

**In Support of Oregon Children with
Developmental Disabilities
and Their Families:
Policy Options and Recommendations**

August 11, 2006



Human
Services
Research
Institute

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All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Oregon Department of Human Services, Division of Seniors and People with Disabilities, or any other government authority.

What follows are findings stemming from recent work in Oregon completed by HSRI related to efforts funded through DHS to support children with developmental disabilities and their families.

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1. Introduction

Respite services are well documented as a critical support needed by families who have family members with special needs living at home. These family members often have needs stemming from various disabling conditions (e.g., developmental disabilities, medical fragility, physical disabilities, mental health challenges) or as a function of aging. Respite provides a temporary break for caregivers, reducing family and caregiver stress and strengthening the family's ability to meet the extraordinary care demands. Families report that respite is essential to the preservation and well-being of their family.



There are many forms of respite. Variations include supports offered inside or away from the family home, provided formally by paid staff or informally by friends, neighbors, or other family, or paid for by public or private funds, or some combination. And, there are contrasting options within each iteration. It is a service that families and caregivers most often request and is a critical element in the prevention of abuse, neglect, and family crisis. Yet, family access to respite services remains in short supply.

In this context, the focus of this project centers on children with disabilities, and in particular developmental disabilities. At issue are the services these children and their families receive through the Department of Human Services (DHS), with a particular emphasis placed on respite services.

DHS serves as the umbrella agency for health and human services and Oregon's Single State Medicaid Agency. DHS supports seniors, at-risk children, people with disabilities, low-income families working toward self-sufficiency, and people facing alcohol or drug issues. The DHS administrative branch responsible for services for people with developmental disabilities is Seniors and People with Disabilities (SPD). SPD primarily contracts with local governments and service providers to carry out this responsibility.

SPD's long-term support linchpin is Case Management, primarily Medicaid Targeted Case Management, provided by local government Community Developmental Disability Programs (CDDPs). When a child with developmental disabilities requires support not typical of children in general, a case manager helps the child's family to access options – including respite services – that may or may not be supported by Medicaid.

DHS presently offers respite supports to families of children with disabilities through several sources, including:

- *Local family support services offered through county auspices.* Since the mid 1980s, Oregon has worked to offer a range of family supports, including respite services, under the state Family Support program. Presently, the program has two components: (a) the General

Assistance Family Support Fund, and (b) Department Designated Funds. The combined allocation for these two programs for the '05-'07 biennium totals, just over \$9 million. Funding for these programs have experienced increases, but overall have decreased over the past years.

- *Local Lifespan Respite Programs for families seeking respite and/or qualified respite providers.* The Lifespan Respite Care Program was established in 1997 to assist communities in building respite networks to serve families who support individuals at home with a variety of disabilities, including developmental disabilities, mental illness, emotional or behavioral disorders, chronic illness, Alzheimer's disease, medical fragility or those at risk of abuse or neglect. Overall, these programs are intended serve as a central point of contact for families seeking respite. Lifespan staff are asked to offer families information, referral and training regarding respite, recruit respite providers for families, take action to spur increased community involvement in offering respite.
- *Medicaid Model Waivers for Children.* Oregon operates two "Model 200" Medicaid HCBS waivers that cannot support more than 200 children at any point in time. One is directed at children with disabilities who are medically fragile (i.e., technology dependent). The other is aimed at children with mental retardation or developmental disabilities with extraordinary behavioral challenges. Both waivers offer a range of services, including respite; tailored to the targeted populations.
- *Medicaid Personal Care services for children eligible for Medicaid State Plan services.* This service has become an important part of the means available for offering "incidental" respite to family caregivers. The service is directed at the "Medicaid beneficiary" as a direct support to him or her to undertake daily life activities. The effect, however, of having a paid staff present to offer such assistance, in essence, also offers respite to family members.

Oregon, like many other states, is struggling with funding shortfalls that challenge the state's ability to maintain respite and other services to families of children with developmental disabilities at current levels. Given rising costs and the scope of continuing unmet needs, the state is unable and unwilling to continue providing high-cost out-of-home placements and crisis-related services to meet needs that could be better met by quality children's respite services at a reasonable cost and at the right time. In response, DHS applied for a federal grant to explore the use of Medicaid and other resources to more broadly and effectively meet the growing unmet needs of Oregon families with children with developmental disabilities.

Early in 2004, DHS was awarded a "Real Systems Change Grant" from the Centers for Medicare and Medicaid Services (CMS) for the expansion and improvement of children's respite services. To complete the work, DHS contracted with the National Center for Family Support at the Human Services Research Institute (HSRI). HSRI was charged with conducting a study to help the state develop a statewide respite service delivery system that serves the maximum number of children with developmental disabilities who need respite services, and makes optimum use of all resources, including Medicaid.

Respite, however, fits within a larger context. As the study unfolded, it became apparent that it was difficult to study respite alone without considering it as it exists within the larger context of family support. As a result, study efforts broadened to consider larger issues pertaining to the Family Support and Lifespan Respite programs, and the role that Medicaid could play in helping to finance these systems.

In this context, the purpose of the study was to:

- Identify how DHS can use Medicaid and other resources more broadly and effectively to meet the family support and respite needs of Oregon families of children with developmental disabilities.
- Assess what SPD might do to improve its response to families through its Family Support system.
- Assess what DHS might do to improve the effectiveness of the Lifespan Respite program.

This final report documents the activities, findings and recommendations associated with the study. The remainder of the report is organized as follows:

Chapter 2 -- Study Methods: This chapter provides an overview of the methods that were applied to complete the study.

Chapter 3 -- Study Findings: In this chapter, findings emerging from all project activities are brought together and organized by three primary service modes, specifically Family Support Programs, the Lifespan Respite Care Program, and the Model waivers.

Chapter 4 -- Recommendations And Concluding Remarks: This chapter offers final summary observations and conclusions regarding project findings, and offers a series of recommendations for improving family support and respite services in Oregon.

2. *Study Methods*

Several activities were undertaken to coordinate the project, review and analyze Oregon's current respite and family support systems, and develop policy options for SPD to consider. These activities include a review of state and national written materials, state and county data, Oregon administrative rules, family forums, face-to-face and telephone interviews, an email survey, and a roundtable discussion with stakeholders and two structured discussion meetings with DHS and SPD staff.

In addition, we worked with a 12-member Consumer and Partner Advisory Group (CPAG) assembled by HSRI and SPD staff. This group represented a combination of family members, advocacy organizations, provider agencies, and community and government agencies. During the course of the project, we hosted quarterly meetings with this group and sent them several documents for their review. Overall, the CPAG worked with SPD and HSRI staff to advise project activities, review findings stemming from project efforts, and discuss key issues pertaining to Oregon's developmental disability policies.

Three primary methods were used to collect information, including: (a) review of data provided to us by SPD staff, (b) results of a FACT Listening Tour conducted by families, and (c) structured discussions involving family members, program staff and others.

State Data Review and Review of Relevant Documents

During the project, we collected a range of data and materials made available to us or that we acquired through our own effort. These included:

- Data illustrating the characteristics and service use patterns associated with the Lifespan Respite Care Program, Family Support Program services offered through SPD and CDDPs, and the state's two Model waiver programs. These data were gathered and provided to us by SPD staff.
- Documents to describe the legislative origins of particular programs, associated administrative rules, and other relevant reports tied to specific programs. Many of these materials and rules were summarized within a matrix to describe the respite services for families of children up to age 18 with developmental disabilities in Oregon (See Appendix A). Overall, we reviewed documents such as:
 - Oregon Administrative Rules Chapter 410, Division 015, Oregon Lifespan Respite Care Program;
 - Oregon Administrative Rules Chapter 411, Division 300, Children's Intensive In-Home Services;
 - Oregon Administrative Rules Chapter 411, Division 305, Family Support Services for Children with Developmental Disabilities;

- Oregon Administrative Rules Chapter 411, Division 034, Personal Care Services;
- Oregon Administrative Rules Chapter 411, Division 350, Medically Fragile Children Services;
- Lifespan Respite Legislation, Oregon House Bill 2013, 69th Oregon Legislative Assembly, 1997 Regular Session;
- Various iterations of efforts at the federal level to have passed national lifespan respite legislation, the Lifespan Respite Care Act (United States Senate Bill 1283; House Resolution 3248);
- Building Oregon’s Lifespan Respite Care System;
- Various materials on Lifespan Respite made available through national organizations such as The National Respite Coalition and the ARCH National Resource Center for Respite and Crisis Care Services. These sources make available by internet numerous alerts, reports and comparison studies on lifespan respite (e.g., Statewide Lifespan Respite Programs: A Study of Four State Programs (Baker & Edgar, 2004)).

FACT Listening Tour

To complement data gathered from these sources, HSRI contracted with the Family Action Coalition Team (FACT), a coalition of family members and disability organizations. FACT members conducted several family forums, face-to-face interviews with professionals, and an email survey. These efforts provided a human perspective on the status of family support and respite services from first-hand experiences of families and professionals throughout Oregon. What follows is a description of each.

FACT Listening Tour		
Family Forums	95	family respondents
Interviews	21	program staff
Email Survey	140	family respondents

- *Family forums.* FACT conducted family forums during the “Listening Tour” through seven counties (i.e., Benton, Clackamas, Deschutes, Jackson, Josephine, Multnomah, and Umatilla) in urban, rural, and suburban areas of the state. These forums occurred between October 28th and November 28th, 2004. The forums were conducted by three FACT family members, usually in teams of two, to facilitate and record responses.

Families were recruited for each event through local CDDPs. Flyers were developed and distributed to each CDDP and to a listserv of individuals on the Oregon Network, a statewide data base maintained by the Oregon Developmental Disabilities Council of over 5,000 families, self-advocates, and professionals who indicated an interest in developmental disability issues. Contact was made with each County program staff to inform them of the study and seek assistance recruiting families. County staff agreed not to attend the events to elicit an open and honest response from families.

When a local community leader was known, contact was made to ask for assistance in recruiting families for the event and encouraging them to attend. In several locations, family forums were linked with an Advocacy Days training or another family disability-related

event. The most successful events occurred when a local leader encouraged families to participate.

Forums were structured as informal discussions that included pizza dinners held at a variety of locations in local communities including county offices, a community college, local libraries, and a motel. Families were asked about family support and respite services they were receiving or waiting to receive, their experiences with the Family Support and Lifespan Respite programs, barriers experienced in accessing these services, and what they would change to make things better.

FACT family members facilitated each discussion using a series of questions regarding what is working and not working to help families meet their respite needs within local Lifespan Respite and Family Support programs. Participant responses were recorded either on paper or a flip chart. A total of 95 family members participated in the forums. Questions used during these forums are located in Appendix B.

- *Face-to-face and telephone interviews.* To gather complementary information from professionals, FACT contacted County Developmental Disability program managers and case managers, Family Support staff, and Lifespan Respite coordinators to describe the Listening Tour and schedule interviews. FACT members conducted face-to-face and telephone interviews with a total of 31 CDDP and Lifespan Respite Program staff representing 12 counties (Clackamas, Clatsop, Jackson, Lane, Linn, Marion, Morrow/Wheeler, Multnomah, Tillamook, Umatilla, and Washington). These interviews occurred with one or more county staff at the Direct Supports Conference, the State Interagency Coordinating Council Conference, or in local county offices. Efforts were made to conduct face-to-face interviews whenever possible. When this was not possible, interviews were completed by phone.

The interviews occurred between July 2004 and December 2005 using 13 questions designed to gather information regarding: (a) local program description and numbers served, (b) family demographic data and access to services, (c) what is and is not working regarding local Family Support or Lifespan Respite programs, and (d) program funding structures and trends (See Appendix B).

- *Email survey.* In January 2005, FACT distributed an email survey (see Appendix C) based on the questions used during the family forums. The survey included 18 questions designed to gather information regarding: (a) demographics; (b) use of family support services and supports; (c) experience with local Family Support programs; (d) use of respite services; and (e) experience with local Lifespan Respite programs.

The survey was emailed to individuals through several email groups including the Oregon Network, the FACT listserv, the EI/ECSE listserv, and to CDDP managers and organizations that serve families of children with developmental disabilities across the state. Over 140 responses were received from 15 counties (i.e., Clackamas, Coos, Curry, Douglas, Jackson, Josephine, Lane, Linn, Multnomah, Polk, Tillamook, Umatilla, Washington, and Yamhill).

Briefly, using the data collection methods described above, FACT members discovered that family access to respite services is hampered by several issues related to how the Family Support system and funding structures have evolved over the past two decades. A complete description of these findings is found in the FACT Listening Tour report located in Appendix D. A discussion of our overall findings is included in the Study Findings section.

Structured Discussions

As noted above, HSRI assembled a 12-member Consumer and Partner Advisory Group (CPAG) to help us review and consider the information that was collected. The group met five times in total at offices in Salem. During its meeting, the group reviewed project activities, offered feedback and guidance, and shared opinion and analysis regarding the several policy options available to SPD.

In part based on their analysis of our initial findings, we discussed three issues with SPD staff that led to a contract amendment to revise the remaining project tasks. First, we conducted the study within a dynamic state environment. Soon after the study began, DHS solicited proposals to Counties for projects to enhance the delivery of Family Support services to children with developmental disabilities through capacity building activities. In addition, the state Family Support coordinator began conducting trainings around the state. Second, County data revealed significant insight into Family Support practices and expenditures across the state. And third, the data collected by FACT revealed a wealth of information about practices in many areas of the state. As a result, HSRI staff submitted a letter to the state requesting several contract amendments in March 2005. DHS accepted the following amendments in May.

