

**HB**

**72**

# FISCAL NOTE

STATE OF ALASKA  
1999 LEGISLATIVE SESSION

BILL NO. SSHB 72

Revision Date/Time (Note if correction): \_\_\_\_\_ Dept. Affected: Health and Social Services  
 Title: Relating to services for persons with handicaps BRU: Medical Assistance  
(DD waitlist) Component: Medicaid Services  
 Sponsor: Brice COMPONENT SERIAL NO. 2077  
 Requestor: House (HES) See also (SN#): \_\_\_\_\_

**Expenditures/Revenues:** (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

OPERATING	FY2000	FY2001	FY2002	FY2003	FY2004	FY2005
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS	7,127.8	27,870.7	34,873.0	42,422.4	50,552.9	59,300.5
MISCELLANEOUS						
<b>TOTAL OPERATING</b>	<b>7,127.8</b>	<b>27,870.7</b>	<b>34,873.0</b>	<b>42,422.4</b>	<b>50,552.9</b>	<b>59,300.5</b>

CAPITAL EXPENDITURES						
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CHANGES IN REVENUES ( )						
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**FUND SOURCE** (Thousands of Dollars)

1002 Federal Receipts	4,262.4	16,666.7	20,854.1	25,368.6	30,230.6	35,461.7
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1037 GF/Mental Health	2,865.4	11,204.0	14,018.9	17,053.8	20,322.3	23,838.8
Other (please specify)						
<b>TOTAL</b>	<b>7,127.8</b>	<b>27,870.7</b>	<b>34,873.0</b>	<b>42,422.4</b>	<b>50,552.9</b>	<b>59,300.5</b>

Estimate of any current year (FY1999) cost: \$0.0

**POSITIONS:**

FULL-TIME						
PART-TIME						
TEMPORARY						

**ANALYSIS:** (Attach a separate page if necessary)

Sponsor Substitute for House Bill 72 would require state agencies to provide services to all individuals with developmental disabilities who meet the criteria in statute. Approximately 60 percent of individuals currently receiving these services are funded by the Medicaid Home and Community-Based Services Waivers, either the waiver for People with Mental Retardation or Developmental Disabilities (PMRDD) or the waiver for Children with Complex Medical Conditions (CCMC).

The Division of Mental Health and Developmental Disabilities estimates that 1000 people would receive services under this legislation initially, with an additional 250 per year in subsequent years. This fiscal note shows the cost to the Medicaid program of providing services for the 60 percent of those individuals who will qualify for Medicaid home and community-based waivers.

See the following page for our assumptions.

Prepared by: Jon Sherwood Phone: 465-3355  
 Division: Medical Assistance Date/Time: 3/1/99 9:08 AM  
 Approved by Commissioner: Karen Perdue, Commissioner Date: 3/3/99  
 Agency: Department of Health & Social Services

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**ANALYSIS (cont.):**

The cost to Medicaid of adding new Home and Community Based Services Waiver recipients has two components. First there is the cost of waiver services. Second, for individuals who do not currently receive Medicaid, there is the cost of providing regular Medicaid services in addition to waiver services.

The estimates below are based on the weighted average of the costs of the two waiver that serve these individuals, the PMRDD and the CCMC waivers. Two adjustments have been made. Because current costs include people deinstitutionalized from Harborview and Hope Cottages, who are more expensive to serve, the average cost of waiver services was reduced by one-third. Also, the cost of providing regular Medicaid services has reduced to reflect that an estimated 60 percent of all individuals newly eligible for waivers are already receiving regular Medicaid services.

	<u>FY 00</u>	<u>FY 01</u>	<u>FY 02</u>	<u>FY 03</u>	<u>FY 04</u>	<u>FY 05</u>
Total Number of client added	1,000	1,250	1,500	1,750	2,000	2,250
Percent on Medicaid HCB Waivers	60%	60%	60%	60%	60%	60%
Total New Clients on HCB Waivers	600	750	900	1,050	1,200	1,350
Weighted Ave. FY 98 Cost per Year	32,780	32,780	32,780	32,780	32,780	32,780
Inflation Rate	4.27%	4.27%	4.27%	4.27%	4.27%	4.27%
Adjustment factor for inflation	1.0872	1.1336	1.1821	1.2325	1.2852	1.3400
Estimated Annual Cost per Client	\$ 11,880	\$ 37,161	\$ 38,748	\$ 40,402	\$ 42,127	\$ 43,926
Total Cost of New Clients	<u>\$7,127,836</u>	<u>\$27,870,729</u>	<u>\$34,872,971</u>	<u>\$42,422,388</u>	<u>\$50,552,942</u>	<u>\$59,300,497</u>

**Assumptions:**

Ratio of new recipients on PMRDD and CCMC waiver is equal to the ratio of current recipients on the two waivers.

Waiver services for new recipients are one-third less expensive than for current recipients.

60 percent of new waiver recipients are already eligible for regular Medicaid services.

In FY 00, new recipients will be eligible for an average of 4 months.

# FISCAL NOTE

STATE OF ALASKA  
1999 LEGISLATIVE SESSION

BILL NO. HB 72

Revision Date: 03/02/99 Dept. Affected: Health and Social Services  
 Title: Relating to Services for Persons with BRU: Community DD Grants  
Handicaps (DD Waitlist) Component: Community DD Grants  
 Sponsor: Brice COMPONENT SERIAL NO. 309  
 Requestor: House (HES) See also (SN#): 1827; 236

**Expenditures/Revenues:**

(Thousands of Dollars)

OPERATING	FY00	FY01	FY02	FY03	FY04	FY05
PERSONAL SERVICES	309.0	309.0	309.0	309.0	309.0	309.0
TRAVEL	50.0	50.0	50.0	50.0	50.0	50.0
CONTRACTUAL	25.0	25.0	25.0	25.0	25.0	25.0
SUPPLIES	5.0	5.0	5.0	5.0	5.0	5.0
EQUIPMENT	40.0	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES						
GRANTS, CLAIMS	4,752.0	18,580.5	23,496.6	28,812.7	34,528.8	40,644.9
MISCELLANEOUS						
<b>TOTAL OPERATING</b>	<b>5,181.0</b>	<b>18,969.5</b>	<b>23,885.6</b>	<b>29,201.7</b>	<b>34,917.8</b>	<b>41,033.9</b>

CAPITAL EXPENDITURES						
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CHANGES IN REVENUES ( )						
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**FUND SOURCE**

(Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1037 GF/Mental Health	5,181.0	18,969.5	23,885.6	29,201.7	34,917.8	41,033.9
Other (please specify)						
<b>TOTAL</b>	<b>5,181.0</b>	<b>18,969.5</b>	<b>23,885.6</b>	<b>29,201.7</b>	<b>34,917.8</b>	<b>41,033.9</b>

**POSITIONS:**

FULL-TIME	5.0	5.0	5.0	5.0	5.0	5.0
PART-TIME						
TEMPORARY						

Estimate of any current year (FY99) cost: \$0.0

**ANALYSIS:** (Attach a separate page if necessary)

HB 72 will eliminate the Developmental Disabilities wait list and make all services for eligible individuals an entitlement. This will require the Division to serve people within a specific time-frame from when they become determined eligible. Individuals who are eligible for Medicaid services will be served on a Medicaid Waiver. Those ineligible for Medicaid will be served with Division GF/MH grant funds. If passed, HB 72 will go into effect January 1, 2000.

