

**THE ADVISORY COMMITTEE REPORT
ON THE WAITING LIST FOR
COMMUNITY-BASED
MENTAL RETARDATION SERVICES**

**THE ADVISORY COMMITTEE ON WAITING LIST FOR
COMMUNITY-BASED MENTAL RETARDATION SERVICES**

JUNE 2008



General Assembly of the Commonwealth of Pennsylvania
JOINT STATE GOVERNMENT COMMISSION
108 Finance Building
Harrisburg, PA 17120

The release of this report should not be interpreted as an endorsement by the members of the Executive Committee of the Joint State Government Commission of all the findings, recommendations and conclusions contained in this report.

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The Joint State Government Commission was created by the act of July 1, 1937 (P.L.2460, No.459) as amended, as a continuing agency for the development of facts and recommendations on all phases of government for the use of the General Assembly.

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TO THE MEMBERS OF THE GENERAL ASSEMBLY:

The Joint State Government Commission is pleased to present The Advisory Committee Report on the Waiting List for Community-Based Mental Retardation Services. House Resolution 159 of 2007 directed the Joint State Government Commission to assemble an advisory committee of experts in the area of mental retardation, to compile a status report on Pennsylvania's waiting list for community-based mental retardation services, and to recommend ways to reduce or eliminate the waiting list.

The advisory committee consisted of a number of individuals with long experience in the field of intellectual disabilities, including those representing state agencies, service providers, advocates, and self-advocates. The advisory committee members' experience in working with both MR systems and persons with intellectual disabilities, and their assistance in writing this report were invaluable.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Roger A. Madigan".

Roger A. Madigan,
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INTRODUCTION

The past 40 years have seen a revolution in service delivery for persons with intellectual disabilities, both in Pennsylvania and nationwide. The revolution had been marked by changes in understanding the nature of intellectual disabilities, the role of individuals with intellectual disabilities in society, and funding for services for such individuals.

Historically, individuals with intellectual disabilities were viewed as uneducable and incapable of personal growth. Based on this understanding, beginning in the late 19th century individuals with intellectual disabilities routinely were placed in large, isolated institutions funded and operated by the states. Although these institutions were intended to offer a form of protective shelter, they generally evolved into little more than warehouses where people lived and died, cut off from their families and forgotten by society, with no life training and minimal services and care.

Beginning in the 1960s, professionals began to understand that individuals with intellectual disabilities could best be served in the community where they could interact with a variety of people, participating in and contributing to society. These professionals urged states to adopt a goal of “normalization.” Normalization is based on the premise that a person with intellectual disabilities, when placed in a normal environment, will attempt to live up to normal expectations. This, of course, does not mean that these individuals do not need supports, but that the supports they receive should maximize the possibility that the individual will live in his own home and community and be “mainstreamed” with the rest of society.

The shift in the understanding of the nature of intellectual disability was reflected in Pennsylvania’s enactment of the Mental Health and Mental Retardation (MH/MR) Act of 1966, which directs the Department of Public Welfare’s (DPW) administration of the MH/MR systems. The MH/MR Act for the first time required the Commonwealth to

fund community-based mental retardation services. At around the same time, normalization became the official policy of the Commonwealth.

In the early 1970s, Congress enacted the Individuals with Disabilities Education Act (IDEA). IDEA recognized that all people are capable of learning and guaranteed persons with intellectual disabilities the right to a free, appropriate public education in the most integrated setting appropriate to meet their needs. By affording a right to education, IDEA enables many parents to keep their children at home rather than institutionalizing them.

The movement to provide community alternatives to state institutions for people with intellectual disabilities gained further momentum through a number of events. In the 1970s, media exposure of horrific institutional conditions led to a public outcry and to litigation. In Pennsylvania, for example, the Pennhurst State School and Hospital was publicly revealed as deplorable, and multi-year litigation led to a far-reaching consent decree that required Pennhurst residents to receive appropriate community-based services.

In the 1980s, the movement away from institutionalization and toward community integration was further strengthened by Congress's amendment of the federal Medicaid statute. Between enactment of the federal Medicaid law in 1965 and the early 1980s, states could secure federal Medicaid funding only for mental retardation services provided in intermediate care facilities for persons with mental retardation (ICFs/MR). ICFs/MR tended to be congregate, segregated facilities, including state-operated institutions. Recognizing the national trend toward community services, Congress in 1981 allowed states to seek "home and community-based services (HCBS) waivers" to secure Medicaid funding for services that otherwise could not be funded under Medicaid and to target those services to particular populations. HCBS waivers thus afforded state flexibility to provide community services, including habilitation services, vocational services, and behavior therapies to persons with intellectual disabilities. Even more important, HCBS waivers provided the states with a new funding stream that facilitated significant expansion of community services. While the costs of community services

previously had been borne exclusively by the local governments, HCBS waivers gave states the opportunity to tap federal funding to pay more than at least half of the costs of community services.

Pennsylvania promptly took advantage of the HCBS waiver opportunity. In the mid-1980s Pennsylvania received approval for an HCBS waiver that has become known as the “Consolidated waiver.” The Consolidated waiver provides a range of community-based services to more than 14,000 Pennsylvanians with intellectual disabilities. To supplement the Consolidated waiver and provide services for persons who need a less extensive array of supports, Pennsylvania secured approval in 1999 for the Person/Family Directed Support (P/FDS) waiver. The P/FDS waiver provides community supports for more than 7,000 Pennsylvanians. While the Consolidated waiver has no cap on the amount of services that can be provided, an individual in the P/FDS Wavier cannot receive services that cost more than \$22,225 per year.

The most recent boost for community services came in 1999 when the United States Supreme Court decided *Olmstead v. L.C.*¹ In *Olmstead*, the Court held that unnecessary segregation of people with disabilities in state institutions constitutes discrimination that can violate the American with Disabilities Act unless the provision of community alternatives to such individuals would constitute a fundamental alteration in the state’s programs. Subsequently, the Court of Appeals for the Third Circuit, which governs Pennsylvania, held that, at a minimum, states must have an integration plan, with specific benchmarks for discharges to community programs for individuals who are unnecessarily institutionalized.

All of these changes have had a profound impact on the service delivery system in Pennsylvania. At the time Pennsylvania enacted the MH/MR Act in 1966, there were more than 13,000 persons with intellectual disabilities living in numerous state-funded institutions. Today, there are approximately 1,300 people living in these institutions and many state-operated mental retardation institutions have closed. Over the past ten years alone, there has been a 50 percent decrease in the number of persons living in state

¹ OLMSTEAD V. L. C. (98-536) 527 U.S. 581 (1999) 138 F.3d 893.

mental retardation institutions. At the same time, the number of people with intellectual disabilities receiving community services has expanded dramatically. Currently, approximately 47,000 Pennsylvanians with intellectual disabilities receive some type of community services, including nearly 15,000 who receive community residential services. Most of Pennsylvania's funding for community mental retardation services comes from the Consolidated and P/FDS waivers.

The significant increase in the number of Pennsylvanians with intellectual disabilities who live in the community has changed their lives and the lives of non-disabled Pennsylvanians. By living in their own homes and communities, Pennsylvanians with intellectual disabilities can maximize their participation in community life – living, working, socializing, and communicating with their non-disabled peers. The lives of non-disabled persons are enriched by these experiences, and previous stereotypes, prejudices, and fears are slowly but surely being eliminated.

The progress in serving people with intellectual disabilities in Pennsylvania and nationwide is undeniable. Yet, the work is not finished. Public funding for community services has simply not kept pace with demand. Pennsylvania and many other states have waiting lists for community mental retardation services, a direct result of their insufficient system capacity.

A state's system capacity can be measured in different ways, but it is essentially a measure of how effectively the state can provide community-based mental retardation services, expressed as the ratio of individuals with intellectual disabilities to its general population. Pennsylvania's ratio, or system capacity, stands at 146/100,000. It has been determined that a sustained capacity of 200/100,000 is necessary for a state to eliminate waiting lists for MR services. As can be seen, Pennsylvania's capacity falls short of a level at which the system could reach stasis, a point where the number of individuals coming into the system could equal the number of individuals leaving the system. Further discussion of system capacity is found in the section of this report titled, "Pennsylvania and Other States."

In 1999, DPW promulgated “A Long-Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania.” At the time the Plan was published, approximately 14,000 persons were on the waiting list in Pennsylvania, including 411 persons in the “emergency” group who needed services immediately. In many (though not all) of the years since the Plan was published, Pennsylvania has increased funding for community services to provide services to people on the waiting list. Despite these increased allocations, the waiting list today is actually larger than it was in 1999. As of January 2008, there were nearly 21,500 Pennsylvanians with intellectual disabilities on the waiting list. Of that number, more than 4,600 were determined to have “emergency” needs for services and more than 9,500 were determined to have “critical” needs for services within a year or so.

