

# **Policies and Resources Related to Waiting Lists of Persons with Mental Retardation and Related Developmental Disabilities**

by

Research and Training Center on Community Living  
Institute on Community Integration (UAP)  
College of Education and Human Development  
University of Minnesota  
214 Pattee Hall, 150 Pillsbury Dr. SE  
Minneapolis, MN 55455

Contributions by: Lynda Anderson, Mary Hayden, Shannon Kim, Charlie Lakin,  
Barbara Polister, Bob Prouty and the many survey respondents

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## **Introduction**

In summer and fall of 1998, in response to rising concern about the growing numbers of persons with mental retardation and related developmental disabilities waiting long periods for services, the Research and Training Center on Community Living conducted a national survey of state directors of developmental disabilities services.

The survey sought to explore four areas:

- 1) type and content of statewide waiting lists;
- 2) state laws and regulations addressing waiting lists;
- 3) policies and initiatives to reduce or eliminate waiting lists; and
- 4) assistance and access to interim services for persons on waiting lists.

In addition, agencies were asked to identify documents relevant to these four areas.

Following completion of the survey and additional collection of documents, a summary with tables was prepared and mailed to all state directors for comments, corrections and additions. All (51) state developmental disabilities agencies responded.

In May 1999, a draft report was distributed to participants at the mid-year national conference of the National Association of State Directors of Developmental Disabilities Services, with a request that any additions, changes and comments be provided to the survey office. Mailings with the same request were made to all state directors not in attendance shortly following the conference. Responses to these requests were incorporated in the FY 1998 final report.

This report is an updated report using information gathered from the states for FY 1999. All state DD directors were sent a copy of the FY 1998 report and asked to report any changes in the past year. As many as three follow-up calls were made to non-responding states. Forty-two states and the District of Columbia responded to the inquiry for updated information.

## **A Summary of Findings from a Survey of States on Waiting Lists of Persons with MR/DD**

All state directors of developmental disabilities services responded to the survey for FY 1998 information, and 43 responded for FY 1999. One state reported that it turned away no eligible person requiring services; another state reported that it was required by law to provide services to all eligible persons and therefore was prohibited from maintaining waiting lists; a third state listed services all persons may receive and indicated additional services were provided as needed.

### *Types of Statewide Waiting Lists*

Table 1 presents responses about statewide waiting lists of persons with MR/DD waiting for services. Of the 43 states having statewide waiting lists, 20 states have a single, inclusive list, 21 states have more than one list by types of service, 7 states have more than one list by other categories, 3 states have both an inclusive list and multiple lists by service types, and 1 state has multiple lists by service types and by other categories.

### *Service Needs Identified in Statewide Lists*

Table 2 presents responses about service needs identified in statewide waiting lists. Thirty-four states reported service needs identified in their statewide waiting lists, including "residential services not in the family home"(34 states), "vocational and other day training"(33), "support services in the family home"(29), "case management"(22), "homemaker/personal care assistant"(18), "modifications to home/vehicle, and other adaptive devices"(13), "respite"(18), "therapies"(11), "transportation"(9), and "other service needs"(13).

### *State Laws/Policies Regarding Waiting Lists*

Table 3 presents responses about state laws and policies regarding lists of persons with MR/DD waiting for services. Twenty-four states are required to periodically report the number of persons with MR/DD waiting for services and another two are in the process of developing policies requiring regular reporting of people with MR/DD, three states limit the length of time a person with MR/DD may be required to wait for services, and 13 states require that persons with MR/DD waiting for service receive certain specified services while waiting. One state is in the process of developing such a policy.

### *Factors Used to Determine Order of Access to Services*

Table 4 presents responses about the relative importance of factors used to determine order of access to services among persons with MR/DD on waiting lists. Forty-three states responded, rating up to eight factors as "very important", "important" and "only somewhat important" in determining persons' order of access to services.

By assigning numeric values of 3, 2, and 1, respectively, to the three ratings it is possible to obtain a sense of the relative importance overall of the eight factors. This rating produces the following (number in

parenthesis = number of states rating factor, "very important"):

<u>Factor</u>	<u>Rating of Importance</u>
Family crisis/emergency	125 (39)
Length of time waiting	73 (11)
Severity of disability	64 (10)
Potential service benefits	45 (3)
Strength of advocacy, family influence, etc.	41 (1)
Cost of needed services	30 (0)
Age of consumer	36 (2)
Other:	
Age of parent, caregiver	19 (5)

*Policies and Initiatives to Reduce or Eliminate Waiting Lists*

Table 5 presents responses about policies and initiatives to reduce or eliminate waiting lists of persons with MR/DD and recent reports about waiting lists. Forty states reported having state agency policies or initiatives to reduce or eliminate waiting lists, 31 states reported other public or private initiatives and 25 states reported recent published reports about state residents with MR/DD on waiting lists for services. Two states are in the process of developing reports on the status of their waiting lists. Three states reported neither current state policies or initiatives to reduce or eliminate waiting lists nor recent reports about waiting lists in their state.

*States Providing Assistance to Persons Waiting for Services*

Table 6 presents responses about states providing assistance to persons with MR/DD while on a waiting list for services. Thirty-nine states reported that they provided assistance to persons on waiting lists. Of these, the majority reported case management or a similar planning activity to be the assistance provided.

Table 1: State Agency Lists of Persons with MR/DD Waiting for Services				
State	One single, inclusive list	More than one list, by service	More than one list, by other categories	No statewide list
AL		X		
AK	X			
AZ	X			
AR		X		
CA				X
CO	X	X		
CT		X		
DE			X	
DC		X		
FL		X		
GA	X			
HI		X		
ID		X		
IL				X
IN			X <sup>1</sup>	
IA				X
KS	X			
KY			X <sup>2</sup>	
LA	X			
ME		X		
MD	X			
MA			X <sup>3</sup>	
MI	X			
MN		X		
MS		X		
MO			X	
MT	X			
NE	X			
NV		X		
NH	X			
NJ		X	X <sup>4</sup>	
NM	X			
NY		X		
NC	X			
ND				X
OH				X <sup>5</sup>
OK	X			
OR		X		
PA	X <sup>6</sup>			
RI				X
SC		X		
SD		X		
TN	X <sup>7</sup>			
TX		X		
UT	X	X	X <sup>8</sup>	
VT	X			
VA				X
WA	X	X		
WV	X			
WI		X		
WY	X			

Footnotes:

<sup>1</sup> Day services; residential services

<sup>2</sup> ICFs/MR, by facilities; Supports for Community Living (SCL) Waiver; state wide waiting list; SCL emergency list

<sup>3</sup> Priority lists of persons needing day, residential or both services as follows:

- a) Consumer turning 22 years
- b) Primary caregiver 60+ years
- c) Consumer is elderly

<sup>4</sup> Urgent residential; nonurgent-residential; eligible-placement not requested at this time

<sup>5</sup> Waiting lists are maintained and managed by the 88 county boards of MR/DD

<sup>6</sup> Waiting lists are maintained and managed by the 45 county MH/MR programs

<sup>7</sup> Priority lists of persons based on a critical needs assessment score

<sup>8</sup> Waiting lists are maintained and managed on a regional level

Table 2: Needs Identified in Statewide Lists of Persons with MR/DD Waiting for Services

State	Support Services in Family Home	Residential Services not in Family Home	Vocational and Other Day Training	Respite	Case Management	Homemaker/ Personal Care Assistant	Therapies	Modification to Home/Vehicle, Other Adaptive Devices	Transportation	Other Services(see footnotes)
AL	X	X	X	X	X	X	X	X	X	
AK	X	X	X		X	X				X <sup>1</sup>
AZ	X	X	X	X		X	X		X	X <sup>2</sup>
AR	No comprehensive list									
CA	No waiting lists									
CO	X	X	X							X <sup>3</sup>
CT		X	X							
DE	X	X	X	X	X	X		X		
DC	No response									
FL	X	X	X	X	X	X	X	X	X	X <sup>4</sup>
GA	X	X	X	X						
HI	X	X	X	X		X		X		
ID	No response									
IL	No comprehensive list									
IN	No comprehensive list									
IA	No comprehensive list									
KS	X	X	X		X					
KY	No comprehensive list									
LA	No comprehensive list									
ME	X	X	X		X	X		X		
MD		X	X							X <sup>5</sup>
MA	X	X	X							
MI	X	X	X	X	X	X				X <sup>6</sup>
MN	X	X		X		X		X		X
MS	X	X	X	X	X	X	X		X	
MO	X	X	X	X	X	X	X	X	X	X <sup>10</sup>
MT	X	X	X	X	X <sup>7</sup>	X <sup>8</sup>	X <sup>8</sup>	X	X	
NE	X	X	X	X	X					
NV		X	X		X					
NH	X	X	X		X					
NI		X	X							
NM		X	X	X	X					
NY	X	X	X		X	X		X		
NC	X	X	X	X	X	X	X	X	X	
ND	No waiting lists									
OH	No comprehensive list <sup>9</sup>									
OK	Service needs not identified									
OR	X	X	X							
PA	X	X	X	X	X	X	X	X	X	X
RI	No waiting lists									
SC	No comprehensive list									
SD	No comprehensive list									
TN	X	X	X			X				
TX	X	X	X	X	X		X			
UT	X	X	X	X	X	X				
VT	X <sup>10</sup>	X	X	X	X		X		X	X <sup>11</sup>
VA	X	X	X		X	X		X		X
WA	X	X	X				X			X
WV	Service needs not identified									
WI	X	X	X		X			X		X
WY	Service needs not identified									

<sup>1</sup>Sexual offender treatment

<sup>2</sup>Attendant care, aid to families, consultation, habilitation, parent aide services, pharmacological management, behavioral health

<sup>3</sup>Early intervention, family supports, children's extensive supports

<sup>4</sup>Behavioral analysis, infant stimulation, parent training, employment support, community integration support

<sup>5</sup>General category, "support services"

<sup>6</sup>Clinic services, semi-independent residential services, employment support, community integration support

<sup>7</sup>All persons over age 16 receive case management as desired/needed. Persons under age 16 receive case management as a support service in the home.

<sup>8</sup>Title XIX state plan entitlement

<sup>9</sup>Waiting lists maintained by 88 county boards of MR/DD are broken down by service needs such as residential, vocational and day supports.