**Fiscal Assumptions:**

1. This fiscal note assumes that the current waitlist is approximately 1000 persons as of this date. HB 72 would eliminate the waitlist by providing full services for all individuals.

Assuming that historically 60% (600) individuals are Medicaid eligible then approximately 40% (400) would have to be served using GF/MH grant funds, and;

Assuming the average amount for full-services for each individual is \$37,161 a year. If the bill goes into effect on January 1, 2000, there would be approximately 4 months in FY2000 where individuals would be fully served with GF/MH state funds. The total amount for the 400 individuals being fully served for 4 months would be \$4,752.0.

Prepared by: Constance E. Anderson Phone: 465-4827 TTY  
 Division: Mental Health and DD Date: 03/02/99  
 Approved by Commissioner: Karen Perdue, Commissioner Date: 3/3/99  
 Agency: Department of Health & Social Services

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**ANALYSIS (cont.):**

Over the past 4 years the average number of individuals added to the waitlist was approximately 250 per year. Assuming that 40% of these individuals are not Medicaid eligible, 100 consumers would need to be funded by state GF/MH grant funds.

Historically, the cost of providing full services has risen consistently by \$2000 per individual per year. The amount of funding needed to fully serve each individual has averaged over the past 4 years approximately \$37161/year. Given this assumption, FY00 would require an average full services amount of \$37161 per consumer. This would bring the total amount of GF/MH needed to serve the 100 new consumers to \$18,580.5 in FY01. Following this trend there is a projection of: FY02 - \$23,496.6; FY03 - \$28,812.7; FY04 - \$34,528.8; and FY05 - \$40,644.9.

2. There would be an initial and on-going need for increased Developmental Disabilities staff. Based on current workload, is projected that there would need to be one full-time Project Assistant to process the Medicaid Waivers, including Prior Authorizations and billing issues.

Each of the four regions would also require additional staff. At present Northern Regional Office has one person on staff. Considering the average workload per Regional Program Specialist, it is assumed that an additional staff member would be required to serve those removed initially from the waitlist and those who are newly determined eligible each year.

Anchorage Regional Office currently has three Regional Program Specialists on staff. It is projected that they too will need an additional person to cover the increased workload.

Southeast Regional Office also has one staff member and it is projected that another would have to be hired to provide services in a timely manner.

The South-central Office, which also covers the Yukon-Kuskokwim area, the Kenai Peninsula, Valdez area, Kodiak Island and the Aleutian Chain, is currently understaffed with one full-time Regional Program Specialist. Bringing the office to two full-time employees is the minimum needed to cover an area this size.

The additional staff would not only be required to complete their own duties pertaining to the increase of fully-served individuals, but would also be required to provide support to the provider agencies who would have to increase their infrastructure to accommodate those individuals.

DD Grant	FY2000	FY2001	FY2002	FY2003	FY2004	FY2005
Served	400	500	600	700	800	900
Cost/Svd	11880	37161	39161	41161	43161	45161
	4,752.	18,580.5	23,496.6	28,812.7	34,528.8	40,644.9

Note: The amount calculated for FY2000 is based on a 6 month period from January 1, 2000 to June 30, 1999.

# FISCAL NOTE

**STATE OF ALASKA**  
**1999 LEGISLATIVE SESSION**

**BILL NO. SSB 72**

Revision Date/Time (Note if correction): \_\_\_\_\_ Dept. Affected: Health and Social Services  
 Title: Relating to services for persons with handicaps BRU: Public Assistance Admin  
 (DD waitlist) Component: Public Assistance Admin  
 Sponsor: Brice COMPONENT SERIAL NO. 233  
 Requestor: House (HES) See also (SN#): \_\_\_\_\_

**Expenditures/Revenues:**

(Thousands of Dollars)

OPERATING	FY2000	FY2001	FY2002	FY2003	FY2004	FY2005
PERSONAL SERVICES	48.6	48.6	48.6	48.6	48.6	48.6
TRAVEL						
CONTRACTUAL	6.0	6.0	6.0	6.0	6.0	6.0
SUPPLIES	0.5	0.5	0.5	0.5	0.5	0.5
EQUIPMENT	5.0	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
<b>TOTAL OPERATING</b>	<b>60.1</b>	<b>55.1</b>	<b>55.1</b>	<b>55.1</b>	<b>55.1</b>	<b>55.1</b>

CAPITAL EXPENDITURES						
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CHANGES IN REVENUES ( )						
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**FUND SOURCE**

(Thousands of Dollars)

1002 Federal Receipts	30.0	27.5	27.5	27.5	27.5	27.5
1003 GF Match	30.1	27.6	27.6	27.6	27.6	27.6
1004 GF						
1005 GF/Program Receipts						
1037 GF/Mental Health						
Other (please specify)						
<b>TOTAL</b>	<b>60.1</b>	<b>55.1</b>	<b>55.1</b>	<b>55.1</b>	<b>55.1</b>	<b>55.1</b>

Estimate of any current year (FY1999) cost: \$0.0

**POSITIONS:**

FULL-TIME	1	1	1	1	1	1
PART-TIME						
TEMPORARY						

**ANALYSIS:** (Attach a separate page if necessary)

This legislation sets limits on the length of time an individual may remain on the waiting list for developmental disability services from the Division of Mental Health and Developmental Disabilities. Eliminating this wait list will allow additional people to qualify for Medicaid home and community-based waiver services. The Division of Public Assistance will be required to devote additional staff time to determine eligibility for home and community-base Medicaid waiver services.

**Assumptions:**  
 This legislation will be implemented July 1, 1999.  
 Approximately 250 additional individuals who are now on the waitlist will qualify for Medicaid waiver services.  
 One staff person is able to maintain a Medicaid waiver caseload of between 250 to 300 persons.  
 Caseloads will remain level from FY2000 through FY 2005.

Prepared by: Jim Nordlund Phone: 465-2680  
 Division: Division of Public Assistance Date/Time: 2/26/99 2:28 PM  
 Approved by Commissioner: Karen Perdue, Commissioner Date: 3/3/99  
 Agency: Department of Health & Social Services

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**DEVELOPMENTAL DISABILITIES AND AGING**

By Barbara Wright and Martha King

*Medicaid accounts for about 70 percent of public funding for residential and day services for people with developmental disabilities.*

*States are under pressure to provide community services for people moving out of institutional care.*

Medicaid accounts for about 70 percent of public funding for residential and day services for people with such developmental disabilities as mental retardation, cerebral palsy, autism or epilepsy. As the baby boom generation ages, state legislators face growing demands in this area. Nearly two-thirds of people with developmental disabilities, including the majority of adults, live with their families—and nearly 500,000 live with caregiver, age 60 or older. As these aging caregivers die or can no longer provide assistance, additional demands will strain services that already have waiting lists in most states.