People on the waiting list more often than not, cannot afford to wait. People on the waiting list include:

- middle-aged to elderly men and women who continue to live at home with their even more elderly and infirmed caregivers. Too often, parents who did not institutionalize their children have paid a price. These parents, of course, have usually been the sole caregivers for their loved ones. As they are, they are no longer able to provide their loved ones with the care they need. Yet, they are told that there is no money for services. At times, individuals with intellectual disabilities who live at home have been unable to receive necessary services until their caregivers are deceased or placed in nursing facilities. The strain on these elderly caregivers is unbearable;
- young people who, having secured the benefits of the IDEA’s right to a free and appropriate public education, graduate from school with no or inadequate community services in place. Without community habilitation, employment, vocational, and other services, the progress that they made during their school years will be lost and their skills will regress. In the meantime, their families, many of whom have work or other responsibilities, often are forced to choose between leaving their loved ones home alone where they can be at risk or

abandoning their other responsibilities. For many families, particularly one-parent families, this choice is untenable; and

- individuals who could live in the community but are currently institutionalized. While much progress has been made in funding community alternatives for adults who are institutionalized, the past few years have seen that progress slow to a virtual standstill. Approximately 2,800 Pennsylvanians remain in public and private ICFs/MR. Almost all of these facilities are large and segregated. Many of these individuals would not oppose placement in community programs, yet they remain isolated from society. Since they are already receiving services, they are not considered a priority for any waiting list funding that becomes available.

House Resolution 159 (P.N. 1531) of 2007 directed the Joint State Government Commission to form an advisory committee to study the extent of the waiting list for community-based mental retardation services in Pennsylvania. Members of the Advisory Committee included representatives of stakeholders in the system, including: executive staff of DPW's Office of Developmental Programs; self-advocates (people who are recipients of services) and their families; advocates for individuals with intellectual disabilities; providers; and employees in the service system.

As detailed in this report, members of the Advisory Committee concluded that both the emergency and critical waiting lists can be eliminated within five years if adequate funding is appropriated. Funding is needed both to expand the availability of community services and to train and retain staff who provide those services. For decades, the Commonwealth has provided funding to serve people with intellectual disabilities. It is imperative that the Commonwealth continue to meet this responsibility by adopting and implementing a comprehensive plan that, once and for all, will eradicate the waiting list.

In 2008, the community-based service system is the primary mode of providing services to Pennsylvanians with mental retardation. It is where Pennsylvanians with mental retardation want to live; it is where the U.S. Supreme Court's Olmstead decision

says they have a right to live; and, it is where research has demonstrated they benefit the most. Serving Pennsylvanians with mental retardation is a core function of state government, and state officials have a responsibility to meet all needs within a reasonable period of time.

Mental Retardation, Intellectual Disability, and Developmental Disability

Pennsylvania's Mental Health and Mental Retardation (MH/MR) Act of 1966 defines mental retardation:

“Mental retardation means subaverage general intellectual functioning which originates during the developmental period and is associated with impairment of one or more of the following: (1) maturation, (2) learning and (3) social adjustment.”²

The American Association on Intellectual and Developmental Disabilities (AAIDD) elected recently to recognize intellectual disability as the preferred term for the condition commonly referred to as mental retardation, and offers the following, more detailed definition:³

“The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need of people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.”

² Act of October 20, 1966 (P.L. 96, No. 6).

³ AAIDD, “Frequently Asked Questions on Intellectual Disability and the AAIDD Definition,” http://www.aamr.org/Policies/faq_mental_retardation.shtml, accessed February 12, 2008.

The AAIDD further states:

“With regard to the intellectual criterion for the diagnosis of intellectual disability, limitations in intellectual functioning are generally thought to be present if an individual has an IQ test score of approximately 70 or below. IQ scores must always be considered in light of the standard error of measurement, appropriateness, and consistency with administration guidelines. Since the standard error of measurement for most IQ tests is approximately 5, the ceiling may go up to 75. This represents a score approximately 2 standard deviations below the mean, considering the standard error of measurement. It is important to remember, however, that an IQ score is only one criterion: Significant limitations in adaptive behavior skills and evidence that the disability was present before age 18 are two additional criteria in determining if a person has intellectual disability.”⁴

It is important to note that the terms mental retardation and intellectual disability, which carry the same definition, are not interchangeable with the term developmental disability.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 offers a definition for developmental disability (DD).⁵ The Act says developmental disability is a severe, chronic disability attributed to a mental or physical impairment (or a combination of the two) that is manifested before age 22, is likely to continue indefinitely, and results in substantial functional limitations in three or more of the following areas of major life activity:

- self-care
- receptive and expressive language
- learning

⁴ AAIDD, “Frequently Asked Questions on Intellectual Disability and the AAIDD Definition,” http://www.aaidd.org/Policies/faq_mental_retardation.shtml, accessed April 28, 2008.

⁵ Administration for Children and Families, U.S. Department of Health and Human Services, “The Developmental Disabilities Assistance and Bill of Rights Act of 2000” PUBLIC LAW 106-402--October 30, 2000, 114 STAT. 1677, <http://www.acf.dhhs.gov/programs/add/ddact/DDA.html>, accessed February, 12, 2008.

- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

SUMMARY OF RECOMMENDATIONS

In order to accomplish the primary goal of serving all individuals with intellectual disabilities who need services within a reasonable amount of time, the advisory committee developed five recommendations. While these five recommendations are spelled out in greater detail in the *Recommendations* section of this report, below is a brief summary of these recommendations.

Recommendation 1

The General Assembly and the Governor should make the elimination of the waiting list a priority. Providing supports and services to Pennsylvanians with mental retardation is a core function of Pennsylvania state government. State officials should commit – in word and in action – sufficient funds and other resources that will a) eliminate the emergency waiting list within 2 years b) eliminate the critical waiting list within 5 years, and c) anticipate future need so that all Pennsylvanians with mental retardation have their service needs met within a reasonable period of time.

Recommendation 2

The General Assembly and the Governor should build on their investment in special education and dedicate annual funding to ensure students with mental retardation who are transitioning to adult life receive services they need.

Recommendation 3

The General Assembly and the Governor should establish a fiscal policy that includes a reasonable and consistent increase annually based on actual costs of maintaining existing service capacity.⁶

Recommendation 4

The executive branch should be directed to convene relevant state agencies and stakeholders to identify methods for predicting and communicating needs to the appropriate agencies, and make sufficient information available to inform the budget process.

Recommendation 5

The General Assembly should direct the executive branch to conduct a process – with stakeholder involvement – to examine ways to find greater efficiencies, including more community-integrated and consumer-controlled service models.

⁶ An example of this policy would be to include an annual COLA, based on the Federal CMS Home Health Market Basket Index, for all mental retardation services.

Pennsylvania, like many states, has a waiting list for people who are in need of MR services. In an effort to address the needs of these individuals, Pennsylvania began a series of initiatives in the mid-1980s that were aimed at reducing the wait for services. For decades, money was requested by the Governor and appropriated by the General Assembly to address the need, but the waiting list continued to grow. Families often waited for decades without ever getting services. Over time, it became evident that the system did not address the full scope of the problem.

Counties did not employ a uniform procedure to gather data in support of annual county plans, and individual counties varied widely in their reporting. In some instances, a county's waiting list amounted to little more than a list of names handwritten on a tablet. Moreover, there was a lack of a clear definition of exactly what a waiting list should comprise. As a result, during Fiscal Year 1996-97, DPW's Office of Developmental Programs (ODP) (formerly Office of Mental Retardation) commissioned Temple University's Institute on Disabilities, Pennsylvania's University Center for Excellence in Developmental Disabilities, to conduct a standardized survey of people who were waiting for services and supports in Pennsylvania.⁷ To address these problems in reporting, the Office of Mental Retardation, in collaboration with system stakeholders, developed consistent definitions and data collection methods for determining the size of the waiting list and the characteristics of persons on the waiting list. The system that developed from this effort became known as the Prioritization of Urgency of Need for Services (PUNS)⁸

PUNS serves several vital roles. For the first time, a statewide study captured consistent information about the needs of the unserved and underserved populations with

⁷ Planning Advisory Committee, *A Long Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*, Planning Advisory Committee, OMR, DPW, October 1999, 7.

⁸ Feinstein, Lemanowicz, and Clark, 1999.

intellectual disabilities. Those individuals listed as unserved are those who report receiving no supports from the MR system other than supports coordination.⁹ People listed as underserved are those who are receiving some level of supports but the supports are inadequate to meet the individuals' health and welfare needs. For example, someone living at home with an 85-year-old single mother may be receiving a day support of some kind, but the mother may not be able to continue to provide the support needed in the home or may require assistance of her own, such as in-home supports, chore services, etc. PUNS is a critical planning tool that is used for planning and funding services or supports for persons with intellectual disabilities.

For individuals applying for waiver funding, PUNS provides them and the service system with an initial record of their needs. The person's needs for services are documented in a face-to-face meeting with the supports coordinator. After the meeting, the individual receives a form detailing his or her needs and the urgency of those needs as recorded in PUNS. Each time an individual's needs change, the PUNS is revised.¹⁰

When a person is registered in PUNS, he or she is placed into one of three categories, depending on need:

- Emergency category: those who need services within the next six months;
- Critical category: those more than six months but less than two years from needing services;
- Planning category: those more than two but less than five years from needing services.

Table 1 shows the number of persons in each PUNS category as of January 2008.

⁹ Supports coordination is the service provided to persons with intellectual disabilities that assists them in developing ISPs and provides ongoing oversight of the ISP.