<sup>10</sup>Includes flexible family funding to provide services chosen by the family

<sup>11</sup>Community supports, crisis supports

**Table 3: State Laws/Policies Regarding Waiting Lists**

State	Periodic reporting of number waiting	Limiting time persons may be required to wait	Requiring services to persons while they wait
AL	No	No	No
AK	No	No	No
AZ	Yes	No	Yes
AR	No	No	No
CA <sup>1</sup>	NA	NA	NA
CO	Yes	No	Yes
CT	No	No	No
DE	No	No	No
DC	No	No	Yes
FL	No	No	No
GA	Yes	No	Yes
HI	Yes	No	No
ID	No	No	No
IL	No	No	No
IN	No	No	No
IA	No	No	No
KS	Yes	Yes	Yes
KY	No	No	No
LA	Yes	No	No
ME	No	No	No
MD	Yes	No	No
MA	Yes	No	No
MI	Yes	No	No
MN	Yes	No	Yes
MS	Yes	No	No; in progress
MO	No	No	Yes <sup>2</sup>
MT	No	No	Yes
NE	Yes	No	Yes
NV	No	No	No
NH	Yes	No	No
NJ	Yes	No	Yes
NM	Yes	No	No
NY	Yes	No	No
NC	Yes	Yes	Yes
ND	No	No	No
OH <sup>3</sup>	Yes	No	No
OK	No	No	No
OR	No	No	No
PA	Yes	No	No
RI	No	No	No
SC	Yes	No	Yes
SD	Yes	No	No
TN	No; in progress	No	No
TX	Yes	No	No
UT	No	No	No
VT	Yes	No	No
VA <sup>4</sup>	No; in progress	No	No
WA	Yes	No	No
WV <sup>5</sup>	No; informal reporting	Yes	Yes
WI	No	No	No
WY	No	No	No

<sup>1</sup> Entitlement state; no waiting lists<sup>2</sup> Case management only<sup>3</sup> Statute requires a biannual assessment of needs of persons on county board waiting lists; department of MR/DD requires quarterly reports on the numbers of individuals waiting for residential services.<sup>4</sup> No statewide waiting list; use aggregated data from county service boards.<sup>5</sup> Registry in development

**Table 4: Factors Determining Order of Access to Services and Supports by Persons with MR/DD on Waiting Lists**

V = very important I = important S = only somewhat important

State	Severity of Disability	Length of Time Waiting	Crisis/ Emergency in Family	Cost of Needed Services	Age of Consumer	Strength of Advocacy, Family Influence, etc.	Potential Benefits of Services	Other (see footnotes)
AL	S	S	V	S	S	I	I	
AK	I	S	I			S		
AZ		I	V	S	I	S		V <sup>9</sup>
AR	V	S	V	I	S	I	I	
CA	No waiting lists							
CO		V	V					I <sup>6</sup>
CT			V	S	S	S	S	I <sup>1</sup>
DE	I		V		S	I	I	I <sup>1</sup> V <sup>7</sup> V <sup>8</sup>
DC	I	I	V	S	I	S	V	
EL	No statewide waiting list: list in development							
GA	S	I	V	S	S	S	I	
HI	V	V	V			S	I	
ID	No response							
IL	V	S	V	I	S	S	I	
IN	I	S	V	I	S	S	I	
IA	No statewide waiting list							
KS	S	I	I	S				
KY		V	V					
LA		V	I	S	S	S	I	
ME	I	V	V			I		
MD		I	V					V <sup>1</sup>
MA	I	I	V	I	S	I	I	V <sup>2</sup>
MI	V	I	V			S	S	
MN			V		V			V <sup>1</sup>
MO	V	S	V		I	S	I	3, 4
MS	V	I	V					
MT	V	V	V	S	S <sup>3</sup>	V	I	
NE	I	I	V		I	I	I	
NV	I	S	V	I	S	I	V	
NH	I	I	V	I	S	S		
NJ		V	V					V <sup>1</sup>
NM		V	V					
NY	V	I	V		S			
NC	I	V	V	I	V	S	S	V <sup>1</sup>
ND	No waiting lists							
OH		I	V					
OK		V	V					
OR	S	S	V	S	S	S	S	
PA	I	I	V	S	S	S	I	V <sup>1</sup>
RI	No waiting lists							
SC	I	S	V	S	S	S	I	
SD			V			I		
TN		I	V					
TX	S	V	V	S	S	S	S	
UT	I		V	S				
VT	S	S	V	S	S	I	V	V <sup>5</sup>
VA	No statewide waiting list: list in development							
WA	I	S	V	I	I	S	S	
WV	V	S	V	S	S	I	I	
WI	Decisions made at the county level							
WY	V		I		S			



Footnotes:

<sup>1</sup> Age of caregiver/parents

<sup>2</sup> Determined by counties

<sup>3</sup> Under 3 years, entitlement applies

<sup>4</sup> At county discretion

<sup>5</sup> Meet Vermont's funding priorities including:

- a) Keep children under 18 years of age with their natural or adoptive families;
- b) Prevent abuse/neglect, mental or physical regression or threat to health and safety of person;
- c) Prevent homelessness;
- d) Respond to death/loss of caregiver;
- e) Prevent job loss of the person;
- f) Support young adults aging out of Social Rehabilitation Services (SRS) who require ongoing services;
- g) Supervise/care for adults placed in Commissioner's custody as criminal and dangerous to others;
- h) Prevent or end institutionalization or out-of-state placements;
- i) Assist persons in nursing home;
- j) Assist towards independence from paid services

Ref: Vermont State System of Care Plan authorizes and requires a set of funding priorities.

<sup>6</sup> Match of programmatic needs to prospective vacancy

<sup>7</sup> Health status of caregiver

<sup>8</sup> At risk for abuse

<sup>9</sup> Health and safety

**Table 5: Policies and Initiatives to Reduce or Eliminate Lists of Persons with MR/DD Waiting for Services**

State	State MR/DD Agency Policies or Initiatives	Other Public or Private Initiatives	Recent Published Reports on State Residents with MR/DD Waiting for Services
AL	Yes	Yes	No
AK	Yes	Yes	No
AZ	Yes	Yes	No
AR	Yes	Yes	No
CA	No waiting list		
CO	Yes	Yes	Yes
CT	Yes	No	Yes
DE	Yes	Yes	Yes
DC	Yes	No	No
FL	Yes	No	No
GA	Yes	Yes	Yes
HI	Yes	Yes	Yes
ID	Yes	Yes	No
IL	No waiting list		
IN	Yes	Yes	Yes
IA	No	No	No
KS	No	No	No
KY	Yes	No	No
LA	Yes	Yes	Yes
ME	Yes	Yes	No
MD	Yes	Yes	No
MA	Yes	Yes	Yes
MI	Yes	No	Yes
MN	Yes	Yes	Yes
MS	Yes	No	No; in progress
MO	Yes	No	Yes
MT	Yes	Yes	Yes
NE	Yes	Yes	No
NV	Yes	No	No
NH	No	No	No
NJ	Yes	Yes	Yes
NM	Yes	No	No
NY	Yes	Yes	Yes
NC	Yes	Yes	Yes
ND	No waiting list		
OH	Yes	Yes	Yes
OK	Yes	No	Yes
OR	Yes	Yes	No
PA	Yes	Yes	Yes
RI	No waiting list		
SC	Yes	Yes	No
SD	No	Yes	Yes
TN	Yes	Yes	No; in progress
TX	Yes	Yes	Yes
UT	No	Yes	Yes
VT	Yes	Yes	No
VA	No	No	Yes
WA	Yes	Yes	Yes
WV	Yes	No	No
WI	No	No	Yes
WY	Yes	Yes	Yes

Table 6: States Providing Assistance to Persons Waiting for Services				
State	Assistance Provided	Assistance Not Provided	Not Applicable	No Response
AL	X			
AK	X			
AZ	X			
AR		X		
CA			X	
CO	X			
CT	X			
DE	X			
DC				X
FL	X			
GA	X			
HI	X			
ID				X
IL			X	
IN	X			
IA			X	
KS	X			
KY	X			
LA	X			
ME	X			
MD	X			
MA	X			
MI	X <sup>1</sup>			
MN	X			
MO	X			
MS	X			
MT	X			
NE	X			
NV	X			
NH	X			
NJ	X			
NM	X			
NY	X			
NC	X			
ND			X	
OH	X			
OK	X			
OR		X		
PA	X			
RI			X	
SC	X			
SD	X			
TN		X		
TX	X			
UT	X			
VT	X			
VA				X
WA	X			
WV	X			
WI				X
WY	X			

<sup>1</sup> On a prioritized basis some receive service

# Alabama

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,433	48.8
7 to 15 residents:	798	27.2
16 or more residents:	705	24.0
Total:	2,936	100.0

Residential utilization rate/100,000 pop.: 67.2  
Persons waiting for residential services: 608  
Annual ICF-MR expenditure/state resident: \$13.53  
Annual HCBS expenditure/state resident: \$17.81  
Federal Medicaid expenditure share: 0.69

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## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Advocacy/influence; potential service benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Alaska**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	455	98.3
7 to 15 residents:	8	1.7
16 or more residents:	0	0
Total:	463	100.0

Residential utilization rate/100,000 pop.: 74.7  
Persons waiting for residential services: 735  
Annual ICF-MR expenditure/state resident: \$0.00  
Annual HCBS expenditure/state resident: \$37.21  
Federal Medicaid expenditure share: 0.60

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Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: None

Important: Crisis/emergency; severity of disability

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Alaska's legislature passed HB346 in 2000 which will require the Division of Mental Health and Developmental Disabilities to review the waiting list on an annual basis and report the results of the review to the Governor and legislature. Rules for implementation of the bill are in the process of being drafted.

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

# Arizona

## Residential Settings and Services on June 30, 1999:

	Number		Percent
6 or fewer residents:	2,956		90.3
7 to 15 residents:	105	3.2	
16 or more residents:	211		6.4
Total:	3,272		100.0

Residential utilization rate/100,000 pop.: 68.5  
Persons waiting for residential services: 134  
Annual ICF-MR expenditure/state resident: \$3.72  
Annual HCBS expenditure/state resident: \$52.90  
Federal Medicaid expenditure share: 0.66

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Crisis/emergency, Health and Safety

Important: Time waiting; consumer's age

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Arkansas**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,048	28.4
7 to 15 residents:	879	23.8
16 or more residents:	1,759	47.7
Total:	3,686	100.0

Residential utilization rate/100,000 pop.: 144.5  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$45.68  
Annual HCBS expenditure/state resident: \$9.88  
Federal Medicaid expenditure share: 0.73

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Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: NA

State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Crisis/emergency; severity of disability

Important: Cost; advocacy/influence; potential benefits

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: No



State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Arkansas plans to increase its ACS waiver program by \$4 million per year for each year in the FY1999-2000 biennium to address its waiting list for DDS services.