States are also under pressure to provide community services for people moving out of institutional care settings—stemming from federal policy changes, residents' preferences, and from budgetary considerations. A 1987 federal law requires an annual review of residents with mental retardation in Medicaid-certified nursing homes to determine if they actually need such care. When the policy was first begun, residents in nursing care 30 months or longer had the option to stay, but states had to discharge people who were determined not to need nursing home care. This resulted in a decrease of 6,000 nursing home residents between 1992 and 1996. Even so, only 10 percent to 25 percent of the 38,438 people with mental retardation residing in nursing homes in 1996 actually met the criteria for the expensive 24-hour care. But many states lack enough community facilities to house them—in 1996, state waiting lists for community-based services already contained more than 83,000 names.

Although legislators face increasing demands for services, they also have options to make services appropriate and cost-efficient. For example, the Illinois Home-Based Support Services Program helps 600 adults with severe disabilities live with their families, for about \$8,839 per person in 1996. In contrast, individual institutional care in Illinois averaged \$82,350 that year.

Residential services for people with developmental disabilities include supported living, in which people live alone or with roommates in their own homes or apartments. Other successful residential services and supports include personal assistance, home health care, "assistive" technologies and home modifications. Activities for seniors with developmental disabilities include opportunities to continue working (e.g., work

**The Number of People with Developmental Disabilities Living with Elderly Caregivers (1996)**

Alabama	8,362
Alaska	402
Arizona	8,898
Arkansas	4,694
California	49,374
Colorado	5,611
Connecticut	6,378
Delaware	1,345
District of Columbia	1,017
Florida	40,145
Georgia	10,949
Hawaii	2,209
Idaho	1,764
Illinois	20,602
Indiana	10,208
Iowa	5,631
Kansas	5,019
Kentucky	7,325
Louisiana	6,808
Maine	2,270
Maryland	8,526
Massachusetts	11,745
Michigan	17,453
Minnesota	7,283
Mississippi	4,777
Missouri	10,378
Montana	1,560
Nebraska	3,048
Nevada	2,787
New Hampshire	1,985
New Jersey	15,789
New Mexico	2,630
New York	32,391
North Carolina	13,483
North Dakota	1,110
Ohio	21,109
Oklahoma	6,235
Oregon	6,150
Pennsylvania	27,115
Rhode Island	2,219
South Carolina	6,432
South Dakota	1,291
Tennessee	9,766
Texas	29,129
Utah	2,547
Vermont	1,011
Virginia	11,115
Washington	8,747
West Virginia	3,760
Wisconsin	8,572
Wyoming	691
United States	479,862

Source: Braddock, 1999.

activity centers, supported employment, job placements) as well as retirement activities (e.g., adult day care, leisure and volunteer options). Support services that benefit older families include respite services and information that helps families make future residential, legal and financial arrangements for their relative with a disability.

### State Actions

Medicaid's home- and community-based services waiver provides federal money for states to fund community-based services. Created in 1981, the waiver allows states to use Medicaid funds for long-term care services for people moving from institutions or who are at risk of institutional care. Nearly all states operate waiver programs for people with disabilities and such waivers serve nearly 200,000 people nationwide. The Balanced Budget Act of 1997 will extend supported employment services to about 150,000 participants. In addition to Medicaid, many states also sponsor programs funded solely with state general funds.

Between 1977 and 1996, 32 states reduced their reliance on institutional care by more than 50 percent, transferring residents with developmental disabilities to smaller community-based residences. The District of Columbia, Michigan, New Hampshire, Rhode Island, Vermont and West Virginia reduced their institutional populations by more than 90 percent.

Maryland's "Waiting List Initiative" is designed to help the state reduce its backlog of people waiting for community services. The five-year initiative gives priority to households where elderly parents care for adult children with developmental disabilities. When someone in Maryland moves from an institution into the community, the savings from the reduced service costs are allocated to the "Waiting List Equity Fund." An estimated 2,000 people from the state's waiting list will receive services in FY 1999, including all people who have primary caregivers who are over age 70.

Connecticut supports nearly 2,000 people with developmental disabilities who are age 55 or older, with services such as its Day Support Options program. The state encourages employers to hire people with disabilities. Seniors with disabilities have a number of residential options, including community living arrangements, community training homes, individual homes or apartments, and family homes.

From a peak institutional population of 26,000 in the late 1960s, New York has transferred all but about 1,000 people with mental retardation to the community. Now the state has initiated a major Aging in Place initiative to train staff and clinicians about what happens when people with mental retardation age and how to meet their special needs. New York also funds the nation's largest series of day programs for older people with developmental disabilities. Approximately 60 senior programs serve over 900 people, with \$3.5 million in state funds.

### Selected References

- Braddock, D. "Aging and Developmental Disabilities: Demographic and Policy Issues Affecting American Families." *Mental Retardation* (in press).
- National Association of State Directors of Developmental Disability Services. "Senate Panel Holds Forum On Aging Caregivers of Persons With DD," *Perspectives* 4, no.10, October 1998.

### Contacts for More Information

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*Medicaid's home- and community-based services waiver provides federal money for states to fund community-based services.*

# Representative Tom Brice

## ALASKA STATE LEGISLATURE

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Juneau, AK 99801-1182  
907-465-3466

### Representative Tom Brice Sponsor Statement for Sponsor Substitute House Bill 72

The State of Alaska, following the national trend, eliminated institutionalized care for citizens with developmental disabilities (DD) in favor of community based care. When the state changed its approach for care it failed to appropriate adequate funds to provide community based services for the disabled community. To catalogue the needs for care that these folks have, the Department of Health and Social Services created a wait list. Needless to say, there are a number of concerns that families have about their inability to receive services. The duration on the state's (DD) waitlist can be up to seven years, but is dependent on the level of crisis the individual is facing, among other things.

Currently, there is between 840 and 1100 disabled Alaskans on the state's (DD) waitlist. In a survey titled "State Ranking for Services Needed by People on the Waiting List per 100,000 State Population -1997," Alaska was ranked as the 5th worse in the nation with 209.3 people needing services per 100,000. SSHB 72 establishes mechanisms to eliminate that problem.

SSHB 72 does three primary things. 1) It implements a concrete time line to eliminate Alaska's DD waitlist; 2) It removes funding barriers so the Department of Health, and Social Services Developmental Disabilities Division can administer the community based care program at an appropriate financial level and 3) It revises sections of our current statutes to reflect correct terminology used for persons with disabilities.

SPONSOR STATEMENT

**District 30**




# Representative Tom Brice

## ALASKA STATE LEGISLATURE

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Fairbanks, AK 99701  
907-456-7423 / Fax: 451-9293  
*While in Juneau*  
State Capitol  
Juneau, AK 99801-1182  
907-465-3466

To: Representative Fred Dyson Co-Chairman, Health, Education and Social  
Services Committee

From: Representative Tom Brice 

Date: February 24, 1999

Re: Sectional Analysis for SSHB 72 Persons with Disabilities

Sections 1,2,3 Revises language within AS 47.80. to replace "handicaps with  
"disabilities."

Section 4 Amends AS 47.80.100 (a) and (b) to replace "handicaps with "disabilities."