- Original project tasks called for HSRI staff to collect additional data by developing and administering a survey of county administrators and respite care providers, conducting telephone interviews of key stakeholders, and conducting additional on-site visits to select Lifespan Respite Care Programs. The purpose of these tasks was to collect additional information regarding respite services statewide to compliment earlier findings and inform policy options for the state's consideration. However, given results of the initial data analysis these tasks were eliminated.
- HSRI intended to develop a "Best Practices Toolkit" to include existing effective and or innovative tools from throughout the state that could be utilized in an improved and expanded future respite care system. However, data collected from DHS and FACT revealed an insufficient pool of best practice exemplars to develop a toolkit from. As a result, this task was eliminated as well.

The activities above were replaced with two types of meetings that were intended to affirm initial findings and gather recommendations for what might be done to improve services for children and their families. These included:

- *A Stakeholders Roundtable.* This meeting occurred on July 20, 2005 at the Eola Center on the Chemeketa Community College campus near Salem. HSRI staff worked closely with CPAG members and SPD staff to select a group of stakeholders to participate. Ultimately, this group of 20 individuals included CDDP case managers, Lifespan Respite Program

coordinators, individuals representing family disability advocacy organizations and family members from around the state.

During the meeting, HSRI staff presented initial findings based on the FACT Listening Tour and the literature and data review, and facilitated discussion of what is and is not working within the Family Support and Lifespan Respite programs locally. Meeting minutes are located in Appendix E for a description of this discussion. Gary Smith of HSRI followed this meeting by preparing a paper to describe options for using Medicaid to finance family support services in Oregon (See Appendix F, Medicaid Pathways report).

- *Meetings with stated DHS staff.* Two meetings were held with DHS staff as a follow-up to the roundtable gathering. The first was held on October 5, 2005 and the second on January 26, 2006. Both were held in Salem at the DHS offices with the Director of SPD, Mary Lee Fay, and selected DHS personnel.

At the first meeting HSRI staff presented initial findings, stakeholder comments and suggestions resulting from the July 20th meeting. A good portion of this meeting also focused on the use of Medicaid to help finance Family Support services. The second meeting focused on issues aside from Medicaid, and more particularly on what SPD might do to improve services.

3. *Study Findings*

To complete study objectives, HSRI staff reviewed Oregon’s current respite and family support systems that serve children up to age 18 and their families. This review included an in depth look at the state Family Support program, the Lifespan Respite program, and Oregon’s two Model Medicaid waivers using the methods described above. What follows is a description of the study findings according to our observations regarding the Oregon Family Support program, the Lifespan Respite Program, and Oregon’s Model waivers for children.

Oregon Family Support Program

Family Support Programs were initiated in Oregon almost twenty years ago. They grew from strong family advocacy for the program that resulted in the creation of a few pilot programs that explored various means for supporting families. At the time, Oregon was on the leading edge of efforts nationally to establish Family Support systems.

Later, based on a series of principles regarding Family Support, legislation was passed and associated rules (OAR 411-305-0010) were developed to administer the program. As described in the rule, DHS, through the Division of SPD, provides assistance to families caring for their children with developmental disabilities at home. The program is described within relevant SPD literature as follows:

- The program is administered through county developmental disability programs.
- Funding for the program stems from State revenue only, and SPD divides these resources into two categories. The “General Assistance Fund” may be thought of as the “mainstay” Family Support effort since it is directed at most children and families who seek this service. “Department-designated Funds” refer to resources that SPD ties specifically to a particular child, typically to avoid out-of-home placement.
- To be eligible for Family Support services, a child must be between the ages of birth and 18 years, and be eligible for developmental disability services as determined by the CDDPs. Eligibility for the Family Support program is based upon disability, not upon financial need. A child may enter Family Support services once the CDDP finds him or her eligible and that there are sufficient funds available. A child may receive Family Support services any time the Department designates funds for the child through a contract with the CDDP.
- Once deemed eligible and approved for services, the child is assigned a CDDP case manager to devise a child and family centered supports plan. The plan includes an estimate of service costs and identifies sources of funding. It also includes an estimate of the cost of services, and documents where the funding and support will come from. Plans are reviewed at least annually. It should be noted that the intent embedded in the rule is not to consider the planning process as a means for tying money to services. Before Family Support funds are spent, the rule indicates that the CDDP case manager or Family Support staff and the family

must work together to explore all available resources from the family and community. These might include people, support groups, public and private programs, private insurance, and many other resources.

- The rule is designed to promote flexible spending to support families, though the goods or services purchased must be necessary for a child to be supported in the family home. Family Support funds cannot be used to supplant normal parental responsibility. Moreover, all other available means of providing needed supports must be exhausted before using Family Support funds. For instance, Family Support funds could not be used to pay for educational services that schools are required to provide.

The services that may be purchased fall into 13 categories:

Behavior consultation	Physical therapy
Community inclusion	Respite care
Environmental accessibility and adaptations	Special diets
Family caregiver supports	Specialized equipment and supplies
Family training	Speech hearing and language services
In-home support	Transportation services
Occupational therapy	

- Where funds are dispersed so that the services of a fiscal intermediary are used to manage the expenditures, the rule provides provisions to guide the actions of the intermediary.
- Finally, in operating these programs locally, CDDPs must also satisfy other requirements. For instance, they:
 - May appoint a “Family Support Policy Oversight Group” to advise and assist the CDDP in matters pertaining to Family Support;
 - Must maintain an up-to-date written list of eligible children that have been assigned an order for service, but are still awaiting services;
 - Must provide or arrange for training for case managers related to Family Support;
 - Must maintain required records pertaining to the children and families served, and to provide satisfactory fiscal accounting;
 - Must provide for a complaint, grievance and appeals process as specified in the rule; and
 - Must participate in statewide quality assurance or evaluation activities as directed by DHS.

Funding for the program. Funding was set at just over \$9 million for the 2005-2007 biennium and is divided into two categories. The General Assistance Fund is allocated about \$4.7 million, and Department Designated Funds total about \$4.3 million. CDDPs do not receive a flat and even amount of funding, but rather are allocated funds based on a formula that accounts for population.

Children served and expenditure patterns. As illustrated by the accompanying graphic, in the nine month period of July 2005 through March 2006, a total of 910 children received family

support services. Most, totaling 787, received supports through the General Assistance Fund with another 137 receiving services through Department-Designated contracts to CDDPs. (Note that these numbers sum to 924; There were 14 “dual billed” individuals.) These numbers may fluctuate some over the biennium, but are a good reflection of the number of children served.

Regarding the General Assistance Fund, Family Support plans generally average under \$2,000 per year. Given the nine month period under review, we estimate that over the first 12 months of the biennium plans across the state will average \$1,694. As shown, however, there is notable variance across counties. Several counties report plan sizes of under \$1,000 annually (e.g., Baker, Benton, Tillamook). To contrast, the average plan size in Marion County is about \$3,161.

Family Support Data					
General Assistance Funds Only					
(CPMS Billing Summary - July 1, 23005 through March 31, 2006)					
County	Allocation	Indiv. Served	Amt Billed In Period	Average Plan Per Month First 9 months	Estimated 12 Month Plan Allocation
Baker	\$21,671	8	\$3,294	\$46	\$549
Benton	\$107,046	49	\$25,319	\$57	\$689
Clackamas	\$465,295	69	\$126,677	\$204	\$2,448
Clatsop	\$47,664	7	\$12,915	\$205	\$2,460
Columbia	\$59,776	8	\$7,524	\$104	\$1,254
Coos	\$80,569	22	\$32,782	\$166	\$1,987
Crook	\$27,040	10	\$9,838	\$109	\$1,312
Curry	\$27,695	10	\$5,777	\$64	\$770
Descutes	\$177,362	26	\$30,633	\$131	\$1,571
Douglas	\$131,864	29	\$39,312	\$151	\$1,807
Grant	\$10,148	0	\$0	NA	NA
Harney	\$10,017	4	\$4,640	\$129	\$1,547
Jackson	\$250,363	51	\$70,892	\$154	\$1,853
Jefferson	\$26,516	6	\$5,931	\$110	\$1,318
Josephine	\$102,921	23	\$18,958	\$92	\$1,099
Klamath	\$84,852	23	\$37,837	\$183	\$2,193
Lake	\$9,820	1	\$117	\$13	\$156
Lane	\$437,643	79	\$104,125	\$146	\$1,757
Lincoln	\$58,139	20	\$10,144	\$56	\$676
Linn	\$139,258	23	\$26,838	\$130	\$1,556
Malheur	\$41,705	2	\$300	\$17	\$200
Marion	\$390,799	35	\$82,979	\$263	\$3,161
Mid-Columbia	\$63,834	16	\$11,401	\$79	\$950
Morrow	\$17,415	4	\$1,183	\$33	\$394
Multnomah	\$899,394	82	\$109,485	\$148	\$1,780
Polk	\$85,047	22	\$21,409	\$108	\$1,298
Tillamook	\$32,671	13	\$9,669	\$83	\$992
Umatilla	\$94,607	15	\$25,995	\$193	\$2,311
Union	\$32,539	10	\$12,005	\$133	\$1,601
Wallowa	\$9,362	0	\$0	NA	NA
Washington	\$624,772	99	\$134,817	\$151	\$1,816
Yamhill	\$116,801	21	\$17,063	\$90	\$1,083
Totals	\$4,684,604	787	\$999,858	\$141	\$1,694

Information compiled by the Oregon Developmental Disabilities Coalition from 18 counties shows that 2,007 are on waitlists for Family Support services, with 886 in Multnomah County alone. These data, however, are regrettably incomplete given the number of counties without such data but nonetheless indicate a strong unmet demand for the service.

Regarding the Department-designated funds, individual plans are more ample. Individuals and families gain entrance to this program owing to extraordinary circumstances, and so have greater needs. Relatively few plans run over \$20,000 per year. During the nine month period reported here (July 1, 2005 through March 31, 2006), \$847,181 was billed for all participants. This averages out to about \$687/month/participant. When projected across 12 months, we estimate these plans at about \$8,245 annually per participant.

Family Support Data	
Department Designated Funds Only	
(Summary CPMS Billing – 7/1/05 through 3/31/06)	
Biennial allocation ('05-'07)	\$4,362,643
Billed this Period	\$847,181
Individual participants	137
Average Plan per Month	\$687
Average Estimated 12 month Allocation	\$8,245

Review of these data also reveal that the overall allocations are not spent out evenly month to month across the biennium. The nine months reported on amount to 37.5% of the biennium. Yet just about 20% of the allocation was billed out during this time. This pattern should not be taken to mean that the program has ample resources overall. In fact, the opposite is true with external factors and the scarcity of resources itself encouraging extraordinarily careful spending.

During the listening tour, for instance, families in some counties complained that they could not find respite workers, and so could not spend out their allocations. Others observed that families sometimes hold onto their allocations, not spending them down because they want to hedge on unexpected expenses. As the year goes on, however, and such expenses do not arise, funds are left unspent.

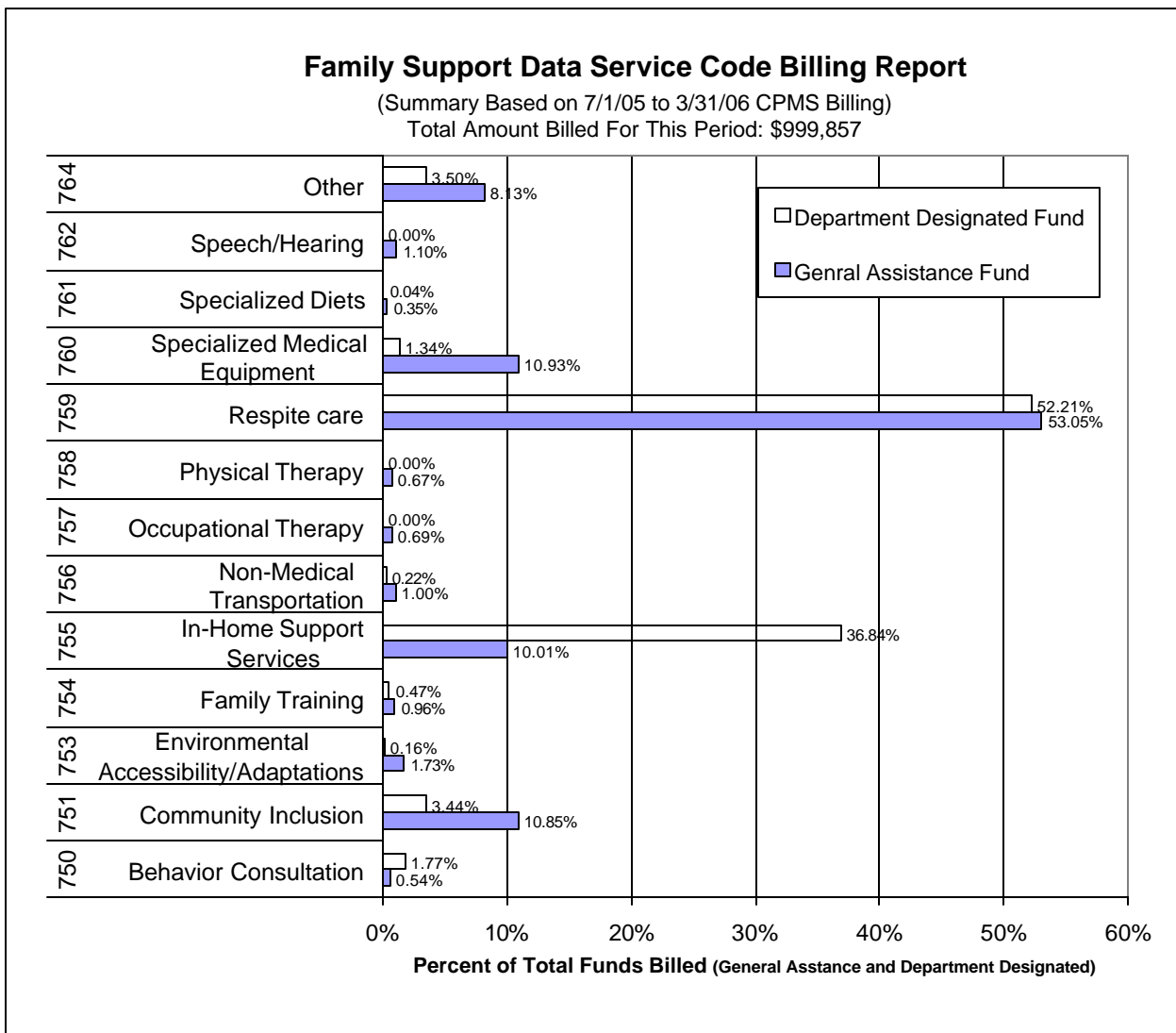
Additionally, CDDP case managers may well apply the same decision making when helping to fashion a support plan, seeking to conserve resources so that they may be available later in the year if needed. Finally, others argued that the CDDPs simply do not have the staff to develop creative support plans, build local capacity and help families utilize their allocations. This circumstance acts to drive down spending per family.

