SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

February 25, 1997 Hearing Room B
3:00PM Tapes 24 - 25
MEMBERS PRESENT:
Sen. Bill Fisher, Chair
Sen. Jeannette Hamby, Vice-Chair
Sen. Lenn Hannon
Sen. Marylin Shannon
Sen. Susan Castillo
Sen. Thomas Wilde
MEMBER EXCUSED:
STAFF PRESENT:
Anne E. Tweedt, Administrator
Sandy Thiele-Cirka, Administrative Support
MEASURES/ISSUES HEARD:

Informational Meeting

Overview of Long Range Plan for Developmental Disability Services (Fairview Training Center)

- * Panel of Parents of former Fairview Residents and Self-Advocates
- * Panel of Wait List Family Members
- * The Arc of Oregon

John Murren, Executive Director

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

Tape/#	Speaker	Comments	
TAPE 24, A			
003	Chair Fisher	Calls meeting to order at 3:07pm, opens informational meeting Welcomes parents and announces Hearing Room A is available for overflow audience.	
INFORMATIONAL MEETING			
		Opening remarks, identification of panel testifying.	
016	Kathryn Weit	Submits testimony from Oregon Developmental Disabilities Council (EXHIBIT A) in support of community services.	
		Parent and advocate of 16 year old son and other developmentally disabled individuals.	
		States that her son will receive community services until he turns 21.	
		Submits testimony from individuals in support of community services (EXHIBIT B).	
		Discusses community services available to the disabled community. Provides the following statistics:	
065	Weit	* 4,000 DD individuals currently live within the community	
		* 3,500 DD individuals are eligible for services but are not receiving them	

		* approximately 13,500 children are currently in the public school system			
080	Chair Fisher	Questions the percentage of 13,500 that are on the wait list.			
082	Weit	Responds that this figure includes all individuals, including those on the wait list.			
		Outlines wait list process.			
		Continues with individuals on the wait list that are receiving some services.			
117	Weit	* 25 percent of the care givers are over the age of 60 (1990 study)			
		Continues with county by county breakdown of statistics.			
155	Chair Fisher	Questions those individuals on the wait list that receive 24-hour care.			
158	Weit	Responds that the specifics are not available, she will obtain them and provide them to the committee.			
169	Sen. Castillo	Clarification for `family support'.			
172	Weit	Responds that it is small program located in several counties within the state that provides some funding for respite care, purchase supplies, targeted to keep individuals in their homes.			
183	Michael Bailey	Portland, daughter Eleanor, invited by Developmental Disabilities Council to speak as a parent.			
197	Chair Fisher	Addresses incoming audience.			
		Acknowledges that persons entering the hearing room are either on the wait list or are waiting to be placed on the wait list.			
232	Bailey	Introduces Jan Stalley, Oregon City, who received Governor's award for her advocacy work and commitment to disability rights.			
		Continues with personal testimony, identifying personal journey of having a daughter affected by multiple disabilities.			
295	Bailey	Continues outlining involvement with the long range plan development for the developmentally disabled.			
335	Bailey	Discusses how to spend the current budget in a more equitable fashion. Discusses the proposed \$70 million to be spent in 50 new group homes; expresses concerns about this figure.			
		Notes if Fairview closes, some Medicaid money would be lost. Expresses support to increase community service salaries.			

390	Bailey	Continues with the future of a developmentally disabled person upon reaching 21 years of age and their education is completed, there is nothing in place to continue their productivity.		
TAPE 25, A				
010	Bailey	Continues testimony and summarizes personal concerns regarding the proposed budget.		
048	Chair Fisher	Comments directed towards the audience.		
058	Sen. Hannon	Thanks Mr. Bailey for testimony.		
063	Vice-chair Hamby	Questions Mr. Bailey regarding the Fairview property value.		
067	Bailey	Responds a partnership would have to occur between private parties and the state to bring the property up to market value. The issue has been looked at as a possibility, but the decision was that it wasn't a pot of gold at the end of the rainbow.		
089	Vice-chair Hamby	Notes that there would be an increased value once the property is brought up to market value and the funds should be directed towards developmental disabilities services.		
095	Bailey	Responds in support.		
103	Larry Bentley	Parent, son Ethan, submits (EXHIBIT C) and provides testimony of being a parent of a severely disabled child.		
153	Maritza Soler	Parent, daughter Jessie, submits and provides testimony (EXHIBIT D).		
200	Soler	Continues testimony.		
228	Chair Fisher	Directs supportive comments to the witness.		
239	Sen. Castillo	Thanks the witness for providing the committee with her experiences and information.		
246	Kathy Feller	Parent, introduces daughter Krissie, submits and provides testimony (EXHIBIT E).		
300	Feller	Continues personal experience.		
337	Chair Fisher	Acknowledges audience members that have to leave.		
345	Feller	Summarizes testimony.		
360	Margieann Boss	Mother, son Alan, provides testimony of family environment with a developmentally disabled child. Outlines the changes that occurred when Alan turned 21 years old, and services were discontinued.		
400	Boss, M	Continues testimony.		