(c) Is a substantive change. Lines 4-5 on page 3 were deleted to allow various  
departments to attain full funding for services requested.

Section 5 Amends AS 47.80.110 (6) to replace "handicaps with "disabilities."

Section 6 Adds a new section 47.80.115 which provides a timeline for persons with  
disabilities who are deemed eligible to receive services.

Section 7 - 8 Revises language within AS 47.80. to replace "handicaps with "disabilities."

Section 9 Corrects the reference to the Federal Act and sets out the Act using the citation  
method commonly used in the Alaska Statutes.

Section 10 - 19 Revises language within AS 47.80. to replace "handicaps with  
"disabilities."

SECTIONAL ANALYSIS

District 30



**Waiting lists for DD and ILP services--Analysis by Legislative District**  
As of January 1998

House District	Senate District	Community reference points	ILP wait list	DD wait list
1	A	Ketchikan, Meyers Chuck, Ward Cove, Annette, Hyder	26	20
2	A	Sitka, Petersburg, Wrangell	0	18
3,4	B	Juneau, Douglas, Auke Bay, Hunter Bay	9	58
5	C	Haines, Angoon, Craig, Gustavus, Yakutat, Hoonah, Kake, Klawock, Skagway, Thorne Bay	0	18
6	C	Kodiak, Port Lions, Afognak	5	13
7	D	Homer, Anchor Point, Kasilof, Nikolaevsk	14	24
8	D	Seward, Soldotna, Cooper Landing, Sterling	12	34
9	E	Kenai, Nikiski, Salmonoff	15	14
10-23	E-L	Anchorage, Elmendorf AFB, Fort Richardson	22	260
24, 25	L, M	Eagle River	5	28
25, 26	M	Chugiak	1	10
26, 28	M,N	Wasilla, Big Lake	8	47
27	N	Palmer, Sunton	5	34
28	N	Willow, Houston, Talkeetna	2	5
29-31	O, P	Fairbanks, Emmonak, Eielson AFB	10	84
32-34	P, Q	North Pole, Healy, Two Rivers, Salcha	6	20
35	R	Valdez, Cordova, Delta Junction, Glennallen	8	19
36	R	Tok, Aniak, Fort Yukon, Copper Center, Crooked Creek, Galena, Kalskag, Lower Kalskag, Nikolai, Stevens Village, Koyukuk, Huslia, Grayling, Marshall, Nenana, Russian Mission, Pilot Station, Tuluksak, Shageluk, Sleemute, Northway, Chitina	18	28
37	S	Barrow, Kotzebue, Nuiqsut, Point Hope, Selawik, Wainwright	10	13
38	S	Alakanuk, Nome, St. Mary's, Chevak, Emmonak, Gambell, Hooper Bay, Scammon Bay, Kotlik, Tununak, Stebbins, Koyuk, Shaktoolik, Mekoryak, Unalakleet	92	28
39	T	Bethel, Aleknagik, Akiachak, Akiak, Dillingham, Togiak, Kwethluk, Kasigluk, Napakiak, Kipnuk, Kongiganak, Atmauthluk, Goodnewsbay, Tuntutuliak, Kwigillingok, New Stuyahok, Nunapitchuk, Quinhagak	59	52
40	T	Unalaska, St. Paul, Dutch Harbor, False Pass, Igiugik, Iliamna, Naknek, Adak, Sand Point	2	11
		<b>Total</b>	<b>329</b>	<b>838</b>



A STATUS REPORT TO THE NATION  
ON PEOPLE  
WITH MENTAL RETARDATION  
WAITING FOR COMMUNITY SERVICES

by

Sharon Davis Ph.D.  
Director, The Arc's  
Department of Research and Program Services

With assistance from

Alan Abeson, Ed.D., Executive Director  
June C. Lloyd, Intern

November 1997

## A Status Report to the Nation on People with Mental Retardation Waiting for Community Services

*"I don't want to wait until I'm unable to take care of her. I want to be at peace with myself to be able to see she made it on her own."*

*"I'm a widow age 74 and my son is 42 years old. I was in the hospital twice this summer. If I should die tomorrow, I want him to have a place to go."*

*(Quotes from Massachusetts parents in Griffiths, 1997)*

Many thousands of families in the United States provide care for sons and daughters with mental retardation. Many of them depend on community supports and services to assist them in meeting the needs of their family member. Tragically, however, in most states, when these families seek services and supports, they come face to face with lengthy and sometimes unending waiting lists.

In 1987, The Arc of the United States conducted the first ever study of waiting lists for community services (Davis, 1987). We found 63,634 individuals with mental retardation waiting for residential services and 76,039 waiting for day vocational services for a total of 139,673 services needed. Because some individuals were waiting for more than one service, the number of actual people waiting was somewhat fewer than the total number of services needed.

Ten years later, The Arc has again examined the status of waiting lists reported by states for community services across the country. We found 52,072 waiting for residential services; 64,962 waiting for day vocational services; 15,862 waiting for either or both for a total of 132,896 services needed. In addition, in 1997 we collected data on a variety of services not strictly residential or day vocational and found 65,290 people waiting. The total services needed by individuals in communities is 218,186 in 1997. Additionally, there are 5,376 people in state institutions waiting for community placement in 16 states that reported such data. This brings the grand total of services needed to 223,562 in the 48 states reporting waiting list information. Finally, if all 53,661 people living in state institutions are added to the waiting list, consistent with The Arc's position on "Where People Live," the waiting list for community services would grow to 271,847.

In summary, to describe the waiting list situation as a crisis for America is no exaggeration. This report makes clear that in the 10 years since The Arc first collected this information, the situation has only grown worse. Further, because of the data gathering mechanisms used by states, as described in this report, it must be acknowledged that the people waiting for 271,847 community services is probably not the true picture of need. The Arc believes it is even greater. Relieving waiting is a priority for The Arc and one which will continue to be addressed.

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## The Waiting List Problem

Since the early 1970s families have been encouraged to keep children with disabilities at home. Many of these children especially when young can benefit from early intervention and other services, and their families can be greatly helped by family support services, such as respite care, counseling, and cash subsidies which allow them to keep the child at home. This is where many families start to learn about waiting lists, as the service(s) they need or want may not be available to them.

As these children become adults, many still live with their families. Older families especially, who have kept an adult family member at home over the years, are greatly disturbed by the waiting list situation. Sometimes, parents in their 80s who are concerned about what will happen to their sons or daughters after they die, learn they must wait 10 or 12 years for services. Because of long waiting lists for existing residential services in particular, they have difficulty developing thoughtful future plans. They are under a tremendous amount of stress and worry. Some parents believe that the only way off the list for their adult child is for the parents to suffer serious illness or die. This was true for a New Jersey father whose child finally obtained a home in the community after he suffered a massive stroke.

This suffering is not limited only to families, but also to the thousands of individuals who are waiting and waiting! Many of them are young people leaving school only to encounter waiting lists for employment and other daytime services. They are often deprived of the opportunity to experience full life in the community. As these people age, their families cannot help them make the transition to a new living situation and ease the way to such change before the parents die. This means that when the crisis hits, the person with mental retardation loses a parent and moves out of the family home at the same time--a traumatic situation for all !

