



**Rutgers** Center for  
State Health Policy

*The Institute for Health, Health Care Policy and Aging Research*

**Individuals with Developmental Disabilities  
and/or Mental Retardation in Adult Day  
Health Services: Perspectives from Several  
States and New Jersey**

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# **Individuals with Developmental Disabilities and/or Mental Retardation in Adult Day Health Services: Perspectives from Several States and New Jersey**

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## **Executive Summary**

### ***Introduction***

As a result of our previous work comparing adult day health service programs (ADHS) across the 50 states (Scotto Rosato, Lucas, & Howell-White, 2005), several questions have emerged about how the profile and needs of the client with developmental disabilities of ADHS is different from those of the elderly client of ADHS. Are different types of therapeutic and personal services needed and provided in ADHS for those with developmental disability and/or mental retardation? How have ADHS programs in other states attempted to meet these needs, if different? And, do these services require different staff levels and services?

### ***Methods***

To answer these important questions, the Center for State Health Policy engaged in a number of exploratory activities. First, we used a telephone survey of state program staff to obtain specific details about program services, reimbursement for ADHS, and the needs of the DD/MR population. Second, an analysis of data where client identifiers were removed was conducted to describe client characteristics of individuals with and without DD/MR in New Jersey ADHS. Two datasets were used to complete this analysis: one dataset was obtained from the Division of Aging and Community Services (DACS), Department of Health and Senior Services, and the other was obtained from the Division of Developmental Disabilities (DDD), Department of Human Services. The DACS data included Medicaid funded individuals who attended ADHS some time during the period of 2004 and 2006 (n=209). To select individuals with DD/MR from this group, we used the criteria of individuals having a diagnosis of mental retardation and/or cerebral palsy. Although we know that the term developmental disability encompasses more disabilities than mental retardation and cerebral palsy, we restricted our definition to these criteria because the information in the dataset was limited and we were unable to distinguish whether certain other diagnoses or functional and cognitive abilities of

individuals were due to a developmental disability or aging in general. The DDD data, on the other hand, included individuals with potentially any developmental disability in addition to mental retardation and cerebral palsy (e.g., autism, epilepsy) who attended ADHS at one time during the period of 2003 and 2006 and where assessment information was available (n = 120).

## **Results**

### *Survey of States*

15 states reported that they offered ADHS to individuals with developmental disabilities, with the majority of states having no special provisions for ADHS centers that predominately serve individuals with DD/MR.

An in-depth look at 5 states' ADHS programs showed that most programs did not have a different reimbursement rate for individuals with DD/MR. Ohio and Massachusetts were the only states that had reimbursement structures that addressed the different needs of specialized populations such as individuals with DD/MR.

### *New Jersey Client Characteristics*

Comparisons of individuals with and without DD/MR in New Jersey were limited because the DACS dataset had a small number of individuals with DD/MR (n = 18) compared to those without DD/MR (n = 191), and the DDD data, included only individuals with DD/MR. Therefore, no statistical significance test could be performed with either of these datasets. Nevertheless, some findings included:

*DACS Data:* Individuals with DD/MR (n=18) compared to those without DD/MR (n = 191) were:

- Younger and were more likely to live in a group setting with non-relatives (e.g., a group home).
- More likely to report skilled nursing treatment as a long term goal.
- More likely to require bowel and bladder training as one of the services as well as diet/exercise therapy and medication management/administration; however, the differences for the latter two services were small between those with DD/MR and those without DD/MR.



*DDD Data:* Individuals with DD/MR in the DDD dataset (n=120) compared to individuals without DD/MR in the DACS dataset were:

- Younger.
- Functionally similar, with both groups being fairly independent in Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).
- More likely to have behavior problems.

### ***Conclusion and Recommendations***

Based on the findings from our states' ADHS programs review and analysis of the two datasets, we conclude that New Jersey is not dissimilar to other states. Like New Jersey, most states don't have special provisions such as regulations and standards for DD/MR focused ADHS centers. However, New Jersey may consider restructuring their reimbursement method to address the different levels of care needs of special populations such as those with DD/MR.

Although some comparisons were made between individuals with DD/MR and those without DD/MR, the comparisons were limited by the lack of comparable data available and the lack of history of cognitive/functional status for designation of DD/MR. Having an integrated data system that includes health information and service needs of individuals served from multiple departments would help New Jersey in planning for appropriate care, reviewing eligibility, and looking at health outcomes. An integrated data system would assist New Jersey in not only assessing individuals at one point in time but also in tracking individuals through the long term care system as they age.



# **Individuals with Developmental Disabilities and/or Mental Retardation in Adult Day Health Services: Perspectives from Several States and New Jersey**

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## **Introduction and Background**

As a result of our previous work comparing adult day health service programs (ADHS) across the 50 states (Scotto Rosato, Lucas, & Howell-White, 2005), we have now focused on individuals with developmental disabilities and/or mental retardation (DD/MR) in ADHS. This special population has access to many services including ADHS.<sup>1</sup> In New Jersey, persons with developmental disabilities accessing ADH services (approximately 350 according to the New Jersey Department of Health and Senior Services) may be served in either specialized ADHS programs/centers (n = 8), or integrated into general ADHS programs/centers that primarily serve elderly and disabled adults. Some experts and advocates have questioned whether the medical and functional needs of individuals with DD/MR are met appropriately in integrated adult day health service programs and whether the eligibility criteria and reimbursement structure for ADHS should be similar for both groups of participants.

Several questions have emerged about how the profile and needs of the client with developmental disabilities of ADHS is different from the elderly client of ADHS. Are different types of therapeutic and personal services needed and provided in ADHS for those with developmental disability and/or mental retardation? How have ADHS programs in other states attempted to meet these needs, if different? And, do these services require different staff levels and services?

To answer these important questions, the Center for State Health Policy was asked to engage in a number of exploratory activities. First, following the design of our original 50-state survey, we contacted a number of states for information about ADHS for individuals with developmental disabilities and/or mental retardation. Second, administrative and program data on individuals with and without developmental disabilities and/or mental retardation attending ADHS in New Jersey were analyzed and compared.

## **Methods**

### ***Stage 1: Design for Survey of States***

We used a telephone survey of state program staff to obtain specific details about program services, reimbursement for ADHS, and needs of the DD/MR population.

