



The Hilltop Institute

analysis to advance the health of vulnerable populations

Medicaid Long-Term Services and Supports in Maryland: The Autism Waiver FY 2006 to FY 2009

A Chart Book

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Overview of Medicaid Long-Term Services and Supports in Maryland

The Autism Waiver Chart Book is one in a series of five that explores service utilization and expenditures for Medicaid long-term services and supports in Maryland. Together the five chart books provide an overview of the number of Marylanders using long-term services and supports and the cost to Medicaid to finance these services. Other chart books in the *Medicaid Long-Term Services and Supports in Maryland* series are:

- *The Living at Home Waiver*
- *The Medical Day Care Services Waiver*
- *Nursing Facilities*
- *The Older Adults Waiver*

Maryland's Older Adults Waiver, Living at Home Waiver, and Autism Waiver provide community-based services such as personal and attendant care, assisted living services, case management, and intensive individual support services to older adults with low incomes and persons with disabilities. The Medical Day Care Services Waiver is a single-service waiver that provides medical day care services only. Participants in the Living at Home Waiver and Older Adults Waiver also receive medical day care services.

In FY 2009, a total of 9,305 individuals were enrolled in the four Medicaid home and community-based services waivers and 22,635 individuals had a Medicaid-paid nursing facility stay. FY 2009 expenditures for waiver participants and Medicaid nursing facility payments totaled \$1.4 billion.

Introduction

This chart book provides information about Maryland Medicaid participants who receive services through the Autism Waiver program. The Autism Waiver, which became effective on July 1, 2001, provides services to individuals from the age of 1 year through the end of the school year in which the individuals turn 21 years old. The waiver enables individuals with Autism Spectrum Disorder and who meet an institutional level of care (Intermediate Care Facility for Individuals with Mental Retardation (ICF/MR)) to be supported in their homes and communities. The waiver program is authorized under Section 1915(c) of the Social Security Act and approved by the federal Centers for Medicare and Medicaid Services.

In FY 2009, a total of 899 Autism Waiver participants were enrolled in the waiver. Due to the high demand for Autism Waiver services and a defined number of available waiver slots, the Autism Waiver closed in 2002. Marylanders wishing to receive Autism Waiver services must place their names on the Autism Waiver Interest List and are then asked to apply as their names reach the top of the list.

The Autism Waiver allows services to be provided to enrolled participants in their own homes, community-based settings, or school-based settings. It is administered by the Maryland State Department of Education. Services covered under the waiver may include:

- Environmental accessibility adaptations
- Family training
- Intensive individual support services
- Residential habilitation
- Respite care
- Service coordination
- Supported employment
- Therapeutic integration

Waiver participants receive full Medicaid benefits and are entitled to receive other services under the Maryland Medicaid State Plan.

Introduction continued

This chart book summarizes demographic, service utilization, and expenditure data for the Autism Waiver for state fiscal years (FYs) 2006 through 2009. The data are presented through a series of figures that illustrate trends in Autism Waiver utilization, along with accompanying narrative text. Notable trends in the data include:

- The Autism Waiver served a total of 899 participants in FY 2009. The number of participants has been relatively stable since FY 2006.
- The mean age of waiver participants increased, from 11.9 years in FY 2006 to 13.6 years in FY 2009. The percentage of participants in the 16-21 age group increased, from 21% in FY 2006 to 33% in FY 2009. The aging of the waiver population is the result of lack of turnover of the waiver participants.
- In FY 2009, 80% of waiver participants were male. Slightly more than half of waiver participants were White, and one-quarter were Black.
- Total Medicaid expenditures for Autism Waiver participants, excluding administrative costs, increased 39% from FY 2006 to FY 2009 (from \$29.4 million to \$41 million).
- While non-waiver and pharmacy expenditures remained relatively stable from FY 2006 to FY 2009, waiver expenditures increased 65% (from \$17.7 million to \$29.3 million) during the same time period.
- FY 2009 expenditures for assessments and reassessments totaled \$1.7 million, or 4.7% of total Medicaid expenditures for Autism Waiver participants.
- In FY 2009, intensive individual support services, the most widely used Autism Waiver service, was used by 827 waiver participants, at a cost of \$20.4 million.

Chart Book Organization

The data in this chart book are presented in two sections.