## How This Study Was Conducted

### Data Collection

State chapters of The Arc were contacted by mail and requested to assist in collecting information on waiting lists from the appropriate state agency or to provide a contact person who would have the waiting list information. Where additional information was needed or where there was no state chapter of The Arc, the state Developmental Disabilities Council or the state mental retardation/developmental disabilities agency was contacted. Written reports on the waiting list were obtained if available.

The following data were collected:

- Name of agency collecting and maintaining waiting list information
- Sources of waiting list data
- The frequency with which data is collected and date last collected
- Numbers of individuals waiting for each type of community service

- Whether or not numbers were an unduplicated count (meaning that no one was counted more than once)
- Numbers of individuals by age or by age of caregiver, where available
- Number of individuals residing in state institutions
- Number in state institutions on waiting list for community placement

The nature of the data varied considerably from state to state. Some states maintained detailed information on types of services requested; others did not. In general, the following descriptions explain the data in the tables:

- **Residential Services.** Requests for community-based residential placements, including group homes, supported apartments, supported living and any other community living arrangement.
- **Day/Vocational Programs.** Requests for placement in day activity centers, adult day care, work activity centers, sheltered workshops, supported employment programs, job placements and other day programs.
- **Support and Other Services.** Requests for family support services, respite care, personal assistance services, case management, early intervention services, transportation and other services not included in residential and day employment

No attempt was made to collect data on waiting lists for transportation services. In reality, however, a lack of transportation deprives many people with disabilities from taking advantage of services which do exist.

### Overview of State Data Collection Activities

Information regarding waiting lists was obtained from all states and the District of Columbia. Four states reported no waiting lists (California, Rhode Island, Nevada, Kansas). Three did not collect statewide data (Iowa, Ohio, West Virginia). Several others collected limited waiting list data (i.e. Medicaid waiver only in Idaho, family support only in Illinois). Several did not break out the list by type of service for which people were waiting.

### Cautions Regarding Interpreting State Data

The Arc urges caution in interpreting the numbers of services for which people are waiting in each state. While some states are quite confident that their data collection process is at least capturing those with the most needs, some are unsure. Others are concerned that their numbers may be inflated by people placing their names on more than one community program's waiting list. Further, the data from other states is sketchy. The Arc believes that no matter the effort, most states' numbers probably underestimate the true need. Many families are managing on their own and are out of touch with the service system. Their needs only become apparent when a crisis occurs. Finally, despite these cautions the fact is that waiting lists are a serious problem for the entire nation.

The numbers collected for this report represent numbers of people waiting for a particular service category. Some people are waiting for more than one service in all but 15 states. Therefore, the total waiting list represents number of individual services needed. The number of individuals waiting for services will be somewhat fewer. In a 1991 survey of people on waiting lists, it was estimated that 19.5 percent of the reported number of people waiting for services could be attributed to duplicate counting (Hayden, 1992).

The data in this report represent the most recent numbers collected by each state at the time of reporting to The Arc during the months of July through October. In most cases, the numbers represent people on the waiting list in 1997. A few states reported 1996 data.

Data are collected by states in a variety of ways, and as indicated few states believe that they accurately identify all of the people with service needs. Most states recognize that many families may not choose to put their family member's name on a waiting list, if they believe it is unlikely to result in a service. Wisconsin notes that the 2,215 people who are on waiting lists for a place to live represent a fraction of the 7,600-plus adults with developmental disabilities who are currently living with family members (and not receiving any paid residential supports). On the other hand, there may be individuals on the waiting list who would refuse services if offered, particularly residential, as they are not ready to move from the family home at the present time. A survey of waiting list families in Massachusetts revealed 33 percent estimated they would need residential services in 2-5 years and 18 percent "in the distant future." The family's recognition of future need plus the reality of being forced to wait led them to place their family member's name on the waiting list.

In some cases, individuals whose names are on a waiting list for a particular service, may already be receiving some service. However, they desire additional services or a different type of service. A person living in a group home could be on a waiting list for a supported apartment, for example. Or, someone who was receiving supported employment services, could be on a waiting list for counseling, if counseling services were scarce. While Pennsylvania has a waiting list of 28,000, it is believed only 2,000 are not receiving any services.

Finally, in most states, these numbers waiting for services also include people with other developmental disabilities and conditions related to mental retardation. However, in a study of people receiving state supported employment services, approximately 90 percent were identified as having mental retardation (McGaughey *et al.*, 1993). Based on this information, we estimate most people on waiting lists are people with mental retardation.

## The National Waiting List

The number of community services requested by families across the country in the 48 states providing data is 223,562. This includes 5,376 people living in state institutions who have been identified as waiting for community placement. While four states reported no waiting lists, other states with no data collected acknowledge they know people need services. They simply have not created the capacity to collect the data on a statewide basis. The states falling into this category are Iowa, Ohio and West Virginia. Illinois collects data on waiting lists for its family support program only. Wyoming reports no adults waiting for residential or day/vocational programs, but 12 children are reported as waiting for services.

Table 1 displays the numbers of services requested in each state. The total number of residential services requested is 52,072. The total number of day or vocational services requested is 64,962. A third category includes services needed which could be either or both residential or day/vocational. This includes data from five states where numbers were not broken out by type of service and totals 35,862 service requests. The number of support/other services requested is 65,290. The total service requests from people living in the community is 218,186. In 1991, the University of Minnesota collected waiting list data for residential, day, vocational, support and other services and found a total of 186,272 services requested (Hayden, 1992). Thus, the increase in total requests for services in six years is 31,914. Add the 5,376 people living in state institutions who are ready to leave, and the increase becomes 37,290. If the 53,661 people in state institutions are also added to the list, as The Arc believes they should be, the waiting list for community services grows to 271,847.

The numbers represent services needed and should not be considered the total number of individuals requesting services and supports. Only 15 states indicated that the numbers reported were unduplicated numbers of individuals waiting.

## State Rankings on 1997 Data

Table 2 illustrates the number of services for which people are waiting per 100,000 state population in 1997. It is based on each state's total numbers of services for which people are waiting, combining residential, day/vocational and support/other services. By examining the number of services people are waiting for as a function of a specific population figure, large and small states can be compared on an equal basis. The states with the most services needed are at the top of the list.

