVICES:</b> Behavior management and consultation Mental health crisis diversion bed services Skilled nursing Specialized psychiatric services	Limits determined by a mental health professional or DDD
	Personal care	Limited by the DDD assessment

**WAC 388-845-0220 Community Protection Waiver Services.**

<b>COMMUNITY PROTECTION WAIVER</b>	<b>SERVICES</b>	<b>YEARLY LIMIT</b>
	Behavior management and consultation Community transition Environmental accessibility adaptations Occupational therapy Physical therapy Sexual deviancy evaluation Skilled nursing Specialized medical equipment and supplies Specialized psychiatric services Speech, hearing and language services Staff/family consultation and training Transportation	Determined by the Plan of Care or Individual support plan, not to exceed the average cost of an ICF/MR for any combination of services
	Residential habilitation	
	Person-to-person Prevocational services Supported employment MENTAL HEALTH STABILIZATION SERVICES: Behavioral management and consultation Mental health crisis diversion bed services Skilled nursing Specialized psychiatric services	Limits determined by a mental health professional or DDD

## APPENDIX 5

The chart below summarizes the services for Oregon, Michigan, Colorado, Massachusetts, and Wisconsin.

<b>Summary of Follow-up Interviews &amp; Website Reviews</b>					
<b>STATE</b>	<b>SERVICE TYPE</b>	<b>ELIGIBILITY</b>	<b>WAIVER</b>	<b># SERVED &amp; COST LIMITS</b>	<b>SERVICES PROVIDED</b>
Oregon	Children's intensive in-home services for children with challenging behaviors	Age: Birth – 18 yrs. Child must live in family home and meet Behavioral Scoring Criteria	Model Home and Community Based Services Waiver	Average of 125 children served – Funding available for 140–145  Cost Limit: average \$36,000/year/client  Average of 40 – 60 hours/week provided for children/families  Funding follows the child when they transition to adult programs.	Behavior Consultation/Training; Home/Vehicle Adaptations; Respite; In-home daily care Assist. w/household chores; Specialized diet Translation Transportation Supervision
Michigan	Intensive in-home services for children with challenging behaviors	Age: Birth – 18 yrs. Child must live with family, or out of home with plan to return to family home  Access to services determined by "Priority Weighing Criteria"	Home and Community Based Services Waiver	Currently serving 435 children – based on funding availability  Cost Limit – Average of \$42,000 - \$45,000/child/year  Cost levels based on "Decision Guide" to	Therapies; Community Living Supports (including ADL skill development, supporting child's integration into community, promote mobility, sensory-motor, communication, socialization and relationship-building skills); Enhanced Transportation; Respite; Family Training/counseling;

### Summary of Follow-up Interviews & Website Reviews

STATE	SERVICE TYPE	ELIGIBILITY	WAIVER	# SERVED & COST LIMITS	SERVICES PROVIDED
		based on 10 elements: 1) availability of other resources; 2) behavioral/medical issues; 3) risk of out-of-home placement; 4) # and ages of other minor children in home; 5) family stress and/or physical health problems; 6) more than one special needs child in home; 7) child presently in nursing home; 8) child presently in ICF/MR facility; 9) reserved for future use; 10) child in foster care and needs support		determine client's level of service w/range of 2-16 hours/day; average of 6 hours/day for children with significant behavioral issues	Provider training; Specialized medical equipment; Environmental Accessibility Adaptations; Assessment/Evaluations; Crisis Intervention; Health Services; Medication Administration/Review
Colorado	In-home services for children – priority for children with extensive behavioral issues	Age: Birth – 18 yrs. Child must live in family home and meet Behavioral Issues Criteria	Home and Community Based Services Waiver	Currently serving 395 children - based on funding availability  Cost Limit: \$35,000/year/client; average of \$15,000/year/client	Personal Assistance Environmental Engineering Professional Services Behavioral Services Community Connection Services
Massachusetts – Autism Waiver	In-home services for children with	Age: Must be less than 9 years of age to enter	3-Year Demonstratio	Serve a maximum of 80 children	Expanded Habilitation Education (includes behavioral interventions,

### Summary of Follow-up Interviews & Website Reviews

STATE	SERVICE TYPE	ELIGIBILITY	WAIVER	# SERVED & COST LIMITS	SERVICES PROVIDED
	diagnosis of Autism Spectrum Disorder	services. Child must reside in family home and have confirmed diagnosis of Autism Spectrum Disorder	Home and Community Based Services Waiver	Cost limit: Average of \$25,000/client/year	ABA Therapy) Habituation/Community Integration (includes skills training/support in self-help, socialization and adaptive skills) Family Training Respite
Massachusetts – Dept. of Education/Dept. of Mental Retardation Project	In-home services for children requiring intensive level of support	Age: 6 – 18 yrs Child must reside in family home and be at risk of Residential Special Education School placement; or be returning to family home from Residential Special Education School	Non-waiver services	Currently serving 350 children Cost Limit: Average of \$25,000/client/year Average of 12 – 20 hours/week of direct support	In-Home ADL support/skills training Respite Community Integration Behavior Management Training./Consultation Parent Training/capacity building Professional Services Specialized Therapeutic Activities Adaptive Equipment- Environmental Modifications Recreational fees/membership Emergency/Crisis Support
Wisconsin	Intensive in-home autism treatment services	Must enter services prior to age 8 and have a diagnosis of Autism, Asperger's or Pervasive Developmental Disorder Access to services limited to 3 years without an exception	Home and Community Based Services Waiver-	Cost Limit: \$40,000/client/year. Personal care services provided in addition. Average of 20 – 35 hours/week of direct therapeutic support	Variety of therapeutic approaches (heavily ABA focused) implemented with intent to enhance behavior, communication and social skills. State Plan Medicaid Personal Care is provided in addition to services under Intensive In-Home Autism Treatment Services Waiver