¹⁰ Vision for Equality, Inc., et al. *Understanding the Mental Retardation System in Pennsylvania*, Vision for Equality, Inc., Pennsylvania Waiting List Campaign, Disability Rights Network of Pennsylvania, The Training Partnership for People with Disabilities and Families, February 2007.

TABLE 1
THE WAITING LIST
BY NEED AND PERCENTAGE
JANUARY 2008

	Number of People	Percentage of Total
Emergency	4,617	22%
Critical	9,501	44
Planning	7,357	34
Total	21,475	100

SOURCE: The Pennsylvania Waiting List Campaign, "Prioritization of Urgency of Need for Service Data," http://www.pawaitinglistcampaign.org/WL_County.html, accessed March 10, 2008.

For the MR system, PUNS provides a consistent and standardized record of the population across the Commonwealth. The data are used for planning and funding purposes, and to support compliance with the Centers for Medicare and Medicaid Systems (CMS) regulations. PUNS allows the counties to report data directly to the state in a consistent manner. This information is used by the state to plan for future needs, especially as supporting documentation for county and state annual budget requests.¹¹ In addition, PUNS provides the ability to track legislative initiatives throughout the fiscal year.

Table 2 shows the regional distribution of people who are in each category of need. Of the four regions, Southeast, Northeast, Central, and Western, the highest level of emergency need is, not surprisingly, in the population centers. The Southeast and Western Regions of the state account for 1,999 and 1,106 people in emergency need, respectively. The Cameron/Elk, Clarion, and McKean county systems list only one person in emergency need, while Philadelphia counts close to 1,500 people who are in emergency need of services. The emergency category accounts for 29 percent of the waiting list in the Southeast Region, 23 percent in the Northeast, 20 percent in the Central, and 15 percent in the Western.

¹¹ Planning Advisory Committee, *A Long Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*, Planning Advisory Committee, OMR, DPW, October 1999, 7.

TABLE 2
THE WAITING LIST
BY REGION, COUNTY, AND NEED
JANUARY 2008

Region	County	Emergency	Critical	Planning	Total
Central	Bedford/Somerset	17	56	38	111
	Blair	21	83	49	153
	Cambria	9	66	37	112
	Centre	38	104	48	190
	Columbia/Montour/Snyder/Union	12	153	123	288
	Cumberland/Perry	64	144	111	319
	Dauphin	171	325	176	672
	Franklin/Fulton	3	45	60	108
	Huntingdon/Mifflin/Juniata	52	86	61	199
	Lancaster	232	360	222	814
	Lebanon	16	73	73	162
	Lycoming/Clinton	29	80	40	149
	Northumberland	30	91	55	176
	York/Adams	113	312	249	674
Total	807	1,978	1,342	4,127	
Northeast	Berks	102	203	119	424
	Bradford/Sullivan	11	34	52	97
	Carbon/Monroe/Pike	148	152	58	358
	Lackawanna/Susquehanna	23	132	84	239
	Lehigh	197	284	162	643
	Luzerne/Wyoming	80	213	338	631
	Northampton	119	153	135	407
	Schuylkill	12	62	66	140
	Tioga	3	15	8	26
	Wayne	10	26	14	50
Total	705	1,274	1,036	3,015	
Southeast	Bucks	89	229	218	536
	Chester	75	322	449	846
	Delaware	126	309	255	690
	Montgomery	226	441	333	1,000
	Philadelphia	1,483	1,546	865	3,894
	Total	1,999	2,847	2,120	6,966
Western	Allegheny	455	1,527	1,471	3,453
	Armstrong/Indiana	60	95	89	244
	Beaver	41	100	131	272
	Butler	71	117	97	285
	Cameron/Elk	1	17	22	40
	Clarion	1	10	6	17
	Clearfield/Jefferson	13	107	46	166
	Crawford	7	80	113	200
	Erie	169	547	287	1,003
	Fayette	20	98	73	191
	Forest/Warren	16	28	13	57
	Greene	4	26	16	46
	Lawrence	28	93	90	211
	McKean	1	19	22	42
	Mercer	35	92	113	240
	Potter	6	14	3	23
	Venango	20	41	36	97
	Washington	64	82	36	182
	Westmoreland	94	309	195	598
	Total	1,106	3,402	2,859	7,367
Grand Total	4,617	9,501	7,357	21,475	

SOURCE: The Pennsylvania Waiting List Campaign, "Prioritization of Urgency of Need for Service Data," http://www.pawaitinglistcampaign.org/WL_County.html, accessed March 10, 2008.

The most requested services and supports are similar in each category of need (emergency and critical).¹² In the emergency category, the highest level of need is for transportation, habilitation, community employment, respite supports (less than 24 hour), and respite supports (24 hour). In the critical category the top five supports requested include: transportation, habilitation, respite supports (less than 24 hour), community employment and respite supports (24 hour).

¹² The Pennsylvania Waiting List Campaign, "By Region, County Joinder, Urgency of Need and Service Need Name," http://www.pawaitinglistcampaign.org/WL_County.html, accessed April 7, 2008.

Over the past couple of decades, the aging population has been a growing concern for policymakers in fields as diverse as financial markets to human services. The baby boom generation is fully expected to place enormous strains on existing systems as it ages. The aging phenomenon will be felt particularly hard by individuals with intellectual disabilities and their care providers.

Dr. David Braddock notes in *The State of the States in Developmental Disabilities, 2005*, that with the number of persons over age 65 expected to double over the next 30 years, there will be increased demand for services for people with intellectual disabilities who currently reside with aging family caregivers.¹³ According to Dr. Braddock, in 2004 approximately 2.8 million of the 4.6 million people with mental retardation / developmental disabilities (MR/DD) in the U.S. were receiving residential support from family caregivers. It was estimated that 710,000 (25 percent) were living with caregivers age 60 and over. This arrangement, where people are cared for in family homes by relatives, serves about six times the number of people served by the formal out-of-home residential care system.¹⁴ Further analysis shows that an additional 35 percent of people are living in “transitional” households, meaning that family caregivers were middle-aged and transitions for the people with intellectual disabilities from home to out-of-home services were a near-term consideration.

Moreover, increased longevity of people with intellectual disabilities places further demand on systems. People with MR/DD who live longer may require more intensive services and supports than the aging population in general. The capacities of the states’ systems, which are responsible for their care, are directly affected by their needs. The substantial increase in the number of the intellectually disabled who outlive

¹³ Braddock, David, et al, *State of the States in Developmental Disabilities: 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado, 2005. 2.

¹⁴ *Ibid.*, 2, 58.

family caregivers is placing considerable demands on state systems. The mean life expectancy of a person with ID was 66 years in 1993, whereas it had been 59 years during the 1970s. With improved care and medical advances, people with ID are expected to soon have a life expectancy equivalent to that of the general population. Over the past three decades the improved life expectancy has increased the demand for residential services by an estimated 10 percent to 20 percent.¹⁵

Table 3 shows the 2004 estimated numbers of people with intellectual disabilities who live with aging caregivers in all 50 states. With 37,288 people living with aging caregivers, Pennsylvania lags only California, (75,748), Florida (59,868), New York, (45,486), and Texas (44,533).¹⁶

It is widely accepted among people working with the MR system in Pennsylvania that the aging population will strain the community-based services systems across the Commonwealth. Table 4 shows the number of Pennsylvania's residents with intellectual disabilities on the waiting list and the number of aging caregivers who are caring for people on the waiting list. The table breaks the data down by PUNS category, as well.

There were 583 people, 13 percent, on the emergency list with a caregiver age 60 or older in 2007. The critical list contained 2,174 people, 23 percent, with a caregiver age 60 or older, which has decreased from about 33 percent in 1999.¹⁷ Overall, 20 percent had an aging caregiver in 2007, which is down from 38 percent in 1999.

¹⁵ Ibid., 59

¹⁶ Ibid., 60.

¹⁷ Planning Advisory Committee, *A Long Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*, OMR, DPW, October 1999, <http://www.keystonehumanservices.org/pdf/mrwaitlist1.pdf>, accessed December 5, 2007.

TABLE 3
 PERSONS WITH MR/DD LIVING WITH A CAREGIVER AGE 60
 OR OLDER BY STATE 2004

State	Number of People	State	Number of People
Alabama	12,138	Nebraska	4,548
Alaska	796	Nevada	5,223
Arizona	14,391	New Hampshire	3,075
Arkansas	7,129	New Jersey	22,734
California	75,748	New Mexico	4,478
Colorado	8,756	New York	45,486
Connecticut	9,385	North Carolina	19,268
Delaware	2,187	North Dakota	1,723
District of Columbia	1,233	Ohio	30,220
Florida	59,868	Oklahoma	9,088
Georgia	17,145	Oregon	9,363
Hawaii	3,584	Pennsylvania	37,228
Idaho	2,910	Rhode Island	2,989
Illinois	30,482	South Carolina	10,410
Indiana	14,417	South Dakota	1,948
Iowa	7,574	Tennessee	14,749
Kansas	7,013	Texas	44,533
Kentucky	10,526	Utah	4,100
Louisiana	10,110	Vermont	1,560
Maine	3,365	Virginia	17,215
Maryland	12,822	Washington	13,518
Massachusetts	17,027	West Virginia	5,082
Michigan	24,818	Wisconsin	12,636
Minnesota	11,275	Wyoming	1,199
Mississippi	6,788		
Missouri	15,201	Total	711,474
Montana	2,413		

SOURCE: Braddock, David, et al., *The State of the States in Developmental Disabilities: 2005* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2005.