Regardless of the reasons, SPD is well aware of the pattern and has taken steps to offset factors like these. Again, we want to emphasize that these patterns are indicative not of a system that is amply resourced. Rather, they reveal an under-funded system whose underlying dynamics promote extraordinarily guarded spending and fails to provide case managers the margin they need to craft comprehensive plans around families.

Services purchased. Service plans for children and families can include purchase of goods or services associated with any of 13 service categories. We understand that there may be some types of supports that may be classified into this or that category, depending on the preference of the case manager. Still, the accompanying graphics illustrate that “respite” is the most popular service purchased, totaling just over half of the dollars expended within both the General Assistance and Department Designated Funds.

Specific to the General Assistance Fund, after respite other popular services include specialized medical equipment, in-home services and community inclusion. To contrast, specific to the Department Designated Fund, after respite the most often billed service are in-home support services.

The graphic on the following page indicates for the General Assistance Fund only what services are billed by county. As expected, respite is most frequently offered. The graphic, however, also suggests significant variance across the state regarding what services are billed.



In Support of Oregon Children with Developmental Disabilities

Family Support Data															
Services Billed For By Code and County															
(Summary Based On 7/01/05 to 3/31/06 CPMS Billing)															
County	Individuals Served	Billing Code													Total Number of Services Billed
		750	751	753	754	755	756	757	758	759	760	761	762	764	
Baker	8		x		x					x	x		x	x	5
Benton	49		x	x	x	x	x			x	x	x	x	x	10
Clackamas	69	x	x	x	x	x		x	x	x	x	x	x	x	12
Clatsop	7					x				x					2
Columbia	8		x			x				x	x			x	5
Coos	22			x			x			x	x			x	5
Crook	10		x							x	x				3
Curry	10		x							x	x			x	4
Descutes	26		x				x		x	x	x	x	x	x	8
Douglas	29		x			x	x			x	x			x	6
Grant	0									x					1
Harney	4					x									1
Jackson	51	x		x	x	x	x			x	x			x	8
Jefferson	6									x	x				2
Josephine	23			x	x					x	x			x	5
Klamath	23			x	x					x	x	x		x	6
Lake	1					x	x								2
Lane	79	x	x	x	x	x				x	x	x		x	9
Lincoln	20		x	x	x		x			x		x		x	7
Linn	23		x			x	x		x	x	x			x	7
Malheur	2									x	x				2
Marion	35		x	x	x	x	x			x	x		x	x	9
Mid-Columbia	16	x	x	x	x					x	x			x	7
Morrow	4					x				x	x				3
Multnomah	82	x	x	x	x	x				x	x	x	x	x	10
Polk	22	x	x	x		x	x			x	x			x	8
Tillamook	13	x				x	x			x	x	x		x	7
Umatilla	15	x	x				x			x	x			x	6
Union	10					x	x			x	x			x	5
Wallowa	0														0
Washington	99		x	x	x	x	x	x	x	x	x		x	x	11
Yamhill	21					x				x	x				3
Total Served	787														
Total Counties		8	17	13	12	18	14	2	4	29	26	8	7	22	

Billing Code Key:

750	Behavior Consultation	758	Physical Therapy
751	Community Inclusion	759	Respite care
753	Environmental Accessibility/Adaptations	760	Specialized Medical Equipment
754	Family Training	761	Specialized Diets
755	In-Home Support Services	762	Speech/Hearing
756	Non-Medical Transportation	764	Other
757	Occupational Therapy		

Observations. During the course of the project, review of the information collected, findings generated through the listening tour, and discussions with SPD staff and members of our Advisory Group led us to several notable observations:

- *People are working hard with many families receiving support, but the present investment in Family Support is insufficient.* There is no escaping this conclusion and its subsequent impacts on service delivery. Based on FY 2004 spending, Braddock et al., (2005) rank Oregon 47th among states regarding the number of families served per 100,000 citizens in the general population. In terms of overall spending on Family Support, this same source ranks Oregon 41st.

We recognize the difficulties associated with compiling data on Family Support across states and appreciate that these data are not always precisely accurate. Even so, these data cannot be discounted. Simply put, compared with other states, Oregon has not invested strongly in Family Support for children birth through 18 years.

To put this matter in perspective, consider what is spent on supporting families in a few other selected states. As illustrated by the accompanying table, Oregon does not compare well with states in terms of the numbers of families served. Regarding spending, Oregon spends annually about a dollar per citizen in its general population. This is much more than states like Alabama, Idaho and Arkansas. Yet, this amount is much less than several of the other states profiled, and far under the national average of \$7.04.

Selected State Family Support Programs (FY 2004)				
Population, Participants and Spending				
State	2000 State Population	Families Supported Per 100K	Total Spending	Spending per Citizen in the Population
South Dakota	754,844	230	\$3,037,557	\$4.02
New Hampshire	1,235,786	281	\$6,366,736	\$5.15
Idaho	1,293,953	61	\$243,300	\$0.19
Arkansas	2,673,400	32	\$412,769	\$0.15
Mississippi	2,844,658	108	\$7,090,441	\$2.49
Connecticut	3,405,565	251	\$35,301,039	\$10.37
Oklahoma	3,405,654	103	\$44,445,693	\$13.05
Oregon	3,421,399	31	\$3,821,684	\$1.12
Alabama	4,447,100	62	\$656,622	\$0.15
Minnesota	4,919,489	89	\$21,651,521	\$4.40
Washington	5,894,121	132	\$52,295,124	\$8.87
Massachusetts	6,349,087	223	\$43,524,515	\$6.86
United States	281,421,906	135	\$1,981,749,567	\$7.04

Source: Braddock et al., 2005

- *Overall, past the guidance offered by the administrative rule, there is no definitive shape to the program across the State.* Put another way, there is considerable variance among CDDPs in terms of how Family Support is administered. The accompanying table illustrates the difference between two counties, Benton and Multnomah.

As shown, Benton County with a population of 78,640 people serves 49 children and billed on average at \$57 monthly per family. The County reports no waitlist.

An Example of Differences Between Two Counties		
(CPMS Billing Data 7/1/05 – 3/31/06)		
	Benton	Multnomah
Population *	78,640	672,906
Children Served	49	82
Average Plan Cost Per Month per Family	\$57	\$148
Number Served per 100,000 population	62.30	12.19
Number on Waitlist	0	886
* 2005 population estimate, US Census Bureau		

Multnomah County with a population of 672,906 serves 82 families with average monthly plans of about \$148. The county reports a waitlist of at least 886 children.

We cannot say which approach serves families “best.” Such variance is within the parameters set by the governing administrative rule, and circumstances from county to county vary. These data, however, illustrate that CDDPs are coping with a scarcity of resources and local demand for services in their own ways.

- *Case managers do not always know well the children and families they seek to serve.* The administrative rule describes a child and family centered planning process whereby case managers and families would carefully work together to fashion a responsive support plan. The reality experienced by families across the state does not match well with this ideal. Case managers report high caseloads of individuals that include these children as well as others receiving services from other SPD and county auspices. These individuals may include those in “crisis” or receiving other long term supports. As a result, case managers are hard pressed to spend as much time with Family Support recipients as they might like.
- *Quick-minded service purchasing is a key response to families.* Case managers have little, if any time, to work at building relationships with other community serving organizations or community businesses that may be called upon to help support families. Not surprisingly then, we heard from families that their plans are often designed quickly and with an eye toward providing respite or simply purchasing goods and services. Little attention is paid to considering what other supports a family may need to acquire supports from other community sources.

Increasingly, then, CDDPs may be thought of as a “pass through” for funds to be directed at purchasing approved goods or services without sufficient attention to fashioning well thought out support plans or marshalling other community supports around families.

- *It is often difficult to find respite workers.* Families repeatedly reported difficulties with finding people to provide respite. They cited low pay as an important reason why, but also referred to a general scarcity of workers. We also surmise that individual families may experience difficulties related to the nature of their child's disability. Families of children with extraordinary disabilities, such as those with medical complications or difficult to manage behaviors, may well have more difficulty finding respite than other families. We found, however, that this circumstance varied by CDDP area, with some reporting more difficulty than others. In addition, families reported difficulties with training the workers they found.



- *Regarding fiscal intermediary services, some families reported relatively high costs associated with the purchase of this service.* Some, in fact, reported costs amounting to about a third of their allotments. Given the relatively small service allotments they wondered why so much money was needed to pay for these services.
- *During the course of our work, SPD staff found and reported to us that about 80 children were residing in nursing facilities at a cost of about \$14 million.* This was a surprising finding given the state's strong commitment to promoting family care and in trying to prevent unnecessary out-of-home placements.

Lifespan Respite Care Program

In 1997, Oregon was the first state to pass Lifespan Respite legislation and implement a Lifespan Respite Program with House Bill 2013. Since then, Oklahoma, Nebraska, and Wisconsin have modeled their Lifespan Respite programs after Oregon's. Oregon's program was designed to create local Lifespan Respite programs intended to serve as a single point of contact for families and caregivers seeking respite and related supports for individuals with special needs.

The program is administered by DHS with state general funds which are distributed to county sponsoring agencies or local networks, to maintain the infrastructure of each local program. This infrastructure is complemented by partnerships developed with community-based non-profit, for-profit or public agencies and interested citizen groups to develop local respite resources for families needing respite care across disability and age groups. Currently, 26 local Lifespan Respite programs serve families in 36 counties.

Each local program is legislated to:

- Act as a single point of contact for families to access to respite care services locally;
- Recruit and screen potential respite providers and volunteers;
- Coordinate respite training for caregivers, respite providers, and families;
- Publicize program contact information to provide access to respite services; and
- Comply with other requirements laid out in the Oregon Administrative Rule 410-015.

Despite these requirements to help families access respite care services across populations, funding for this program is limited. During the current 2005-2007 biennium, the budget for the Lifespan Respite Care Program is \$1.1 million dollars. Divided between 26 programs, each program will receive annual operating funds ranging from \$15,000 to \$45,000 with a 12% reduction occurring in FY 2007. Most programs are able to supplement this income with in-kind or cash contributions raised locally. However, limited funding has been a historical issue for Lifespan Respite programs that interferes with each local program's ability to meet mandated requirements. Despite this limitation, local programs are able to help some families access respite services.

Review of data associated with the 2005 Lifespan Respite Care Program Annual Report reveals the following:

- Local Lifespan Respite programs are located within a variety auspices, though a common location involves aging or senior services.

Location	26 Sites
Area Agency on Aging	6
Childcare Resource and Referral	4
Local Arcs	4
Community Action Agency	3
Hospital	2
Developmental Disabilities Agency	1
AAA/Community Action Agency	1
Senior Center	1
Independent Living Center	1
Sites Not Reporting	2

- Reporting local programs were able to interact with thousands of Oregon families in a variety of ways. Programs maintain a registry of over 5,000 families, provide nearly 2,000 respite referrals and served 3,362 families.

➤ **2005 Lifespan Respite Annual Report Families Served by County**

County	Families Served	County	Families Served
Baker	16	Lane	142
Clackamas	803	Lincoln	88
Clatsop	8	Linn/Benton	77
Columbia	29	Malheur	78
Coos/Curry	60	Marion	*
Dschts/Clark/Jffrsn	455	Multnomah	456
Douglas	272	Polk	48
Gilliam	0	Sherman/Wheeler	0
Grant	0	Umatilla/Morrow	25
Harney	9	Union	56
Jackson	204	Wallowa	31
Josephine	0	Wasco/Hood River	0
Klamath	255	Washington	107
Lake	9	Yamhill	52
Total			3,362

* Missing data

Source: Lifespan Respite '05 Annual Report

- Lifespan Respite serves families of individuals of all age. Nearly half, however are seniors and elders. Of 3,346 individuals served, 1,554 (47%) are seniors or elders, 750 (22%) are adults aged 18-59 years, and 1,042 (31%) are aged under age 18.

