

HOUSE COMMITTEE ON HUMAN RESOURCES

March 17, 1997 Hearing Room H-170

1:00 P.M. Tapes 50 -51

MEMBERS PRESENT:

Rep. Patricia Milne, Chair

Rep. Jackie Taylor, Vice-Chair

Rep. Richard Devlin

Rep. Jeff Kruse

Rep. Jane Lokan

Rep. Kitty Piercy

Rep. Steve Harper

MEMBER EXCUSED:

STAFF PRESENT:

Lori A. Long, Administrator

Diane M. Quinones, Administrative Support

MEASURE/ISSUES HEARD:

HB 2779 PUBLIC HEARING

INFORMATIONAL MEETING

Oregon Respite Care

These minutes are in compliance with Senate and House Rules. Only text enclosed in quotation marks reports a speaker's exact words. For complete contents, please refer to the tapes.

Tape/#	Speaker	Comments
TAPE 50, A		
001	Chair Milne	Calls the meeting to order at 1:05 p.m.
002	Chair Milne	Opens a public hearing on HB 2779.

<u>HB 2779 PUBLIC HEARING</u>		
006	Tom Gallagher	Represents, The Home Care Association, submits and presents written testimony in favor of HB 2779 (EXHIBIT A). * explains the intent of the bill * discusses language changes this bill affects
048	Rep. Piercy	Asks if there has been objection to this bill.
053	Gallagher	* unaware of current opposition
066	Chair Milne	Closes the public hearing on HB 2779.
068	Lori Long	Committee Administrator, explains testimony received on HB 2525.
077	Chair Milne	Opens an informational meeting. Stands the committee at ease.
<u>INFORMATIONAL MEETING</u>		
<u>Respite Care in Oregon</u>		
O87	Katherine Weit	Policy Anylist, Oregon Developmental Disabilities Council, introduces a small panel of families in need of respite care services.
093	Crystal Jensen	Parent of triplets, has two daughters with cerebral palsy * discusses what respite care would mean to her * asks the committee for consideration when respite funding is proposed
110	Rep. Taylor	Asks about the help she has in place now.
115	Jensen	* She relies mostly on friends, her church, and other mothers. * There isn't enough money to hire respite help. * She doesn't have the time it takes to investigate the respite care that's out there.
		Parent of twins, has two children with special needs. * qualifies for \$40.00 of respite care per month through Polk County

130	Kathy Teal	<ul style="list-style-type: none"> * recently discovered that she was losing this benefit * must have an LPN or RN for her daughter - costing \$17.00 Hr. * she or her husband must be available when ever a nurse is not present * nurses are present when she is at work and ends at 3:45 p.m., then begins at 10:00 p.m. when she goes to bed. * No respite care is available on the week-ends.
180	Rep. Piercy	Asks if they were able to afford services, what is offered in their communities.
190	Jensen	

1. The Association for Retarded Citizens (ARC) is available in her community.

* pay if you can program

* difficult to access when there's no money to pay for help

2. There are social service agencies that may help

* doesn't want to confess to being at the point of child abuse in order to get care

* wants her children at home

3. Family Services from Developmental Disabilities provided respite care for one year.

204 Teal Polk County has the ARC.

210 Rep. Lokan Asks about the help she has during the day.

* Has Blue Cross/ Blue Shield HMO, and they provide nursing care

217 Teal * Her family had to fight to keep the care they have.

* Finding nurses and coordinating schedules is up to her and her husband.

238 Rep. Lokan Asks if benefits for the year are used up.

explains how insurance reimbursement is handled

240 Teal * reviews every three months

* not always sure what benefits will be in place for each quarter

Submits and presents written information on Respite Care in Oregon (**EXHIBIT B**).

* defines "Respite Care"

* discusses how respite care functions

- 265 Weit
- * explains how the dynamic of the family changes with a special needs individual in the home
 - * discusses some history of respite care and how the needs are changing
 - * describes the separation that takes place within a family when an individual with special needs is a member

**TAPE
51, A**

Continues presentation.

- 001 Weit
- * discusses policies being set by state agencies to keep individuals with special needs and disabilities at home

* talks about what families are looking for in respite care

- 070 Rep.
Lokan
- Asks how much time is usually taken for respite relief.

* Explains that respite care looks different to various families.

* Families define what it means to take a break.

Requests can include:

- 074 Weit
- * a few hours

* a full day

* a week for a vacation

- 092 Rep.
Kruse
- Asks for clarification for the term "temporary" when applying it to respite care.

* A better term might be "Short Term."

- 104 Weit
- * Respite care does not occur on a regular basis eight hours a day seven days a week.

* Families need to depend on support for short periods of time.

Respite Care Coordinator, The Respite Care Initiative, provides an overview of the key resources of respite care in Oregon. Refers to the map as part of **(EXHIBIT B)**.