- **Waiver Participants:** This section includes data on the number of Autism Waiver participants with breakdowns by age, race, gender, county of residence, average length of stay, and reason for leaving the waiver. It also contains data on the settings from which individuals entered the waiver program and prior Medicaid coverage.
- **Medicaid Expenditures and Service Utilization:** This section provides data on expenditures for waiver, non-waiver, and pharmacy services used by participants in the Autism Waiver program.

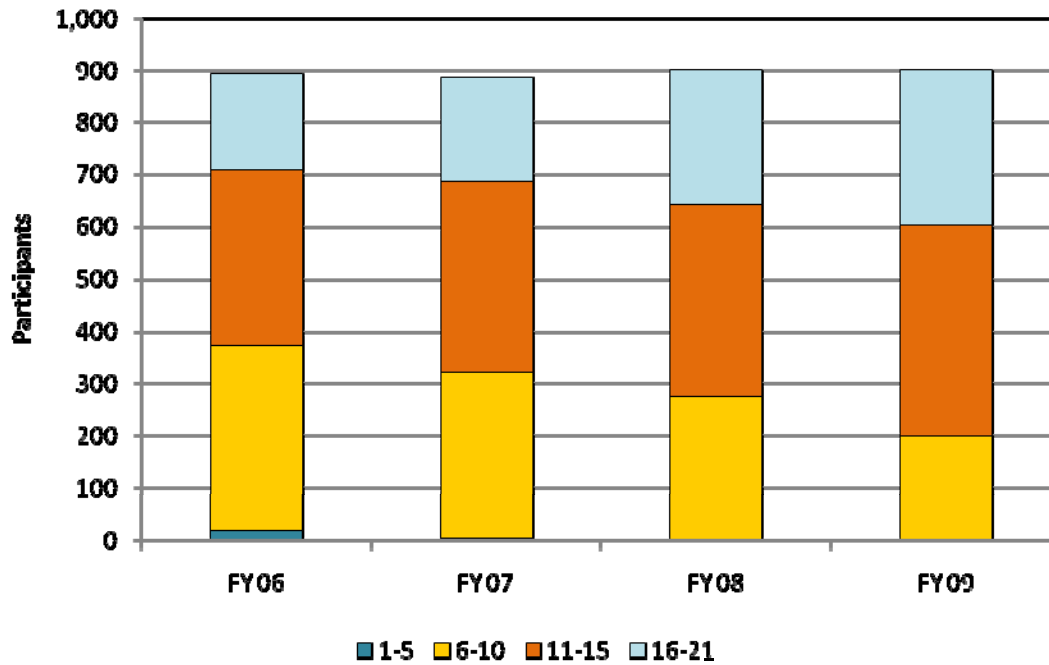
Data Sources

The information in this chart book was derived from the following data sources.

- **Maryland Department of Health and Mental Hygiene (DHMH) Medicaid Management Information System (MMIS2):** This system contains data for all individuals enrolled in Maryland Medicaid during the relevant fiscal year, including Medicaid eligibility category and fee-for-service claims.
- **DHMH Decision Support System (DSS):** This system provides summary reports based on MMIS2 files and functions as a data resource for figures in this chart book derived from the DSS.
- **DHMH Long-Term Care and Waiver Services:** FY 2009 Interest List and administrative costs data.

Waiver Participants

Figure 1. Autism Waiver Participants, by Age Group



Source: DSS.

Figure 2. Autism Waiver Participants, by Gender

Gender	FY 06	FY 07	FY 08	FY 09
Female	185	184	188	181
Male	707	701	713	718
Total	892	885	901	899