Elderly 76+	716	}	⇒	1,554	47%	}	⇒	3,346 Individuals
Seniors 60-75	848							
Adults 18-59	750	⇒	1,042	31%				
Adolescents 13-17	521	}	⇒					
Children 0-12	521							

Source: Lifespan Respite 2005 Annual Report

- These individuals may also be described by their particular special needs condition. The accompanying graphic shows that Lifespan Respite touches individuals with a great variety of special needs. It is difficult, however, to take more from these data than this fundamental observation. Some of the conditions (e.g., medical fragility and chronic illness or Alzheimer’s and elderly) could be grouped and counted together. Individuals may also have multiple special needs and so could be fit into more than one group.

In addition, the raw numbers provide no comparative context related to their prevalence among the overall special needs population. For instance, when compared to other groups, individuals with developmental disabilities appear to be strong users of Lifespan Respite. Yet, the prevalence of the condition in comparison to the other groups is not known, so it is impossible to compare their relative use of the Lifespan Respite with the other groups.

Developmental Disability	714	19.4%
No disability/Special Needs	505	13.7%
Physical Disability	430	11.7%
Alzheimer’s	410	11.1%
Emotional Behavioral Disorder	345	9.4%
Elderly Fragility	340	9.3%
Chronic Illness	295	8.0%
Medical Fragility	165	4.5%
Mental Illness	143	3.9%
At Risk of Abuse or Neglect	102	2.8%
Other Circumstances	228	6.2%
Total	3,677	100%

Source: Lifespan Respite 2005 Annual Report

- Report data also illustrate the number of providers who are willing to provide respite by the age category they prefer. Not surprisingly, these data are similar to the distribution of the individual who receive respite supports. Again, the data show that the program has breadth across age groups, but is weighted toward the senior or elder population. As shown

Elderly 76+	703	}	⇒	1,418	44%	}	⇒	3,219 Providers
Seniors 60-75	715							
Adults 18-59	688	⇒	688	21%				
Adolescents 13-17	542	}	⇒	1,113	35%			
Children 0-12	571							

Source: Lifespan Respite 2005 Annual Report

These data illustrate that individuals across the state are working hard to translate the intentions of HB2013 into practice that helps families to receive the respite they need. The 2005 Lifespan Respite Report shows that the program has breadth and has touches thousands of Oregonians. Yet these data also hint at the difficulties the program is experiencing. Some counties make greater use of lifespan respite than others, and the program -- while touching on the needs of many -- appears to be tilted to support seniors and elders. More specifically, our findings lead us to the following observations:

- *The ideals and expectations declared in HB 2013 are not enforced in the rule.* The Lifespan program, as stated in the original 1997 Oregon legislation of HB 2013 was intended to promote coordination among state and local agencies and community Lifespan Programs “to encourage efficient provision of respite care and reduce duplication of effort.” Yet, DHS does not require state agencies to coordinate their respite care efforts with local Lifespan Respite programs. State agencies do not pool resources to provide respite care through local Lifespan programs and respite care systems are duplicated across public agencies for each specific population. In fact, several CDDP staff interviewed talked about recruiting and training their own list of respite providers without collaboration from their local Lifespan Respite programs because these programs lack the capacity to do so. This duplication of effort works against the ideal of a “single point of contact” for families to access respite services in their communities as stated in the rule.

HB 2013 also states that DHS shall establish the Lifespan Respite program to provide, among other things, policy and program development and support, assistance to resolve local and state level policy concerns regarding respite, and provide technical assistance to community Lifespan programs. DHS currently funds one full-time program administrator position to oversee the program. However, the scope of these charges alone extends beyond the capacity of one full-time position.

➤ *The Oregon Lifespan Respite Care Program is unable to effectively provide service requirements stated in OAR 410-015.* According to selection 0040 of the rule, local lifespan programs are mandated to:

- Develop and maintain a point of contact for access to Lifespan services within a designated geographical area;
- Develop and maintain a mechanism to recruit and screen potential respite providers and volunteers;
- Identify local training resources and coordinate respite training opportunities for caregivers, respite providers, and families;
- Publicize the Lifespan program phone number and address; and
- Comply with all program policies and guidelines established by the Oregon Lifespan Respite Care Program.

Additionally, these programs are required to serve families with respite needs for individuals regardless of age and across “special needs” populations. As noted in the rule, these populations include people with “developmental disabilities, physical disabilities, mental illness, emotional and behavioral disorders, Alzheimer’s disease and related disorders, chronic illness, and medical fragility” and special situations which may include “high risk of abuse and/or neglect.” These requirements are expected to be accomplished with a state budget of \$1.1 million dollars to support program infrastructure. Divided between 26 programs serving 36 counties, this is an average about \$19,000 per program per year. This is not sufficient.

➤ *Lifespan programs are not funded for a full FTE position and staff rarely have a single focus on respite, making it impossible to aggressively recruit and train providers willing to work with children with developmental disabilities.* Lifespan coordinators interviewed expressed frustration with the need for respite in their communities and their lack of capacity to address it. In fact, several coordinators stated that they simply refer families of children with developmental disabilities to other agencies. Some coordinators questioned whether the mission of providing respite resources to a wide range of populations was too broad for the funding allocated to the program.

Additionally, with funding reductions in the public and private sectors occurring over the past several years, local community partners are no longer available to participate in Lifespan Network meetings. These meetings served as a primary means for problem solving, maintaining collaborative relationships with local agencies and organizations, and developing and coordinating community resources to support the program. The initial assumption of simply providing “seed” money to local communities has not worked well to increase community capacity.

➤ *The Listening Tour revealed a general lack of information about the purpose and function of Lifespan Respite.* Anecdotal data gathered from families and professionals during the Listening Tour revealed general misperceptions and lack of awareness about the program. Many participants thought the program serves only seniors and the elderly. Others thought

the program provides funding for respite. Many families who had not heard of the program said they did not know who to call for help to find respite services and had not heard of the Lifespan program even though they had tried to find respite providers in their communities.

Families and professionals who had tried to locate respite resources through Lifespan stated that the program does not serve families of children with developmental disabilities well. Common complaints included programs having few, if any, respite providers listed who are willing to serve children with developmental disabilities, lack of provider availability when respite was needed, and that criminal records checks, whether preformed by the County or the Lifespan program, take too long. Yet, in some cases the data collected by Lifespan indicates that many programs are working well to reach out to a full spectrum of special needs individuals.

- *The location of local Lifespan programs may have an influence on the populations programs serve.* State data reveals that local Lifespan programs are housed in a variety of community-serving organizations, though the most popular choice is an Area agency on Aging (AAA). Where a program is housed may have an impact on the numbers of specific populations served over others, perceptions of populations that are eligible to receive respite services, and the types of community partners programs collaborate with. However, more data is needed to substantiate this finding.

As noted above, families and professionals had misperceptions of who Lifespan programs are supposed to serve. This was especially true when local programs were located in an agency or organization that serves seniors or elders.

- *Families want a single point of contact to access respite care.* Families repeatedly stated that they would like a single point of contact to access respite services. The need for an entity that recruits, trains, and facilitates respite care and in-home providers was an issue mentioned by both families and professionals. However, families often described local Lifespan programs as being of no use to them because they felt that the programs do not provide respite providers for children with developmental disabilities or when families need them. In fact, according to the most recent figures, only 32% of respite care accessed through local Lifespan programs is provided to children under age 18.

Families reported during the Listening Tour that they felt that the proportion of individuals being served with developmental disabilities was relatively low. The perception varied by location, and is likely fueled by the location of the program and the fact that the age group most served was elders. To illustrate, many families had not heard of the Lifespan Respite Care program while others complained about their experiences of receiving outdated lists of respite providers whose phones were disconnected, who no longer provided respite services, or who were not willing to provide respite to children with developmental disabilities. Few families that participated in the forum described Lifespan programs as a resource for finding respite providers.

- *Families are supported best in communities where there are a number of options to meet their needs.* Both professionals and families agreed that in areas where collaboration

between local Lifespan programs, community organizations, agencies, and families is strong, programs are better able to meet family needs. Professionals interviewed said that Lifespan programs were most successful in areas where programs have advisory groups and coordinators work closely with community partners to recruit respite providers, write grants, or pursue other funding sources to supplement the services they offer. Families spoke highly of community programs that provided opportunities for families to meet and share information.

Children's Model Medicaid Waivers

Oregon operates two home and community-based services "Model waivers," the Children's Intensive In-home Supports waiver (CIIS) and the Medically Fragile Children's waiver (MFC), that target children up to age 18 with developmental disabilities. Each of these waivers cannot serve more than 200 children at any one time.

Under each waiver children could receive specialty services under terms of the Model waiver, as well as acute care services available under the Oregon Health Plan. Specialized waiver services include homemaker services, respite, environmental access adaptations, non-medical transportation, specialized medical equipment and supplies, chore services, family training, physical therapy, occupational therapy, speech therapy, special diets, translation services, and behavior consultations. OHP acute care services include inpatient hospital, physician, outpatient hospital/clinic, and laboratory and X-ray services, as well as prescribed drugs, and others.

- The CIIS waiver is designed to support children with intense behavioral needs through the provision of "flexible and efficient services" that enable the family to care for their child at home.

According to state FY 2003/2004 data (HCFA A-372 Report), there were a total of 91 children being served under the CIIS waiver, though we understand that the number has grown to 105. The total cost during this period was \$2,387,428, and included costs associated with services available through the state plan (i.e., Oregon Health Plan) as well as costs associated with specialized waiver services. (See Table on the next page.)

Aside from OHP acute care services, service plans under this waiver may include behavior consultations, minor home adaptations, motor vehicle adaptations, in-home daily care or other goods, services, and supplies. Service plans must not exceed the monthly maximum payment of \$1,500 to \$2,500 depending on a child's behavior criteria score (OAR 411-300).

Overall, the average cost for children participating under this waiver totaled \$26,235.

- Under the MFC waiver there are four different service levels that children must qualify for based on determined severity of need. Only children who have a health impairment that requires long-term, intensive, specialized services on a daily basis are eligible for services under this waiver. These services are intended to enable the family to meet the needs of caring for a medically fragile child at home. Service plans tied to specialty waiver services may include in-home daily care, minor home adaptations, or good, services, and supplies and must not exceed monthly plan payments of \$18,000, \$12,500, \$9,500, or \$4,500 (OAR 411-350).

HCBS Model Waiver Services		
HCFA A-372 Reports (Report Year 2003-2004)		
	Behavioral CIIS Waiver	Medical MFC Waiver
Children Served	91	86
Specialized Waiver Services		
Homemaker	\$13,635	\$16,032
Respite	\$2,406	\$5,614
Environmental Access Adapation	\$75,666	\$20,339
Non-Medical Transportation	\$875	\$0
Special Medical Equipment & Supplies	\$62,136	\$112,203
Chore	\$0	\$0
Family Training	\$2,612	\$195
Physical Therapy	\$0	\$0
Occupational Therapy	\$2,080	\$0
Speech	\$103	\$0
Special Diets	\$2,230	\$0
Translation	\$1,146	\$5,084
Behavior Consultation	\$62,699	\$0
Acute Care Services Through OHP		
Inpatient Hospital Services	\$2,172	\$158,210
Physician Services	\$123,385	\$1,485,418
Outpatient Hospital/ Clinic Services	\$20,269	\$126,986
Laboratory and Xray	\$0	\$153,833
Prescribed Dugs	\$109,365	\$249,976
Other State Plan Services	\$1,906,649	\$3,986,972
Total Spent	\$2,387,428	\$6,320,862
Average Per Child	\$26,235	\$73,498

Again, according to state FY 2003/2004 data and the associated HCFA A-372 Report, there were a total of 86 children being served under the CIIS waiver, though we understand that the number has grown to 89. The total cost during this period was \$6,320,862, and included costs associated with services available through the state plan (i.e., Oregon Health Plan) as well as costs associated with specialized waiver services. (See Table on the next page.).

Overall, the average cost for children participating under this waiver totaled \$73,498.

Each of these waivers plays an important role within the state system by seeking to serve children with intensive service needs that are not easily addressed by other means. And both are tied to Medicaid as “Model waivers” so that the state may capture federal reimbursement to offset about 60% of the cost.

Yet both are limited in what they can do. The MFC waiver, for instance, is dedicated to children with medical needs that make them “technology dependent.” It does not support children with intensive physical health needs.

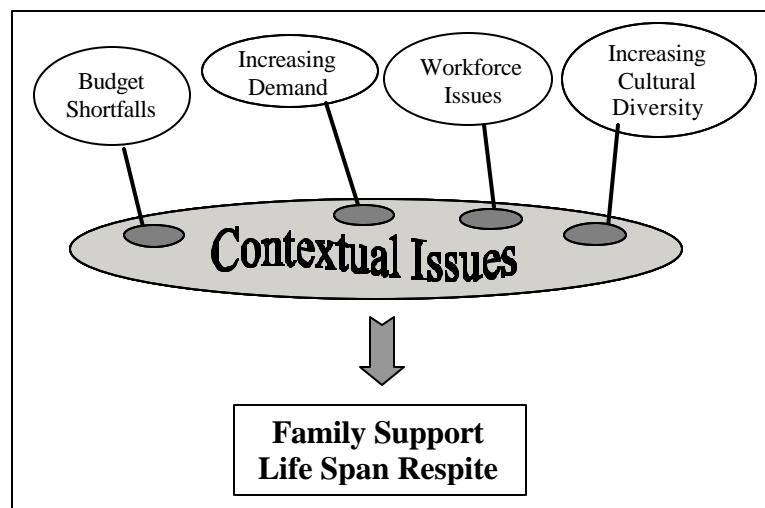
Likewise, both waivers have relatively high eligibility thresholds that screen out all but the most needy children. These criteria keep the number of children who qualify down, but some children with high needs, but who do not qualify for these waivers, likely drift over to other family support programs such as those offered through CDDPs. And some may have comparatively higher cost plans.