Recent Reports on State Waiting Lists:

# California

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	35,916	78.4
7 to 15 residents:	2,520	5.5
16 or more residents:	7,360	16.1
Total:	45,796	100.0

Residential utilization rate/100,000 pop.: 138.2  
Persons waiting for residential services: 0  
Annual ICF-MR expenditure/state resident: \$12.48  
Annual HCBS expenditure/state resident: \$13.93  
Federal Medicaid expenditure share: 0.52

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## Statewide Waiting List(s):

Waiting List Type(s): No statewide lists

Service Needs Identified: NA

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: No waiting list

Important: No waiting list

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No waiting list

Public/private initiatives: No waiting list

Reports on Waiting List(s): No waiting list

## Assistance to Persons on Waiting Lists: NA

State Laws Concerning Waiting Lists:

Services in California are an entitlement, based on *Association for Retarded Citizens v. Department of Developmental Services* (1985) 38 Cal.3d384 which stated, in part, “*It is through the IPP procedure that the right the Act grants to each developmentally disabled person and the obligation it imposes on the state are implemented; through it, the developmentally disabled person on an individual basis receives, as an entitlement, services that enable him to live a more independent and productive life in the community.*” ; therefore there are no waiting lists for services.

The Act referenced in the above court decision was the Lanterman Act which is codified, in part, as Section 4502 of California’s Welfare and Institutions Code, which states:

*“ It is the intent of the Legislature that persons with developmental disabilities shall have rights including, but not limited to, the following:*

- (A) A right to treatment and habilitation services and supports in the least restrictive environment. Treatment and habilitation services and supports should foster the developmental potential of the person and be directed toward the achievement of the most independent, productive, and normal lives possible. Such services shall protect the personal liberty of the individual and shall be provided with the least restrictive conditions necessary to achieve the purposes of the treatment, services, or supports.*
- (B) A right to dignity, privacy and humane care. To the maximum extent possible, treatment, services and supports shall be provided in natural community settings.*
- (C) A right to participate in an appropriate program of publicly supported education, regardless of degree of disability.*
- (D) A right to prompt medical care and treatment.*
- (E) A right to religious freedom and practice.*
- (F) A right to social interaction and participation in community activities.*
- (G) A right to physical exercise and recreational opportunities.*
- (H) A right to be free from harm, including unnecessary physical restraint, or isolation, excessive medication, abuse or neglect.*
- (I) A right to be free from hazardous procedures.*
- (J) A right to make choices in their own lives, including, but not limited to, where and with whom they live, their relationships with people in the community, the way they spend their time, including education, employment and leisure, the pursuit of their personal future, and program planning and implementation.*

State Budget Initiatives to Reduce Waiting Lists:

California provided \$118 million for FY98-99 in increased funding for DD services to cover projected case load increases and related expenses.

Recent Reports on State Waiting Lists:

No reports required because there are no waiting lists.

# Colorado

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	3,503	85.5
7 to 15 residents:	440	10.7
16 or more residents:	152	3.8
Total:	4,095	100.0

Residential utilization rate/100,000 pop.: 101.0  
Persons waiting for residential services: 2,413  
Annual ICF-MR expenditure/state resident: \$5.49  
Annual HCBS expenditure/state resident: \$43.49  
Federal Medicaid expenditure share: 0.51

---

## Statewide Waiting List(s):

Waiting List Type(s): One database, but lists from that database are organized by how long waiting within service needed.

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: yes, must report updates monthly, must verify persons still waiting annually

Limited Waiting Period: No

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency

Important: Match programmatic needs to prospective vacancy.

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Colorado passed SB215 (Long Bill) providing resources to move 350 people off waiting lists.

Colorado passed SB1451 (Long Bill) providing resources to serve 176 more people in comprehensive residential services in FY 2001.

Recent Reports on State Waiting Lists:

Harper, C.J. (1993). *A study...Colorado's waiting list for developmental disability services*. Denver, CO: Colorado Developmental Disabilities Planning Council.

This waiting list study was to provide a clearer picture of the waiting list in Colorado. The study's goals were to verify waiting list information and to gather information from consumers about the services which would best meet their needs. The report covers areas such as a description of the consumers surveyed, length of time on the waiting list, services for which consumers are waiting, fears consumers have about not receiving services, service needs of consumers on waiting list, and the needs of consumers no longer on the waiting list. The report also contains next steps to be taken in addressing the waiting list.

Author (1997). *Spring 1997 adult waiting list survey*. Colorado Department of Human Services, Developmental Disabilities Services. Denver, CO.

Author (1999). *The Colorado waiting list registry: Changes in definitions, information collected, reports and accuracy*. Department of Human Services, Developmental Disabilities Services. Denver, Colorado.

Author (1999). *Waiting list guideline*. Department of Human Services, Developmental Disabilities Services. Denver, Colorado.

# Connecticut

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	4,645	76.5
7 to 15 residents:	430	7.1
16 or more residents:	995	16.4
Total:	6,070	100.0

Residential utilization rate/100,000 pop.: 184.9  
Persons waiting for residential services: 1,487  
Annual ICF-MR expenditure/state resident: \$62.90  
Annual HCBS expenditure/state resident: \$89.82  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Age of caregiver

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Connecticut restored \$11 million operating funds in FY98-99, enabling services to 736 people on the day and residential waiting lists.

Connecticut received \$16 million annualized funding in FY 99-00 to provide residential supports to 325 people on the residential waiting list and \$2.4 million to support 161 school graduates.

Recent Reports on State Waiting Lists:

Waiting List Planning Committee (1994). *Planning report to eliminate the DMR waiting lists*. Hartford, CT: Department of Mental Retardation.

This is a report of a committee convened to develop a plan to eliminate the growing list of people waiting for services from the Department of Mental Retardation. The plan report covers such areas as the history of the waiting list, a description of the waiting list process, a description of the people on the waiting list, the overlaps between residential and day treatment lists, factors which contribute to the existence of the waiting list, an overview of current services, recommendations to address the waiting list, and cost projections for providing supports to those on the waiting list.

DuPree, K. & Staugaitis, S.. (1999). Waiting list report: A preliminary analytical report. Connecticut Department of Mental Retardation.

Waiting list Focus team (2000). *How to eliminate the waiting list: Study and recommendations*. Hartford, CT: Department of Mental Retardation.

# Delaware

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	501	65.5
7 to 15 residents:	0	0
16 or more residents:	264	34.5
Total:	765	100.0

Residential utilization rate/100,000 pop.: 101.5  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$43.49  
Annual HCBS expenditure/state resident: \$24.47  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by other categories

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency; age and health status of caregiver, at risk for abuse

Important: Severity of disability; advocacy/influence; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes



State Laws Concerning Waiting Lists:

Summary of Executive Order 79 from Governor of Delaware: In this executive order, the Governor requested that DHSS submit a written plan to improve programs for persons with mental retardation, including a plan to increase community-based opportunities for persons residing in Stockley Center, as well as for those residing in the community needing alternative services. The order also requested a review of all support systems available to people with disabilities in Delaware, including the availability, application and efficacy of community-based alternatives for people with disabilities.

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

# District of Columbia

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	955	97.6
7 to 15 residents:	23	2.4
16 or more residents:	0	0
Total:	978	100.0

Residential utilization rate/100,000 pop.: 188.4  
Persons waiting for residential services: 0  
Annual ICF-MR expenditure/state resident: \$130.20  
Annual HCBS expenditure/state resident: \$0.00  
Federal Medicaid expenditure share: 0.70

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: No response

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Crisis/emergency; potential benefits

Important: Severity of disability; time waiting; consumer's age

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: No response

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Florida**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	6,785	57.5
7 to 15 residents:	1,346	11.4
16 or more residents:	3,661	31.1
Total:	11,792	100.0

Residential utilization rate/100,000 pop.: 78.0  
Persons waiting for residential services: 662  
Annual ICF-MR expenditure/state resident: \$17.70  
Annual HCBS expenditure/state resident: \$8.08  
Federal Medicaid expenditure share: 0.56

---

Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: No statewide waiting list

Important: No statewide waiting list

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Funding in FY 99-00 and 00-001 to eliminate the 7/1/99 waiting list and serve persons in crisis by June 30, 2001.

Recent Reports on State Waiting Lists:

Hall, J., Powell, A., Tocco, K. Linton, D., & Wells, C. (1998). *An exploratory analysis: The developmental services service needs identification process and the services waitlist*. Tallahassee, FL: The Center for Prevention and Early Intervention Policy, Florida State University Institute for Science and Public Affairs.

This was a study of the service needs identification process and waiting list of the Developmental Services Program. This report describes the data system and procedures used to record unmet service needs in Florida. The study gathered information on consumer and family perspectives of the process of identifying and obtaining service needs and reviewed support plans of consumers.

# Georgia

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	3,133	65.0
7 to 15 residents:	0	0
16 or more residents:	1,687	35.0
Total:	4,820	100.0

Residential utilization rate/100,000 pop.: 62.0  
Persons waiting for residential services: 1,750  
Annual ICF-MR expenditure/state resident: \$14.00  
Annual HCBS expenditure/state resident: \$12.62  
Federal Medicaid expenditure share: 0.60

---

## Statewide Waiting List(s):

Waiting List Type(s): one inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Time waiting; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Code Section 37-2-7, relating to the state plan for disability services:

“(b.1) (1) The plan shall include state-wide guidelines for short-term and long-term planning lists for the provisions of requested disability services for persons whose disability is mental retardation or another neurologically disabling condition which requires treatment similar to that for the mentally retarded, when such services are not available at the time of the request. The guidelines shall provide for the commencement of services, as soon as practicable but no later than 180 days following a request, to such persons who are placed on a short-term planning list. The guidelines shall also include criteria under which a person named on a planning list may obtain priority to receive the requested services when they become available and under which such persons not named on a planning list may receive requested services in emergencies.

(2) The plan shall include state-wide guidelines for a registry of persons who have been diagnosed with mental retardation or another neurologically disabling condition which requires treatment similar to that for the mentally retarded and wish to make such diagnoses known to the division and regional boards, but who have not yet requested disability services.”

State Budget Initiatives to Reduce Waiting Lists:

In response to a statewide advocacy effort in Georgia, the Governor allocated money to serve 296 persons from the waiting list. These placements will be through an existing waiver with waiver funding of \$15,719,376.00.

Recent Reports on State Waiting Lists:

Author (2000). Addressing the need; Services for Georgians with Mental Retardation. Atlanta: Georgia Division of Mental Health, Mental Retardation and Substance Abuse Services.

This report provides a summary of the factors influencing Georgia’s waiting list (e.g., use of family support, eligibility criteria). The report also details factors which will affect expected growth in service demand (e.g., demographics, family circumstances and expectations). Finally, the reports give recommendations on eliminating Georgia’s waiting lists and projected costs to implement such a plan.

# Hawaii

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,293	98.6
7 to 15 residents:	7	0.5
16 or more residents:	11	0.8
Total:	1,311	100.0

Residential utilization rate/100,000 pop.: 110.6  
Persons waiting for residential services: 0  
Annual ICF-MR expenditure/state resident: \$8.07  
Annual HCBS expenditure/state resident: \$16.62  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Severity of disability; time waiting; crisis/emergency

Important: Potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Session Laws of Hawaii 1995, Act 189, Section 5 requires the Department of Health to:

(A) Keep waiting lists of all individuals who are eligible for services and supports from the developmental disabilities service system, but for whom services and supports have not been provided for any reason; and

(B) Submit annually to the legislature the number of persons waiting for services and supports and the reasons for the lack of services and supports.