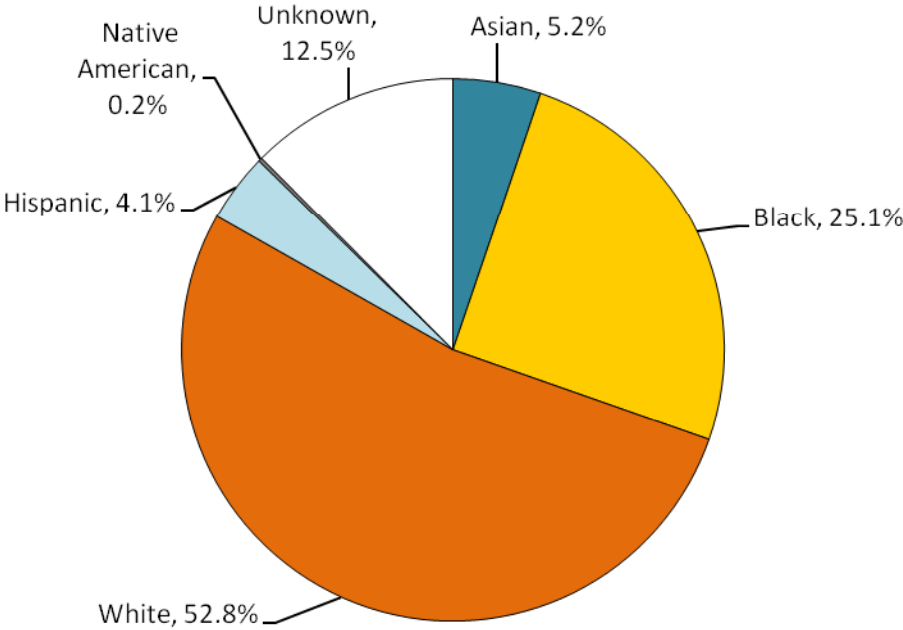
Source: DSS.

Due to the low turnover rate among Autism Waiver participants, the waiver population is aging. The percentage of waiver participants in the 11-15 age group increased, from 38% in FY 2006 to 45% in FY 2009. The percentage of waiver participants in the 16-21 age group also increased, from 21% in FY 2006 to 33% in FY 2009.

Newly enrolled Autism Waiver participants tend to be older as a result of being on the waiting list. In FY 2009, the average age of newly enrolled participants was 11.31 years.

From FY 2006 to FY 2009, the number of male Autism Waiver participants consistently outnumbered the number of female waiver participants by a ratio of 4 to 1.

Figure 3. Autism Waiver Participants, by Race, FY 2009



In FY 2009, slightly more than half of Autism Waiver participants were White. Black participants made up the next largest group, representing one-quarter of the waiver population.

Source: DSS.

Figure 4. Autism Waiver Participants, by County

County	FY 06	FY 07	FY 08	FY 09
Allegany	2	2	2	2
Anne Arundel	72	67	71	65
Baltimore City	98	88	88	85
Baltimore County	117	115	121	125
Calvert	14	13	12	12
Caroline	1	1	2	2
Carroll	18	21	25	23
Cecil	1	2	2	2
Charles	10	11	10	10
Dorchester	2	2	2	2
Frederick	52	52	57	58
Garrett	1	1	1	1
Harford	51	53	52	54
Howard	68	68	72	74
Kent	1	2	2	1
Montgomery	185	191	190	199
Prince George's	127	127	126	122
Queen Anne's	3	2	1	1
Somerset	1	1	1	0
St. Mary's	5	6	6	6
Talbot	2	2	2	0
Washington	36	36	35	35
Wicomico	10	11	9	9
Worcester	12	9	9	9
Out of State*	3	2	3	2
Total	892	885	901	899

* "Out of State" category includes persons residing in Maryland near the state line with an out-of-state postal facility code. Periodically these individuals are manually assigned to the appropriate county.

Source: DSS.

From FY 2006 to FY 2009, Montgomery County consistently had the largest number of Autism Waiver participants. Baltimore and Prince George's counties consistency had the second or third largest number of Autism waiver participants in the state.

Nine counties had less than five Autism Waiver participants enrolled in FY 2009.

Figure 5. Newly Enrolled Autism Waiver Participants, by Pre-Waiver Setting

Pre-Waiver Setting*	FY 06	FY 07	FY 08	FY 09
Chronic Hospital	1	0	0	0
ICF/MR	0	1	1	0
Other	57	87	83	56
Total	58	88	84	56

* Pre-waiver setting refers to the setting in which the participant resided prior to enrolling in the Autism Waiver. To determine an individual's pre-waiver setting, The Hilltop Institute examined MMIS2 claims for the three months prior to waiver enrollment to see if claims were filed for a chronic hospital, institution for mental diseases (IMD), intermediate care facility for individuals with mental retardation (ICF/MR), or nursing facility (NF) stay; if so, new waiver participants were classified accordingly (however, there were no waiver participants with IMD or NF claims). Waiver participants without chronic hospital, IMD, ICF/MR, or NF claims were classified as coming from "other" settings. It cannot be said with certainty—nor can it be assumed—that individuals in the "other" category were residing in the community prior to waiver enrollment.

Source: MMIS2.