#### *Selection of States*

Several steps were taken to select appropriate states for in-depth calls on adult day health services programs and individuals with developmental disabilities and/or mental retardation (DD/MR). First, following our past ADHS survey experience and current knowledge of state programs (Research Triangle Institute, 2005), initial calls were made to program officials in 32 states to ask the general question, “Does your State offer ADHS to individuals with DD/MR?” From those states that answered “yes” to this question, we planned to select 5 to 6 states as cases for further study. Five were initially chosen because of their proximity or demographic similarity to New Jersey. We then reviewed our selection process with the Easter Seals National Headquarters and the National Adult Day Service Association (NADSA). After obtaining their input, the final selection changed slightly to include: Georgia, Kentucky, Maryland, Massachusetts, and Ohio. Calls were made to state officials from both health departments and developmental disabilities departments in each of these five states. In addition, we systematically reviewed pertinent documents such as ADHS regulations and standards.

Open-ended questions and probes were designed to elicit information to answer the following questions: 1) How is the adult day health service delivery system organized in your state? 2) In what way, if any, are the needs of individuals with DD/MR in ADHS different from those of elderly clients in ADHS? and 3) Does the state (through regulations) require DD/MR clients to have different types of therapeutic services such as job training, counseling, or personal services such as toileting, help with eating, and ambulating? These were followed by prompts for more detailed information. Calls were made by the same individual to increase consistency. Documents were also reviewed to supplement and validate survey responses. Information from all of these sources was compiled and summarized to identify if state policies or regulations reflect differences for individuals with DD/MR in ADHS.

### ***Stage 2: Design for New Jersey Client Characteristics***

A retrospective analysis of de-identified data (i.e., personal identifications were removed prior to sending the data to CSHP) was conducted to describe client characteristics of

individuals with and without DD/MR in New Jersey ADHS and to compare these two groups on socio-demographic factors, functional and medical needs, health conditions, and services obtained. For individuals with DD/MR, we also compared specialized and integrated ADHS.

### *Data Sources and Sample Selection*

Data on individuals in ADHS in New Jersey were obtained from two sources: the Division of Aging and Community Services (DACS) in the Department of Health and Senior Services, and the Division of Developmental Disabilities (DDD) in the Department of Human Services. Data from DACS included all individuals that were referred to the Division for eligibility screening by ADHS providers from December 2004 through January 2006 (N=909). The data were part of a new effort conducted by DACS using the Minimum Data Set- Home Care (MDS-HC) instrument to assess the long-term care needs and Medicaid eligibility of individuals seeking community services. The MDS-HC assessment contains items describing functional status, health and mental health conditions, cognitive ability, behavioral problems, and treatment/service needs, and was collected by specially trained case managers. Of the 909 individuals referred to DACS by ADHS providers during the study period, only those individuals who actually were approved for Medicaid funding and attended ADHS during this same period were retained in the sample for analysis. This resulted in an analytic sample of 209 ADHS participants. However, only 18 of the 209 participants were identified as individuals with developmental disabilities and/or mental retardation defined as having a diagnosis of mental retardation and/or cerebral palsy on the MDS-HC. Although the federal definition of developmental disabilities is more inclusive than just diagnoses of mental retardation and cerebral palsy (i.e., diagnoses, function, and cognitive status), we were conservative in our definition since the DACS data includes aging adults and it was difficult to ascertain whether diagnoses such as seizure disorder, functional level, and cognitive impairment, can be classified as developmental disabilities (occurring prior to 22 years of age) or a condition due to aging in general.

A second dataset was obtained from the Department of Human Services, Division of Developmental Disabilities (DDD), which maintains data derived from the Individual Client Assessment Form (CAF). The total number of individuals in this dataset was 746; however, only 120 individuals had complete data that was derived from the CAF. These individuals had developmental disabilities and/or mental retardation (as defined by the DDD<sup>2</sup>), and were attending ADHS at one point in time during the years 2003 through 2006. As in the case of the DACS data, these data were part of a larger effort conducted by DDD and the Developmental Disabilities Planning Institute to plan services targeted for community individuals who were

living at home and either on waiting lists for DDD or were over the age of 55. Although the data were somewhat limited compared to the MDS-HC, select items on functional ability, health conditions, cognitive ability, behavior problems, and services obtained at the time of the assessment were available for potential comparison with the MDS-HC.

### *Analysis*

Since the data format as well as the assessment instrument items and administration process for data collection differed between DACS and DDD, the datasets were analyzed separately and then comparisons were only made for similar items. Whenever possible, items such as activities of daily living (ADLs) were cross-walked using like items from each instrument. Due to the small number of individuals with DD/MR in the DACS data and differences between the instruments, analysis was limited to simple description.

### **Results: State Profiles**

From the 32 states contacted initially, 15 states reported that they offered ADHS for individuals with developmental disabilities (i.e., California, Georgia, Hawaii, Kentucky, Maryland, Maine, Massachusetts, Michigan, Missouri, Nevada, North Carolina, Ohio, South Carolina, West Virginia, and Wyoming). The majority of these 15 states indicated that most of their participants with DD/MR attended integrated centers (i.e., centers with both DD/MR and non-DD/MR participants) as opposed to specialized centers. However, specialized centers were also identified in some of these states, and were often used when additional services such as vocational support were needed by individuals with developmental disabilities.

The five states we surveyed provided a more in-depth picture of ADHS programs in their state and the service needs of the participation of individuals with DD/MR in ADHS. Key findings from the state officials' interviews and document reviews are provided in Table 1. A more detailed description of each of the five states' ADHS program structure, regulatory status, availability of specialized centers, any special services provided, reimbursement structure and rates, and staffing information is provided following the table.

**Table 1: Summary of State Programs and Services Provided for Individuals with Developmental Disabilities/Mental Retardation in Adult Day Health Services**

State	“Specialized” <sup>a</sup> Centers Present (yes/no, #)	Reimbursement Rates (same/different)	“Specialized” Services for Individuals with DD/MR	Special Staff Training Required
Georgia	No.	Same.	No.	Staffing type & level is determined by the characteristics of the participants.
Kentucky	No.	Same. However, if an ADHS provider has more than 80% of their occupancy individuals with DD/MR, they may request a higher reimbursement rate.	No.	Not required.
Maryland	Yes, number not reported.	Same.	No. Only if they are attached to a provider who provides other services to DD/MR such as ARC.	Not required.
Massachusetts	Yes, 4.	Reimbursement uses a tiered system based on functional level.	No, because all ADHS centers adhere to the same regulations; however, “specialized” centers may offer services designed for a particular population.	Not required. Although the “specialized” centers are not required, many do train their staff to deal with problem behaviors or crisis situations.
Ohio	Yes, 1.	Same.	None.	Required. Regulations state that the staff must be trained to meet the needs of the consumers.