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:



# Idaho

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,822	67.7
7 to 15 residents:	487	18.1
16 or more residents:	383	14.2
Total:	2,692	100.0

Residential utilization rate/100,000 pop.: 215.0  
Persons waiting for residential services: 100  
Annual ICF-MR expenditure/state resident: \$39.08  
Annual HCBS expenditure/state resident: \$8.63  
Federal Medicaid expenditure share: 0.70

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: No response

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: No response

Important: No response

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: No response

State Laws Concerning Waiting Lists:

In 1999, the Idaho Legislature voted to remove the “cap”, allowing consumers access to needed waiver services, eliminating the waiting list in Idaho.

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

# Illinois

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	4,286	25.4
7 to 15 residents:	5,241	31.1
16 or more residents:	7,336	43.5
Total:	16,863	100.0

Residential utilization rate/100,000 pop.: 139.0  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$51.78  
Annual HCBS expenditure/state resident: \$12.31  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): No statewide list

Service Needs Identified: NA

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Severity of disability; crisis/emergency

Important: Cost; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No waiting list

Public/private initiatives: No waiting list

Reports on Waiting List(s): No waiting list

## Assistance to Persons on Waiting Lists: NA

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Indiana**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	4,852	49.6
7 to 15 residents:	2,754	28.2
16 or more residents:	2,167	22.2
Total:	9,773	100.0

Residential utilization rate/100,000 pop.: 164.4  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$46.19  
Annual HCBS expenditure/state resident: \$12.49  
Federal Medicaid expenditure share: 0.61

---

Statewide Waiting List(s):

Waiting List Type(s): Multiple, by residential and day services

Service Needs Identified: NA

State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Severity of disability; cost; potential benefits

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

317 Task Force was successful in gaining additional fiscal allocations in order to serve more individuals with developmental disabilities in Indiana - including increasing the number of slots available for the ICF/MR HCBS Waiver program in Indiana by 624 (over 2 years).

Recent Reports on State Waiting Lists:

Author (1998). *Comprehensive Plan for the Design of Services for People with Developmental Disabilities*. Indianapolis, Indiana: Indiana SB317 Task Force.

This draft of a comprehensive plan for the design of services to persons with developmental disabilities in Indiana is the work of a task force appointed by the governor. One part of the report includes analysis of current and anticipated needs for different types of services and recommendations for addressing those needs.

# Iowa

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	6,023	23.1
7 to 15 residents:	750	25.3
16 or more residents:	3,688	51.6
Total:	10,461	100.0

Residential utilization rate/100,000 pop.: 364.6  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$64.35  
Annual HCBS expenditure/state resident: \$25.87  
Federal Medicaid expenditure share: 0.63

---

## Statewide Waiting List(s):

Waiting List Type(s): No statewide list

Service Needs Identified: NA

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: No waiting list

Important: No waiting list

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: No

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: NA

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Kansas**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	3,700	81.6
7 to 15 residents:	188	4.1
16 or more residents:	647	14.3
Total:	4,535	100.0

Residential utilization rate/100,000 pop.: 170.8  
Persons waiting for residential services: 87  
Annual ICF-MR expenditure/state resident: \$24.78  
Annual HCBS expenditure/state resident: \$59.09  
Federal Medicaid expenditure share: 0.60

---

Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: Yes

Services While Waiting: Yes

Factors Determining Access Priority:

Very Important: None

Important: Time waiting; crisis/emergency

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: No

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

39-1804(2).

(b) To accomplish the policies set forth in subsection (a), the secretary, subject to the provisions of appropriation acts, shall annually propose and implement a plan including, but not limited to, financing thereof which shall: (1) Provide for an organized network of community services for persons with developmental disabilities; (2) maximize the availability of federal resources to supplement state and local funding for such systems; and (3) reduce reliance on separate, segregated settings in institutions or the community for persons with developmental disabilities.

(c) The secretary shall report to the legislature the number of persons with developmental disabilities eligible to receive community services and shall make a progress report on the implementation of the annual plans and the progress made to accomplish a comprehensive community services system for persons with developmental disabilities.

State Budget Initiatives to Reduce Waiting Lists:

\$5.8 million was specifically appropriated in 1999 to reduce the waiting list in FY 2000.

Recent Reports on State Waiting Lists:

The Kansas Department of Social and Rehabilitation Services/Substance Abuse, Mental Health and Developmental Disabilities Commissions summary reports of June 1998, June 1999, June 2000 include:

- 1) adults and families served in community settings,
- 2) private ICF/MR beds and residents,
- 3) total adults and families served in the Kansas DD system,
- 4) status of service requests,
- 5) persons unserved for more than 60 days,
- 6) services received by families,
- 7) living arrangements of adults,
- 8) day activities of adults, and
- 9) primary funding sources.

Kansas Department of Social and Rehabilitation Services (1999). Substance abuse, mental health & developmental disabilities division of DD 1999 annual report. Topeka, KS: Division of Substance abuse, Mental Health & Developmental Disabilities.

This report provides a summary of the types of services and number of people receiving residential services for people with developmental disabilities in Kansas. The report also provides expenditure information, strategic planning information and performance goals, which include the number of adults and families waiting for services.

Kansas Department of Social and Rehabilitation Services (2000). Substance abuse, mental health & developmental disabilities division of DD 2000 annual report. Topeka, KS: Division of Substance abuse, Mental Health & Developmental Disabilities.

This report provides a summary of the types of services and number of people receiving residential services for people with developmental disabilities in Kansas. The report also provides expenditure information, strategic



planning information and performance goals, which include the number of adults and families waiting for services.

# Kentucky

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,226	46.0
7 to 15 residents:	274	10.3
16 or more residents:	1,164	43.7
Total:	2,664	100.0

Residential utilization rate/100,000 pop.: 67.3  
Persons waiting for residential services: 1,450 (estimated)  
Annual ICF-MR expenditure/state resident: \$21.60  
Annual HCBS expenditure/state resident: \$10.65  
Federal Medicaid expenditure share: 0.71

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service and other categories

Service Needs Identified: NA

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency

Important: None

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Louisiana**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	2,304	39.5
7 to 15 residents:	779	13.3
16 or more residents:	2,753	47.2
Total:	5,836	100.0

Residential utilization rate/100,000 pop.: 133.5  
Persons waiting for residential services: 491  
Annual ICF-MR expenditure/state resident: \$78.32  
Annual HCBS expenditure/state resident: \$17.05  
Federal Medicaid expenditure share: 0.70

---

Statewide Waiting List(s):

Waiting List Type(s): One inclusive list (However, all requests are listed under the consumer's name so the request may be for multiple services.)

Service Needs Identified: NA

State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Time waiting

Important: Crisis/emergency; potential benefits

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Since July 1997, the Louisiana legislature has appropriated additional state funds to provide services to individuals on the waiting list. This was done in addition to expanding the HCBS the number of waiver slots during the same period.

Recent Reports on State Waiting Lists:

Buco, S.M. (1996). *OCDD Waiver Waiting List: A Survey of Individuals Waiting for the Waiver*. Statistical Resources, Inc. Baton Rouge, LA.

This report is based on a survey of a sample of persons waiting for services under the Medicaid MR/DD waiver in Louisiana. Based on findings of the survey, including eligibility for MR/DD waiver services, 7220 persons eligible were estimated to be on the waiting list statewide, with significant disproportionality in numbers waiting relative to the general population among some residents.

# Maine

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	3,546	86.4
7 to 15 residents:	459	11.2
16 or more residents:	99	2.4
Total:	4,104	100.0

Residential utilization rate/100,000 pop.: 327.5  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$32.50  
Annual HCBS expenditure/state resident: \$74.28  
Federal Medicaid expenditure share: 0.66

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency

Important: Severity of disability' advocacy/influence

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

In development

State Budget Initiatives to Reduce Waiting Lists:

Maine authorized sufficient funding for FY98-99 to eliminate waiting lists in FY98-99, providing day and residential services for all eligible persons.

The Maine legislature appropriated \$1.7 million for FY 2001 to reduce residential and day services waiting lists.

Recent Reports on State Waiting Lists:

# Maryland

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	4,059	79.9
7 to 15 residents:	356	7.0
16 or more residents:	664	13.1
Total:	5,079	100.0

Residential utilization rate/100,000 pop.: 98.2  
Persons waiting for residential services: 2,830  
Annual ICF-MR expenditure/state resident: \$10.38  
Annual HCBS expenditure/state resident: \$33.42  
Federal Medicaid expenditure share: 0.50

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency; age of caregiver

Important: Time waiting

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Maryland set aside \$34 million to serve 2000 persons on its waiting lists January 1, 1998. Its 5 year plan, if fully funded, will cost \$118 million and serve nearly 6,000 additional persons.

Recent Reports on State Waiting Lists:



# Massachusetts

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	7,177	74.3
7 to 15 residents:	1,108	11.5
16 or more residents:	1,374	14.2
Total:	9,659	100.0

Residential utilization rate/100,000 pop.: 156.4  
Persons waiting for residential services: 2,800  
Annual ICF-MR expenditure/state resident: \$36.43  
Annual HCBS expenditure/state resident: \$66.21  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service and other categories

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Severity of disability; time waiting; cost; advocacy/influence; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Massachusetts, after setting aside \$5.75 million in FY98 to address their waiting list, provided an additional \$10 million to address their "crisis situations" waiting list and an additional \$6.95 million to serve young adults "Turning 22" and leaving school. Massachusetts appropriated an additional \$10 million in FY 1999 to further reduce the waiting list.

Recent Reports on State Waiting Lists:

Author (1999). *Report on the use of funds for services to individuals on the DMR wait list.* Massachusetts Department of Mental Retardation. Boston, MA

This reports the use of a state legislative appropriation to serve 433 persons with MR/DD on a waiting list for services.

Author (1999). *Report on the use of funds for services to individuals turning 22 in fiscal year 1999.* Massachusetts Department of Mental Retardation. Boston, MA.

This reports the use of a state legislative appropriation to serve 462 young persons with MR/DD graduating from special education.

Campbell, P., & Gallant, J. (1996). *Facing the waiting list challenge: responding to the needs of individuals and families.* Boston, MA: Massachusetts Department of Mental Retardation.

This report by the Massachusetts DMR discusses the problem of the growing waiting list in Massachusetts and provides a description of the categories of service needs for people on the waiting list. The plan also details specific efforts that have been implemented to reduce the waiting list. The report offers a new strategy to reduce the waiting list which including financial strategies to cover the costs of providing these services.