Louisiana heads the list with 320.3 services needed per 100,000 state population. It is followed by New York with 276 services for which people are waiting per 100,000 population; Pennsylvania with 232.1; Oregon with 226; Alaska with 209.3; and North Carolina with 171.4. Of these six, Pennsylvania's data is the most questionable. It is currently in the process of collecting more accurate data. However, Louisiana, New York, Oregon, Alaska and North

## APPENDIX

### People in State Institutions Waiting for Community Placement

State	Institutional Population	No. Waiting for Community Placement
Alabama	721	0
Alaska	8	8
Arizona *	114	N/A
Arkansas	1,243	N/A
California	4,000	N/A
Colorado *	219	N/A
Connecticut	1,106	N/A
Delaware	278	150
D.C.	0	
Florida	1,585	N/A
Georgia	1,994	N/A
Hawaii	29	29
Idaho *	123	N/A
Illinois	3,496	N/A
Indiana	1,261	N/A
Iowa *	687	N/A
Kansas *	693	N/A
Kentucky *	644	N/A
Louisiana	2,000	206
Maine	0	0
Maryland	740	0
Massachusetts	1,550	770
Michigan	316	N/A
Minnesota	268	72
Mississippi	1,424	130
Missouri	1,494	N/A
Montana	142	79
Nebraska	395	N/A
Nevada	181	N/A
N. Hampshire	0	
New Jersey	4,055	1,600
New Mexico		
New York *	3,768	N/A
N. Carolina	2,400	96
N. Dakota *	147	N/A
Ohio *	2,087	N/A
Oklahoma	455	0
Oregon	378	307
Pennsylvania *	3,272	N/A
Rhode Island	0	
S. Carolina	1,388	N/A
S. Dakota	229	62
Tennessee	1,438	800
Texas	2,400	N/A
Utah	289	N/A
Vermont	0	
Virginia	1,966	1,000
Washington	1,307	N/A
West Virginia	52	52
Wisconsin	1,179	N/A
Wyoming *	139	15
<b>TOTAL</b>	<b>53,661</b>	<b>5,376</b>
* Data from Prouty & Lakin, 1997		
** N/A = Not available		

TABLE 2

State Ranking for Services Needed by People on the Waiting List per  
100,000 State Population - 1997

<u>Rank</u>	<u>State</u>	<u>Services needed per 100,000</u>
1	Louisiana	320.3
2	New York	276.0
3	Pennsylvania	232.1
4	Oregon	226.0
5	Alaska	209.3
6	North Carolina	171.4
7	Alabama	154.6
8	Utah	152.1
9	Wisconsin	149.5
10	Maryland	147.3
11	Maine	141.7
12	Washington	127.9
13	Nebraska	123.9
14	Hawaii	117.6
15	New Mexico	103.8
16	Montana	98.5
17	Arkansas	77.8
18	Virginia	72.6
19	New Jersey	68.6
20	Tennessee	66.8
21	Connecticut	64.4
22	South Carolina	61.7
23	Oklahoma	61.4
24	Delaware	58.6
25	Texas	57.5
26	Massachusetts	52.1
27	Minnesota	50.8
28	Kentucky	45.6
29	Florida	44.3
30	Vermont	42.2
31	Georgia	41.0
32	Indiana	35.2
33	Missouri	33.0
34	Illinois	31.2
35	Colorado	30.7
36	Michigan	30.6
37	Mississippi	28.5
38	North Dakota	21.2
39	New Hampshire	16.5
40	Idaho	16.0
41	Arizona	14.7
42	DC	10.8
43	South Dakota	3.7
44	Wyoming	2.5
45	California (no waiting list)	
46	Kansas (no waiting list)	
47	Nevada (no waiting list)	
48	Rhode Island (no waiting list)	
	Iowa (data not collected)	
	Ohio (data not collected)	
	W. Virginia (data not collected)	

Carolina have data collection systems in place which provide them with data which they consider relatively accurate. It can easily be that as a function of doing the best job in collecting waiting list numbers, these states appear to be doing less to serve people on the waiting list.

At the bottom of the list are those states reporting no waiting lists: California, Kansas, Nevada and Rhode Island (listed in alphabetical order).

The states reporting the fewest services needed per 100,000 state population are Wyoming (2.5); South Dakota (3.7); District of Columbia (10.8); Arizona (14.7); Idaho (16.0) and New Hampshire (16.5). In Arizona, the numbers for people waiting for day/vocational services were not available in time to include them. Idaho only maintained a waiting list for people waiting for Medicaid Home and Community Based waiver services. The other states are small and rural. We've noted in past reports on community services that they often seem to be able to identify people and provide services to those who need them more easily than larger states.

Each state needs to weigh the value of the information in Table 2 based on what is known within the state about the waiting list and the state's effort to alleviate the waiting for families and individuals. The data should be used cautiously unless the state has confidence in its own data. Comparisons with other states is not recommended because of the variations in the way data is collected by individual states and the concern it may not accurately represent the state.

## Discussion

The effort a state puts into gathering and maintaining waiting list information is a dramatic indicator of the importance and value a state places on supporting persons with mental retardation. In those states where data is maintained, legislators, governors, policy makers, service providers - and even the general public - are more aware of the phenomenon of service waiting lists and how they affect the status and welfare of consumers of services and supports for people with mental retardation as well as their families.

States choose not to maintain waiting lists for several reasons. If an entitlement to services exists in a state, the existence of a waiting list can be cause for litigation. Such litigation was successful in California some years ago. A few states do not collect data out of concern that the visibility of a waiting list will bring too much attention to a problem they already know exists. Other states worry that if families know about the waiting list and the effort to provide services to those on the list, more families will make themselves known to the service system. (New Jersey has found its waiting list growing as more and more families have become familiar with that state's success in obtaining funds for individuals on the waiting list.) A few other states simply have not created the capacity to collect and report aggregate data on waiting lists from local programs across the state. However, The Arc notes that a number of states have created that capacity since 1987 when waiting list data was first collected, including Texas and Connecticut. Other states have upgraded their systems for data collection (i.e. North Carolina).

Waiting lists are a critical public policy issue in almost every state. However, to date, advocates in many states have failed to communicate successfully the immediacy of family and consumer needs to legislators and others. A large number of families and individuals with disabilities on the waiting list need services now, not some time in the future. A survey of families on the waiting list for residential services in Massachusetts found 40 percent needing services immediately or within a year. The caregivers were in poorer health; their sons and daughters had significantly more behavior problems, and fewer had estate plans or designated guardians in their wills than the 60 percent who needed services later. It is possible that some of the families who did not indicate an immediate need may end up requiring services sooner than they anticipate. What is clear is that all will eventually need residential services for their family members (Griffiths, 1997). Many states have a high percentage of people on the waiting list classified as in a crisis or high need situation. In Utah, one such family has been on the waiting list for 18 years and classified as "critically in need of services" for 10 years. Once again, the only sure way for an individual to receive services in many states is for the caretaker to die.

Another issue that goes largely unrecognized is the number of families unknown to the service system. Pennsylvania recently reviewed applications for nursing home placement by aging people with mental retardation and found the majority had never before made contact with the mental retardation service system. These people were never on waiting lists. This is a problem that will likely grow, as families recognize the uselessness in many instances of trying to obtain services. There are also some families who choose not to seek services for their family member with mental retardation while they are living and can provide care. They may suddenly become known to the system only when a crisis occurs.

A major concern of families is how the state deals with individuals moving out of state institutions when many families have been waiting years or are in critical need of services. The population in large state institutions is declining at a rate of about six percent annually. They point out that they have saved the state a considerable amount of money, and now they are waiting for community services and frequently will only be served after people waiting to leave institutions.

### **Detrimental Effects on Individuals and Families**

The unavailability of community services and supports can have detrimental effects on individuals and their families. The following examples are outlined in The Arc's position statement on "Availability of Community Services and Supports."

- Infants who cannot access early intervention services may have greater developmental delays. Early intervention must begin by the time children with disabilities are 2-3 years of age to capitalize on the developing brain's capacity to be sculpted (Thompson, 1997).