<sup>a</sup> We use the term “specialized” in quotes to differentiate ADHS centers that serve individuals with developmental disabilities only. However, while some states refer to these centers as specialized, others preferred not to use this designation.

### **Georgia**

Georgia’s ADHS program is offered through the Community Care Services Waiver and administered by the Division of Aging Services, Department of Human Resources. No licensure is required, but it is under consideration. However, ADHS providers do need to meet standards developed by the Division of Aging Services (Research Triangle Institute, 2005).

Georgia does not have ADHS programs that are specifically developed for individuals with developmental disability/mental retardation. All of their ADHS programs include both individuals with and without DD/MR; however, individuals with DD/MR rarely attend ADHS in Georgia. According to the state contact, most individuals with DD/MR access day habilitation, day support programs, and supported employment, primarily through the Mental Retardation

Waiver Program (MRWP) and the Community Health and Habilitation Service Waiver (CHHS), which is currently not accepting new admissions because it has reached its slot capacity.<sup>3</sup> For medical services, individuals with DD/MR customarily go to their primary care physicians. Some day support programs provide a nurse onsite, but since it's not a requirement, most do not. Recent changes in legislation to the Nurse Practice Act in Georgia will soon allow staff members without a nursing license to administer medications following completion of nine-months of training. According to the state contact, this is expected to offer an alternative to ADHS since residential and day program staff will then administer medication.

The few individuals with DD/MR who do attend ADHS in Georgia obtain the same type of services that the non- DD/MR individuals receive. These include assistance with activities of daily living, health education, and nursing services, including skilled nursing. Reimbursement rates are also the same for individuals with and without DD/MR. In terms of staffing, Georgia has a staffing requirement that is determined by the characteristics of the participants. Georgia requires, at a minimum, one direct service staff person for each four severely impaired participants or eight non-severely impaired adults (Research Triangle Institute, 2005); however it is unknown if Georgia considers a diagnosis of DD/MR as severely impaired.

### ***Kentucky***

Kentucky's ADHS program is licensed by the Office of Inspector General and regulated by the Cabinet for Health and Family Services (Research Triangle Institute, 2005). The majority of individuals who attend ADHS do so under the Medicaid Waiver, specifically the Home and Community Based Waiver (HCBSW) for the Aged and Disabled. Kentucky does not have centers that serve individuals with DD/MR only. All 111 centers are integrated, and the majority of the ADHS participants do not have DD/MR.

No specialized services are required for those individuals with DD/MR. If the ADHS center provides case management services for the HCBSW, then they are required to link individuals to other needed services such as rehabilitation services, respite, vocational training, and so forth. Otherwise, the standard required services include assistance with ADLs, health monitoring, medication administration, nursing services, and skilled nursing services.

Reimbursement rates for individuals with and without DD/MR are the same. However, if a particular ADHS center has "an average daily census of at least twenty individuals of which 80% meet the definition of developmentally disabled, the center may request an enhanced level of reimbursement." Reimbursement rates are per unit of service, with one unit equal to three hours, with a maximum of two units per day. For a Level I rate, the amount is \$28.00 per unit. For a



Level II rate (enhanced), the amount is \$34.00 per unit. Transportation is not included in these rates.

### ***Maryland***

Maryland's ADHS service program is called medical day care and is administered under the Medicaid State Plan by the Office of Health Services (OHS) in the Department of Health and Mental Hygiene. It is licensed by the Office of Health Care Quality and offers such services as assistance with ADLs, health education and counseling, health monitoring and related services, medication administration, skilled nursing services, and rehabilitation services if it's part of the individual's care plan (Research Triangle Institute, 2005). Because medical day care operates under a medical model, a registered nurse (RN) is required to be onsite during operating hours.

Maryland has both specialized centers for individuals with DD/MR and integrated centers. While the majority of individuals with DD/MR attend specialized centers, a good proportion of them also attend integrated centers, especially if the need of that individual is more medical. Attendance at a non-medical day care center is provided when an individual needs vocational support or social support in addition to medical care.

Only recently during a review and re-assessment of their current medical day care participants, did Maryland discover how many individuals with DD/MR actually attend medical day care. It's believed that many of these individuals were eligible for ADHS initially (i.e., they met nursing home level of care criteria), but over time their eligibility and needs have changed. According to the state contact, many would now benefit if moved to other support programs.

Funding for individuals with DD/MR who attend medical day care could come from either OHS or the Developmental Disability Administration, depending on the individual's eligibility. Maryland is focused on providing choices for individuals and strongly supports the concept of "aging in place." According to the state contact, if the individual's medical needs don't change, then nothing triggers a change of the environment even if the funding for that individual moves from the Medicaid State Plan to the Developmental Disability Administration. This funding transition is not a problem according to the state contact because both departments are under the Department of Health and Mental Hygiene and although they have their own separate budgets the flow of funding is not as compartmentalized as in other states.

In sum, individuals with DD/MR in Maryland attend integrated medical day care centers if their needs are mainly medical. The specialized centers, such as those run by the ARC of Maryland, are attended by individuals with DD/MR but usually for the purpose of non-medical support services. The structure and rate of reimbursement for medical day care services is

similar for individuals with and without DD/MR; that is, approximately \$70 for a 6 hour day, with at least 4 hours of service delivery required.

### **Massachusetts**

Massachusetts' ADHS programs are neither licensed nor certified. Providers are under contract with MassHealth (i.e., Massachusetts' Medicaid state plan) and are governed by the regulations in the Adult Day Health Provider Manual (Research Triangle Institute, 2005). Since ADHS providers are approved for MassHealth payment, waivers do not pay for ADHS. Waiver programs may, however, pay for other services needed by individuals. For example, the DD/MR waiver may pay for residential services, respite or vocational support, but it does not pay for ADHS.

According to the state contact, there are about 127 ADHS centers in the state, but only four of them serve individuals with developmental disabilities and/or mental retardation exclusively. The remainder serves both individuals with and without DD/MR, although the number of individuals with DD/MR in these centers is not known. Presently there is no data tracking individuals with DD/MR in Massachusetts' ADHS program.