4. Study Recommendations

Over these past months we have completed numerous activities designed to collect and review information pertaining to SPD’s Family Support system and the Lifespan Respite Program. In previous sections we describe our methods and findings. In this chapter, we offer comment concerning significant contextual issues faced by SPD as it seeks to improve its family services, and a series of recommendations stemming from our work.

Contextual Issues

SPD has achieved much over the years to provide effective Family Support services to children with developmental disabilities. Further, in conducting this study we found that SPD is actively pursuing means for improving its Family Support system. For instance, SPD staff have systematically collected and reviewed information on Family Support and Lifespan Respite, offered training or technical assistance to CDDP staff on how to offer increasingly flexible Family Supports under the prevailing administrative rule, made funding available to CDDPs to build capacity for Family Support, and have begun to consider additional use of Medicaid to fund needed services for children.



Yet, delivering ample and high quality Family Support in Oregon is a difficult business. Before plans can be made for improving Family Support services or the Lifespan Respite system, the contemporary context that SPD works within must be taken into account. Some of these factors include: the effects of recent budget shortfalls, steady increases in service demand, growing cultural diversity among service users, and workforce shortages.

Budget Shortfalls

Over the past few years states have experienced significant budget shortfalls. Hopeful that the crisis would be short-lived, states at first used stop-gap measures in response, such as drawing down reserves and freezing hiring. As budget deficits continued, nearly every state scrambled to balance their budget, looking to balance demand for government services with the resources available. Most states made cuts in core human services, such as school services or state Medicaid plans, and in some cases raised taxes and imposed new fees. These actions also

pressured local entities, such as county governments and school districts, to reorder spending priorities and find alternative resources.

Recent times, however, have brought some good news. Several economic indicators show that the national economy is growing again and that jobless rates are moving down. Unfortunately, even with enduring economic improvement it will take states time to rebuild reserves and begin re-investing in programs. Long term, the consensus is that it is unlikely that state budgets will grow at anywhere near the pace they did in the 1990s.

Oregon felt the brunt of this economic slowdown. Oregon keeps no reserves, and so was unable to cushion budget shortfalls with such funds as other states did. As a result, Oregonians experienced wide and lasting budget cuts to a variety of public services, including social services like Family Support. Moreover, even as the state's economy is improving, schools, public safety or other state services will not be helped this year because all the unanticipated taxes must be returned to taxpayers under the state's unique "kicker law." Oregon's kicker law mandates that businesses and taxpayers get a tax rebate whenever revenues collected by the state exceed estimates by 2 percent or more over a two-year period. Oregon taxpayers are due to receive \$461 million in "kicker" income tax refunds next year. Likewise, corporations will receive a \$205 million state tax rebate.

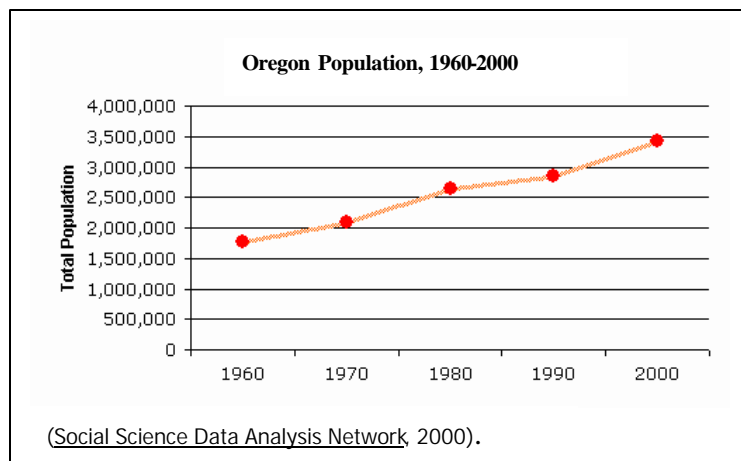
Finally, within DHS there is continued concern for the future. The Director of DHS, Bruce Goldberg, indicates that the President's proposed budget for 2007 may result in significant cuts in funding for services to seniors and people with disabilities. "The Deficit Reduction Act for federal fiscal year 2006 will impact our ability to maintain our current level of services to Oregonians" (Media Release *February 21, 2006*, Washington County, Department of Disability, Aging & Veteran Services).

It is worth noting, however, that a provision under DRA may offer Oregon opportunity to utilize Medicaid to help finance certain services, and in particular respite services for a variety of special needs groups. The Home and Community Based Services State Plan Option included in DRA permits a state to cover in its state plan any of the services specifically enumerated in Section 1915c of the Social Security Act. Respite is one of these services. As a result, states will be able to cover respite under its state plan (See Appendix G).

Presently, CMS is reviewing the legislation and indicates that it will issue instructions regarding the DRA Option this summer through a State Medicaid Directors letter, with regulations following by December 2006.

Increasing Service Demand

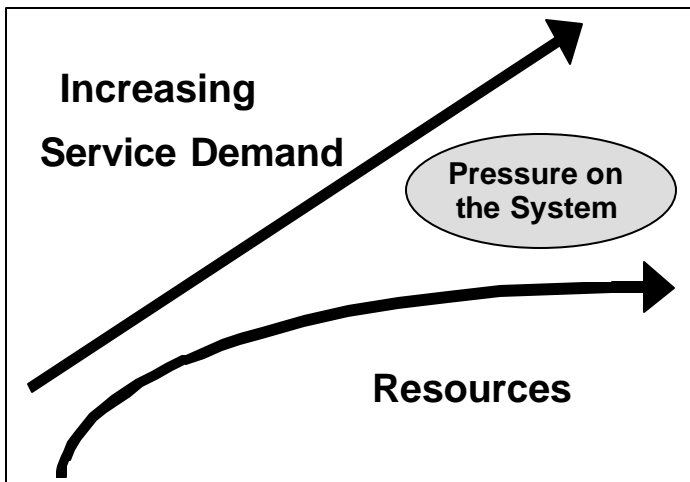
Service demand is surging. This is due to three primary reasons. First, Oregon's population is steadily growing. With a population of about 3.5 million, the US Census Bureau ranks Oregon 11th among states in population growth since 1990, growing 20.37% from 1990-2000.



Oregon’s population is expected to grow to nearly five million by 2030. This follows a consistent growth trend dating to 1960. Given such growth, the prevalence of individuals with developmental disabilities living in Oregon is likely growing as well. At issue is whether the service system is growing fast enough to keep pace with increases in prevalence, and more importantly with associated increases in the demand for services.

Second, due in part to advances in medical care, increased numbers of children are surviving various illnesses, life-threatening traumas, and other challenging health conditions. These children, however, may have developmental disabilities. They and their families may require specialized services and support.

Finally, the expectations surrounding these children have changed so that there is an increased anticipation that they will live quality lives in their community. In the past, some of these children were typically placed into out-of-home residences, while most stayed at home with families with little or no support. These days, there is heightened expectation for these children to attend neighborhood schools, receive other needed services in their community, and participate, as they can, in whatever a community may offer its youth. To succeed they and their families can often use services from SPD.



Mixing these factors together, it is unsurprising to learn that SPD is observing upswings in the numbers of individuals seeking services. More particularly, SPD reports increases in the number of children seeking services through the state’s crisis response system, and through referrals from other public agencies. As illustrated by the accompanying graphic, present circumstances pairing together increased demand with a flattened fiscal response can only yield increased pressure on the service system.

Increasing Cultural Diversity

Cultural diversity is becoming an American mainstay. Almost one-third of the U.S. population is from racially, ethnically and culturally diverse groups, a proportion that is expected to grow steadily. In Oregon, in 2000 about 16.5% of the population was from such groups, up from 9.5% in 1990. Among these individuals, Latinos are the most populous. In 2000 they composed 8.5% of the population, up from 3.9% in 1990.

Key to their participation in their communities is language. *Linguistic isolation* refers to households in which no person over the age of 14 speaks English at least “very well.” US Census data (2000) shows that 30% of the foreign-born population in Oregon lives in linguistic isolation (Summary File 3, Tables P19, PCT13 and PCT 14).

**Top Ten Languages Spoken
in Oregon (2000)**

English	2,810,654
Spanish or Spanish Creole	217,614
German	18,400
Vietnamese	17,805
Russian	18,344
Chinese	15,504
French (also Patois and Creole)	11,837
Japanese	9,377
Korean	9,185
Tagalog	6,181

Source: US Census data, 2000

Human services systems likewise struggle to respond well to the nation's changing cultural demographics. Many of our nation's minority citizens are excluded from service systems or find that systems are not flexible enough to accommodate their needs.

In Oregon, while the state welcomes a variety of ethnic minorities, the number of Latinos is growing at an especially quickened pace. In 1980, there were 65,847 Latinos in Oregon, composing 2.5%. By the 2000 census, the number had grown to 275,314, or 8.05% of the population. Further, the Hispanic Metropolitan Chamber in Portland reports that presently Latinos are the largest ethnic population in

the state, representing over 11% of the state's population, with over 383,925 people. Between 2000 and 2002, the Latino population grew by 12.4%, one of the top ten fastest growing populations in the nation. In Multnomah, Washington, Clackamas and Clark counties alone, over the last ten years the number of Latinos increased by 191% to 161,831,

The Oregon human services community is aware of this population shift, and of the challenges it brings families and service systems, with some counties feeling a greater impact than others. Consider that:

- People receiving services from the Oregon Department of Human Services (DHS) with FY2000 data indicating that 20% of service recipients were Latino;
- A 1998 Hunger survey conducted by the Oregon Food Bank found that 13% of Willamette Valley, respondents were Latino.
- In focus groups conducted through a federal grant to examine Family Support in Oregon (i.e., the Oregon Blueprint Project, conducted by staff of the Oregon Developmental Disabilities Council in 2002), Latino families express concern that their children are determined eligible for special education because they have limited English skills, not because they need such services.
- Regarding domestic violence, 25% of those served by the Marion County Victim's Assistance Office were Latino, with 36% of that group speaking Spanish primarily.
- State data show that in 2000, 23.6% of Latinos did not have any health insurance coverage, compared to 10.8% of the non-Latino population.

Workforce Issues

Human service systems continually struggle with workforce issues. For many years, it has been difficult for service providers to recruit and retain a stable, skilled workforce to support people with disabilities. Likewise, the rising cost of gasoline affects the willingness of individuals to work for low wages. Issues like these have implications for Family Support, most notably

related to respite. As noted earlier, families often report difficulties with finding qualified respite workers.

Study Recommendations

SPD cannot act to alter strong external factors such as those just described. They are part of the framework that SPD must work within, and so must be taken into account as study findings are reviewed and potential action implications are considered. With these thoughts in mind, what follows is a series of recommendations related to Family Support and Lifespan Respite.

Family Support Services for Children with Developmental Disabilities

As illustrated earlier, there is substantial variance throughout the state regarding Family Support practice. In part such variance may be desired because it assures local flexibility and innovation. Further, the present Family Support administrative rule provides great opportunity for CDDPs to tailor individualized Family Support plans, and evolve in ways that are consistent with local preferences. These benefits, however, also come with a cost. Over time, excessive program variance undercuts SPD's capacity for building a statewide cohesive response to families, and respond effectively to the current challenging policy context.

SPD must consider what vision and related policy objectives it has for Family Support, and in specific, what practices are best suited for establishing a sustainable and effective system of Family Supports. In turn, SPD must act to promote a consistent action bias among CDDPs that is consistent with these intents.

We understand that SPD is already working to improve Family Supports throughout Oregon. Yet, we observe that there are insufficient resources in play to support families and that local practices are evolving unevenly and with varying effectiveness across the state. Moreover, the present policy context is further stressing local Family Support systems, squeezing some families and leaving many others out altogether. These circumstances, if left unchanged, do not offer a sustainable future for Family Support. In response,

SPD should commit to establishing a **sustainable future** for Family Support that is anchored in the principles of Family Support, yet seeks to maximize the resources in play for families, and to utilize these resources in ways to secure the best outcomes possible for children with developmental disabilities and families.

To achieve this primary policy objective SPD must take action to reshape its family support system, including modification of the administrative rule governing the program.

The accompanying graphic, illustrating a "Family Cooperative," offers an alternative future for family support in Oregon. The Cooperative is based on the following two premises:

- **Unless SPD receives significant funding increases, it likely cannot accommodate all those in need, resulting in many children and families winding up on service wait lists.** Thousands of children with special needs may be eligible for developmental disabilities services. We roughly estimate that there are approximately 8,629 Oregonians under age 18

who have a developmental disability. This number is based on a prevalence rate of 1% * and 2005 US Census estimates of the total number of children in Oregon birth through 18 years. Meanwhile, SPD presently serves about 1,000 families through its General Assistance Family Support Funds and other related programs for children.

Certainly not all those children who may be eligible for services will actually seek services. Even so, these data suggest that SPD is and will continue to be hard pressed to meet the demand for family support services. As illustrated earlier by comparison to national profiles, Oregon's level of investment in family support ranks it low among states. SPD simply does not have the resources to meet the present and potentially emerging demand for these services.