- The lack of supports for individuals and families results in emotional and financial hardships. One mother caring for her five-foot-seven-inches tall daughter with severe disabilities reported having back surgery from the heavy lifting. She still continues to care for and diaper her daughter who is 26 years old (Seymour, 1996).
- Inadequate services upon exiting school results in loss of learned abilities, productivity, self-esteem, and the ability to live a more normal lifestyle and, in addition, increases stress on the individual and family. If a community program is not available for the exiting student, when both parents are wage earners, one may have to quit working to stay home to care for the family member.
- Insufficient community housing often results in placing families in a perpetual caregiver situation and keeps the individual in a dependent situation. This is especially critical to elderly families who are literally afraid to die. Several states maintain data on the ages of family caregivers of people on the waiting list. In Maryland, for example, 40 percent of family caregivers are over age 60 and 13 percent over 80.
- The lack of access to transportation results in an inability to access employment and routine community life, thus resulting in social isolation and lost opportunities. In Illinois, the Home-Based Support Services Program has 1700 adults on its waiting list. These support funds could be used to purchase transportation services, but those on the waiting list needing these services remain isolated.

### Action Is Needed to Solve the Waiting List Problem

*Government at all levels must devote more financial resources to eliminating the waiting lists and other barriers to community services and supports. In addition to increased funding, creative usage of existing resources, including generic services, must also be explored to its fullest. Individuals with mental retardation and their families should drive the design of services and supports to assure consumer empowerment, choice and inclusion (The Arc, 1993.)*

The Arc believes eliminating the waiting list to be very difficult, but not an insolvable problem. Solutions lie in society's recognition of the severity of the situation for many families. More effort is urgently needed for solutions to meet families' needs. Described below are some of the efforts already undertaken to find solutions.

We recognize that many states are very concerned about how to offer more services when budgets are strained and competition for existing funds is intense. Some states have increased funding for family support programs, recognizing that for many families, a little support will help them care for their family member at home a little longer. In a number of states, these supports can be used for adults as well as children.

Many states use the Medicaid Home and Community-Based Waiver, which allows Medicaid to pay for community options for people who are in an institution or at risk of going to one. The waiver can be used to move people out of institutions. It can also be used to provide community residential services to people on the waiting list, particularly those with urgent needs. Waiver services typically cost considerably less than institutional services, allowing a state to serve more individuals.

Several states have closed institutions or are in the process of closing institutions which enables them to serve more people on the waiting list. State leaders point out that institutional services are extremely costly. By closing institutions, many more people can be served. Oregon just announced the closing of the Fairview Developmental Center by the year 2000. The state estimates \$1.4 million in savings in 1998, \$6.6 million in 1999 and \$14 million thereafter can be used to serve people from the waiting list. Currently the cost of care at Fairview is about \$212,000 per resident, per year and consumes 30 percent of the state agency's program budget, while Fairview serves only 3 percent of the population with mental retardation receiving services. In Wisconsin, 50 percent of the state's funds support 4 percent of the people in institutions.

Several chapters of The Arc and other advocacy organizations have been actively involved in seeking solutions to the waiting list problem. Some solutions result in increased funds devoted to serving the waiting list. The Arc of New Jersey launched a media campaign to help the public and legislators understand the needs of families on the waiting list titled "A Key of Our Own." As a result, the voters passed a bond issue to finance the construction of community residences. The Arc then advocated for the legislature to allocate operational funds and was successful.

The Arc of New Hampshire reports success in obtaining passage by the state legislature of two bills related to waiting lists in 1997. One urged "the preservation and continued development of community services to people with developmental disabilities and their families" and the other called for "full funding for services for persons with developmental disabilities."

In Nevada, advocates, including members of The Arc, succeeded in convincing legislators to fully fund the residential and day services waiting list in 1997 with funds for two years of growth in day services. An increase in family support funds was allocated to help any families entering the residential waiting list in the next two years.

Arc Massachusetts was instrumental in bringing together a coalition of three statewide family-based groups to create solutions to the waiting list for residential and day services. The collaboration, referred to as Family to Family, unites families in a statewide information network devoted to the waiting list. They are connected with other families in similar circumstances to share experiences and work together on common concerns. Families have been surveyed regarding their needs, assisted in voicing their needs to the state legislature and guided in pursuing creative service options in partnership with other families, private organizations or government agencies. Their efforts did not go unnoticed. The legislature increased funds for

students leaving school, family support, direct support staff, and for the first time, included a separate line item in the budget for the waiting list.

The Arc of Maryland recently launched a campaign to reduce the waiting list in Maryland based largely on The Arc of New Jersey's experience. The "Key Campaign: Unlock the Waiting List" kicked off with a conference where families on the waiting list learned about successful strategies used by The Arc of New Jersey and Arc Massachusetts. The conference was designed to empower families to take specific action - media, town meetings, legislator contacts - in the effort to meaningfully address services to people on the waiting list.

The Arc of Utah has been engaged in a three-year campaign to educate legislators about the personal stories of people on the waiting list. Many people have been willing to have their stories made public. The Arc of Utah contends that maintaining the waiting list implies that there will be services available, but some people classified as having "critical needs" have been waiting 10 years. This year The Arc is sending legislators a monthly update on the waiting list with personal stories and current waiting list statistics.

Finally, The Arc believes the voices of families are key to solving the waiting list crisis. Families within The Arc are speaking out on their concerns. Their voices, heard by legislators across the country, will help make a difference. The following quotes from family interviews in Massachusetts express the sentiments of families across the country (Griffiths, 1997):

*"It does not seem right that family members who were put in institutions at an early age are the first ones to get residential services at 22. Parents who kept their child at home have been abandoned by the system. Something is wrong with this."*

*"I am so discouraged by the 'waiting list.' It seems that I don't know who to speak to or what to say to improve the chances of getting services. I would mostly hope that I could find a safe, family-like situation for my [daughter]. At best, she could continue to thrive in her life without me always there."*

*"...he is very anxious that he is still at home--he sees that move as a goal which indicates being an ADULT and more control over his life. He is so frustrated to still be home with parents."*

*"We want to be involved in his transition to a new home and a new life."*

*"He can't wait much longer. I don't want to drop dead in front of him."*

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TONY KNOWLES, GOVERNOR  
State of Alaska

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

P.O. Box 240249 • Anchorage, Alaska 99524-0249 • Phone: 907-269-8990 • Fax: 907-269-8995

February 25, 1999

FEB 26 1999

Representative Fred Dyson  
State Capitol Building, Room 104  
Juneau, Alaska 99801

Dear Representative Dyson:

On behalf of people with developmental disabilities, we would like to request that HB72 be scheduled for public hearing in the HESS committee. As you may be aware, the Key Campaign will be visiting Juneau next week, March 1<sup>st</sup> through 5<sup>th</sup>. Your presence at the annual dinner was certainly an honor last year, and we are hoping you are available to attend once again this year.