The four centers that primarily serve individuals with DD/MR have more individuals with DD/MR than other centers since they already provide support /training services to individuals with DD/MR (e.g., day habilitation and vocational services), and thus decided to add an ADHS program because there was an identified need. These ADHS programs may offer some specialized services to this population, but in terms of requirements (and what's paid by MassHealth), these programs follow the same regulations as all ADHS programs. As listed in the ADHS program manual, these services include assistance with ADLs, nursing services, meals, health monitoring by a nurse, and fee-for-service rehabilitation, if needed. Rehabilitation services must be prescribed by a physician and billed independently from the ADHS rate.

Reimbursement structure and rates are the same for all ADHS providers. In 2002, Massachusetts adopted a three-tiered model of reimbursement following a careful review and recommendations by the National Adult Day Service Association (NADSA) and a Massachusetts commission. Massachusetts adopted the tiers almost exactly as recommended. The levels include: 1) Basic Level: needing assistance with one ADL or nursing services, at \$46.89 per 6-hour day; 2) Complex Level: needing nursing home level of care (i.e., assistance with 2 ADLs and nursing services for at least 3 days per week), at \$56.66 per day; and, 3) Health Promotion and Prevention Level: the lowest level that includes individuals who may have been in the Basic

Level and no longer need assistance but they want to stay in the program, at \$27.32 per day to cover administrative costs.

Since all ADHS programs adhere to the same regulations, the staffing level and skill mix are the same across all programs. However, the state contact indicated that there may be a higher staff-to-client ratio in “specialized” programs (e.g., programs for clients with DD/MR and for clients with dementia). In terms of training, programs who target special populations may train staff based on the needs of that population, but special training for caring for individuals with DD/MR is not required.

## **Ohio**

Ohio’s ADHS programs are certified under Medicaid through the Pre-Admission Screening System Providing Options and Resources Today (PASSPORT) Waiver that is administered by the Division of Aging (Research Triangle Institute, 2005). Ohio also has programs called Center-based Day Health Services (CBDHS), which are similar to general ADHS and serve individuals with DD/MR. These CBDHS providers are reimbursed for clients with DD/MR under the Ohio Home Care Waiver and the Ohio Transition Waiver, which is a waiver specific to individuals with DD/MR. According to the state contact, 31 CBDHS providers currently exist in Ohio under these two waiver programs.

Ohio has only one center that specializes in serving individuals with cerebral palsy. The majority of CBDHS that are regulated by the State, specifically the Department of Job and Family Services, are centers that serve both individuals with and without DD/MR. The type of services obtained at these integrated centers by these two populations is similar. These services include personal care services and nursing services. The only difference is the funding source. Individuals with DD/MR are primarily funded through the Transition Waiver or the Home Care Waiver for ADHS, although reimbursement rates are the same. According to the state contact, individuals with DD/MR attend CBDHS in Ohio for several reasons including: 1) a need for nursing services; 2) lack of supervision in the home; 3) when there is a question of health or safety; and, 4) to be cost effective with the services that are needed.

## **New Jersey’s ADHS Program**

New Jersey’s ADHS program is licensed by the Department of Health and Senior Services, Division of Long Term Care Systems. In 2006 there were 127 centers licensed in New Jersey with

8 offering services exclusively to individuals with developmental disabilities. No additional certification or accreditation is required in New Jersey.

Funding for ADHS in New Jersey is derived primarily from the Medicaid state plan; some individuals who attend ADHS are funded through Medicaid Waivers such as the Community Care Program for the Elderly and Disabled (CCPED), but these individuals are few. Waivers that primarily target individuals with DD/MR, such as the Community Care Waiver for DD/MR, fund other services such as habilitation services or respite but do not fund ADHS. According to the 2006 regulations for ADHS, services required to be offered by a center include skilled nursing services, medication administration, health monitoring/health related services, assistance with ADLs, rehabilitation services (i.e., physical therapy, speech therapy, and occupational therapy) if part of the individual's plan of care, as well as transportation.

### ***New Jersey's ADHS Clients without Developmental Disabilities/ Mental Retardation***

The demographic and clinical characteristics of individuals who attended ADHS in New Jersey December 2004 to January 2006 varied considerably, according to the data from the Division of Aging and Community Services (DACS). Individuals without developmental disabilities/mental retardation<sup>4</sup> attending ADHS in New Jersey (n= 191) were predominantly female, over the age of 65, and living in a private home without home care (see Table 2). Additionally, most lived with either a child or spouse, and most did not have a recent hospitalization; only a few had a previous nursing home stay (see Table 2 below). In terms of long term care goals, most of these individuals needed health monitoring to avoid complications (n = 158, 82.7%), health education (n=127, 66.5%), and rehabilitation services (n = 113, 59.2%).

**Table 2: Characteristics of New Jersey Adult Day Health Service Participants Without Developmental Disabilities/Mental Retardation: 2004 to 2006**

	Total (N=191)	
	N	%
<b>Gender</b>		
Female	134	70.2
Male	57	29.8
<b>Age</b>		
55 or less	34	17.8
56 to 64	31	16.2
65 to 74	57	29.8
75 to 84	51	26.7
85 and over	18	9.4
<b>Current Living Situation</b>		
Private Home With No Home Care	120	62.8
Private Home With Home Care	63	33.0
Board Care/Assisted Living/Group Home	1	0.5
Unknown	7	3.7
<b>Living Arrangement</b>		
Lives alone	76	39.8
Lives with Family (Spouse or Child)	83	43.5
Lives with Someone Other than Spouse/Child	25	13.1
Unknown	7	3.7
<b>Time Since Last Hospital Stay</b>		
1 to 14 days	3	1.6
15 to 30 days	10	5.2
Over 30 days	61	31.9
No hospitalization within 180 days	109	57.1
Unknown	8	4.2
<b>Prior Nursing Home Placement</b>		
	33	17.3

**Note:** Source, New Jersey Division of Aging and Community Services (DACCS).

The clinical profile of individuals without DD/MR attending ADHS is summarized in Tables 3 and 4. As seen in Table 3, more than half could independently self-perform the ADLs of eating, toileting, and moving to and from a lying position such as a bed (i.e., bed mobility). Less than 10% of individuals were independent in self-performance of the instrumental activities of daily living (IADLs) such as ordinary housework (n = 18, 9.4%) shopping (n=15, 7.9%), and transportation (n=14, 7.3%). Few individuals were able to climb stairs independently or walk

without an assistive device. However, less than half had intact short-term memory, while two-thirds had intact procedural memory and most were able to communicate with others well enough to be understood.