Griffiths, D. (1997). *Waiting in the wings: Full report on a survey of caregivers with family members on the waiting list for residential services from the Massachusetts department of mental retardation.* Waltham, MA: Arc Massachusetts.

This report is a summary of a survey sent to caregivers with family members on the waiting list to determine needs and to provide information for planning. The report includes information about the characteristics of the caregivers, the characteristics of the family members with mental retardation, reasons for placing a family member on the waiting list, what kinds of services are needed and when the family expects to need these services.

Author (1998). *Prioritization and the intake and eligibility process of state developmental disabilities agencies: A national study of strategies to reduce the waiting list for adult services.* Massachusetts: Massachusetts Governor's Commission on Mental Retardation.

# Michigan

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	9,425 (1998 data)	97.2
7 to 15 residents:	0	0.0
16 or more residents:	272	2.8
Total:	9,697	100.0

Residential utilization rate/100,000 pop.: 98.3  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$5.62  
Annual HCBS expenditure/state resident: \$31.50  
Federal Medicaid expenditure share: 0.53

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Severity of disability; crisis/emergency

Important: None

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes, for some on a prioritized basis

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

## Minnesota

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	9,607	80.6
7 to 15 residents:	1,256	10.5
16 or more residents:	1,056	8.9
Total:	11,919	100.0

Residential utilization rate/100,000 pop.: 249.6  
Persons waiting for residential services: 1,045  
Annual ICF-MR expenditure/state resident: \$39.35  
Annual HCBS expenditure/state resident: \$74.53  
Federal Medicaid expenditure share: 0.52

---

Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: Yes

Factors Determining Access Priority:

Very Important: Crisis/emergency in family or age of caregiver/parents; Age of consumer (children at risk of out of home placement); Persons wishing to leave an ICF-MR or who are affected by ICF-MR closures.

Important: none

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Laws of Minnesota, 1998, Chapter 407, Article 4, Section 39

Minnesota Statutes 1996, section 256B.0916, is amended to read 256B.0916 [EXPANSION OF HOME AND COMMUNITY-BASED SERVICES; MANAGEMENT AND ALLOCATION RESPONSIBILITIES.]

(d) Beginning August 1, 1998, the commissioner shall issue an annual report on the home and community-based waiver for persons with mental retardation or related conditions, that includes a list of counties in which less than 95 percent of the allocation provided, excluding the county waived services reserve, has been committed for two or more quarters during the previous state fiscal year. For each listed county, the report shall include the amount of funds allocated but not used, the number and ages of individuals screened and waiting for services, the services needed, a description of the technical assistance provided by the commissioner to assist the counties in jointly planning with other counties in order to serve more persons, and additional actions which will be taken to serve those screened and waiting for services.

(e) The commissioner shall make available to interested parties, upon request, financial information by county including the amount of resources allocated for the home and community-based waiver for persons with mental retardation and related conditions, the resources committed, the number of persons screened and waiting for services, the type of services requested by those waiting, and the amount of allocated resources not committed.

Sec. 60. [MR/RC Waiver Proposal.]

By November 16, 1998, the commissioner of human services shall provide to the chairs of the house health and human service finance division and the senate health and family security finance division a detailed budget proposal for providing services under the home and community-based waiver for persons with mental retardation or related conditions to those individuals who are screened and waiting for services.

State Budget Initiatives to Reduce Waiting Lists:

In the 1999 legislative session, the Minnesota Legislature appropriated \$1,000,000 each year for increased funding in semi-independent living services (SILS); \$3,500,000 total expenditures for family support grants; and \$6,429,000 total expenditures to increase the availability of HCBS services to people with mental retardation or related conditions.

The legislature also reallocated funds expressly to address the waiting list in Minnesota:

*“Resources allocated for a fiscal year to serve persons affected by public and private sector ICF/MR closures, but not expected to be expended for that purpose, must be reallocated within that fiscal year to serve other persons on the waiting list, and the number of waiver diversion slots shall be adjusted accordingly.*

*(d) For fiscal year 2001, at least one-half of the increase in funding over the previous year provided in the February 1999 medical assistance forecast for the home and community-based waiver for persons with mental retardation and related conditions, including changes made by the 1999 legislature, must be used to serve persons who are not affected by public and private sector ICF/MR closure.*

Minnesota has received federal approval to serve additional recipients as long as additional funding was not used. “Service optimization allocations” will be awarded to counties or partnerships submitting a plan requesting these

allocations to provide services to additional people.

Recent Reports on State Waiting Lists:

Author (1998). *Home and community-based services for persons with mental retardation or related conditions, utilization and waiting list*. St. Paul, MN: Community Supports for Minnesotans with Disabilities, Minnesota Department of Human Services.

This survey provides information about the utilization and cost of providing MR/RC waivers in Minnesota as well as information about the numbers of people waiting for services funded under the HCBS waiver for people with MR/RC. The report includes information about the number of people waiting for services, the services requested by those on the waiting list, the current living arrangements of those on the list, and the authorized spending limits for each county.

# Mississippi

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	448	14.8
7 to 15 residents:	502	16.6
16 or more residents:	2,074	68.6
Total:	3,024	100.0

Residential utilization rate/100,000 pop.: 109.2  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$52.07  
Annual HCBS expenditure/state resident: \$0.95  
Federal Medicaid expenditure share: 0.77

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No, in progress

## Factors Determining Access Priority:

Very Important: Severity of disability; crisis/emergency

Important: Length of time waiting

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s); No, in progress

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Increased funding for Home and Community Based Services Waiver and for other community-based services.

Recent Reports on State Waiting Lists:



# Missouri

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	6,132	66.4
7 to 15 residents:	1,196	12.9
16 or more residents:	1,913	20.7
Total:	9,241	100.0

Residential utilization rate/100,000 pop.: 169.0

Persons waiting for residential services: 564 (estimated)

Annual ICF-MR expenditure/state resident: \$18.41

Annual HCBS expenditure/state resident: \$34.12

Federal Medicaid expenditure share: 0.60

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## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by priority

Service Needs Identified: Priority needs identified

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: Case management only

## Factors Determining Access Priority:

Very Important: Age of consumer under 4 years of age; Consumer with aging caregiver.

Important:

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

## Montana

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	955	60.7
7 to 15 residents:	488	31.0
16 or more residents:	130	8.3
Total:	1,573	100.0

Residential utilization rate/100,000 pop.: 178.1  
Persons waiting for residential services: 274  
Annual ICF-MR expenditure/state resident: \$18.54  
Annual HCBS expenditure/state resident: \$30.93  
Federal Medicaid expenditure share: 0.72

---

Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: Yes

Factors Determining Access Priority:

Very Important: Severity of disability; time waiting; crisis/emergency; advocacy/influence

Important: Potential benefits

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Montana, in FY 98-99, appropriated an annualized \$1,039,739 for community support services for 40 persons. Current legislature is reviewing a report to reduce waiting list by refinancing current services and reallocating resources from the institution.

Recent Reports on State Waiting Lists:

# Nebraska

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	2,173	71.4
7 to 15 residents:	228	7.5
16 or more residents:	641	21.1
Total:	3,042	100.0

Residential utilization rate/100,000 pop.: 182.6  
Persons waiting for residential services: 705  
Annual ICF-MR expenditure/state resident: \$27.07  
Annual HCBS expenditure/state resident: \$45.38  
Federal Medicaid expenditure share: 0.61

---

## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Severity of disability; time waiting; consumer's age; advocacy/influence; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

- (1) Beginning July 1, 1995, persons determined to be eligible for specialized services who on or after September 6, 1993, graduate from high school, reach the age of twenty-one years, or are currently receiving services shall receive services in accordance with the Developmental Disabilities Services Act.
- (2) On or after July 1, 1995, the department shall provide directly or by contract service coordination to each person found to be eligible for services.
- (3) It is the intent of the Legislature that beginning by July 1, 2000, all persons determined to be eligible for services shall receive services in accordance with the act. On or before December 1, 1991, the department shall submit a report to the Legislature and the Governor as to the number of persons anticipated to be served, what services would be needed, how the services would be developed, and the cost of serving all eligible persons.
- (4) It is the intent of the Legislature that the Department of Health and Human Services take all possible steps to maximize funding in order to implement subsections (1) and (2) of this section prior to the date of these subsections become entitlements. It is the intent of the Legislature that funding sources within the Department of Health and Human Services, the State Department of Education, specifically including the Division of Rehabilitation Services, and other agencies be utilized to the maximum extent possible.

State Budget Initiatives to Reduce Waiting Lists:

Nebraska added \$1.9 million for FY98-99 to reduce their waiting lists.

Recent Reports on State Waiting Lists:

# Nevada

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	637	74.4
7 to 15 residents:	54	6.3
16 or more residents:	165	19.3
Total:	856	100.0

Residential utilization rate/100,000 pop.: 47.3  
Persons waiting for residential services: 274  
Annual ICF-MR expenditure/state resident: \$14.77  
Annual HCBS expenditure/state resident: \$5.08  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency; potential benefits

Important: severity of disability; cost; advocacy/influence

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Nevada approved \$3,554,800 to address its waiting list.

Recent Reports on State Waiting Lists:

# New Hampshire

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,607	95.9
7 to 15 residents:	43	2.6
16 or more residents:	25	1.5
Total:	1,675	100.0

Residential utilization rate/100,000 pop.: 139.5  
Persons waiting for residential services: 208  
Annual ICF-MR expenditure/state resident: \$1.33  
Annual HCBS expenditure/state resident: \$85.29  
Federal Medicaid expenditure share: 0.50

---

## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Severity of disability; time waiting; cost

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: No

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: Yes



State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

New Hampshire's Governor appropriated close to \$3 million per year over the next biennium to reduce the developmental services waiting lists in her proposed budget.

Recent Reports on State Waiting Lists:

Author (1998). *Excerpts from final proposed standard HE-M 503- eligibility and the process of providing services*. Concord, NH: Department of Health and Human Services, Community Supports and Long Term Care.

Description of proposed standards in New Hampshire for placing people on a waiting list for services for which funds are not immediately available or for services which are expected to be needed in the next two years.