TABLE 4
AGING PENNSYLVANIA CAREGIVERS
BY NEED AND PERCENTAGE
SEPTEMBER 2007

Need	Number of people with caregivers age 60 or older	Number of people on the waiting list	Percentage of people with caregivers age 60 or older
Emergency	583	4,407	13%
Critical	2,174	9,346	23
Total	2,757	13,753	20

SOURCE: Caregivers - Pennsylvania Department of Public Welfare; Waiting List - The Pennsylvania Waiting List Campaign, "Prioritization of Urgency of Need for Service Data" Available at http://www.pawaitinglistcampaign.org/WL_County.html, accessed November 29, 2007.

THE FUNDING STREAM

The Federal Government plays an indispensable role in funding state MR systems, as is the case with most publicly provided human services. Most of these funds are funneled to the states through a number of so-called waiver programs that address a variety of public health and welfare needs. Generally speaking, CMS provide about 50 percent of the funding for mental retardation services.

About 80 percent of the CMS funding received by Pennsylvania comes through the Medicaid Waiver Programs. In 1981, the federal government began to allow states to shift medical assistance funding from institutional settings to integrated community-based settings. The Home and Community-Based Systems (HCBS) program “waives” the regulations that require spending on institutional care. As a result, recipient states can use the money for supports and services to people living in the community.

Traditional Medicaid funding that flows to Pennsylvania provides for institutional care, in the form of state-operated mental retardation centers, and private Intermediate Care Facilities (ICFs/MR). Additionally, there exist two HCBS waiver programs, known as the Consolidated waiver and the Person/Family Directed Support (P/FDS) waiver.

A person who is eligible for care in a state center or an ICF/MR, and chooses to be placed there, is entitled by law to services through those facilities. There is no state-maintained waiting list for those persons, so the number of persons who may be awaiting services is not known. People who are eligible for services through the HCBS waivers, either the Consolidated or the P/FDS waivers, may have to wait for services to be provided to them. There is no federal legal entitlement to services through the waiver programs until the person is admitted into the waiver. Once accepted into the waiver, the person’s needs must be met (up to the cap in the P/FDS waiver, completely in the Consolidated waiver).

The Consolidated waiver is not capped. In other words, there is no financial limit on the services received through it, although the average statewide costs cannot exceed the cost of serving a similar person through an ICF/MR. The P/FDS waiver is currently capped at \$22,525 per year for each participant.¹⁸

The Consolidated waiver provides services, such as:

- In-home supports in one's own home, a family home, or Family Living
- Day habilitation
- Pre-vocational services
- Supported employment services
- Educational services
- Chore services
- Specialized therapy
- Extended State Plan services, including physical therapy; occupational therapy; behavior therapy; visiting nurse; visual/mobility therapy; and speech, language, and hearing services
- Permanency planning for children and youth
- Respite care
- Accessibility adaptations to home or vehicle
- Transportation

The P/FDS waiver provides services such as:

- Day habilitation
- Pre-vocational services
- Supported employment services
- Homemaker/chore services
- Extended State Plan services, including physical therapy; occupational therapy; behavior therapy; visiting nurse; visual/mobility therapy; and speech, language, and hearing services

¹⁸ Vision for Equality, Inc., et al., *Understanding the Mental Retardation System in Pennsylvania* Vision for Equality, Inc., Pennsylvania Waiting List Campaign, Disability Rights Network of Pennsylvania, The Training Partnership for People with Disabilities and Families, February 2007. 36.

- Respite care
- Accessibility adaptations to home or vehicle
- Adaptive appliances and equipment
- Personal support
- Transportation

The bulk of funding that is available to persons with intellectual disabilities comes from the HCBS waiver programs. Forty-eight states and the District of Columbia offer services through HCBS waivers.

PENNSYLVANIA

Pennsylvania served 49,825 people in the MR system in FY 2006-07, for which the total State and Federal budget was \$2.08 billion. The Consolidated waiver program provided services to over 14,000 individuals, and the P/FDS waiver served more than 7,700. Almost half of the people with intellectual disabilities, slightly more than 23,600, received services through the Base¹⁹ program. Private ICFs/MR served 2,600. The state centers accounted for slightly fewer than 1,300 individuals. On a per person basis, the state centers are by far the most expensive. The annual cost per person at a state center is \$182,912. Base services account for the lowest per person costs, at \$9,544 per person. When total expenses, rather than per person expenses, are considered, the P/FDS waiver amounted to the lowest amount at \$99.3 million. See Table 5.

¹⁹ Base funding is state funding from the PA Office of Developmental Programs that is provided to county MR departments as required by the Mental Health and Mental Retardation Act of 1966.

TABLE 5
 MENTAL RETARDATION SYSTEM
 FISCAL YEAR 2006-07

	Number of People	Funding (in dollars)	Funds/Person (in dollars)
Base	23,694	\$226,132,592	\$9,544
Consolidated Waiver	14,359	1,198,621,983	83,475
P/FDS Waiver	7,772	99,251,758	12,770
Private ICF/MR	2,619	304,462,000	116,251
State Centers	1,381	252,602,000	182,912
Total	49,825	2,081,070,333	41,768

SOURCE: Bureau of MR Program Support, Office of Developmental Programs, Pennsylvania Department of Public Welfare, meeting with Joint State Government Commission, November 20, 2007.

In fiscal year 2007-08, about \$1.1 billion was budgeted from Pennsylvania’s General Fund for services to people with intellectual disabilities.²⁰ Specifically, \$107 million was allocated for the state centers and \$125 million for ICFs. The largest allocation, \$868 million, went to community mental retardation services.

The Federal Medical Assistance Percentage (FMAP) is utilized in calculating the portion of Medicaid expenditures that the federal government reimburses a state based on their per-capita income.²¹ The FMAP in Pennsylvania is 54.08 percent for 2008. This means that for every \$100 spent on services and populations covered by Medicaid, the federal government pays \$54.08 and the Commonwealth pays \$45.92. All of the institutional facilities providing services for people with intellectual disabilities are certified for Medical Assistance under CMS.²² Also, most community mental retardation services are eligible for Federal funds under the HCBS waiver.

²⁰ Act No. 8A of July 17, 2007 (Pennsylvania General Appropriation Act of 2007).

²¹ Pennsylvania Medicaid Policy Center, University of Pittsburgh “The Basics of Medical Assistance in Pennsylvania” Available at http://www.pamedicaid.pitt.edu/documents/basic_5%2020%20pak%20_3_.pdf, accessed December 12, 2007.

²² Commonwealth of Pennsylvania “2007-08 Governor’s Executive Budget” Available at http://www.budget.state.pa.us/budget/lib/budget/budget_presentation/2007_08_budget_document.2.pdf, accessed December 12, 2007.

Additionally, \$10 million of state money was budgeted for autism, \$3 million for the closure of the Pennhurst state center, and about \$1 million for residential services for persons with intellectual disabilities in the Lansdowne area.²³

In fiscal year 2007-08, about \$1.2 billion was matched in medical assistance from the Federal government for mental retardation. Specifically, \$155 million was provided for the state centers and \$178 million for ICFs. The HCBS waivers were allocated \$837 million in Federal money. By comparison, the Federal match for autism was about \$13 million.

There are a few other sources of funding for people with intellectual disabilities who are in need of services not provided by the HCBS waiver programs. The Office of Vocational Rehabilitation (OVR) in the PA Department of Labor and Industry provides job training and coaching and is generally available to individuals on a time-limited basis. Supplemental Security Income (SSI) is available to eligible individuals, although they cannot have countable assets of more than \$2,000. DPW administers the Medical Assistance for Workers with Disabilities (MAWD), a state medical assistance program which encourages people to work. MAWD lets persons with disabilities earn more money than normal Medicaid income limits in exchange for paying a premium of five percent of their monthly income. Another program is the state Family Driven Support Service Funding (FDSS) stream, which is generally a small amount of funding awarded on a yearly basis that allows consumers and families to choose the services or supports they need within a loosely defined menu.

State Base Funding is appropriated through ODP for the counties' MR departments as required by the MH/MR Act of 1966.²⁴ This funding is generally placed into "categoricals" such as: residential, day programs, group homes, and the Lifesharing program. This funding is becoming more limited as Pennsylvania turns to federal dollars to support community programs.

²³ Act No. 8A of July 17, 2007 (Pennsylvania General Appropriation Act of 2007).

²⁴ Act of October 20, 1966 (P.L. 96, No. 6).

NATIONAL PROFILE

It is significant to note that there has been no national survey of persons with mental retardation or developmental disabilities since the 1994-95 National Health Interview Survey (NHIS-D), entitled “Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D.”²⁵ The National Health Interview Surveys are conducted by the National Center for Health Statistics at the Federal Centers for Disease Control and Prevention (CDC).