➤ **SPD must respond by creating a multi-tiered approach to meeting individual and family needs.** This approach must assure that all children and families receive a base level of support, and that additional services are made available as needed. A multi-tiered approach should consist of the following:

- *Family members should have a forum from which they may offer their strong input and guidance in shaping Family Support policy and practice. Oregon has a long history for welcoming family-based leadership regarding Family Support issues. This tradition, however, has weakened over time. To improve the Family Support system, however, SPD should re-engage families, informing and encouraging their participation in re-shaping the system.*
- *“Family Support Cooperatives” should be established to accommodate basic needs of any eligible children and families. The present response to families presumes that once a child is found eligible for services, CDDP staff will act to develop a service plan and assure delivery of designated services. Yet SPD has insufficient resources in play to achieve this goal effectively for all those children and families who need such support.*

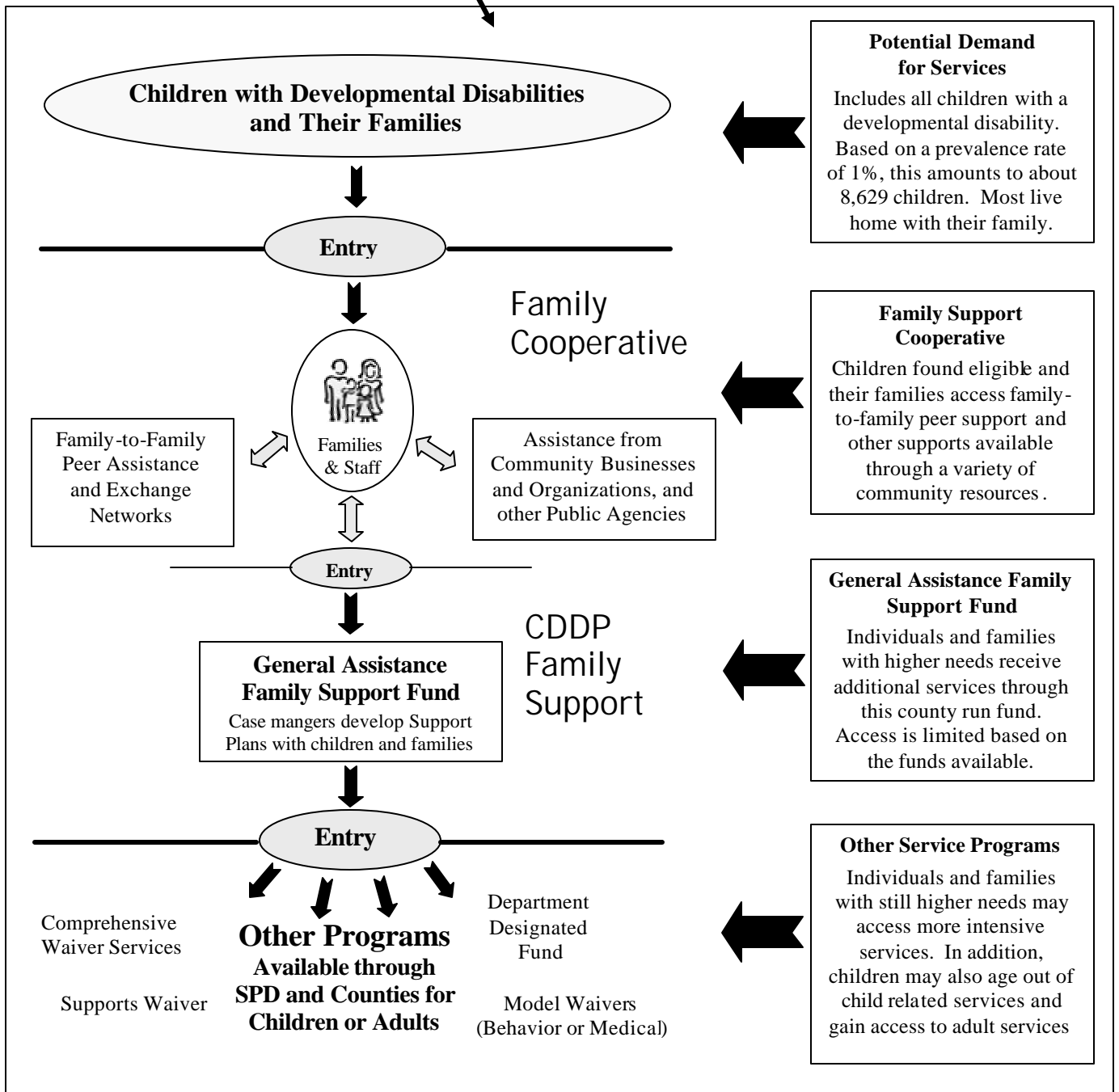
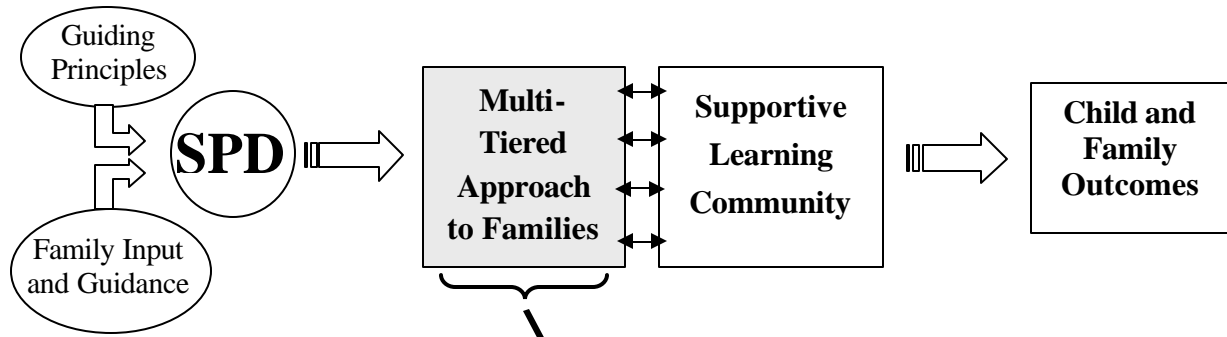
SPD, however, can take action to establish a base or fundamental level of support for all children and families does not involve individual planning and investment for each participant. Within a “cooperative,” paid staff:

1. Create opportunity for families to work together to offer each other mutual support. They may do so by offering one another “peer support” in any number of ways, such as by forum for: (a) gaining and sharing information, (b) offering emotional support, (c) standing with one another at planning meetings, (d) offering informal advice or guidance on disability specific issues, or (e) finding needed services.

Families may also work together more formally within an “exchange network” where goods or supports are exchanged among families. For example, families may

* “Prevalence” refers to the number of people in a population who have a designated condition or characteristic. Determining the prevalence rate of “developmental disabilities” is troublesome because definitions of the term vary by state and there is no definitive measure of the condition. ODDC (1990) estimates a prevalence rate of 1.57%. Our work, however, to estimate such rates in various states (e.g., MO, IA, AR, NM) consistently reveal a rate of just under or above 1%. Our work in Oregon in 1990 yielded a rate closer to 1%. For our purposes here, an estimated rate of one percent is reasonable.

Establishing a Sustainable Future for Family Support in Oregon



participate in a mutual respite network where parents take turns watching one another's children.

Overall, the idea is to create a spirit and resolve for families to help each other to work at addressing each other's needs.

2. Seek out and make available to families a variety of services or supports available within the public sector, or through community businesses or community serving organizations. Staff, for example, will help families to apply for social security benefits, food stamps or other public services.

The most essential part of any community is its people, and in turn the assets they put in place for one another. Accordingly, staff should also develop opportunities for local businesses to help families to contribute donated goods or services to families. Likewise, staff should establish opportunities for families to receive supports from various community organizations, such as churches, recreational leagues, civic clubs and others.

- *Individuals and families who require more support than is offered by the Cooperative should have access to the present General Assistance Family Support Fund. We understand that the family Cooperative, while offering needed base level support, will not be sufficient for helping those with more challenging needs. These individuals and families should have access to the current assistance fund administered by CDDPs.*

Once selected, these families will work with case managers to develop meaningful Child and Family Support Plans (CFSPs). Greater care, however, must be taken to assure that the spirit of these plans, as described in the governing administrative rule (411-305-0080) is realized. This spirit is reflected within the "Family Support Principles" and calls for a "child- and family-centered process" where, among other ideals, the planning process and subsequent service delivery:

1. Is built on a relationship of respect and trust that recognizes that families are better able to determine their own needs than have their needs determined by the state or a public agency,
2. Are provided in a manner that develops comprehensive and flexible support to families,
3. Focuses on the entire family and is responsive to the needs of the individual and the family, should be available to families before they are in crisis, should encourage maximum use of existing social and natural resources of support and encourage community integration.

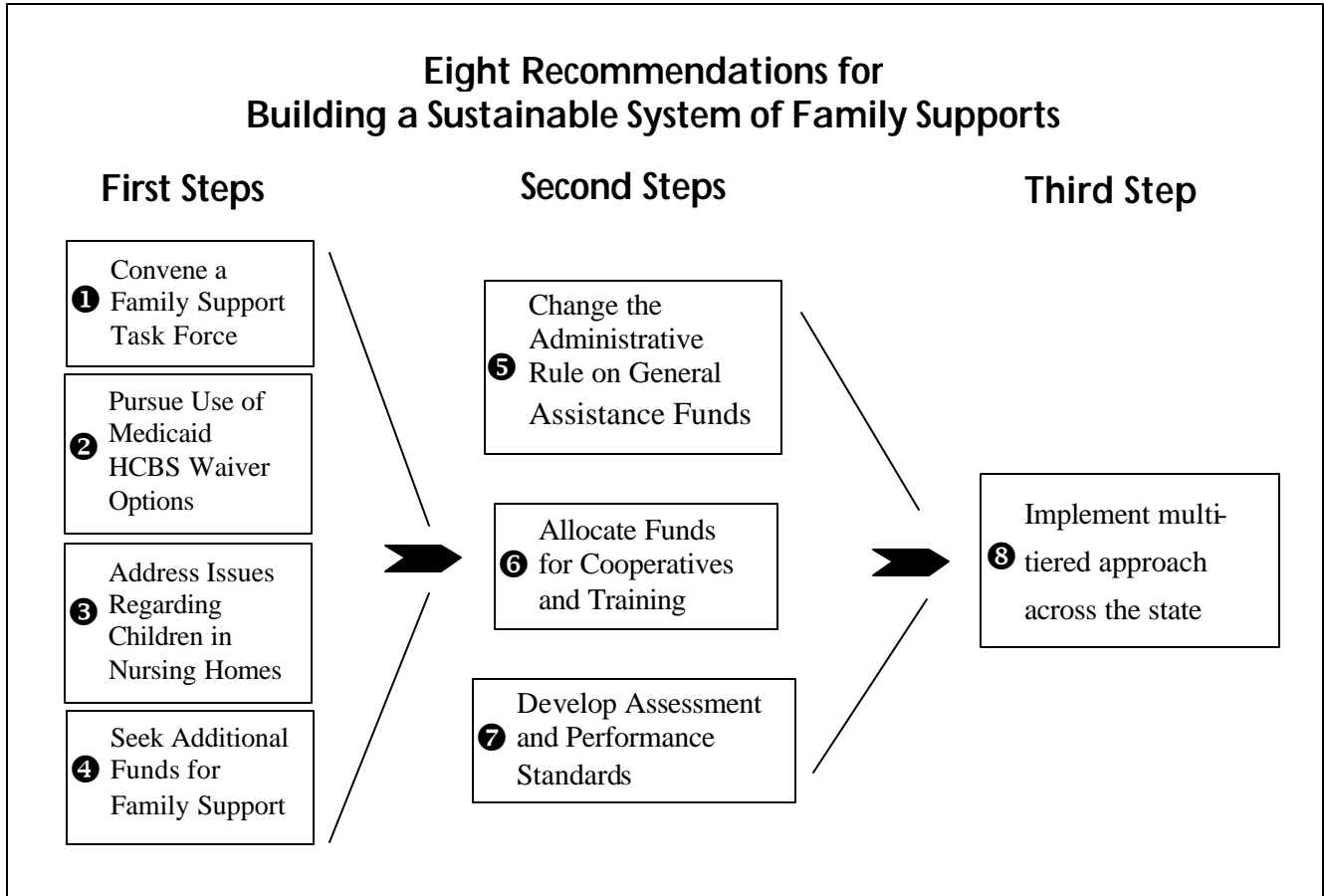
As illustrated earlier, many agree that resource constraints, high caseloads and other factors have cut away at what case managers might do to translate these ideals into consistent practice. Instead, the planning process often becomes a brisk means for working through required paperwork to allocate funds and services, very often respite. In essence, the system has become increasingly less a "Family Support Program" as set out

by the guiding principles and more a “pass through venue” for funds to purchase approved services. SPD will need to change this dynamic if it is to realize the program’s potential for families.

- *Individuals and families who require more support than is offered by the CDDPs should have access to still more intensive supports.* Again, we recognize that some children and families have significant needs that require a more comprehensive response than is available through the Cooperative or the CDDP general assistance family support fund. In such instances, SPD should make available to families more intensive supports, as may be delivered through the Department Designated Fund or targeted Medicaid HCBS Model Waivers. In addition, as children age they may also transition into appropriate adult services.
- **SPD must establish a learning community dedicated to Family Support.** Relevant activity here must be consistent with the governing administrative rule and vision for developing a sustainable future for Family Support. Many reported to us an enduring scarcity of opportunity for families and CDDP staff alike to learn of best practices, or to think collectively about what can be done to work more cohesively, test innovative ideas, or improve services. To build a sustainable future for Family Support, SPD will need to establish a culture of learning and mutual support for CDDPs, involving information sharing, training and technical assistance.
- **SPD must set program expectations and standards consistent with the administrative rule and vision, and assess CDDP related performance.** Once SPD decides on what must be done to achieve a sustainable future, it must also invest in data collection to monitor progress and performance, using such information to improve policy and practice.