## New Jersey

### Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	5,238	53.8
7 to 15 residents:	820	8.4
16 or more residents:	3,671	37.7
Total:	9,729	100.0

Residential utilization rate/100,000 pop.: 119.5  
Persons waiting for residential services: 4,768  
Annual ICF-MR expenditure/state resident: \$46.41  
Annual HCBS expenditure/state resident: \$34.94  
Federal Medicaid expenditure share: 0.50

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### Statewide Waiting List(s):

Waiting List Type(s): Multiple by service and other categories

Service Needs Identified: Yes

### State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: Yes

### Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency; age of parent

Important: None

### Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

### Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

An ACT concerning the Division of Developmental Disabilities' community residential and day program waiting list.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

(1) The legislature finds and declares that:

- (a) Between June 30, 1996 and April 30, 1998, the number of persons on the Division of Developmental Disabilities' Alternate Living Services Waiting List increased from more than 1,500 to over 4,455;
- (b) As of April 30, 1996, nearly 900 persons had no day program available;
- (c) The \$80 million in bond funds available to the Division of Developmental Disabilities from the Developmental Disabilities' Waiting List Reduction and Human Services Facilities Construction Fund will only deal with the capital requirements of the approximately 2,000 persons who are in Categories 1 and 2 of the waiting list;
- (d) The March 28, 1996 initiative announced by Governor Whitman to develop community residential programs for approximately 600 developmentally disabled persons between FY 1997 and FY 1999 at an annual cost of \$32 million will only maintain the waiting list at current levels, even though the waiting list increases by one client per day;
- (e) Statistics from the New Jersey Department of Education, Office of Special Education Program indicate that there will be significant increase in the number of multiply handicapped classified pupils who will graduate from educational programs and that such pupils are likely to require community services from the Division of Developmental Disabilities; and;
- (f) The Division of Developmental Disabilities does not have a long-term plan to eliminate the current and future waiting list and to provide for the associated capital and operational cost needed to address the current and future waiting list.

C.30.6D-42 Preparation, submission of plan to eliminate waiting list.

- (2a) The Commissioner of Human Services shall prepare and submit a plan to the Governor and the Legislature within 180 days after the effective date of this act to eliminate the current and future Division of Developmental Disabilities' waiting list by the year 2008.
- (b) The plan shall include:
  - (1) Statistical information on the current and projected increase in the waiting list;
  - (2) Financial information on the capital funds necessary to eliminate the current and future waiting list by the year 2008; and
  - (3) Financial information on the amount of additional State, federal and other funds that may be required annually for operating costs associated with eliminating the waiting list by the year 2008.
- (c) In developing the plan, the commissioner shall conduct public hearings and obtain public input from persons with developmental disabilities or their families or guardians and providers of services to the developmental disabilities community.
- (d) The commissioner shall update the statistical and financial data in the plan annually and submit the updated plan to the Governor and the Legislature by December 31 of each year.
- (3) This act shall take effect immediately.

State Budget Initiatives to Reduce Waiting Lists:

New Jersey proposed a multi-million dollar budget increase for FY2001 to provide 500 residential placements and 400 day placements for persons on waiting lists. This, with other major initiatives in FY 96, 97, 98, 99 and 00 brought total investments in waiting lists to over \$163 million.

Recent Reports on State Waiting Lists:

Waiting List Planning Work Group (1998). *A plan to eliminate the waiting list for community residential services by 2008*. Trenton, NJ: Department of Human Services, Division of Developmental Disabilities.

This plan was developed in response to legislation which required the development of a plan to eliminate the waiting list for community residential services for people with developmental disabilities. Included in this report are descriptions of the background and history of the waiting list, of the current waiting list, and a projection of the waiting list into the future if no changes are made. The report than details a plan eliminate the waiting list by the year 2008.

## New Mexico

### Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,772	85.2
7 to 15 residents:	291	14.0
16 or more residents:	16	0.8
Total:	2,079	100.0

Residential utilization rate/100,000 pop.: 119.5  
Persons waiting for residential services: 1,746  
Annual ICF-MR expenditure/state resident: \$8.81  
Annual HCBS expenditure/state resident: \$57.54  
Federal Medicaid expenditure share: 0.73

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### Statewide Waiting List(s):

Waiting List Type(s): one inclusive test

Service Needs Identified: Yes

### State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

### Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency

Important: None

### Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

### Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

28-16A-15. Admission, transfer, withdrawal and discharge of persons receiving support and services purchased or provided by the department.

(A) In cooperation with other state agencies, the department shall adopt requirements for admission, transfer, withdrawal and discharge of persons receiving support and services funded in whole or in part by state funds.

(B) The department shall maintain a centralized registry of persons who are requesting or receiving support and services and a centralized referral system that promotes the delivery of support and services within the person's home community and reflects the person's informed selection and choice of a support or service provider. This centralized referral system shall determine eligibility based on a comprehensive assessment and shall prioritize individuals waiting to access publicly funded developmental disability support and services.

(C) The centralized referral system shall maintain information regarding the needs of persons not receiving services and shall report the information annually to the legislature. The department shall have the authority to provide assessments and case management services to persons applying for and receiving publicly funded support and services necessary to implement the provisions of this section.

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

# New York

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	13,763	38.7
7 to 15 residents:	18,015	50.6
16 or more residents:	3,818	10.7
Total:	35,596	100.0

Residential utilization rate/100,000 pop.: 195.6  
Persons waiting for residential services: 6,611  
Annual ICF-MR expenditure/state resident: \$116.88  
Annual HCBS expenditure/state resident: \$85.79  
Federal Medicaid expenditure share: 0.50

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive test

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Severity of disability; crisis/emergency

Important: None

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s); Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

New York proposes spending \$230 million over the next 5 years to create housing for 4,900 persons on waiting lists.

Recent Reports on State Waiting Lists:



# North Carolina

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	4,869	62.8
7 to 15 residents:	349	4.5
16 or more residents:	2,535	32.7
Total:	7,753	100.0

Residential utilization rate/100,000 pop.: 101.3  
Persons waiting for residential services: 2,303  
Annual ICF-MR expenditure/state resident: \$51.42  
Annual HCBS expenditure/state resident: \$17.78  
Federal Medicaid expenditure share: 0.63

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive test

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: Yes

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency; consumer's age; parents' age

Important: Severity of disability; cost

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

## FUNDS TO REDUCE WAITING LIST FOR SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS/DEVELOPMENTAL DISABILITY SERVICES REVIEW AND INITIATIVES

Section 12.34. (a) Of the funds appropriated in this act to the Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, the sum of six million dollars (\$6,000,000) for the 1998-99 fiscal year all of which shall be annually recurring, shall be used to provide family support services to developmentally disabled individuals who are not eligible for the Medicaid Community Alternative Program for Mentally Retarded/Developmentally Disabled persons and who are on the Department's waiting list for services. An additional \$3.3 million (\$3,300,000) was transferred from TANF on a non-recurring basis.

(b) The Department of Health and Human Services shall review and implement initiatives to provide and enhance person-centered and family support services to developmentally disabled individuals served by the State and local public mental health services system. \$500,000 for support dollars was allocated for the wait list. In order to accomplish this, the Department shall do all of the following:

- (1) Immediately pursue approval from the Health Care Financing Administration to implement flexible funding under the CAP-MR/DD Waiver as soon as possible and expansion of CAP/MR slots by 1700.
- (2) Study the feasibility of providing new or additional services as part of the regular Medicaid program which are aimed at keeping developmentally disabled individuals in their homes rather than using the current criterion used in the Medicaid CAP-MR/DD Waiver Program. The study shall include a projected cost-benefit analysis;
- (3) Work with area mental health authorities to determine why Medicaid-eligible individuals are waiting for services in the area mental health programs;
- (4) Establish goals for the State and area mental health programs that require not more than a six-month wait for services for developmentally disabled individuals;
- (5) Collaborate with area mental health programs to maximize the use of existing funds to increase services to the developmentally disabled, non-Medicaid and non-CAP-MR/DD eligible population; and
- (6) Pursue additional Medicaid waivers, which emphasize person-centered and family support services for developmentally disabled individuals.

The Department shall work with other State agencies as necessary to implement this section.

The Department shall report the results of its compliance with this section to the members of the Senate Appropriations Committee on Human Resources not later than May 1, 1999. The report shall also include the impact of expansion funds on the waiting list for services for developmentally disabled individuals.

State Budget Initiatives to Reduce Waiting Lists:

North Carolina allocated \$6 million to providing family support services to persons on the waiting lists but not eligible for Medicaid Waiver Services.

Recent Reports on State Waiting Lists:

Porter, P. & Eguez, S. (1997). *Developmental disabilities services: Single portal of entry and exit interpretive guidelines*. Raleigh, NC: Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services.

The Single Portal of entry law was enacted in 1994 in order to determine the need for homes and other services for persons with developmental disabilities and to be used in planning services. The plan requires that person-centered planning be used by area agencies, that there is consumer/family involvement, that each area form interagency councils and that each area use the waiting list tracking system.

# North Dakota

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,269	64.3
7 to 15 residents:	453	22.9
16 or more residents:	252	12.8
Total:	1,974	100.0

Residential utilization rate/100,000 pop.: 311.4

Persons waiting for residential services: 0

Annual ICF-MR expenditure/state resident: \$71.07

Annual HCBS expenditure/state resident: \$59.36

Federal Medicaid expenditure share: 0.70

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## Statewide Waiting List(s):

Waiting List Type(s): No statewide list

Service Needs Identified: NA

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: No waiting list

Important: No waiting list

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No waiting list

Public/private initiatives: No waiting list

Reports on Waiting List(s): No waiting list

## Assistance to Persons on Waiting Lists: NA

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

**Ohio**

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	8,501	50.2
7 to 15 residents:	2,892	17.1
16 or more residents:	5,544	32.7
Total:	16,937	100.0

Residential utilization rate/100,000 pop.: 150.5  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$45.48  
Annual HCBS expenditure/state resident: \$15.97  
Federal Medicaid expenditure share: 0.58

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Statewide Waiting List(s):

Waiting List Type(s): No statewide list, lists are managed by the 88 county boards of MR/DD

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Time waiting; based on date of request for service

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Section 5126.042

(A) As used in this section:

(1) "Emergency" means any situation that creates for an individual with mental retardation or developmental disabilities a risk of substantial self-harm or substantial harm to others if action is not taken within thirty days. An "emergency" may include one or more of the following situations:

- (a) Loss of present residence for any reason, including legal action;
- (b) Loss of present caretaker for any reason, including serious illness of the caretaker, change in caretaker's status, or inability of the caretaker to perform effectively for the individual;
- (c) Abuse, neglect, or exploitation of the individual;
- (d) Health and safety conditions that pose a serious risk to the individual or others of immediate harm or death;
- (e) Change in the emotional or physical condition of the individual that necessitates substantial accommodation that cannot be reasonably provided by the individual's existing caretaker.

(2) "Priority" means any situation that would constitute an emergency except that action to resolve the situation may be taken in more than thirty but less than ninety days without creating a risk of substantial harm to self or others.

(B) If a county board of mental retardation and developmental disabilities determines that available resources are not sufficient to meet the needs of all individuals who request programs and services and may be offered the programs and services it shall establish waiting lists for services. The board may establish priorities for making placements on its waiting lists according to an individual's emergency or priority status.

The individuals who may be placed on a waiting list include individuals with a need for services on an emergency or priority basis and individuals who have requested services for which resources are not available.