**Table 3: Rate of Independence in Physical and Cognitive Functions by Individuals without Developmental Disabilities/Mental Retardation in New Jersey's Adult Day Health Services Program: 2004 to 2006**

	Total (N=191)	
	N	%
<b>Independent in ADLs</b>		
Eating	125	65.4
Toileting	97	50.8
Dressing	64	33.5
Ambulating (locomotion)	83	43.5
Bed Mobility	144	75.4
Personal Hygiene	79	41.4
Bathing	50	26.2
<b>Independent in IADLs</b>		
Ordinary House Work	18	9.4
Managing Finances	46	24.1
Shopping	15	7.9
Meal Preparation	33	17.3
Transportation	14	7.3
Managing Medications	61	31.9
<b>Independent in Other Functions</b>		
Stair Climbing	55	28.8
Mobility	75	39.3
<b>Use of Assistive Devices</b>	111	58.1
<b>Cognitive Competencies</b>		
Intact Short-Term Memory	93	48.7
Intact Procedural Memory	126	66.0
<b>Communication</b>		
Able to be Understood	140	73.3

**Note:** Source, New Jersey Division of Aging and Community Services (DACS).

Table 4 illustrates that the majority of individuals without DD/MR in ADHS had a heart/circulation problem such as hypertension or coronary artery disease (88.0%) and/or a muscular/skeletal problem such as arthritis (70.7%). A significant proportion also had other

health conditions such as neurological problems (31.9%), glaucoma or cataracts (25.1%), and bladder incontinence (35.6%). In terms of psychiatric and behavior issues, just over a third of this population had a psychiatric diagnosis, and less than ten percent exhibited problem behaviors such as being verbally or physically abusive.

**Table 4: Medical Conditions and Problem Behaviors of Individuals without Developmental Disabilities/Mental Retardation in New Jersey's Adult Day Health Service Program: 2004 to 2006.**

	Total (N= 191)	
	N	%
<b>Disease Diagnoses</b>		
Heart/Circulation <sup>a</sup>	168	88.0
Neurological <sup>b</sup>	61	31.9
Muscular/Skeletal <sup>c</sup>	135	70.7
Glaucoma/Cataract	48	25.1
Infectious Diseases <sup>d</sup>	22	11.5
Seizure Disorder	19	9.9
Other <sup>e</sup>	143	74.9
<b>Other Health Conditions</b>		
Vision Impairment	19	9.9
Hearing Impairment	12	6.3
Bladder Incontinence	68	35.6
Bowel Incontinence	27	14.1
<b>Psychiatric Diagnosis<sup>f</sup></b>	74	38.7
<b>Problem Behaviors Present<sup>g</sup></b>	17	8.9

<sup>a</sup> This includes cerebrovascular accident, congestive heart failure, coronary artery disease, hypertension, irregular pulse, peripheral vascular disease.

<sup>b</sup> This includes Alzheimer's Disease, dementia other than Alzheimer's, head trauma, hemiplegia/hemiparesis, multiple sclerosis, and Parkinsonism.

<sup>c</sup> This includes arthritis, hip fracture, other fractures, and osteoporosis.

<sup>d</sup> This includes HIV infection, pneumonia, tuberculosis, and urinary tract infection in the last 30 days.

<sup>e</sup> Other includes those with cancer, diabetes, emphysema/asthma, renal failure, thyroid disease, hyperlipdemia, and/or Huntington's .

<sup>f</sup> This includes those who have any psychiatric disorder including depression, schizophrenia, and/or bipolar.

<sup>g</sup> Problem behaviors include wandering, verbally & physically abusive, socially in appropriate or disruptive and/or resistive to care.

**Note:** Source, New Jersey Division of Aging and Community Services (DACs).

The type of services obtained or scheduled to be received by this population is highlighted in Table 5. The majority of individuals needed health monitoring (n = 148, 77.5%) and

medication management, administration, or injection (n = 139, 72.8%). A significant proportion also needed special diets and exercise therapy (n = 98, 51.3%). Surprisingly, very few needed specialty care services such as tube feeding or peritoneal dialysis (n =13, 6.8%). However, these services were assessed in the MDS-HC with a look-back period of only seven days; many may either have received these services in the past or may need them in the future. Furthermore, although obtained or scheduled, these services were not necessarily received at an adult day health service facility.

**Table 5: Medical Treatments and Services Obtained by Individuals without Developmental Disabilities/Mental Retardation in New Jersey’s Adult Day Health Services Program: 2004 to 2006**

	Total (N=191)	
	N	%
<b>Medical Services/Treatments</b>		
Health Monitoring <sup>a</sup>	148	77.5
Medication Management, Administration, or Injection	139	72.8
Special Diet/Exercise Therapy	98	51.3
Respiratory Treatment <sup>b</sup>	41	21.5
Rehabilitation Therapies <sup>c</sup>	41	21.5
Bowel/Bladder Training	25	13.1
<b>Specialty Care Services<sup>d</sup></b>	13	6.8

<sup>a</sup>Includes pacemaker check, blood pressure check and glucose monitoring.

<sup>b</sup>Includes oxygen, respirator for assistive breathing, all other respiratory treatments.

<sup>c</sup>Includes speech therapy, occupational therapy, and physical therapy.

<sup>d</sup>Includes the following care services: chemotherapy, dialysis, IV infusion, ostomy care, radiation, tracheostomy care, blood transfusion, alcohol/drug treatment, wound care, peg tube feeding, and instructions in prosthetic devices.