Moving from the present system to one that engenders these characteristics cannot be achieved immediately. To succeed, SPD needs to build a platform to work from and sequence the steps it takes thereafter to implement the changes it seeks. As illustrated in the accompanying graphic (see next page), we offer the following eight recommendations to support these policy intents:

1. **Convene a Task Force on Family Support to plan in greater detail how to implement these recommendations to re-shape the family support system.** The purpose of convening this task force is to consider the present findings and recommendations, and fashion a more detailed blueprint for moving forward. This recommendation is consistent with the recent legislative budget note instructing SPD to work with the Oregon Developmental Disabilities Council to offer recommendations on how to develop a comprehensive integrated system of services and supports for children with disabilities and their families (See Box next page). The Task Force should:
 - Expand on the description of “Family Cooperatives” offered above to provide greater detail related to its expected operations, including their formal affiliation with the CDDPs, if any. The Task Force should decide on the number, size and scope of the Cooperatives, staffing, operations and budget. In addition, protocol for families to move from this level of support to the next, involving CDDP family support, must be clarified.



- Review the present administrative rule on Family Support to advise SPD of any changes it should make to make the system better able to achieve this vision. Note that a particular administrative rule change pertaining to the General Assistance Fund is recommended below.

Aside from this change, the Task Force may press for others. For instance, it might examine the use of fiscal intermediaries among CDDPs and families to manage funds disbursement. Families wondered at the perceived fees that were being charged to manage relatively small amounts. Where large enough amounts are being

The Department of Human Services, Seniors and People with Disabilities, in collaboration with the Oregon Council on Developmental Disabilities, shall convene a workgroup to review institutional, residential, foster care, waiver and family support programs that serve children birth to eighteen with disabilities. The workgroup shall review eligibility, demographics, funding options, program design, administration, implementation, and best practice. The workgroup will report to the appropriate Interim Committee early in 2006 with their findings and recommendations for implementation of a comprehensive integrated system of services and supports for children with disabilities and their families, including a range of options to prevent out of home placement whenever possible.

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disbursed to trigger concerns over tax or other liabilities, perhaps use of an intermediary is justified. When managing small amounts, however, an intermediary may still be used but costs should be commensurate with the task being performed.

Likewise, the Task Force might re-examine the service categories allowed under the rules, their descriptions and the parameters offered to illustrate what supports are disallowed. The purpose of such inspection would be to give opportunity for the Task Force to advise SPD of what new service categories might be added, if any, and/or to sharpen existing definitions.

- Gain consensus across CDDPs and family advocates to commit to establishing a sustainable future for Family Support consistent with the themes described above.
- Compile and finalize standards and indicators that will be used to assess CDDP performance (See Recommendation 7).
- Document the decisions made by the Task Force and SPD to re-shape the family support system within a logic model. Logic models provide a systematic and visual way to present the relationships among the resources that are put in play to operate the program, the activities that are planned, and the results that are expected. Logic models can be modified as time passes, but they provide cohesive structure to what is intended and offer a effective basis for designing data collection protocols to monitor system operations and outcomes. Generally, logic models are composed of the following elements:
 - *Inputs*: These are materials that the program takes in and then uses to produce desired results. Examples inputs are people, money, equipment, facilities, supplies, people's ideas, people's time and contributions. Additionally, inputs include the various regulations or rules that will guide activities.
 - *Actions* or *Activities*: these are the actual activities that reach the people who participate. This includes services, events, mutual support, products and training.
 - *Outputs*: These are the tangible results of the major actions or activities of a program. They are usually accounted for by their number. For example they may include the number of individuals or families served and how, the number receiving what service and at what cost. Outputs are often misunderstood to indicate success of a program. They are not a good direct measure of success, given that they instead simply offer a count of what was done.
 - *Outcomes*: these are the results of the activities undertaken and the associated outputs. They should indicate changes for individuals, groups, communities, organizations, communities, or systems.
 - *Assumptions*: describes the beliefs participants have about the program, the people involved, and the way participants think the program should be run and work.
 - *External Factors*: describes the environment in which the program exists, including a variety of factors that interact with and influence program actions.

- 2. Make greater use of Medicaid to fund Family Support services for children living at home.** Over the biennium, Oregon presently invests about \$7.5 million in Family Support through “general assistance” and “department designated” funds. Neither fund is tied to Medicaid. If Oregon were to move its entire investment to Medicaid through an HCBS waiver, it could leverage about \$11 million in additional federal funding. This would be a welcome addition of dollars and would help greatly to improve the service response to families.

These potential benefits, however, must be considered against other dampening effects. For instance, the gain in service dollars will be in part offset by increased administrative costs. Likewise, not all children may qualify for Medicaid, and so waiver services. Those that do would also become eligible for Medicaid services available through the Oregon Health Plan, increasing costs to OHP. Also, the shift must be achieved in ways to demonstrate “cost neutrality,” that is, that the dollars gained through federal reimbursements are not overrun by added administrative and OHP cost impacts. A fuller discussion of the options available is provided in Appendix F.

Based on this analysis, we recommend that Oregon pursue Medicaid funding by pursuing a targeted waiver strategy whereby it concentrates attention on children to whom substantial state resources are already being directed, that is children with relatively “high cost plans.” These children are generally being served within the long-term extended services component of the Family Support system (i.e., Department Designated Fund). About \$2.8 million is allocated to this component. If it were all converted to Medicaid it would yield about another \$4.3 million in federal reimbursement. While this strategy will result in added costs associated with administration and use of OHP, such effects are less likely to erode the gains realized.

Note too, that this option, if successfully pursued, could be used to fund the two previous recommendations offered earlier to help CDDPs operate more effectively and to establish a Technical Assistance and Capacity Building Fund. In fact, SPD should consider sequencing their actions to secure the Medicaid financing in advance of implementing those other recommendations.

SPD may efficiently achieve this end, at least in part, through use of its two existing Model waivers tied to children with intense behavioral challenges and who are medically fragile respectively. These waivers provide intensive supports to children who are technology dependent or require intensive behavioral supports respectively. The two operate under high eligibility thresholds that screen out all but those children with the most intensive service needs. By gaining approval to relax these thresholds, additional children could be served within these waivers, thus freeing up state dollars that could be re-directed to support other children and their families.

Note that neither of these waivers support children who have intensive physical health needs, but are not technology dependent, or other children who may have relatively high cost plans. To capture these children within a waiver, SPD may develop another waiver aimed specifically at these children.

How exactly Oregon should go about shifting these children into waiver services will require additional analysis to look carefully at the children in question, their service costs, and the potential cost impacts. Regardless of the approach, Oregon could approach the matter conservatively by regulating entry into these waivers through a “reserved slot strategy.” Using this strategy, Oregon would reserve waiver slots for children currently receiving state-funded Family Support and reserve additional slots for children to allow for expansion in the near or longer term. This strategy assures that Oregon could utilize the option effectively without over-running available state dollars.

- 3. Take prompt action to establish community living opportunities for children with developmental disabilities living in nursing homes.** Bluntly put, children should not grow up in nursing homes. The best place for children is with their families. Failing that, the next best place is with another caring family. We understand that SPD staff share these beliefs. Yet, about 80 children with disabilities presently reside in Oregon nursing homes at a reported cost of \$14 million.

We also understand that SPD is already taking action to establish community alternatives for these children and prevent any further placements of children into nursing facilities. In doing so, SPD should:

- Review and adjust as needed the present Preadmission Screening and Resident Review (PASSR) process for children with regard to nursing home admissions. SPD may agree that any use of pediatric nursing home beds shall be for children who satisfy the appropriate screening criteria and require short term respite or rehabilitative care. SPD should, however, set clear policy to govern the relationship between children with disabilities and nursing homes.
- Take action to develop a Home and Community Based Services waiver that is targeted specifically to children currently residing in nursing homes. Note that HSRI staff are presently working with SPD to achieve this end. The resulting waiver would offer a range of needed services and community residential supports to children being relocated from nursing homes into community settings, as well as in-home supports to help children return home or to prevent other unwanted out-of-home placement. Additional analysis will be required to decide on the precise waiver strategy to apply. Ideally, the strategy applied here around these children will fit neatly with SPD’s overall plans for Family Supports, including any other actions it takes to utilize Medicaid.

- 4. Seek additional state investment for Family Support Services for Children with Developmental Disabilities.** These recommendations provide SPD with a variety of suggestions for working toward a sustainable future for Family Support that presumes that: (a) no additional state funds will be injected into the system, and (b) SPD seeks to maintain its commitment to administering a principles-based program.

The scarcity of resources, however, makes it most difficult to keep this commitment. The program is starved of resources. If SPD is to field a program that works effectively to put to practice the Family Support principles it embraces, then the program must have more

resources. SPD and the Department should argue for additional funds to more amply fund this program.

National data sets show that Oregon ranks 47th among states in terms of the number served per 100,000 in population. Moreover, Oregon invests \$1.12 per citizen in its general population while the national average stands at over seven dollars. After years of chronic under-funding of Family Support, requesting a significant increase is justified given Oregon's longstanding commitment to families in principle.

- 5. Change the administrative rule on Managing and Accessing Family Support Funds (411-305-0090) to allow the CDDPs to use 5% of its allocated General Assistance Funds to build capacity.** The present administrative rule indicates that “the CDDP must allocate 100% of funds contracted by the Department for Family Support... to the General Assistance Fund. This Fund must only be used to purchase one or more of the supports described in OAR 411-305-0120 for children according to each child’s CFSP.” This provision leaves no margin for CDDPs to utilize these funds outside of direct service purchases tied to family plans, such as to build community capacity or test innovative practices.

This rule should be changed to allow CDDPs to use up to 5% of the funds allocated to it by the Department to its General Assistance Fund. SPD should assure that these funds are spent in accordance with its overall policy goals. The amount offered to each CDDP will vary based on its total allocation, though the overall amount, based on 2003-2005 allocations, totals about \$230,180 for the biennium.

- 6. Retain sufficient funds to establish local Family Cooperatives and a “Technical Assistance and Capacity Building Fund.”** If SPD is to change the actions of its Family Support system, it must allocate resources to fund a network of Family Cooperatives and invest in the learning community that will be needed to educate the participating family and staff. We realize that fiscal resources are limited and that the present allocations are already being distributed. If SPD acquired additional resources, these could be used to finance development of these two essential parts to the new system. Without new resources, however, these dollars must be found with the existing budget.

Understandably, there may be resistance to a reallocation of existing resources. This poses a difficult decision, but the family support system cannot continue as is and must be re-positioned to better meet the challenges ahead. How much money should be reallocated is to a great extent an empirical question tied to whatever decisions are made pertaining to the nature of the cooperatives and judgments regarding the amount of training and technical that the new system will require. These funds must be directed at:

- *Establishing Family Cooperatives:* As noted above within Recommendation 1, the Family Support Task Force should be charged with providing greater detail to describe the number, operational nature and budget required of the Cooperatives.
- *Establishing a Technical Assistance and capacity building Fund.* Cooperative staff, CDDP staff and participating families will need information, training and technical assistance to gain and apply new skill sets effectively. Moreover, such effort will help

SPD to push the system evenly along, nurture family leadership, encourage innovation, and develop a learning community among all those involved.

Allocated funds should be allocated to a single entity to establish coordinated uses for the funds over time to work closely with SPD staff to build momentum for achieving the stated vision for Family Support. This entity should involve families in a strong advisory capacity to guide its activities.

The Fund might be used to:

- Promote family leadership in guiding local and state policy.
- Offer training and technical assistance to Family Cooperative staff over how to link families together effectively, complete community asset maps, and make better use of community resources to support families. This may involve building supportive relationships with community businesses (e.g., day care centers, clothing stores, hotels) and community serving organizations (e.g., churches, civic clubs). It may also involve establishing peer support or exchange networks between families to offer periodic mutual aid and support.
- Offer training and technical assistance to CDDP case managers over how they can better set CFSPs with families, purchase supports permitted by the administrative rule, and utilize other community assets to support families.
- Exchange information on best practices related to Family Support.

- 7. Develop Assessment and Performance Standards for Family Support.** By implementing these recommendations, SPD will field a systematic means for supporting children with developmental disabilities and their families. Local efforts, however, will not be uniformly applied across the state. Local differences in resources, opportunities and preferences will naturally influence programs as they take shape. Yet SPD should be able to observe core similarities among local programs to indicate that the system is working as a cohesive unit and as envisioned. Moreover, once such a cohesive system is established across the state, SPD can collect information on its operations and outcomes over time to: (a) describe how funds are being spent and on whom, (b) systematically sharpen individual program efforts or the system as a whole, (c) describe the program's outcomes and impacts on the families and the service system, and (d) inform overall policy decisions on how family support can be best funded and fit into the overall service system.

At the least SPD should:

- Develop needed assessment protocols to indicate how individuals can move through the system. SPD already utilizes procedures to govern what children are eligible for developmental disability services. All eligible children and their families will have access to the Family Cooperative. In addition, SPD will need to develop assessment protocols to determine entry into the next levels of support. This includes entry into the CDDP General Assistance Family Support Fund, and beyond that into other more intensive services.