According to a *DD Data Brief* published in June 2005 by the Research and Training Center on Community Living at the University of Minnesota, there are no plans to conduct further surveys. The authors of the June 2005 *DD Data Brief*, however, drew conclusions from refining existing data and predicted that there were 2,032,000, (0.78 percent of the total population), persons with mental retardation who were in the “household population.” In other words, they were not institutionalized.²⁶

A primary resource on states’ MR/DD programs is *The State of the States in Developmental Disabilities 2005*,²⁷ a national survey of states’ expenditures and policies. It is published through the University of Colorado. According to the ‘State of the States,’ the national expenditure on MR/DD funding was \$38.56 billion in 2004. The expenditures have been steadily climbing since 1977, and more than tripled from \$10.46 billion in 1977 to \$38.56 billion in 2004, a growth of about five percent per year. During this same time frame, the portion of unmatched state and local funds fell from 57 percent

²⁵ Larson, Sheryl A. K. Charlie Lakin, and Robert Doljanac, “Problems in Defining Mental Retardation and Developmental Disability: Using the National Health Interview Survey,” *DD Data Brief*, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Vol. 7, No. 1, June 2005.

²⁶ *Ibid.* 4.

²⁷ Braddock, David, et al., *The State of the States in Developmental Disabilities 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2005.

in 1977 to 14 percent in 2004. In absolute dollar terms, the portion of unmatched state and local funds remains at around \$5 billion per year, with a high point of about \$7 billion in the years 1989 – 1990.

During the years 1977 – 2004, the MR/DD system saw a huge growth in dollar support for community services (which correlates with changing philosophies about how best to serve people with intellectual disabilities). Community services programs garnered about \$3 billion in support in 1977 and grew in importance steadily to a high of just over \$30 billion in 2004. These years saw a relatively steady allotment of funding for institutional settings, for most years remaining close to \$8 billion in 1977 to around \$7 billion in 2004.

The years 1990 and 1991 saw financial support for institutional settings of just over \$10 billion in each. As a portion of overall funding, however, institutional settings receive less and less support. In 1977 institutional settings nationwide received nearly triple the funding that community-based services did. In 1989, community settings surpassed institutional settings for the first time. By 2004, community settings were receiving over four times the funding of institutional settings.

Individual and Family Supports (IFS) were merely a blip on the national screen in 1989, with well below \$1 billion in support. IFS support grew steadily in the years leading up to 2004. With roughly \$6 billion in funding, IFS is close to overtaking institutional settings in terms of funding.

The Home and Community-Based Services (HCBS) waiver is the principal Medicaid program that provides funding for long term care, which amounted to \$9.2 billion in 2004.²⁸ Dr. Braddock estimated that 73 percent of the total MR/DD spending in the U.S. was committed to settings of six-or-fewer people.²⁹

Pennsylvania was among the group of states that provided the greatest number of people with services, as well as among the states that had the greatest expenditures on

²⁸ Ibid.

²⁹ Ibid. 16.

MR/DD services. Pennsylvania, California, Florida, and New York each serve between 24,000 and 57,000 participants in the HCBS waiver program. In terms of total dollars spent, Pennsylvania ranks near the top along with California, Florida, Massachusetts, Minnesota, New York, Ohio, and Wisconsin.

The number of participants in the HCBS waiver program grew significantly from a low point of 1,379 in 1982 to over 416,000 in 2004, a growth of over 300 percent. Likewise, waiver spending per participant grew from \$3,200 in 1982 to \$37,800 in 2004, a nearly eleven-fold increase in per person funding.

Table 6 shows states' spending on MR services, as a measure of dollars per \$1,000 of personal income of their resident populations. In the three years shown, 1984, 1994, and 2004 New York ranks first in spending per \$1,000 of personal income, topping out at \$7.49 in 2004. While Pennsylvania's expenditures increased in each of the years, its rank relative to 12 other states studied fell from fourth in 1984, with \$3.52/\$1,000 personal income, to fifth in 1994 with \$4.22, to sixth in 2004 in spending \$5.33/\$1,000 personal income. The national averages were \$2.58/\$1,000 personal income for 1984, \$3.47 for 1994, and \$4.11 for 2004.

Table 7 shows, in 2004 dollars, states' waiver spending per participant for the years 1984, 1994, and 2004. Eight of the states did not have waiver expenditures in 1984. Of the five states that did, Pennsylvania led the way with \$35,200 per participant. States that had been lagging quickly caught up and overtook the states that had been participating in 1984. In 2004, Tennessee, which reported no waiver expenditures in 1984, spent \$65,000 per participant, which gave it top ranking. Connecticut, likewise, had no waiver expenditures in 1984, yet ranked second in expenditures in 2004 with \$62,100. Pennsylvania dropped from first in 1984 to second in 1994 in spending \$67,500 per person, to sixth in 2004 in spending \$43,500 per person. The national average for these periods was \$14,500 in 1984, \$33,200 in 1994, and \$37,800 in 2004.

TABLE 6
 MENTAL RETARDATION SPENDING PER \$1,000 OF PERSONAL INCOME
 OF SELECT STATES AND THE UNITED STATES 1984, 1994 AND 2004

State	Mental retardation spending per \$1,000 of personal income		
	1984 (in dollars)	1994 (in dollars)	2004 (in dollars)
California	\$1.98	\$2.89	\$3.57
Connecticut	3.26	6.02	7.03
Colorado	1.99	2.28	2.33
Florida	1.68	1.55	2.40
Maryland	1.92	2.54	2.60
Massachusetts	3.95	5.14	4.87
Minnesota	4.38	5.53	7.07
Missouri	2.24	3.19	3.27
New York	4.68	6.35	7.49
Pennsylvania	3.52	4.22	5.33
Ohio	3.08	4.22	5.66
Tennessee	1.63	2.03	3.92
Wisconsin	2.93	4.18	5.41
United States	2.58	3.47	4.11

SOURCE: Braddock, Hemp, & Rizzolo, Coleman Institute and Department of Psychiatry, University of Colorado, 2005.

TABLE 7
 WAIVER SPENDING PER PARTICIPANT OF SELECT STATES
 AND THE UNITED STATES 1984, 1994 AND 2004

State	Waiver spending per participant		
	1984 (in thousands of 2004 dollars)	1994 (in thousands of 2004 dollars)	2004 (in thousands of 2004 dollars)
California	a	\$20.7	\$20.2
Connecticut	a	79.9	62.1
Colorado	\$32.4	42.3	37.8
Florida	10.4	18.8	27.7
Maryland	32.9	40.8	39.3
Massachusetts	a	51.8	47.7
Minnesota	a	39.6	56.0
Missouri	a	35.8	28.9
New York	a	31.1	52.0
Pennsylvania	35.2	67.5	43.5
Ohio	a	37.0	38.8
Tennessee	a	17.6	65.0
Wisconsin	10.9	27.6	37.1
United States	14.5	33.2	37.8

a. Data not applicable because state did not have any waiver participants in 1984.

SOURCE: Braddock, Hemp, & Rizzolo, Coleman Institute and Department of Psychiatry, University of Colorado, 2005.

Dr. Braddock addressed the problems associated with direct support staff wage issues in *The State of the States*.³⁰ There are serious nationwide deficiencies in the recruitment and retention of direct care staff in community day and residential programs. Citing published studies, Dr. Braddock noted that excessive staff turnover directly affects persons with intellectual disabilities, magnifying their sensitivity to disruptions in the nurturing, consistency, and understanding on which they rely.

³⁰ Braddock, David, et al., *The State of the States in Developmental Disabilities 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2005, 23.

Dr. Braddock found, in a large nationwide sample of providers, that starting and average wages were significantly correlated with turnover in community residential programs. Three general economic constraints were identified in the recruitment and retention of direct care workers:

- rapidly increasing health insurance costs
- growing demand in competing service industries
- the advantage that private sector employers have over the publicly funded human services system

Dr. Braddock surmises that legislative control over the costs of care is leveraged in the areas of staff wages and benefits, which constitute 60 to 70 percent of community program budgets. According to the U.S. Bureau of Labor Statistics, in 2003 direct care wages in privately operated, community-based long-term programs were well below the wages of all workers covered by unemployment insurance. The wages approximated the 2001 poverty level for a family of four.

Moreover, the Bureau of Labor Statistics, in 2001, projected a demand for direct care staff in disabilities to grow by 63 percent by 2010. This growth is more than double the expected need for “nursing aides, fast food workers, and all occupations.”³¹

PENNSYLVANIA AND OTHER STATES

The April 1999 paper by Gary Smith, “Serving & Waiting: The Question of System Size,” addresses the capacity of MR/DD systems to serve individuals in need.³² Mr. Smith stated that sufficient service capacity was necessary to prevent the growth of waiting lists in the short run. In the long run, elimination of waiting lists is contingent upon the system’s ability to expand capacity in the face of demographic factors such as

³¹ Braddock, 25.

³² Smith, Gary, “Serving & Waiting: The Question of System Size,” an appendix to *Closing the Gap, Addressing the Needs of People with Developmental Disabilities Waiting for Supports*, National Association of State Directors of Developmental Disabilities Services, Inc., Alexandria, VA, May, 1999.

population growth, aging family caregivers, and young people graduating from special education.

Mr. Smith measured the relative sizes of waiting lists in two ways. One measure is the number of individuals waiting as a proportion of the number served. The other is the number waiting as a proportion of the state's general population. Mr. Smith found that there is a "quantifiable, inverse relationship between relative system size and the relative size of a state's waiting list."³³ Relatively speaking, the larger the system, the smaller the waiting list.