In FY 2009, 100% of newly enrolled Autism Waiver participants were in a setting other than a chronic hospital or ICF/MR in the three months prior to enrolling in the waiver. It cannot be said with certainty—nor can it be assumed—that individuals in the "other" category were residing in the community prior to waiver enrollment.

Figure 6. Prior Medicaid Coverage for Autism Waiver Participants

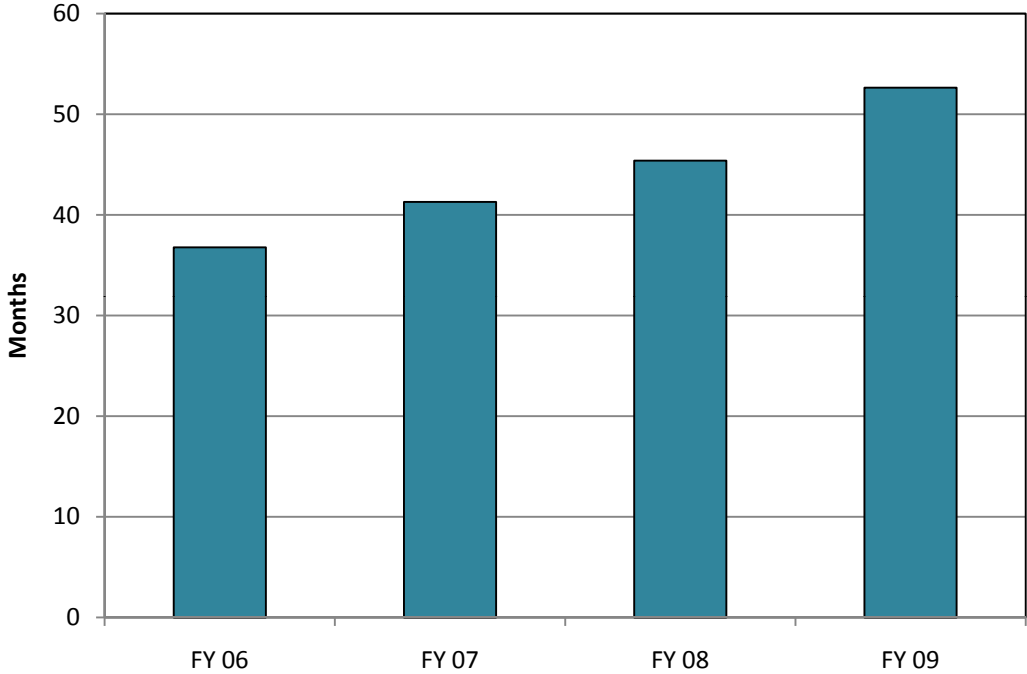
Prior Coverage Status	FY 06	FY 07	FY 08	FY 09
Prior Coverage	184	183	190	184
No Prior Coverage	708	702	711	715
Total Participants	892	885	901	899

Note: Prior Medicaid coverage status is defined as the last Medicaid coverage status assigned to each waiver participant prior to enrollment in the waiver.

Source: DSS.

In FY 2009, 715 (or 79% of) Autism Waiver participants had no prior Medicaid coverage in the three months prior to enrolling in the waiver. This number remained relatively stable throughout the four-year reporting period.

Figure 7. Average Length of Stay in the Autism Waiver, in Months, for Current Autism Waiver Participants



The average length of stay for Autism Waiver participants in FY 2009 was 52.6 months; 16 months longer than the average length of stay in FY 2006 (38.8 months). This increase is a reflection of the low turnover rate.

Note: Participants enrolled in the Autism Waiver in each fiscal year were identified using each participant’s last Medicaid Autism Waiver eligibility span. Individual participant lengths of stay were calculated from the beginning date of the participant’s last Autism Waiver eligibility span to the last day of each fiscal year (June 30). The lengths of stay for persons still in the waiver on June 30 in a given year were totaled and averaged to obtain the average length of stay for all participants in the waiver on June 30 of that fiscal year.

Source: MMIS2.