**Note:** Source, New Jersey Division of Aging and Community Services (DACS).

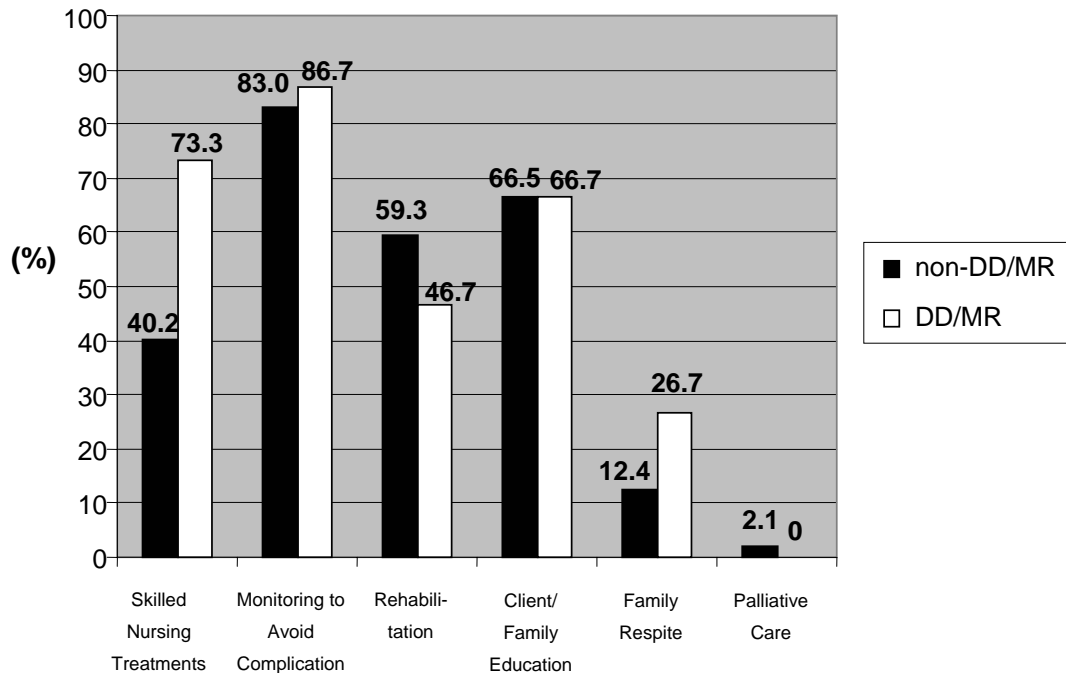
### **Comparison of Individuals With and Without DD/MR in ADHS**

Because of the limited number of individuals with DD/MR in the sample (n = 18 versus n = 191), few analytical comparisons were made using the data obtained from DACS. Nevertheless, compared to those without DD/MR, the individuals with DD/MR in this data were younger and were more likely to live in a group setting with non-relatives. In terms of their long term care goals, it was apparent that those with DD/MR needed more skilled nursing treatments than those without DD/MR (see Figure 1). Conversely, those without DD/MR needed more rehabilitation services than those with DD/MR. Again, due to the small sample size we were



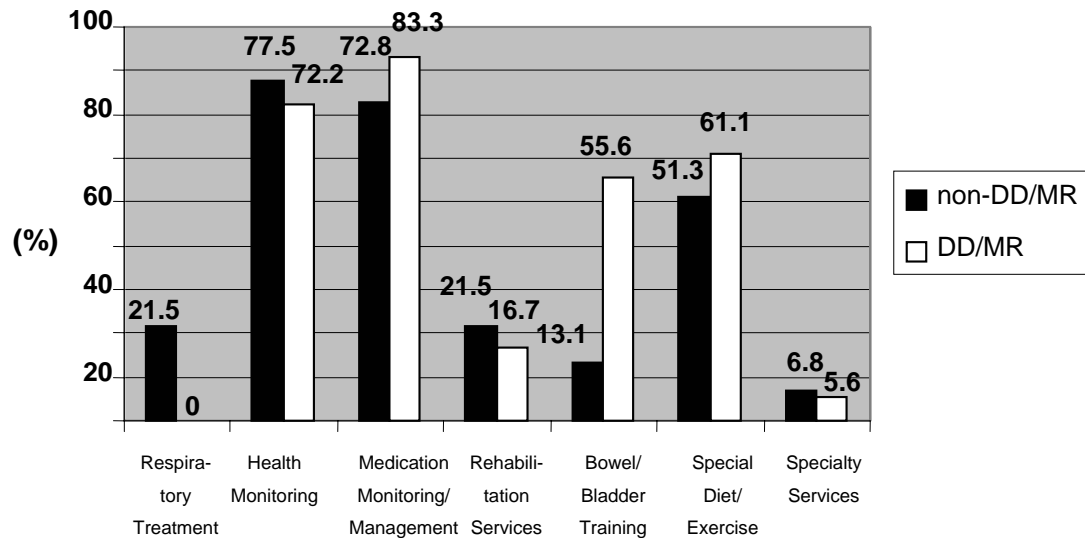
unable to conduct tests of significance for these differences; and these may not be representative of all individuals with DD/MR who attend adult day health services.

**Figure 1: Long Term Care Goals of Individuals With and Without DD/MR Attending Adult Day Health Services: DACS Data 2004 to 2006**



In terms of services obtained or scheduled to be received, some differences between individuals with and without DD/MR in ADHS were noteworthy (see Figure 2). For example, individuals with DD/MR were more likely to receive bowel and/or bladder training than individuals without DD/MR (55.6% and 13.1% respectively). They were also more likely to obtain diet and exercise therapy (61.1% and 51.1% respectively) and medication management, administration, or injection (83.3% and 72.7% respectively); however, these latter differences appear small.

**Figure 2: Comparison of Services Obtained by Individuals With and Without DD/MR Attending Adult Day Health Services: DACS Data 2004-2006.**



### ***Individuals With DD/MR in New Jersey’s ADHS Program***

Because of the small sample of individuals with DD/MR in ADHS in the DACS dataset, we also closely examined data that were available from the Division of Developmental Disabilities (DDD), Department of Human Services. These data included individuals with DD/MR living in the community who attended adult day health services at a point in time during the years 2003 and 2006 and where assessment information was available (N= 120). We begin with a general description of the individuals in the DDD data and end with a comparison of individuals in the DDD data and the DACS data. However, it is important to note that the comparison between the two datasets is an approximate comparison because two different assessment instruments were used to collect the data and items were asked differently in each of the instruments.

The majority of these individuals were younger, with most being under the age of 55. An equal proportion of males and females attended adult day health services (48.3% and 51.7% respectively), and most lived in their own home (n = 109, 91.0%). Functionally, most were independent in the ADLs of eating, toileting, dressing, and ambulating and IADLs such as managing finance, meal preparation and so forth (see Table 6).