Mr. Smith defined capacity as the sum of (a) the number of individuals receiving residential services and supports and (b) the number of individuals who live with family and are recipients of the HCBS waiver. The measure of the capacity is this sum per 100,000 people.

Mr. Smith concluded that "when a state's system capacity was less than 200 [persons receiving services] per 100,000 population, the state was more likely to have a waiting list."³⁴ As a state's capacity falls, its waiting list grows. Seen another way, as a state's capacity to serve grows beyond 200 per 100,000 population it becomes increasingly likely that the state will have relatively small, if any, waiting list. Based on Mr. Smith's measure, Pennsylvania's capacity is 146/100,000 population.

Some of the states have initiated programs and policies aimed at reducing their waiting lists. This report highlights the efforts of a selection of twelve states, along with data reported in *Residential Services for Persons with Developmental Disabilities: States and Trends Through 2006* by the Research and Training Center on Community Living, Institute on Community Integration/UCEDD at the University of Minnesota.

Much of the information in the following section was gathered for the Advisory Committee via email through the Pennsylvania Developmental Disabilities Council.

³³ Ibid., 1.

³⁴ Ibid., 4.

California

The state of California does not compile a waiting list for MR/DD services because by law such services are an entitlement. Section 4502 of California's Welfare and Institutions Code contains language that guarantees the right to treatment, habilitation, education, medical care, social and physical activities, among others. The advisory committee noted that people's needs are not necessarily met simply because a state guarantees services and does not maintain a waiting list.

Two recent court decisions were made in favor of persons with disabilities in California. In the first, class-action status was granted to over 7,000 persons with developmental disabilities who filed for placement in community settings. In the second, an agreement requires San Francisco to provide community-based services within a reasonable period of time to persons who are eligible and capable of residing in community settings.³⁵

Colorado

There are currently 3,746 individuals with developmental disabilities on a waiting list to receive services in Colorado.³⁶ The state organizes its waiting list based on categories of need:³⁷

- Comprehensive (intensive residential, daytime, and other needs)
- Supported Living (daytime supports plus other in-home family supports)
- Family Supports & Early Intervention

³⁵ National Association of State Directors of Developmental Disabilities Services, "Litigation Updates, May 2007 to January 2008," [http://www.nasdds.org/pdf/LitigationUpdates\(2-2008\).pdf](http://www.nasdds.org/pdf/LitigationUpdates(2-2008).pdf), accessed April 2, 2008.

³⁶ The Imagine! Initiative website, <http://www.imaginecolorado.org/initiative.htm>, accessed December 3, 2007.

³⁷ Smith, Gary A., "Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports," National Association of State Directors of Developmental Disabilities Services, Inc., Gary A. Smith., Alexandria, VA, May 1999.

The waiting list is further organized by those who need services immediately, within twelve months, within two years and those who can wait longer than two years.

There are two modes evident in the data. There is a population bubble of young people in transition from special education and a population of elderly people with intellectual disabilities.³⁸ Colorado state Representative Michael Garcia proposed legislation that would increase the state's sales tax to generate up to \$240 million per year to fund services and care for people with developmental disabilities.³⁹

A lawsuit initiated against the state of Colorado over the extensive waiting list was unsuccessful. It had been dismissed based on the fact that services are optional Medicaid services, i.e. the state is not obligated to provide them under an HCBS waiver. Further, the court found that allocations for spending on Medicaid waiver programs are the purview of state legislatures and not the courts. The appeal was filed in March 2005. The Arc of Colorado reported that the appeal was denied in May 2006. The U.S. Supreme Court declined to hear further appeals in March 2007.⁴⁰

Connecticut

Connecticut classifies individuals on its waiting list as Emergency; needing services within one year; needing services within two years; and needing services within three years. Its system is similar to Colorado's in that the population of people needing services is growing faster than the capacity to serve them.

Connecticut has 125 filled slots in a waiver program targeted at children, with 140 people on the waiting list. Although legislation was passed to expand the waiver to 180 children, as of January 2006 the funds were not yet available.

The Connecticut Department of Mental Retardation had been appropriated for FY 2007 funding for 150 new residential placements and 100 in the category of family

³⁸ Ibid.

³⁹ O'Connell, J.C., "Garcia Proposes Tax Hike to Shorten Wait," The Aurora Sentinel, Wednesday, September 5, 2007.

⁴⁰ The Arc of Colorado, "Waiting List Lawsuit, Current Situation," <http://www.thearcofco.org/current.html>, accessed April 2, 2008.

support. There are 751 people who live with their parents and who are considered “urgent.” There is no official count of people with developmental disabilities on waiting lists.

Florida

A report of the Florida legislature cited 17,467 individuals on the waiting list for the HCBS waiver as of May 3, 2006.⁴¹ Of these people, 5,798 were receiving services from the Family and Supported Living waiver. Approximately 85 percent of people on the waiting list have been waiting for five years or less. According to the report, during fiscal year 2005-06, nearly 10,500 individuals were offered waiver services and 28 percent declined to enroll. A total of \$851.5 million was expended on HCBS and Family and Supported Living waivers in FY 2006-07.

The report makes three recommendations. It suggests that the state’s Agency for Persons with Disabilities should obtain and maintain accurate information about individuals on the list. It recommends that the agency maintain better information for projecting future needs for waiver services. Finally, the report recommends that the agency develop a multi-year plan for addressing the state’s waiting list for waiver services.

Maryland

Maryland’s waiting list expanded because improved outreach and effective information dissemination have contributed to a significant growth in the number of applications from individuals and families for services.

⁴¹ Office of Program Policy Analysis & Government Accountability, “APD Waiting List Should Be Improved for Agency’s Planning and Budgeting Purposes,” OPPAGA Report No. 06-54, Florida Legislature, July 2006.

Maryland began a waiting list initiative in FY 1999. The initiative focused on providing more money for Individual Support Services, Family Support Services, Residential Services and Day services.⁴²

For FY 2002, Maryland's total DD spending was \$460,426,959, with a total of \$102,612,021 committed to the waiting list initiative.⁴³ The initiative provided the following funds, per recipient:⁴⁴

- day services, \$11,464;
- individual support services, \$6,002;
- family support services, \$2,745; and
- residential services, \$24,324.

By FY 2003, the initiative exceeded goals by serving 54 percent more individuals than had been anticipated.⁴⁵ Overall, there was a 30 percent increase in the number of people receiving services over the period 1998 – 2003.⁴⁶

Massachusetts

The wait for mental retardation services in Massachusetts was most significantly decided not by state policy, but by a court order. In January 2001, a judge ruled in favor of plaintiffs in “Boulet vs. Cellucci,” a class action lawsuit that claimed the plaintiffs were being unfairly denied access to services.

The decision required Massachusetts to provide services to 2,437 individuals who had been on waiting lists.⁴⁷ As a result, \$114 million was allocated to their supports, with \$85 million in new funding. Boulet funding reflected a tripling of new dollars for those

⁴² Maryland Department of Health and Mental Hygiene, “Developmental Disabilities Administration, The Waiting List Initiative, FY 1999-2003,” n.d.

⁴³ Ibid., 2, 10.

⁴⁴ Ibid.

⁴⁵ Ibid., 3.

⁴⁶ Ibid., 10.

⁴⁷ Sarkissian, Leo, “A Retrospective on the Boulet Settlement,” The Arc of Massachusetts, n.d.

on the Waiting List when compared to legislative appropriations from fiscal years 1998 through 2000.

Evidently, the Massachusetts Department of Mental Retardation does not characterize individuals as waiting if they are receiving any type of service. However, it is estimated that 522 individuals are still awaiting services under the Boulet decree. Other states, such as Pennsylvania, count people on waiting lists if they are currently receiving services but await additional services.

Individuals who were not part of the Boulet settlement are being placed on waiting lists. At this time, it is estimated that over 200 people are on these waiting lists, and the number is expected to grow.

Minnesota

In 1987, the Minnesota legislature created the Office of the Ombudsman for Mental Health and Developmental Disabilities to:

“...promote the highest attainable standards of treatment, competence, efficiency, and justice... for persons receiving services or treatment for mental illness, mental retardation or a related condition, chemical dependency, or emotional disturbance...”⁴⁸

Missouri

The Arc of Missouri provided the advisory committee with information on the development of plans to eliminate the waiting list in that state.⁴⁹ Primarily, the effort was based on a senate bill that appropriated extra money to serve individuals on the list. The Missouri Division of Mental Retardation and Developmental Disabilities (MRDD) published “Waiting List Management Advisory Team Response to Senate Bill 266,” in

⁴⁸ Office of the Ombudsman for Mental Health and Developmental Disabilities, State of Minnesota, <http://www.ombudmhm.state.mn.us/>, accessed May 28, 2008.

⁴⁹ Missouri Department of Mental Health, Division of Mental Retardation & Developmental Disabilities, <http://www.dmh.missouri.gov/mrdd/issues/waitlist/reports.htm>, accessed December 4, 2007.

November 2003.⁵⁰ The central component of the plan was an appropriation of \$5 million to meet the needs of 203 of 641 people on the waiting list, mostly through residential services. It was hoped that waiting times would be no longer than 90 days provided there was a continued growth in Medicaid funding.