Figure 8. Average Length of Stay for Autism Waiver Disenrollees, by Reason for Leaving

	FY 07		FY 08		FY 09	
	Number of Discharges	Average LOS (in months)	Number of Discharges	Average LOS (in months)	Number of Discharges	Average LOS (in months)
Administrative Determination	0	0	0	0	1	13
Admitted to an Institution	1	22	0	0	0	0
Deceased	0	0	0	0	1	14
No Longer Needs Waiver Services	2	38	9	52	29	53
Not Medically Eligible	0	0	1	48	1	12
Not Technically Eligible	0	0	7	40	10	53
Lost Eligibility	28	36	37	45	11	52
Lost Financial Eligibility	1	20	0	0	1	20
Other	33	28	5	32	0	0
Total	65		59		54	

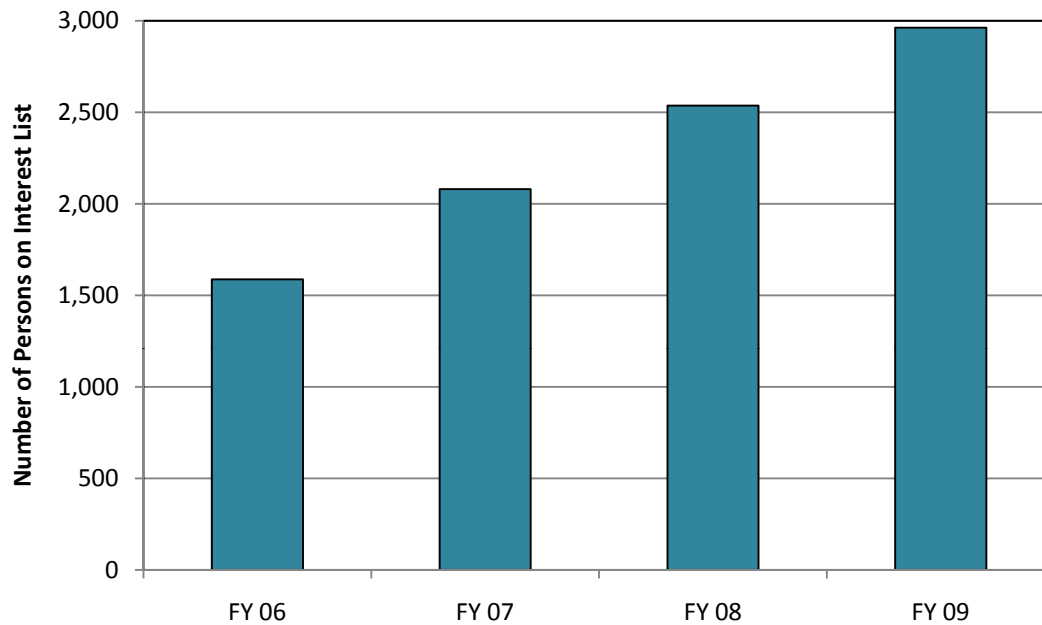
In FY 2009, over half (54% of) individuals who disenrolled from the Autism Waiver program did so because they no longer needed Autism Waiver services. On average, these individuals were enrolled in the waiver for four years.

Note: Autism Waiver participants leaving the waiver in each of the fiscal years were identified by examining participants' Medicaid Autism Waiver eligibility spans, which run from the beginning date of waiver eligibility to the last date of waiver eligibility. For participants with more than one Autism Waiver eligibility span, the last eligibility span was used. Autism Waiver participants whose last eligibility end date occurred during the given year are represented in this chart. Individual lengths of stay were calculated from the beginning date of the participant's last Autism Waiver eligibility span to the last day of each fiscal year (June 30). Each participant was categorized by reason for disenrollment and the lengths of stay were totaled and averaged to obtain the average length of stay by disenrollment reason. Persons in the "Lost Eligibility" category include Autism Waiver participants who were no longer financially eligible for the waiver or ineligible for an unknown reason.

Due to missing MMIS2 "reason for disenrollment" data, no information is available for persons leaving the waiver in FY 2006.

Source: MMIS2.

Figure 9. Number of Persons on the Autism Waiver Interest List



The number of Marylanders on the Autism Waiver Interest List increased 86.6%, from 1,587 individuals in FY 2006 to 2,962 individuals in FY 2009.

Note: Due to limited funding, the Autism Waiver closed in 2002 and the state did not accept applications for this waiver during the reporting period. Marylanders interested in receiving Autism Waiver services were required to place their name on the Autism Waiver Interest List and were asked to apply as slots became available. The number of Autism Waiver slots did not increase during this reporting period.

Source: DHMH Long-Term Care and Waiver Services.