An individual who currently receives a service but would like to change to another service shall not be placed on a waiting list but shall be placed on a service substitution list. The board shall work with the individual, service providers, and all appropriate entities to facilitate the change in service as expeditiously as possible. The board may establish priorities for making placements on its service substitution lists according to an individual's emergency or priority status.

In addition to maintaining waiting lists and service substitution lists, a board shall maintain a long-term service planning registry for individuals who wish to record their intention to request in the future a service they are not currently receiving. The purpose of the registry is to enable the board to document requests and to plan appropriately. The board may not place an individual on the registry who meets the conditions for receipt of services on an emergency or priority basis.

(C) A county board shall establish a separate waiting list for each of the following categories of services, and may establish separate waiting lists within the waiting lists:

- (1) Early childhood services;
- (2) Educational programs for preschool and school age children;
- (3) Adult services;
- (4) Case management services;
- (5) Residential services and supported living;

(6) Transportation services;

(7) Other services determined necessary and appropriate for mentally retarded or developmentally disabled persons according to their individual habilitation or service plans;

**OH**

(8) Family support services provided under section 5126.11 of the Revised Code.

(D) Prior to establishing any waiting list under this section, a county board shall develop and implement a policy for waiting lists that complies with rules that the department of mental retardation and developmental disabilities shall adopt in accordance with Chapter 119. of the Revised Code. The department's rules shall include procedures to be followed to ensure that the due process rights of individuals placed on waiting lists are not violated.

Prior to placing an individual on a waiting list, the county board shall assess the service needs of the individual in accordance with all applicable state and federal laws. The county board shall place the individual on the appropriate waiting list and may place the individual on more than one waiting list.

At least annually, the county board shall reassess the service needs of each individual on a waiting list. If it determines that an individual no longer needs a program or service, the county board shall remove the individual from the waiting list. If it determines that an individual needs a program or service other than the one for which the individual is on the waiting list, the county board shall provide the program or service to the individual or place the individual on a waiting list for the program or service in accordance with the board's policy for waiting lists.

When a program or service for which there is a waiting list becomes available, the county board shall reassess the service needs of the individual next scheduled on the waiting list to receive that program or service. If the reassessment demonstrates that the individual continues to need the program or service, the board shall offer the program or service to the individual. If it determines that an individual no longer needs a program or service other than the one for which the individual is on the waiting list, the county board shall provide the program or service to the individual or place the individual on a waiting list for the program or service in accordance with the board's policy for waiting lists.

(E) A child subject to a determination made pursuant to section 121.38 of the Revised Code who requires the home and community-based services provided through the medical assistance waiver programs operated under sections 5111.87 and 5111.88 or the Revised Code shall receive services through the waiver programs adopted under Chapters 5111., 5123., and 5126. of the Revised Code. For all other services, a child subject to a determination made pursuant to section 121.38 of the Revised Code shall be treated as an emergency by the county boards and shall not be subject to a waiting list.

(F) Not later than the fifteenth day of March of each even-numbered year, each county board shall prepare and submit to the director of mental retardation and developmental disabilities its recommendations for the funding of services for individuals with mental retardation and developmental disabilities and its proposals for reducing the waiting lists for services.

State Budget Initiatives to Reduce Waiting Lists:

Sub. H.B. 403, recently approved by the legislature, provides \$6 million in new state funding for Home and Community Based Waiver services, which will result in the addition of \$14.6 million in additional waiver services for 400 individuals. Approximately 75% of this funding will be used to support 267 individuals through the Individual Options Waiver managed by the Ohio Department of MR/DD and 25% will be used for the Ohio Home Care Waiver managed by the Ohio department of Jobs and Family Services.

Recent Reports on State Waiting Lists:

Arndt, C.H. (1998). *1998 critical issues conference: Waiting and service substitution lists, issues and resolutions*. Cleveland and Columbus, Ohio: Ohio Association of County Boards of MR/DD.

This report details the proposed changes to Ohio's waiting list regulations.; the law which defines what constitutes an emergency; and how priorities ought to be set. The Ohio law provides for people wishing to change services, as opposed to those without services at all. The proposed changes in Ohio's law suggest that changes be made to give priority to individuals who if served, would make resources available to others on the waiting list.

McAvoy, N (1999). Information Notice on waiting lists in Ohio. Department of Community Services, Columbus, Ohio.

This report provides background on Ohio's legislative code pertaining to waiting lists, principles related to waiting lists, eligibility determinations, waiting list management guidelines, administration of waiting lists, placement of individuals on waiting lists, and other guidelines related to service usage and planning and waiting lists.

# Oklahoma

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	2,231	51.0
7 to 15 residents:	265	6.1
16 or more residents:	1,875	42.9
Total:	4,371	100.0

Residential utilization rate/100,000 pop.: 130.2  
Persons waiting for residential services: 2,700  
Annual ICF-MR expenditure/state resident: \$30.29  
Annual HCBS expenditure/state resident: \$39.98  
Federal Medicaid expenditure share: 0.71

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: No

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency

Important: None

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes



State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Oklahoma is implementing a plan to serve an additional 100 people per month from the waiting list during FY 01.

Recent Reports on State Waiting Lists:

Bell, P., Johnson, M., & Yates, D. (1997). *Report of the results for the DSDD waiting list survey.*  
Department of Sociology, Oklahoma State University, Stillwater, OK.

This survey of Oklahomans with developmental disabilities on a waiting list for services was conducted in 1996. It sought to identify the current residence and needs of each person, the priority of the individual's needs, alternatives to meeting the current needs, and the highest risk factors in meeting the needs.

# Oregon

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	3,390	83.7
7 to 15 residents:	390	9.6
16 or more residents:	269	6.6
Total:	4,049	100.0

Residential utilization rate/100,000 pop.: 122.1  
Persons waiting for residential services: 2,277  
Annual ICF-MR expenditure/state resident: \$20.12  
Annual HCBS expenditure/state resident: \$48.70  
Federal Medicaid expenditure share: 0.61

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## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: None

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: No

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

Agosta, J., Keating, T., Deane, K., Ashbaugh, J., Bradley, V., Close, D., & Bergman, A. (1990). *Oregon long range plan for developmental disability services: Commitment to community*. Monmouth, OR: The Human Services Research Institute.

This report includes information about the profiles of consumers and their unmet needs, information about the waiting list and policies which effect the waiting list, and special concerns related to the service needs of people with developmental disabilities.

Author (1995). *An Oregon family album: Portraits from the waiting list for community services for people with developmental disabilities*. Salem, OR: Oregon Developmental Disabilities Council and The Arc of Oregon.

Includes pictures of adults and children with developmental disabilities waiting for services in Oregon. Next to each picture is the person's name, age and Oregon Senate and House district.

Author (1996). *Draft of a long range plan for developmental disability services in Oregon*. Salem, OR: Oregon Mental Health and Developmental Disability Services Division.

This report provides information about the number of people on the waiting list and their characteristics, projections of the growth of the waiting list, a description of the services needed, a description of funding priorities, and provides recommendations for action to stem the growth of the waiting list.

# Pennsylvania

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	12,497	72.5
7 to 15 residents:	817	4.7
16 or more residents:	3,926	22.8
Total:	17,240	100.0

Residential utilization rate/100,000 pop.: 143.7  
Persons waiting for residential services: 2,309  
Annual ICF-MR expenditure/state resident: \$43.22  
Annual HCBS expenditure/state resident: \$44.36  
Federal Medicaid expenditure share: 0.54

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## Statewide Waiting List(s):

Waiting List Type(s): Maintained and managed by all (45) county MR programs

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency; caregiver's age

Important: Severity of disability; time waiting; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Pennsylvania has provided over the last three fiscal years more than \$84 million for people waiting for services. These funds have provided services for approximately 3,100 people. The FY 2000-2001 budget contains a five year initiative to serve over 4,000 persons on the waiting lists for a total investment of \$853 million.

Recent Reports on State Waiting Lists:

Feinstein, C., Lemanowicz, J., & Steele, K. (1998). *Waiting for services in Pennsylvania: A review and analysis*. Philadelphia: Temple University, Institute on Disabilities.

This report, contracted by the State Office of Mental Retardation describes the nature of waiting list enrollment practices as well as the numbers of persons waiting and the services for which they wait. An important finding of this study was that 49% of persons who came into service or received "significantly enhanced services" in 1995-1996 were not previously on the waiting list for services.

Feinstein, C., Lemanowicz, J., & Clark, A. (1999). *Waiting for Services in Pennsylvania: Phase II*. Philadelphia: Temple University, Institute on Disabilities.

A follow up to the previous report.

Author (1999). *A long term plan to address the waiting list for mental retardation services in Pennsylvania*. Pennsylvania Department of Public Welfare, Office of Mental Retardation Planning Advisory Committee.

# Rhode Island

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,633	87.4
7 to 15 residents:	186	10.0
16 or more residents:	50	2.6
Total:	1,869	100.0

Residential utilization rate/100,000 pop.: 186.1  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$5.32  
Annual HCBS expenditure/state resident: \$98.51  
Federal Medicaid expenditure share: 0.54

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## Statewide Waiting List(s):

Waiting List Type(s): No statewide list

Service Needs Identified: NA

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: No waiting lists

Important: No waiting lists

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No waiting list

Public/private initiatives: No waiting list

Reports on Waiting List(s): No waiting list

## Assistance to Persons on Waiting Lists: NA

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

## South Carolina

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	2,164	48.3
7 to 15 residents:	1,084	24.2
16 or more residents:	1,228	27.4
Total:	4,476	100.0

Residential utilization rate/100,000 pop.: 115.2  
Persons waiting for residential services: 1,532  
Annual ICF-MR expenditure/state resident: \$43.17  
Annual HCBS expenditure/state resident: \$23.73  
Federal Medicaid expenditure share: 0.70

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Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: NA

State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: Yes

Factors Determining Access Priority:

Very Important: Crisis emergency

Important: Severity of disability; potential benefits

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

## South Dakota

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,186	58.8
7 to 15 residents:	637	31.6
16 or more residents:	195	9.6
Total:	2,018	100.0

Residential utilization rate/100,000 pop.: 275.3

Persons waiting for residential services: 16

Annual ICF-MR expenditure/state resident: \$25.22

Annual HCBS expenditure/state resident: \$64.62

Federal Medicaid expenditure share: 0.68

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Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: NA

State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Advocacy/influence

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes



State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

## Tennessee

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	2,204	49.2
7 to 15 residents:	1,154	22.8
16 or more residents:	1,119	25.0
Total:	4,477	100.0

Residential utilization rate/100,000 pop.: 81.6  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$43.35  
Annual HCBS expenditure/state resident: \$24.64  
Federal Medicaid expenditure share: 0.63

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Statewide Waiting List(s):

Waiting List Type(s): Single, inclusive list; Waiting list managed at a regional level

Service Needs Identified: Yes

State Laws/Policies Require:

Periodic Reporting: No, in progress

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Length of time waiting

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s); No, in progress

Assistance to Persons on Waiting Lists: No

TN

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Tennessee approved a 67% increase for F98-99 to \$4.95 million to serve persons on waiting lists.