In conjunction with the new appropriation, the state planned to continue its efforts to reduce the waiting list through three programs.⁵¹ It would continue to utilize waivers to enhance funding; continue to expand relationships with county MRDD boards; and reduce the list through attrition.

The Missouri MRDD reported 4,186 individuals waiting for residential and in-home services as of August 31, 2007.⁵² It has been suggested that,

“families are afraid to attempt to transition young people to living independently due to the risks brought about by Missouri’s shortage of funds and community services.”

Such a phenomenon was evident in Pennsylvania prior to the development of the PUNS system. It is widely held that the intellectual disability community was frustrated and mistrustful of public initiatives, believing it was fruitless to sign on to waiting lists.

Missouri spent \$561.8 million in total MRDD funding in 2004, of which 19 percent was unmatched state and local funding. Its HCBS waiver program served 8,111 persons. All told, Missouri spent \$28,900 for each participant in its waiver programs.⁵³

⁵⁰ Deaton, Anne S., Dr. Director, Division of MRDD, “Waiting List Management Advisory Team Response to Senate Bill 266,” The Missouri Division of Mental Retardation and Developmental Disabilities.

⁵¹ Ibid.

⁵² DRMDD, “State Wide Wait List Report Utilization Review,” August 31, 2007, <http://www.dmh.missouri.gov/mrdd/issues/waitlist/documents/2007Aug.pdf>, accessed May 28, 2008.

⁵³ Braddock, David, et al., *The State of the States in Developmental Disabilities 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2005.

New York

The New York Office of Mental Retardation and Developmental Disabilities maintains two waiting lists: one for out-of-home residential services and one for children who have medically complex needs and are awaiting services under the Care at Home Medicaid waiver. There are no other statewide waiting lists maintained by the state.

In 1998 the state introduced a five year plan called New York State Creating Alternatives in Residential Environments & Services (NYS-CARES). The NYS-CARES program was created to provide services for those on the waiting list for residential service and to build capacity for future needs.⁵⁴ At the time, nearly 31,000 people were being served in community placements. The plan was designed to add 4,000 new beds and approximately 1,000 new day services, and meet the needs of 8,100 people.

The plan would eliminate the waiting list for community beds within the five years allotted by creating 977 placements annually. The five year initiative was projected to cost \$130 million in state funding. Overall, including federal Medicaid funding, the cost was projected at \$228 million.

The NYS-CARES program has served almost 12,000 people since its inception in 1998. Approximately 100 residential opportunities are created each month. The waiting list for the Care-at-Home waiver, which serves children under the age of 18, fluctuates monthly.

Ohio

There are several types of waiting list in Ohio, but no statewide list. The state department of Mental Retardation Developmental Disabilities has not collected waiting list data for several years. County MR / DD boards are responsible for maintaining their own lists. It is estimated that about 1,500 people are not receiving services of any kind

⁵⁴ New York Office of Mental Retardation and Developmental Disabilities (OMRDD), "Governor Announces 'NYS-CARES' To Reduce Housing Waiting List," OMRDD, press release August 19, 1998, http://www.omr.state.ny.us/nyscares/hp_nyscares.jsp, accessed December 7, 2007.

and that a further 2,500 are receiving services but are waiting to move to a community-based program (either supported living or HCBS).

The Ohio Waiting List Campaign led the state to redesign the MR/DD Medicaid system. The redesigned system allowed the state to use county MR/DD dollars as a match for Medicaid funding. As a consequence, the state's share of budgeted funding for MR/DD programs has declined.

In Ohio, roughly 60 percent of people with intellectual disabilities reside with family caregivers. As many of the caregivers are aging, Ohio stands to face the same problems Pennsylvania does in this regard. The current waiting list policies in Ohio help to address this issue by prioritizing individuals into four categories: Individuals whose funding can be refinanced through Medicaid matching; individuals living with aging caregivers (age 60+); children with intensive needs; and adults with intensive needs. Individuals with emergency needs are given highest priority.

Tennessee

Over 22,600 individuals are on the waiting list in Tennessee; it is not known, however, how many people are eligible for services but are not on the waiting list.⁵⁵ The state's Division of Mental Retardation Services was developing a plan to increase outreach efforts to identify people who are not on the list but who are in need of services. Legislation was proposed in the Tennessee Senate that established a time table to expand the state's Self Determination waiver by 4,000 slots and its comprehensive services program by 3,000 slots beginning in 2009 and ending in 2013.⁵⁶

Class action lawsuits were filed by Tennessee Protection & Advocacy and People First.⁵⁷ In 2004 a federal district court approved of settlements in the lawsuits. The results of the settlement:

⁵⁵ Edwards, Holly, "State Ready to Help Mentally Disabled Get Housing, Therapy," *Tennessean.com*, February 11, 2005.

⁵⁶ "An Act to amend Tennessee Code Annotated, Title 33, relative to mental retardation."

⁵⁷ "The Waiting List Lawsuits Settlement," The Arc of Tennessee website, <http://thearctn.org/Waiting-List.php>, accessed December 3, 2007.

- provided for enrollment of up to 600 persons in a Self Determination waiver during 2004-2005. The waiver had an annual budget cap of \$30,000 for an enrollee;
- provided for enrollment for an additional 900 persons in the Self Determination waiver during 2005-2006. If enrollment did not begin in the Self-Determination waiver by July, 2004 the state of Tennessee would pay \$500,000 per month in services for each month until enrollment began;
- provided for enrollment of approximately 200 new enrollees in the existing Home and Community-Based waiver in 2004-2005;
- provided for enrollment of approximately 200 new enrollees in the existing Home and Community-Based waiver in 2005-2006; and
- provided for planning by parties for additional necessary services for persons eligible for waiver services that are on the waiting list until December, 2009.

For those on the waiting list that are eligible for enrollment in the waiver but are waiting and not receiving services under the Family Support program, the State would provide up to \$2,280 in a Consumer Directed Support Program on an annual basis per person, with a maximum annual expenditure under this program at \$5 million. These services included respite services and transportation, among others.

The settlement provided targeted case management for those on the waiting list that are eligible for waiver services but are waiting to be enrolled. Case managers were to assist in accessing other services and plan for enrollment in the waiver.

Wisconsin

In Wisconsin waiting lists are maintained at the county level and reported to the state Department of Health and Family Services (DHFS). Ongoing analysis shows that the waiting lists are growing, and currently stand at 3,650 waiting for Adult Long Term Support Services; 3,500 for Family Support Program; and 125 for Children's Intensive In-Home Autism services.

The state launched a five year initiative in 2006 to eliminate the wait for services.⁵⁸ The program, called Family Care, is a collaboration between the state DHFS and the counties.

⁵⁸ DAWN “Waiting List Initiative,” http://www.dawninfo.org/advocacy/issues/waiting_list.cfm, accessed December 7, 2007.

RECOMMENDATIONS

RECOMMENDATION 1

The General Assembly and the Governor should make the elimination of the waiting list a priority. Providing supports and services to Pennsylvanians with mental retardation is a core function of Pennsylvania state government. State officials should commit – in word and in action – sufficient funds and other resources that will a) eliminate the emergency waiting list within 2 years b) eliminate the critical waiting list within 5 years, and c) anticipate future needs so that all Pennsylvanians with mental retardation have their service needs met within a reasonable period of time. These goals can be accomplished in the following way.

At the time this report was published, DPW proposed serving 1,818 new people beginning with the Governor's 2008-09 budget, in part by adding \$39 million of state and federal funding through DPW's appropriation. To kick off the Advisory Committee's five-year plan in the following year, the increase in funding for 2009-10 will be \$104 million of state and federal funds. An additional \$132 million of state and federal funding will be required for the succession of plan years 2010-11 through 2013-14. The move from plan year 2013-14 to 2014-15 will require an additional \$64 million of state and federal funding.

The Advisory Committee's plan for years 2009-10 through 2013-14 will have an additional 2,646 persons served in each plan year. The total number of new persons served beginning with DPW's proposal for 2008-09 and through the Advisory Committee's five year plan is 15,048. No new people are scheduled to be served under this plan in year 2014-15; that year is included to round out the funding to match the fiscal year appropriations cycle. More detailed information regarding the funding of this five-year plan is available in Appendix A of this report and by contacting the Joint State Government Commission.

RECOMMENDATION 2

The General Assembly and the Governor should build on their investment in special education and dedicate annual funding to ensure students with mental retardation who are transitioning to adult life receive services they need. Pennsylvania state government spends about \$1 billion annually in state general fund dollars to support special education programs at the local school district level. This investment produces positive results. Young adults with mental retardation graduating from special education often times have marketable skills that can be used to become successful, contributing adults provided they are given the proper support structure once they leave the special education system. Unfortunately, if there is a delay in receiving proper support upon graduating from special education, the marketable skills of these young adults can quickly deteriorate. If this delay is long enough, individuals may eventually require more expensive and extensive supports than they would have needed if they were given the supports they needed immediately following graduation from special education. In such cases, the individuals end up on the waiting list, making the waiting list challenge worse.

Table 8 shows the estimated expenses of serving 800 special education graduates in fiscal year 2007-08.