Figure 10. Number of Persons on the Autism Waiver Interest List, by County

County	FY 06	FY 07	FY 08	FY 09
Allegany	5	12	17	16
Anne Arundel	101	139	169	202
Baltimore City	111	159	194	237
Baltimore	256	324	397	445
Calvert	25	34	42	45
Caroline	5	8	6	7
Carroll	39	63	88	107
Cecil	13	23	27	33
Charles	25	40	46	53
Dorchester	8	6	7	8
Frederick	119	160	201	227
Garrett	3	3	2	5
Harford	82	112	138	165
Howard	118	156	177	202
Kent	2	3	5	8
Montgomery	340	430	520	591
Prince George's	210	277	337	414
Queen Anne's	11	13	20	20
Somerset	6	6	6	7
St. Mary's	15	18	24	31
Talbot	2	5	6	5
Washington	28	40	53	71
Wicomico	24	26	30	40
Worcester	14	19	19	16
Unknown	22	1	1	0
Out of State*	3	3	5	7
Total	1,587	2,080	2,537	2,962

* "Out of State" category includes persons residing in Maryland near the state line with an out-of-state postal facility code. Periodically these individuals are manually assigned to the appropriate county.

Source: DHMH Long-Term Care and Waiver Services.

In FY 2009, 15%, 20%, and 14% of individuals placed on the Autism Waiver Interest List resided in Baltimore County, Montgomery County, and Prince George's County, respectively. These same counties also had the highest number of waiver participants in FY 2009.

Medicaid Expenditures and Service Utilization

Figure 11. Medicaid Expenditures for Autism Waiver Participants, by Service Category

Service Category	FY 06	FY 07	FY 08	FY 09
Waiver Expenditures	\$17,746,893	\$20,776,952	\$25,643,512	\$29,312,102
Non-Waiver Expenditures*	\$10,286,347	\$9,233,271	\$9,263,586	\$10,037,248
Pharmacy Expenditures	\$1,363,671	\$1,483,589	\$1,669,110	\$1,612,120
Total Expenditures	\$29,396,911	\$31,493,811	\$36,576,208	\$40,961,470

* Non-waiver expenditures include both non-waiver service and administrative costs.

Sources: DSS, DHMH Long-Term Care and Waiver Services.

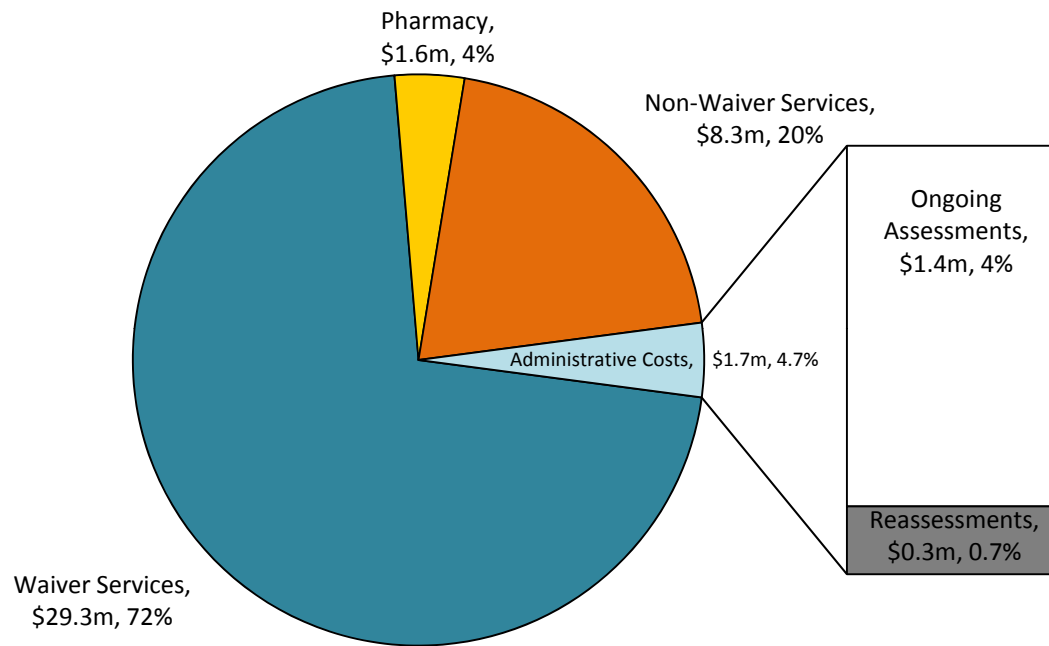
From FY 2006 to FY 2009, total Medicaid expenditures for Autism Waiver participants increased an average of 11.8% from year to year.