TAPE 24, B					
011	Boss, M	Continues testimony and shares personal experiences of transitioning Alan into a state group home. Expresses concern about helping individuals in the system, and not those in the system.			
045	Boss, M	Summarizes and requests equity for parents that have chosen care for their children.			
051	Ron Boss	Parent, Beaverton, testifies in support of providing support services for families. Comments on difficulties that surface once the client reaches 2 years of age.			
095	Boss, R	Continues and summarizes testimony.			
106	Teresa Cody	Parent, submits and provides testimony regarding son William (EXHIBIT F), a medically fragile child.			
150	Cody	Continues testimony describing the partnership between family, insurance company and the state to access community resources			
175	Cody	Summarizes testimony.			
190	Chair Fisher	Announces after the five hearings surrounding this issue, there will be a follow-up meeting to assess all the information presented.			
210	Emily Diehm	Parent, son George William Diehm, former Fairview resident. Submits and provides testimony (EXHIBIT G) in support of increasing community support services.			
261	Diehm	Continues and summarizes testimony.			
280	George Diehm	Father, provides additional testimony.			
		Continues and summarizes testimony.			
315	Diehm, G	Speaks to his son's strength and the home's ability to care for him.			
344	Diehm, E	Notes the restrictions that they face as parents growing older. Follow-up comments supporting group home environment.			
365	Judy Cunio	Former Fairview resident, submits and provides testimony in support of community living (EXHIBIT H). Introduces Cynthia Fox, personal assistant.			
TAPE 25, B		JL			
010	Cunio	Continues testimony, emphasizes that community support services are necessary.			
015	Chair Fisher	Directs supportive comments to witness.			

Cunio	Continues with personal experiences of transitioning out of Fairview into the community.				
Chair Fisher	Responds to concerns.				
Cunio	Summarizes testimony.				
John Murren	Executive Director, Arc of Oregon, submits and provides testimony in support of community living (EXHIBIT I). Advocates on behalf of persons with developmental disabilitie and their families.				
Murren	Continues testimony, presenting argument about cost and efficiency. Notes the reduction of resources, necessary for a more equitable distribution.				
Murren	Continues and summarizes testimony.				
Chair Fisher	Questions Arc's concern on closing Fairview too early, too fast. What happens when the state's economic stability falters?				
Murren	Responds that limited funding is an ongoing concern. Regarding the long range plan, it is to early speculate.				
Chair Fisher	Questions if the is Arc supportive of speeding up the plan, if possible?				
Murren	Responds with two concerns: * infrastructure within the community to be stable enough to absorb new clients * that the needed support is available for the medically fragile individuals				
Chair Fisher	Asks if those two are made possible, does the Arc have any objections.				
Murren	Responds not if they are done well.				
Mary Jo Weaver	Parent, Corvallis, daughter Hannah Benes. Daughter is on the wait list, the only services being received are those provided by her (mother). Questions what services are going to be available to her as she gets older? Education is a big concern, Individual Education Plan (IEP) not available.				
Stephanie Strom	Parent, Corvallis, daughter Rachel Joy Strom. Single parent, adopted daughter as a newborn, medically fragile child. Urges the committee to consider continuing and expanding community support services.				
Vice-chair Hamby	Addresses Kathryn Weit on assistance for IEP.				
Weit	Responds affirmatively.				
	Chair Fisher Cunio John Murren Murren Chair Fisher Murren Chair Fisher Murren Chair Fisher Stephanie Strom Vice-chair Hamby				

332		Parent support coordinator, Arc of Benton County, daughter Lorrie Cleven. Daughter not on the wait list, thanks the committee for the opportunity to testify.		
11356	Sen. Shannon	Questions what guarantee is in place that, if Fairview closes, the money will go to community services?		
1136/1	Chair Fisher	Comments on reviewing existing programs and options that might be acceptable. Additional hearings to work on a possible plan.		
377	Chair Fisher	Adjourns meeting 4:50pm.		

Submitted By, Reviewed By,

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Sandy Thiele-Cirka, Anne E. Tweedt,

Administrative Support Administrator

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EXHIBIT SUMMARY

- A -Oregon Developmental Disabilities Council, Kathryn Weit, 33pp
- B-Individual written testimony, Kathryn Weit, 9pp
- C -Written testimony, Larry Bentley, 2pp
- D-Written testimony, Maritza Soler, 3pp
- E -Written testimony, Catherine Feller, 3pp
- F-Written testimony, Teresa Cody, 4pp
- G-Written testimony, Emily Diehm, 2pp
- H-Written testimony, Judy Cunio, 2pp
- I-The Arc of Oregon, John Murren, 4pp