**Table 6: Rate of Independence in Physical and Cognitive Functions of Individuals with Developmental Disabilities/Mental Retardation in New Jersey's Adult Day Health Service Program: 2003 to 2006.**

	Total (N=120)	
	N	%
<b>Independence in ADLs<sup>a</sup></b>		
Eating	104	86.7
Toileting	95	79.2
Dressing	88	73.3
Ambulating	98	81.6
<b>Independence in IADLs<sup>b</sup></b>		
Ordinary House Work	76	63.3
Managing Finance	63	52.5
Shopping	80	66.7
Meal Preparation	53	41.2
Transportation	13	10.8
<b>Independent in Other Functions</b>		
Stair Climbing	66	55.0
Mobility	47	39.2
<b>Use of Assistive Devices</b>	27	22.5
<b>Cognitive Competencies</b>		
Long-Term Memory Intact	70	58.3
Procedural Memory Intact	88	73.3
<b>Communication</b>		
Able to be Understood	86	71.7
<b>Other Health Conditions</b>		
Vision Impairment	21	17.5
Hearing Impairment	10	8.3
Respiratory	12	10.0
Heart/Circulatory	26	21.7
Digestive	16	13.3
Bladder/Kidney	19	15.8
Hormone/Endocrine	12	10.0

<b>Psychiatric Diagnosis</b>	32	26.7
<b>Problem Behaviors Present<sup>c</sup></b>	43	35.8

<sup>a</sup>Definitions for each ADL: *Eating* - Feeding himself/herself, Drinking from a glass or cup, and chewing and swallowing food. *Toileting* - Toileting with regards to bladder, toileting with regards to bowels. *Dressing* - Dressing himself/herself. *Ambulating* - Moving around in familiar settings.

<sup>b</sup>Definitions: *Ordinary Housework* - making his/her bed, cleaning his/her room, doing laundry, caring for his/her clothes. *Managing Finances*- making minor purchases. *Shopping* - Shopping for simple meal, choosing items to buy. *Meal Preparation* - Preparing foods that do not require cooking & using stove or microwave. *Transportation* - using public transport for a simple direct trip.

<sup>c</sup>This category includes dangerous behaviors to self and others such as harassment, threatening, hits self or others etc.

**Note:** Source, New Jersey Division of Developmental Disabilities (DDD).

As expected, most of the individuals from this dataset had a diagnosis of mental retardation (n=87, 72.5%) or cerebral palsy (n=19, 15.8%). A good proportion of them, however, also had co-occurring developmental disabilities (n= 15, 12.5%), such as autism or epilepsy. In addition, a sizable proportion also had psychiatric disorders (n = 32, 26.7%), with most having these disorders in conjunction with a primary medical condition (n=26, 21.7%). Although present, the proportions of individuals who had additional health conditions such as vision impairment or hearing impairment were small (see Table 6).

Compared to individuals without DD/MR in ADHS from the DACS data, these individuals were younger. However, functionally, they were similar, with both groups being fairly independent in such ADLs as eating, toileting, dressing and ambulating. In terms of IADLs, individuals in the DDD dataset were more independent than those in the DACs dataset in such activities as ordinary housework, managing finance, shopping, and meal preparation (see Tables 3 and 6).

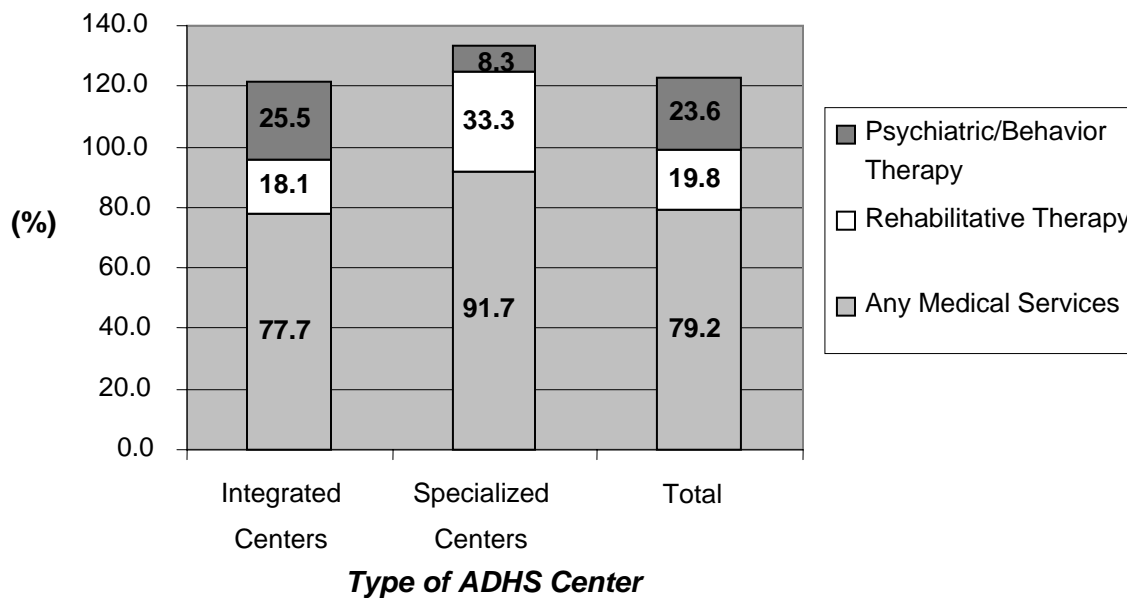
Clinically, compared to those in the DACS data, these individuals had just as many health conditions; however, a considerably higher proportion of individuals in the DDD data had behavioral problems (35.8% versus 8.9%) (see Tables 4 and 6). This difference, of course, may have been due to the use of different assessment instruments in evaluating these individuals. DACS/DHSS uses a more detailed assessment of health conditions than DDD, whose concern was mostly with the individual's basic functions and needs in the community.

### ***Comparison of Individuals with DD/MR Attending Specialized and Integrated ADHS***

Because information on specialized and integrated ADHS centers was available in the DDD dataset and the sample size was fairly large, we were able to compare those in specialized centers with those in integrated centers and test for statistical significance. Several differences

were found between individuals with DD/MR who attended specialized centers versus those who attended integrated centers (i.e., centers serving both individuals with and without DD/MR). Demographically, those in integrated centers looked similar to those in specialized centers. Most were under the age of 40 and living in their own homes. However, those in specialized centers were less independent in performing ordinary housework, making meals, walking without an assistive device, and being able to walk up and down stairs. These differences may have been due to the larger proportion of individuals in specialized centers that had cerebral palsy as their developmental disability compared to those in integrated centers (32.8% and 12.1% respectively). Finally, although not statistically significant, individuals in integrated centers were more likely than those in specialized centers to obtain psychiatric and/or behavior services (25.5% versus 8.3% respectively); while those in specialized centers were more likely to obtain medical services such as tube feeding, respiratory care, special diets (91.7% versus 77.7%), and rehabilitation services (33.3% versus 18.1% respectively) (see Figure 3).