TABLE 8
HIGH SCHOOL GRADUATES ENTERING
THE MENTAL RETARDATION SYSTEM
FISCAL YEAR 2007-08

Estimated number of high school graduates	800
Estimated cost per graduate	\$18,250
Total annual cost	\$14,600,000
Dollars used to pay for graduates	
State	\$6,721,840
Federal	\$7,878,160
Total	\$14,600,000

SOURCE: Bureau of MR Program Support, Office of Developmental Programs, Pennsylvania Department of Public Welfare, Meeting with Joint State Government Commission, November 20, 2007.

RECOMMENDATION 3

The General Assembly and the Governor should establish a fiscal policy that includes a reasonable and consistent increase annually based on actual costs of maintaining existing service capacity.⁵⁹ If state funding for current services is not consistently adjusted upward for inflation, then one of two things occurs: either existing service capacity is reduced to free up resources to cover the added cost of inflation, or waiting list funding is used to offset inflation.

RECOMMENDATION 4

The state executive branch should be directed to convene relevant state agencies and stakeholders to identify methods for predicting and communicating need to the appropriate agency, and making sufficient information available to inform the budget process. Having sufficient service capacity to meet future need (and avoid waiting lists to reemerge) requires not only the funding necessary to build that but also sufficient information on which to base funding and capacity building decisions. The community service system must know at least 5 years in advance that an individual will be entering the system with a service need so that appropriate planning and capacity building can be accomplished in an appropriate and timely manner.

For example, areas that ought to be explored in this arena are the following:

- school districts notifying county MH/MR Offices, Administrative Entities, or the Office of Vocational Rehabilitation (OVR) when a special education student with mental retardation turns age 14;
- school districts notifying county MH/MR Offices or Administrative Entities when a student whose IEP contains services funded from Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) program is 3 years from entering the service system;
- school districts encouraging parents of these students to seek consultation beginning at age 16 with their County MH/MR Office or Administrative

⁵⁹ An example of this policy would be to include an annual COLA, based on the Federal CMS Home Health Market Basket Index, for all mental retardation services.

Entity to discuss possible services upon the student's graduation from special education;

- Children & Youth agencies should notify County MH/MR office or Administrative Entities when children with mental retardation enter their system;
- criminal justice system should notify County MH/MR office or Administrative Entities when individuals with mental retardation enter their system.

RECOMMENDATION 5

The General Assembly should direct the executive branch to conduct a process – with stakeholder involvement – to examine ways to find greater efficiencies, including more community-integrated and consumer-controlled service models. The existing service system has been built over several decades. Given the rigidity in funding and licensing regulations, programs are often built and maintained in manners that are not as efficient as possible. In light of the need to maximize efficiency and effectiveness of every public dollar entering the service system, the Commonwealth ought to be explore:

- selling vacant property of former state-run centers and reinvesting those dollars into a designed fund for community service capacity building;
- closing or redesigning large or medium-sized group homes and reinvesting the resources into more integrated community settings, such as independent living or life sharing so that perhaps additional persons can be served with the same amount of funding;
- supporting people with mental retardation to live in their own homes, or with their families, or with other families;
- promoting consumer-controlled service delivery models, which have been demonstrated to provide higher quality services at a lower cost; and
- revising existing regulations in a way that would reduce compliance costs while still maintaining the quality of services provided.

EXPLANATION ON FIRST RECOMMENDATION

This appendix section further explains the funding in *Recommendation 1* on page 45 and how the Pennsylvania Department of Public Welfare estimated the additional funding needed to serve all individuals on the waiting list categorized as emergency or critical within five years.

Recommendation 1 on page 45 briefly explains the five-year plan for serving individuals in both the emergency and critical categories on the waiting list, while Table A-1 of this appendix provides a more detailed presentation of the data.

It should be noted as individuals are moved from the waiting list and into services their funding needs will be met by the existing funding streams. That is, the CMS waivers and other sources will be available to continue to provide those individuals with necessary services.

Assumptions

In order to develop the funding figures presented in the recommendations section under recommendation one, PUNS data was used as well as several assumptions listed below.

- The data and funding from the 2008-09 Governor's Proposed Budget will be enacted. This proposed budget calls for a total of 1,818 individuals currently on the waiting list to be served.
- The estimated cost to serve someone on the waiting list requesting residential services is \$85,834/year.

- The estimated cost to serve some on the waiting list requesting non-residential services is \$18,247/year.
- All individuals on the waiting list requesting either residential or non-residential services would have supports coordination costs of \$1,906/year.
- Those individuals seeking residential services would be included under the consolidated waiver, while those seeking non-residential services would be included under the P/FDS waiver.
- The number of people in PUNS database categorized as emergency or critical requesting residential services in January 2008 was 3,926. The projected additional people seeking residential services in the first, second, third, fourth and fifth year of the plan are: 635, 508, 381, 254 and 127 people, respectively. In total, within five years, the plan will serve 5,831 additional people seeking residential services.
- The number of people in PUNS database categorized as emergency or critical requesting non-residential services in January 2008 is 5,298. The projected additional people seeking non-residential services in the first, second, third, fourth and fifth year of the plan are: 700, 560, 420, 280 and 140 people, respectively. In total, within five years, the plan will serve 7,398 additional people seeking non-residential services.

Explanation of Table A-1

Using the above assumptions, data from DPW was used to create Table A-1. The table details the estimated number of additional people to be served each year and the estimated cost of the services they would be receiving (residential versus non-residential and supports coordination) under the five-year plan plus the current proposal in the 2008-09 Governor's Proposed Budget. It should be noted that the table on the following page does show six fiscal years for this five year plan.⁶⁰ The reasoning behind this seemingly contradictory statement is as follows.

⁶⁰ The first column within Table A-1 (Fiscal year 2008-09) is not part of the 5-year plan.

When funding for a new plan is implemented for the first time, it often takes a few months for the funding to work its way down the various disbursement and get distributed to the proper organizations and individuals. Therefore, the first year of the five-year plan (fiscal year 2009-10) would only be partially funded to account for the lead time. During the second year of the plan, all of year one would be funded plus the first half of year two; during the third year of the plan, all of years one and two would be funded plus a portion of year three; etc. Based on this pattern, fiscal year six is included so that year five is fully funded.

TABLE A-1
 PLAN TO SERVE INDIVIDUALS CATEGORIZED
 AS EMERGENCY OR CRITICAL IN PUNS DATABASE AS OF JANUARY 2008¹
 FISCAL YEAR 2008-09 THROUGH FISCAL YEAR 2014-15

	FY 2008-09 (Governor's Proposed budget)	FY 2009-10 (partial year)	FY 2010-11 (1 full year; 1 partial year)	FY 2011-12 (2 full years; 1 partial year)	FY 2012-13 (3 full years; 1 partial year)	FY 2013-14 (4 full years; 1 partial year)	FY 2014-15 (5 full years)
<u>Residential</u>							
People Served	562	1,728	2,894	4,060	5,226	6,393	6,393
Funding							
State	\$12,059,677	\$49,139,965	\$99,184,719	\$149,233,005	\$199,281,291	\$249,329,577	\$274,353,721
Federal	\$12,059,677	\$49,139,965	\$99,184,719	\$149,233,005	\$199,281,291	\$249,329,577	\$274,353,721
Total	\$24,119,354	\$98,279,930	\$198,369,438	\$298,466,010	\$398,562,583	\$498,659,155	\$548,707,441
<u>Non-residential</u>							
People Served	1,256	2,736	4,216	5,695	7,175	8,655	8,655
Funding							
State	\$5,275,777	\$16,768,234	\$29,200,062	\$41,630,359	\$54,060,656	\$66,490,953	\$72,706,101
Federal	\$6,183,339	\$19,652,778	\$34,223,183	\$48,791,794	\$63,360,404	\$77,929,014	\$85,213,319
Total	\$11,459,116	\$36,421,012	\$63,423,246	\$90,422,153	\$117,421,060	\$144,419,967	\$157,919,421
<u>Supports Coordination</u>							
Funding							
State	\$1,594,917	\$3,916,232	\$6,237,372	\$8,558,512	\$10,879,651	\$13,200,791	\$13,200,791
Federal	\$1,869,282	\$4,589,920	\$7,310,352	\$10,030,784	\$12,751,216	\$15,471,648	\$15,471,648
Total	\$3,464,199	\$8,506,152	\$13,547,724	\$18,589,296	\$23,630,868	\$28,672,440	\$28,672,440
<u>Total</u>							
People Served	1,818	4,464	7,110	9,756	12,401	15,048	15,048
Funding							
State	\$18,930,371	\$69,824,431	\$134,622,153	\$199,421,876	\$264,221,599	\$329,021,321	\$360,260,613
Federal	\$20,112,298	\$73,382,663	\$140,718,254	\$208,055,583	\$275,392,911	\$342,730,240	\$375,038,688
Total	\$39,042,669	\$143,207,094	\$275,340,408	\$407,477,459	\$539,614,510	\$671,751,562	\$735,299,301

1. Please see assumptions used to create this table on previous three pages.

SOURCE: Bureau of MR Program Support, Office of Developmental Programs, Pennsylvania Department of Public Welfare, e-mail to Joint State Government Commission, March 10, 2008.