- 128 Terry
Butler
- * explains the importance of provider recruiting and screening

* discusses the nine largest programs in Oregon and their many limitations and

restrictions

* makes the committee aware of programs that will be losing federal funding in September 1997

- 245 Rep. Kruse Asks about the amount of federal grants in Oregon.
- 248 Butler * The federal grant is for \$200,000 per year
- 255 Rep. Kruse Asks about how the federal grant was spent.
- 258 Butler * Some dollars have gone to pay for staff time, administrative costs, office space, telephone, etc.
- * dollars are spent on stipends for families
- 270 Rep. Kruse Asks to see expenditures of federal funds.
- 278 Chair Milne Concurrs with Rep. Kruse, and asks about past state matching funds.
- In September of 1994 state matching funds were at \$67,000.
- 284 Butler This funding was a "one time only" grant program overseen by the Office of Developmental Disabilities Services family support funds.
- 312 Chair Milne Asks for the amount of families being served.
- 315 Butler As of July 1996, 400 plus families were being served.
- * talks about an innovative program in Klamath County
- 330 Butler * talks about respite day sites for dementia disabilities funded by federal dollars
- 380 Chair Milne Asks if state dollars are involved in the day site programs.
- 388 Susan Dietsche Assistant Administrator, Senior Disabled Services Division, talks about state dollars available for respite care programs.
- * two more years of federal funds have been granted
- TAPE 50, B**
- * continues to talk about state matching dollars and other programs being funded to assist dementia disabilities
- 001 Dietsche * putting money into community development so it may sustain itself once programs are started
- 036 Rep. Piercy Asks about plans for keeping programs going once grant dollars are removed.
- 040 Butler * encouraging local programs to sustain themselves
- * programs are always seeking private grants

* HB 2013 would be a major step in providing stability to respite funding.

060 Rep. Lokan Asks how long the existing programs have been operational

063 Butler Family access to Respite Programs has been operational since the spring of 1995.

067 Rep. Lokan Asks what people did before programs provided respite care.

* Families went without respite care.

070 Butler

* Families patched together people willing to lend a hand.

080 Rep. Lokan Asks about private foundation contributions and grants.

089 Butler * talks about ARC programs that have been in place for a long time and act as bases for attracting private funds.

106 Rep. Harper Asks if percentages exist around how much respite care is state funded and how much is private.

110 Butler Those figures are not available.

128 Rep. Piercy Comments that organizations like to help start programs but are not available to help maintain them.

Discusses problem issues faced by respite care providers and recipients:

* no state wide access

* geographic limitations

Butler

* short term and time limited grants

* respite care programs having categorical requirements

* locating adequately skilled providers

* exclusion of families with high level medical needs and behavior problems

185 Rep. Taylor Asks about making parents or family members primary trainers of care providers.

203 Butler Project Adoptive Families Individualized Respite Model (AFIRM), focusing on families adopting children with special needs, is pursuing a program that trains families and care givers together, and provides the family with a stipend.

ARC of Multnomah County, provides the committee with information about respite care in Oregon.

* describes the Oregon Respite Care Association (ORCA)

214 Vicky Swede

* has seen many programs cut

* the needs of families have increased

* funding sources have different priorities and remain inconsistent

* asks the committee to support HB 2013

- 331 Rep. Piercy Asks about numbers of families that can pay for services themselves and families that need assistance.
- 340 Swede * When programs have been terminated in her agency there has been a significant loss of parents
- 360 Rep. Kruse Asks how much is granted by the City of Portland.
- 365 Swede * The ARC of Multnomah County receives no city funds
- 370 Chair Milne Asks about the ARC's main source of funding.
- 376 Swede Her agency is a United Way Member Agency, also donations and grants are sources.
- 385 Chair Milne Asks about an overall budget for the respite program.
- 390 Swede * approximately \$80,000 per year
- TAPE
51, B**
- * will bring additional information on state dollars involved in respite care
- * unlike many states in the country, Oregon does not have a state funded respite program
- 014 Weit * discusses the infrastructure of respite programs throughout the state
- * majority of money that supports these programs is private
- 034 Rep. Piercy Asks what other states are doing.
- 040 Butler Will provide the committee with information on other state programs.
- 063 David Bean * discusses Vermont's state wide respite care
President, People First State Wide, provides the committee with testimony for support to fund services to people with disabilities.
- * wants dollars spent on people with disabilities
- 091 Rep. Taylor Recognizes Mr. Bean from the 1991 session.
- 104 Chair Milne Closes the informational meeting.
- 105 Chair Milne Adjourns the meeting at 2:40 p.m.

Submitted By, Reviewed By,

Diane M. Quinones, Lori A. Long,

Administrative Support Administrator

EXHIBIT SUMMARY

A - HB 2779, written testimony in favor of, Gallagher, 6 pp.

B - Information on Respite Care in Oregon, Butler, 7 pp.