Recent Reports on State Waiting Lists:

# Texas

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	10,065	54.5
7 to 15 residents:	805	4.4
16 or more residents:	7,602	41.1
Total:	18,472	100.0

Residential utilization rate/100,000 pop.: 92.2  
Persons waiting for residential services: DNF  
Annual ICF-MR expenditure/state resident: \$29.30  
Annual HCBS expenditure/state resident: \$13.23  
Federal Medicaid expenditure share: 0.62

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## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Time waiting; crisis/emergency

Important: None

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Sec.534.053. (a) The department shall ensure that, at a minimum, the following services are available in each service area:

- (1) 24-hour emergency screening and rapid crisis stabilization services;
- (2) community-based crisis residential services or hospitalization;
- (3) community-based assessments, including the development of interdisciplinary treatment plans and diagnosis and evaluation services;
- (4) family support services, including respite care;
- (5) case management services;
- (6) medication-related services, including medication clinics, laboratory monitoring, medication education, mental health maintenance education, and the provision of medication; and
- (7) psychosocial rehabilitation programs, including social support activities, independent living skills, and vocational training.

(b) The department shall arrange for appropriate community-based services, including the assignment of a case manager, to be available in each service area for each person discharged from a department facility who is in need of care.

(c) To the extent that resources are available, the department shall:

- (1) ensure that the services listed in this section are available for children, including adolescents, as well as adults, in each service area;
- (2) emphasize early intervention services for children, including adolescents, who meet the department's definition of being at high risk of developing severe emotional disturbances or severe mental illnesses; and
- (3) ensure that services listed in this section are available for defendants required to submit to mental health treatment under Article 17.032 or Section 5(a) or 11(d), Article 42.12, Code of Criminal Procedure.

Sec. 593.022 (a) An eligible person who applies for mental retardation services may be admitted as soon as appropriate services are available.

Sec. 533.038 Facilities and Services for clients with Mental Retardation

(d) A person with mental retardation, or a person's legally authorized representative, seeking residential services shall receive a clear explanation of programs and services for which the person is determined to be eligible, including state schools, community ICF-MR programs, waiver services under Section 1915(c) of the federal Social Security Act (42 U.S.C. Section 1396n(c)), or other services. The preferred programs and services chosen by the person or the person's legally authorized representative shall be documented in the person's record. If the preferred programs or services are not available, the person or her persons's legally authorized representative shall be given assistance in gaining access to alternative services and the selected waiting list.

State Budget Initiatives to Reduce Waiting Lists:

In FY 2000 funds appropriated from the tobacco settlement receipts were used to provide HCBS services to those on the waiting list for the longest period of time. In FY 2001, an additional 234 people from the waiting list are expected to receive services through equity funding allocations to local authorities in Texas.

Recent Reports on State Waiting Lists:

# Utah

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,625	66.3
7 to 15 residents:	47	1.9
16 or more residents:	778	31.8
Total:	2,450	100.0

Residential utilization rate/100,000 pop.: 115.0  
Persons waiting for residential services: 1,264  
Annual ICF-MR expenditure/state resident: \$24.09  
Annual HCBS expenditure/state resident: \$30.88  
Federal Medicaid expenditure share: 0.72

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list; multiple, by service; Priority list based on critical needs assessment score

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Severity of disability

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Utah's legislature appropriated \$1.3 million during the 1998 legislative session to serve people waiting for services.

Recent Reports on State Waiting Lists:

# Vermont

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,041	100.0
7 to 15 residents:	0	0
16 or more residents:	0	0
Total:	1,041	100.0

Residential utilization rate/100,000 pop.: 175.3  
Persons waiting for residential services: 12  
Annual ICF-MR expenditure/state resident: \$2.62  
Annual HCBS expenditure/state resident: \$91.65  
Federal Medicaid expenditure share: 0.62

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency; potential benefits; various funding priorities

Important: Advocacy/influence

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

Regulation implementing the Developmental Disability Act of 1996 (as of July 1998)

Periodic review of need: waiting list

The designated agency shall conduct or arrange for reassessment of a person on the waiting list upon being notified of a significant change in the person's life situations. In addition, the agency shall review the needs of all people on the waiting list at least annually and when there are changes in the System of Care Plan funding priorities.

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:



# Virginia

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	2,091 (1998 data)	43.0
7 to 15 residents:	498 (1998 data)	10.2
16 or more residents:	2,190 (1998 data)	46.8
Total:	4,779 (1998 data)	100.0

Residential utilization rate/100,000 pop.: 69.5  
Persons waiting for residential services: 924  
Annual ICF-MR expenditure/state resident: \$24.70  
Annual HCBS expenditure/state resident: \$16.49  
Federal Medicaid expenditure share: 0.52

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## Statewide Waiting List(s):

Waiting List Type(s): No statewide list

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No; in progress

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: No waiting list

Important: No waiting list

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: No

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: No response

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

FY 99 \$2.75 million to address waiting lists.

FY 99 \$1.25 million for waiver services for persons ready for discharge or on waiting lists.

FY 00 \$9,195,724 to address emergency community MR services.

FY 00 \$6.5 million to increase day support and supported employment.

FY 00 \$2.5 million for individuals ready to return to the community.

FY 00 \$5 million for community waiver services for individuals losing services under other Medicaid waivers and those without services.

FY 01 \$ 1.25 million for employment, transportation and day support waiting lists.

FY01 \$ 1 million for emergency and residential services.

Recent Reports on State Waiting Lists:

# Washington

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	5,496	76.8
7 to 15 residents:	385	5.4
16 or more residents:	1,275	17.8
Total:	7,156	100.0

Residential utilization rate/100,000 pop.: 124.3

Persons waiting for residential services: 0

Annual ICF-MR expenditure/state resident: \$22.51

Annual HCBS expenditure/state resident: \$22.39

Federal Medicaid expenditure share: 0.53

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## Statewide Waiting List(s):

Waiting List Type(s): One inclusive list, multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: Yes

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: Crisis/emergency

Important: Severity of disability; cost; consumer's age

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

Weber, L., Longhi, D. & Tyrell-Smith, J. with Stern, J. (1998). *An analysis of unmet service need for Washington State's Division of Developmental Disabilities*. Research and Data Analysis, Washington State Department of Social and Health Services, Olympia.

This report addresses the magnitude of unmet needs of Washingtonians with MR/DD, types of services needed, costs associated with meeting the unmet needs, and short-term goals to address the problem, with an associated budget.

Author (1998). *Planning for the services and supports needed by people with developmental disabilities and their families in Washington state*. Washington: Washington State Division of Developmental Disabilities.

# West Virginia

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	1,226	74.1
7 to 15 residents:	428	25.9
16 or more residents:	0	0
Total:	1,654	100.0

Residential utilization rate/100,000 pop.: 91.5  
Persons waiting for residential services: 344  
Annual ICF-MR expenditure/state resident: \$25.35  
Annual HCBS expenditure/state resident: \$36.88  
Federal Medicaid expenditure share: 0.74

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## Statewide Waiting List(s):

Waiting List Type(s): Yes, for MR/DD waiver

Service Needs Identified: No

## State Laws/Policies Require:

Periodic Reporting: No; informal reporting process

Limited Waiting Period: Yes

Services While Waiting: Yes

## Factors Determining Access Priority:

Very Important: Severity of disability; crisis/emergency

Important: Advocacy/influence; potential benefits

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: No

Reports on Waiting List(s): No

## Assistance to Persons on Waiting Lists: Yes

State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

The state legislature approved five million in state match funds for 200 additional waiver slots for FY 2000. West Virginia plans to add 875 additional waiver slots over the next five years, and has agreed to increase that number if needed to provide services to additional people.

Recent Reports on State Waiting Lists:

# Wisconsin

## Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	9,727	72.4
7 to 15 residents:	814	6.1
16 or more residents:	2,899	21.5
Total:	13,440	100.0

Residential utilization rate/100,000 pop.: 256.0

Persons waiting for residential services: 2,137 (estimate)

Annual ICF-MR expenditure/state resident: \$30.30

Annual HCBS expenditure/state resident: \$45.22

Federal Medicaid expenditure share: 0.59

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## Statewide Waiting List(s):

Waiting List Type(s): Multiple, by service

Service Needs Identified: Yes

## State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

## Factors Determining Access Priority:

Very Important: At county level

Important: At county level

## Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: No

Public/private initiatives: No

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Determined at the county level

## State Laws Concerning Waiting Lists:

## State Budget Initiatives to Reduce Waiting Lists:

Recent Reports on State Waiting Lists:

## Wyoming

Residential Settings and Services on June 30, 1999:

	Number	Percent
6 or fewer residents:	728	77.9
7 to 15 residents:	87	9.3
16 or more residents:	120	12.8
Total:	935	100.0

Residential utilization rate/100,000 pop.: 194.8

Persons waiting for residential services: 0

Annual ICF-MR expenditure/state resident: \$29.97

Annual HCBS expenditure/state resident: \$85.38

Federal Medicaid expenditure share: 0.64

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Statewide Waiting List(s):

Waiting List Type(s): One inclusive list

Service Needs Identified: no people currently waiting for services

State Laws/Policies Require:

Periodic Reporting: No

Limited Waiting Period: No

Services While Waiting: No

Factors Determining Access Priority:

Very Important: Severity of disability

Important: Crisis/emergency

Initiatives to Reduce/Eliminate Waiting List(s):

State policies/initiatives: Yes

Public/private initiatives: Yes

Reports on Waiting List(s): Yes

Assistance to Persons on Waiting Lists: Yes



State Laws Concerning Waiting Lists:

State Budget Initiatives to Reduce Waiting Lists:

The Governor and legislature allocated funding for 95 new people to receive services to reduce, and by July 2000, eliminate the current waiting list. A total of \$7 million in combined state and federal funds will be used over the FY 2000-2002 biennium to address the waiting list.

Recent Reports on State Waiting Lists:

Allen, J., Fortune, J., & Fortune, B. (1998). *Managing the rising tide. The Wyoming waiting list revisited*. Cheyenne, WY : Wyoming Department of Health

This report provides information about the requests for services and supports for adults and children with developmental disabilities and projects the growth of the eligible population to the year 2002. The report describes some characteristics of the applicants and their projected level of care. The report concludes with the implications for planning for future service needs.

Allen, J. & Fortune, J. (1999). *Treading water in the waiting list sea*. Wyoming Department of Health, Division of Developmental Disabilities. Casper, WY.