**Figure 3: Services Obtained By Individuals with Developmental Disabilities and/or Mental Retardation By Type of Adult Day Health Service Center: DDD Data 2003 to 2006**



## Discussion

Although many states have strong programs for individuals with DD/MR, we found special provisions such as regulations and standards for DD/MR specialized ADHS programs to

be lacking. Of our case study states, Ohio and Massachusetts recognized that functional needs may differ for special populations. Ohio dealt with this by increasing their ADHS reimbursement rate for all individuals when a program reached an 80% capacity of individuals with DD/MR. Massachusetts, on the other hand, chose to develop a tiered reimbursement system based on an individual's level of care need. Although in different ways, both of these states addressed the issue of how individuals with specialized conditions such as dementia or DD/MR may require different amounts of care time and staffing levels. State reimbursement strategies are increasingly using needs-based tiering systems. As demonstrated in our past work in the assisted living setting, models that incorporate ADLs, IADLs, and special services (e.g., medication assistance and cognitive/behavior status) can predict levels of care needed (Howell-White, Gaboda, Scotto Rosato, & Lucas, 2006).

Our findings showed that demographic and clinical characteristics varied considerably among the ADHS population in New Jersey. Those without DD/MR in ADHS were functionally similar to individuals with DD/MR in terms of independence in self-performing such ADLs as eating, toileting, and bed mobility. However, individuals with DD/MR were more likely to have a secondary medical condition and less likely to have a psychiatric disorder. In terms of service needs, those with DD/MR needed more skilled nursing treatments, bowel and bladder training, medication assistance, and nutritional guidance or assistance. In contrast, those without DD/MR were more likely to need rehabilitation services. Furthermore, the DD/MR client's psychosocial goals were less often identified by assessors and may reflect a system bias towards physical function impairments seen in the nursing home criteria and eligibility criteria used; or they may have been due to differences in the communication skill of the consumer.

Differences were also seen between integrated and specialized centers. As seen in the services obtained, integrated centers seem to focus more on psychiatric and behavioral services (3:1, medical to psycho-behavioral) for the DD/MR group than specialized centers. It may be that the DD/MR population that selects care in specialized centers is more in need of basic functional improvement services such as rehabilitation therapies and assistance with activities of daily living. Since specialized centers would naturally have a more homogeneous group, the services would focus more towards the primary needs of the group, which most likely is a medical need.

### ***Limitations***

There are several limitations to this study that may affect the interpretation of the findings. First, because two different datasets were used to compare individuals with DD/MR and those without DD/MR in ADHS, no statistical significance testing could be performed.

Therefore, all of the differences found between those with DD/MR and those without DD/MR were only comparisons of proportions with no statistical certainty that these differences between the two groups were large enough to be considered meaningful. However, in the clinical world services are planned and provided based on individual and group needs, and our descriptive findings may have real meaning for service provision and effectiveness. Second, when the potential for a comparison could be made using the DACS data, the number of individuals with DD/MR in the dataset was extremely small, so that it may not be representative of the DD/MR population in New Jersey's ADHS program. This limits our ability to generalize from the results. However, we were able demonstrate significant differences in services obtained across ADHS settings. Contributing factors need further clarification. For example, are these due to client selection, access, issues, or program characteristics?

The variation in the amount and types of health information available in the DACS data and the DDD data limited our ability to make comparisons. The DACS dataset provided a greater amount of information, which ranged from health and functional indicators to social supports and caregiver involvement. We attributed this to the use of the MDS-HC assessment to gather the data. This assessment tool is part of a family of instruments that are highly regarded in the long term care arena. Although analysis of these data were limited in the present study, future use of the MDS-HC could produce analyses ranging from identifying predictors of long term care needs to describing trends in functional decline. A key strength of this approach will be the standardized use of valid assessment instruments (with at least with the same core items) that can measure multi-dimensional care needs.

### ***Implications***

Findings from the states' survey suggest that New Jersey does not appear to be dissimilar to other states in terms of availability and oversight of specialized ADHS programs. However, some states have made attempts to address any potential inequities in the degree of care time by individuals with specialized needs by creating a tiered system of reimbursement (e.g., Massachusetts). Other states (e.g., Maryland) have focused on tracking individuals and repeatedly assessing their care needs so that services are appropriately matched to the individual. This tracking and reassessment of individuals in ADHS, particularly those with DD/MR, would be beneficial for New Jersey since it would allow departments to plan for appropriate care as well as monitor ADHS program outcomes, especially for individuals served by multiple State departments. Additionally, a monitoring and tracking system has important

implications for rate setting and for innovative programming that focuses on self-determination and choice.

## **Conclusion**

Using the available data from the Department of Health and Senior Services and the Department of Human Services, we found differences between individuals with DD/MR and those without DD/MR who attend ADHS. However, these differences should be interpreted cautiously because the two datasets used were derived from different assessment instruments (i.e., one was the MDS-HC and the other the DDD Individual Client Assessment Profile) and assessment procedures. Because assessment data from DDD and DACS were collected for other purposes, not only related to whether or not a person attended an ADHS, the findings cannot be generalized to all people served by DDD and DACS who attend an ADHS. Stronger and more informative analyses could be performed and tracking systems developed, if an integrated dataset existed that included information on individuals' health, function, cognitive and behavioral abilities as well as community social supports and services. This integrated dataset should be considered by the Departments in the future as a potential way to assess the care needs of individuals at one point in time and to track individuals throughout the long term care system as they age.



## Endnotes

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1. Adult day health care, adult day health services, and medical day care will be used interchangeably throughout the report.
2. DDD defines developmental disabilities as lifelong disabilities beginning prior to the age of 22 that affect a person's ability to live without some assistance. Developmental disabilities include: mental retardation, cerebral palsy, autism, epilepsy, spina bifida, and neurological impairments occurring during the developmental stages. Developmental disabilities substantially limit the individual in at least three of the following areas: self-care, learning, mobility, communication, self-direction, economic self-sufficiency, and the ability to live independently (N.J.A.C. 10:46).
3. Georgia is looking to expand the CHHS Waiver by 1,500 more slots.
4. These individuals include only those that did not have a diagnosis of mental retardation and/or cerebral palsy from information in the DACS dataset.



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