HB72 addresses the statutory usage of the term "handicap", replacing it with the term, "disabled"; and emphasizes the ongoing need for long term financial planning surrounding the issue of waitlist reduction. Despite Medicaid refinancing and modest budget increases by the legislature, the waitlist for Community Development Disability Services continues to grow. The most recent total of people waiting for services is 973, which reflects an increase of 135 individuals just in the last year.

Reasons for the uncontrolled growth of the waitlist include:

- 1) Rising Population
- 2) Families with young adults who have graduated from special education are signing up for vocational supports to find and keep jobs
- 3) Parents of adult family members with developmental disabilities seek respite and other in-home supports to keep their children at home as long as possible
- 4) A growing trend of elderly parents who anticipate being no longer able to provide for their middle-aged children are requesting out of home placements

House Bill 72 allows constituents to discuss the need to eliminate time people spend waiting for these crucial services. By scheduling this bill during the Key Campaign, individuals could have physical access in providing testimony. This is a rare opportunity for these people, who are often restricted in their ability to be heard in the policy making process.

The Governor's Council on Disabilities and Special Education would like to thank you again for your continued support. I look forward to seeing you next week during the Key Campaign.

Sincerely,

A handwritten signature in cursive script, appearing to read "D. Maltman".

David Maltman  
Executive Director



TONY KNOWLES, GOVERNOR  
State of Alaska

**GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION**

P.O. Box 240249 • Anchorage, Alaska 99524-0249 • Phone: 907-269-8990 • Fax: 907-269-8995

February 24, 1999

Representative Tom Brice  
State Capitol Building, Room 426  
Juneau, Alaska 99801

Dear Representative Brice:

On behalf of people with developmental disabilities, we would like to thank you for introducing HB72. This legislation addresses the statutory usage of the term "handicap", replacing it with the term, "disabled"; and emphasizes the ongoing need for long term financial planning surrounding the issue of waitlist reduction.

Despite Medicaid refinancing and modest budget increases by the legislature, the waitlist for Community Development Disability Services continues to grow. The most recent total of individuals waiting for services is 973, which reflects an increase of 135 individuals needing services just in the last 12 months. Reasons for the uncontrolled growth of the waitlist include:

- 1) Rising population
- 2) Families with young adults who have graduated from special education are signing up for vocational supports to find and keep jobs
- 3) Parents of adult family members with developmental disabilities seek respite and other in-home supports to keep their children at home as long as possible
- 4) A growing trend of elderly parents who anticipate being no longer able to provide for their middle-aged children are requesting out of home placements

HB72 addresses the following issues related to people with developmental disabilities:

- Replaces outdated language referring to "handicap" persons with the term "disabled."
- Emphasizes the ongoing need for the state to develop a long-term financial plan for eliminating the time individuals spend waiting on this list.
- Provides a mechanism for people to get services after they are determined eligible.

On behalf of Alaskan's who experience a developmental disability, the Governor's Council on Disabilities and Special Education supports House Bill 72. Thank you again for supporting a measure that addresses the need to eliminate time people spend waiting for these crucial services.

Sincerely,

A handwritten signature in cursive script, appearing to read "David Maltman".

David Maltman  
Executive Director



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#### Programs & Services

Children & Families

Alaska Youth Initiative

Family Services

Student Living Center for  
the Deaf/Hard-of-Hearing

Summer Enrichment Program

Adults

Arctic Resource Center

Community Enrichment  
Quality of Life  
ICE/QLI Program

Community Living Services

Community Support Network

Supported Employment

Supported Parenting

Substance Abuse Treatment

General

Care Coordination

Family Support Project

Information and Referral

Personal Care  
Attendant Services

Pick-Up Service and  
Donation Center

Public Education

Advocacy

February 24, 1999

Representative Tom Brice  
Alaska State Legislature  
State Capitol  
Juneau, Alaska 99801-1182

Dear Representative Brice,

I am writing this letter of support for House Bill 72. I feel very strongly that this bill is the key to the future of services for persons who experience developmental disabilities.

The waitlist for services continues to grow, despite all the efforts and creativity on the part of the Division of Mental Health and Developmental Disabilities, the Governor's Council on Disabilities and Special Education, provider agencies, and the many families and individuals who experience disabilities to reduce the cost of service, provide natural supports in the least restrictive environments, and address the many needs across the state. In part, the continued growth is due to expansion of the federal definition of developmental disabilities several years ago, the increase in survival rates of infants born with disabilities, and age-related trends.

House Bill 72 will help to construct a long-term plan for reducing the time an individual is on the waitlist and provide a mechanism for people to get services once they are determined eligible. It also will replace outdated language referring to a "handicap" with the more popular term "disability."

The Arc of Anchorage strongly supports House Bill 72 and urges the legislature to support its passage.

Sincerely yours,

Mary Jane Michael, M.R.C.  
Executive Director

Sharing the Vision of Community

# FRA/FRA

Paul Robinson, President  
Dora Kempers, Vice-President  
Joanne Trelethen, Treasurer  
Barbara Blackshear, Secretary  
Emily P. Ennis, Executive Director

## FAIRBANKS RESOURCE AGENCY

805 AIRPORT ROAD, SUITE 1 • FAIRBANKS, ALASKA 99701 • (907) 456-8901 • FAX 452-5171

February 25, 1999

FAX: 907 / 465-2937

Representative Tom Brice  
State of Alaska  
State Capitol  
Juneau Alaska 99801

Dear Tom:

It is with pleasure that Fairbanks Resource Agency provides a letter of support for House Bill 72, which includes provision of services for persons with disabilities in a timely manner, and would hopefully eliminate the Division of Mental Health and Developmental DD Wait List. Currently over 1,000 Alaskan children and adults are waiting for critical services including respite care, employment and residential supports. While they wait, families often experience serious crisis, and individual potential for a productive life diminishes.

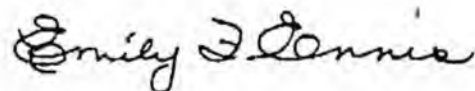
Often families who seek respite care wait until a crisis occurs putting the child with a disability at risk of institutionalization or out of home care. For adults waiting for employment services, the need is also critical. Young adults, who have left school, not only often lose the skills learned but also sit at home day after day with no goals for the future. Residential services offer the next major life step for young adults who experience disabilities. Without supports services, families are reluctant to seek an apartment or other independent living arrangement for their young adult with disabilities. Again, skills learned at school and at home are often lost during the long wait for services.

Representative Tom Brice  
State Capitol  
Juneau Alaska 99801  
February 25, 1999  
Page 2

Through HB72, the provision of needed services in accordance with a prescribed timeline will allow adults and children with disabilities and their family members to plan and maintain life goals and eliminate costly response to crises -- costly in terms of the medical and institutional support that is often required in times of crisis -- and costly in terms of human suffering. Within the four year period as provided by HB72, many families and adults waiting for services will be receiving needed supports and will no longer be at risk of inappropriate placement in institutional settings or out of home placements.

Fairbanks Resource Agency wholeheartedly supports HB72, which addresses the imperative needs of Alaskans with disabilities and their families. We also urge the legislature to seriously consider budget strategies to meet future funding requirements for the services that will continue to be needed by Alaskans with disabilities.

Sincerely,



Emily F Ennis  
Executive Director

EFE/njm