- Develop means to assess operations and performance consistent with the specifications described in the logic model developed by the Family Support Task Force (See Recommendation 1). Such data collection need not be onerous, but programs should be able to regularly supply SPD with information about their operations and outcomes. In developing this capacity SPD should seek to make this data collection process electronic, building on current computer and web based technologies.

8. Implement the Multi-Tiered Approach to Families across the State. These recommendations are designed to change the present family support system into one that makes most efficient use of available resources while getting help to all eligible children and families and providing opportunity for those with greater needs to get additional support.

As the above described recommendations are completed, the best means of taking this final step will grow clearer. Ideally, SPD would launch the new system across the state at roughly the same time. That is to say that Family Cooperatives would be established and begin operations, with eligible families and children being referred, as appropriate, into services available through the CDDP General Assistance Fund. Generally, SPD took this approach in establishing “service brokerages” across the state for adults.

Alternatively, SDP may instead prefer a piloting strategy whereby it would work with a few selected areas to begin and replicate elsewhere systematically. Generally, this was the approach taken in the early 1990s to start-up family support in the state. The lessons learned and the constituency that resulted helped the state to replicate these efforts across the state, culminating in the administrative rule that governs the present family support system.

Each approach has its strengths and shortcomings. Piloting offers a good way to work out difficulties in design and gain experience. With strong commitment and planning, pilots can provide a strong platform for prompt replication elsewhere. Yet, change projects often lose momentum in the piloting phase as interest wanes, resistance builds or resources fall short. Too often states can display exemplary pilots in a specialty service such as family support or supported employment while their overall system remains mediocre. Systems like this are referred to as “pilot rich, but program poor.”

To contrast, launching a system simultaneously statewide sends a strong message to all that the changes cannot be put off and that key players must bore into implementing the targeted changes without delay. Difficulties are managed as the new system rolls out with some areas making better progress than others. Depending on the breadth of the desired changes, local capacity and the support local actors are given, the new system could gain a good stride quickly or take some time to develop.

We cannot say what the best strategy will be at this time. Our preference is for SPD to bypass a piloting phase and work decisively to implement the desired changes statewide. This, however, will require strong planning and ample supportive resources. As the previous seven recommendations are achieved, the best way to proceed will become clear.

Lifespan Respite

Respite care is temporary, short-term care for an individual with special needs. As noted earlier, in July 1997 Oregon passed legislation (HB2013) to establish the Lifespan Respite Program to assist local communities in building respite access networks for a variety of individuals with special needs.



The Lifespan Respite Program is at a crossroad.

Though all agree on the importance of Lifespan Respite, most would also agree that the program operates under great budget stress. In FY 1997-1999, \$250,000 was allocated to Lifespan respite, and this amount was raised to just over \$1 million for the current biennium. This amount seems substantial, but must be applied to fund statewide infrastructure as well as local contracts. Additionally, state budget issues in FY 2001-2003 and the subsequent cuts in programs and staff severely undercut local efforts and emerging collaborations. Today, given the program's intent, Lifespan Respite remains underfunded.

We understand that the state's investment was thought of initially as "seed money." Local programs were expected to generate other complementing funds and collaborations to assure longer term operations. Local contractors, however, receive too little to vigorously pursue this mission, and these other expected resources did not materialize. Moreover, state agencies, whose programs often identify respite as a key service for those they serve, failed to contribute money to Lifespan Respite's infrastructure or administrative needs. Finally, some agencies, rather than collaborating with the Program, continue to fund respite through alternative means, inefficiently duplicating respite efforts and further eroding the Program. And, while use of Lifespan Respite varies from place to place, there appears to be only modest reliance on the Lifespan Respite Program to orchestrate these respite services.

As a result, while the Lifespan Respite Program may touch many, it struggles to build a strong constituency among the many special needs groups it seeks to serve. Inevitably, because of chronic budget stress, and the failure of collaborating agencies to contribute to and participate in the Program, the Lifespan Respite Program -- over time -- touches too few and fails to deliver on its mission in large enough ways to develop a supportive constituency.

The Lifespan Respite Program is at a crossroad. When it was established in 1997 there were great expectations for its success. Now, nine years later, due in great measure to an absence of needed funds, the Program struggles to meet these expectations. The Department may conclude that Lifespan's modest operations and impacts are sufficient for the dollars it allocates to the program and grow content with the program as it is. If the program is to emerge from its present modest standing to reach its expectations,

the Department must re-affirm its commitment to Lifespan Respite by acting to seek out and acquire additional funds for program operations, re-shape the program in the short term to fit better with the present fiscal context and in the longer term to build a supportive constituency for the program.

To achieve this primary policy objective, we offer the Department three recommendations. The Department should:

1. Seek out and acquire additional funding for Lifespan Respite. While respite is a greatly popular service among families and the Lifespan Respite Program shows great promise, the Program endures continual budget stress. If the Department is to make good on its commitment, this fundamental circumstance must be altered. The Department should:

- *Resist action to reduce Lifespan Respite Program funds, and instead advocate for additional funding for the Program.* More specifically, resources to offset any potential budget shortfall in the Program should be either found within the Department or added to the Department's deficit and addressed later within a later legislative session. Moreover, the Department must ultimately address this issue as it fashions future budgets in collaboration with the governor and legislators.

Inevitably the Department must decide: Is it satisfied with present allocations to Lifespan Respite and so with the program's associated modest operations and impacts? If it concludes, as we have, that the Program is not living up to the expectations suggested within with HB 2013 due to budget stress, then it must press for additional funding with the appropriate authorities.

- *Track closely and consider utilizing the new option made available under the Deficit Reduction Act to list respite services as a permitted service under the Oregon Health Plan.* As indicated earlier, under DRA there are provisions whereby Oregon may submit a DRA state plan amendment to CMS to cover respite services. It is worth mentioning here because this approach could permit a state to fashion some type of state plan respite coverage across the "life span."

Note that because the DRA does not provide for a waiver of comparability, a DRA respite benefit would have to be available for all people who meet the functional criteria established by the state. The functional criteria must be less restrictive than institutional criteria, so that the "institutional level of care" criteria for admission to a HCBS waiver would not apply. Moreover, it could not be limited to a certain disability group, such as people with developmental disabilities. And it could not be limited by age.

Additionally, it could not be limited by Medicaid eligibility group (e.g., only SSI recipients). DRA provides that any HCBS state plan benefit can only be made available to recipients with incomes less than 150% of poverty (the HCBS waiver standard of 300% of SSI could not be employed). With respect to children, this means that children who receive SSI could be eligible, but other children who do not receive SSI probably would not be eligible.

If a state instituted DRA respite care coverage, it could still offer respite under its other HCBS waivers to: (a) supplement DRA coverage for waiver participants, or (b) furnish respite to people who do not qualify for it under the state plan because of income but qualify for the waiver.

Final rules on this option are being developed by CMS, though they indicate that they will issue an advisory to state Medicaid directors over the summer and interim final

regulations by December 2006. Presently, we are uncertain of the opportunity this option offers Oregon with regard to its Lifespan Respite Program, but state leaders should track developments closely and determine later whether it is worth pursuing.

2. **Take action in the short term to reshape Lifespan Respite to better fit the present fiscal context.** HB 2013 and its complementing administrative rule were premised on a number of assumptions that emphasized use of numerous local networks, collaboration among multiple state agencies, and utilization of a variety of funds and resources. Overall, it was expected that state agencies and community partners would together contribute to local Programs, and that agencies that funded respite would come to utilize local Programs to recruit and train respite workers to meet their needs.

These and other assumptions have not played out as expected over time. **Given no additional funds, continuing to operate the program based on these assumptions will yield more of the same.** The Department needs to reconsider the driving policy and operational assumptions that underpin the Lifespan Respite Program, and make adjustments. For the short term, we recommend these two:

- The Program should focus on capacity building and shy from any use of its resources to deliver respite directly to families. Clearly, some families who could use respite, may not have access to respite through other DHS service agencies. As a result, there is temptation for Lifespan to sponsor direct respite services. By doing so, however, the scarce resources are diverted away from other essential capacity building tasks.
- Presently, scarce Lifespan Respite programs are spread too thin among too many local contracts. Given current resource constraints, DHS should consolidate these contracts into a smaller number that is each better funded than any are now. The new consolidated contracts would serve regional interests, and with more focused effort on partnering with DHS local agencies to support locally run respite programs.

3. **Take action to reshape Lifespan Respite for the longer term to build a strong constituency for the Program.** It is essential to consider that “family support” of varying kinds is already offered through other DHS and county programs and that these programs are themselves evolving. As a result, the relationship of Lifespan Respite and other family support options must be carefully considered.

Bluntly put, if Lifespan Respite develops in ways that are inconsistent with other efforts, then these other programs will not routinely use Lifespan Respite, and so undercut its utility overtime. Put another way, Lifespan Respite must offer services and supports to complement the DHS family support efforts, adding value to such effort. By doing so, Lifespan Respite can become increasingly relevant to the success of the overall system and so build a strong constituency to assure its enduring presence.

Along these lines:

Lifespan Respite must offer relevant support to complement other DHS funded family support efforts...



- *Lifespan Respite Programs should diversify the services it offers, but in ways that complement the new directions being taken by other family support programs.* For example, within the developmental disabilities field there is strong interest among families to “self-direct” services, including respite. Families may want the freedom to find and retain their own respite staff, potentially bypassing the need for Lifespan Respite. Such practice could be orchestrated through Lifespan Respite, given need for following any required protocols (e.g., criminal background checks, paying workers). Families may also still need training on Department of Labor regulations or other relevant topics.

Likewise, earlier we recommended that SPD establish a network of Family Support Cooperatives. These Cooperatives could easily become strong partners with Lifespan Respite. Related to respite, these Cooperatives will form peer support opportunities among families or “exchange networks” where families offer periodic mutual aid to one another. Lifespan Respite Programs can help these Cooperatives to establish and maintain such networks.

Finally, we note that while families often seek respite, many also see longer term routine relief such as day care or after school care. Such support is not meant to be temporary, but rather is intended often to help a caregiver fulfill other responsibilities, such as keeping a job. Lifespan Respite programs might also work vigorously to help identify or establish such longer term options.

In essence, if Lifespan Respite is to find and keep a valued role within the state’s family support systems, it must seek out its niche, develop it and add value to the family support work already underway.

- *DHS should require participating state agencies to contribute to and utilize the Lifespan Respite Program.* HB 2013 and the associated administrative rule primarily encourage state agencies to build and coordinate with the Program. State agencies, however, have not invested strongly in the Program. To alter this pattern, the Department should press participating agencies to assure the success of the Program. The Department should:
 - Require that participating agencies contribute funds to the Lifespan Respite Program to build infrastructure and offset administrative expenses.
 - Require that participating agencies increasingly utilize Lifespan Respite Programs to recruit and train respite workers, de-emphasizing and eventually eliminating duplicated respite efforts.

In making this recommendation, however, we recognize that agencies will not be happy with investing in Lifespan Respite if they do not receive a satisfactory return on their investment. It is essential that the Department require agencies to utilize the respite tool that was developed for them. Yet, it is equally essential that the Program offer services that the agencies value. If not, then support for the Program will eventually erode and agencies will seek to reclaim their investment.

Concluding Remarks

Oregon was one of the first states to recognize the merit to providing support to families of children with developmental disabilities. Earlier than most states, Oregon took action to craft guiding principles on Family Support and pass legislation to form a statewide Family Support program.

Likewise, Oregon was among the first states to recognize the merit to developing a respite support network that cut across ages and disabling conditions. In fact, Oregon was the first state to pass Lifespan Respite legislation to help counties develop and implement community-based Lifespan Respite networks. Oregon's program was viewed as one of the best in the nation and other states used it to model their programs after.

More recently, these systems are overmatched by short funding and other undercutting factors. The result is that neither system is functioning as envisioned, and that children and their families are not receiving the support they need. Moreover, though local administrators and staff are doing their best to support families day-to-day, they are not responding with common purpose and teamwork to meet the challenges they face.

Still, these circumstances and the commitment at SPD to improve its response to families offer great opportunity. Regarding Family Support, SPD must first fashion an overall policy direction to establish a sustainable future for Family Support that fits more effectively with the funding in play, and that reaches more families by focusing attention on building greater community capacity. To complement this approach, SPD will need to re-direct resources to promote action, develop a learning culture around it and set performance expectations for to measure progress and adjust policy or practice. In addition, SPD must explore use of Medicaid financing options to expand the resource base for children living at home. Such action can free up state resources that might be applied to further develop capacity and/or support other families.

Regarding the Lifespan Respite Program, the Department must act to reaffirm its commitment to the Program. To begin, it must re-consider the premises that were used to fashion the program initially, and re-shape the program to fit better with today's circumstances. Next, it must act aggressively to shore up the program's funding.

DHS should then take action in the short term to consolidate the program while seeking opportunities for the program to complement other Department family support efforts. It may also act to press participating public agencies to use the Program, but in turn the Program itself must have the ample resources to deliver on expectations and do so with services that these agencies value. By taking steps like these to better fit the program into the current fiscal context, a leaner though more effective program may emerge, creating a much needed constituency for the program.

In the end, we hope that this study, including its recommended policy options and action implications, will inform discussion over how Oregon state leaders and family advocates can work together to reclaim the promise of the state's earlier beginning efforts to support families. This is the ultimate outcome we all seek to achieve. Surely, we understand that SPD and its many partners are already working toward that outcome. Given this continued commitment, we confidently anticipate success.