Non-waiver and pharmacy expenditures remained relatively stable.

Waiver expenditures increased 65% from FY 2006 to FY 2009, with intensive individual support being the most widely used waiver service among Autism Waiver participants.

Regular rehabilitation was the least used waiver service during the reporting period, with only two participants using this service in FY 2008 for a total of \$11,851.

Figure 12. Selected Administrative Costs as a Percentage of Total Medicaid Autism Waiver Expenditures, FY 2009



In FY 2009, ongoing assessment services and reassessments totaled \$1,713,825, or 4.7% of total Medicaid Autism Waiver expenditures. Both services are provided under targeted case management.

Note: Administrative costs include both ongoing assessments and reassessments. The Coordinating Center, the Autism Waiver service coordination contractor, provides these assessment services as a part of the targeted case management. Additional administrative costs are incurred in administering the waiver (e.g., staffing and IT expenditures for eligibility determinations, enrollment, claims processing, reporting to CMS, utilization review), but are not easily quantifiable.

Sources: DSS, DHMH Long-Term Care and Waiver Services.

Figure 13. Environmental Accessibility Adaptation Users and Expenditures, by Age Group

Fiscal Year												
Age Group	FY 06			FY 07			FY 08			FY 09		
	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User
1-5	0	\$0	\$0	1	\$1,061	\$1,061	0	\$0	\$0	0	\$0	\$0
6-10	19	\$19,719	\$1,038	21	\$18,346	\$874	25	\$27,882	\$1,115	21	\$22,258	\$1,060
11-15	18	\$18,216	\$1,012	29	\$22,482	\$775	34	\$37,647	\$1,107	32	\$29,782	\$931
16-21	12	\$13,044	\$1,087	10	\$11,730	\$1,173	20	\$22,298	\$1,115	22	\$23,915	\$1,087
Total	49	\$50,979	\$1,040	61	\$53,619	\$879	79	\$87,828	\$1,112	75	\$75,955	\$1,013

Source: DSS.

There was a 53% increase in the number of Autism Waiver participants utilizing environmental accessibility adaptation services from FY 2006 to FY 2009.

Total expenditures per user decreased 3% from FY 2006 to FY 2009. In each fiscal year, the 11-15 age group had the lowest expenditures per user.

Figure 14. Family Training Users and Expenditures, by Age Group

Fiscal Year												
Age Group	FY 06			FY 07			FY 08			FY 09		
	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User
1-5	16	\$45,622	\$2,851	2	\$9,193	\$4,597	1	\$285	\$285	0	\$0	\$0
6-10	285	\$634,111	\$2,225	250	\$585,334	\$2,341	230	\$617,205	\$2,684	174	\$453,853	\$2,608
11-15	256	\$438,165	\$1,712	274	\$586,189	\$2,139	289	\$626,189	\$2,167	321	\$809,283	\$2,521
16-21	105	\$170,077	\$1,620	120	\$207,951	\$1,733	166	\$370,737	\$2,233	214	\$494,791	\$2,312
Total	662	\$1,287,976	\$1,946	646	\$1,388,667	\$2,150	686	\$1,614,417	\$2,353	709	\$1,757,926	\$2,479

Source: DSS.

From FY 2006 to FY 2009, the number of Autism Waiver participants receiving family training services in the 1-5 and 6-10 age groups decreased, while the number of participants receiving family training services in the 11-15 and 16-21 age groups steadily increased. This trend mirrors the aging of the waiver population.

Family training expenditures per user tended to be higher for younger waiver participants.

Figure 15. Intensive Individual Support Services Users and Expenditures, by Age Group

Age Group	Fiscal Year											
	FY 06			FY 07			FY 08			FY 09		
	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User
1-5	16	\$338,438	\$21,152	2	\$30,942	\$15,471	1	\$3,566	\$3,566	0	\$0	\$0
6-10	302	\$5,511,957	\$18,252	278	\$5,750,817	\$20,686	253	\$5,423,339	\$21,436	190	\$4,481,336	\$23,586
11-15	276	\$5,201,201	\$18,845	317	\$6,578,558	\$20,753	325	\$7,337,021	\$22,575	375	\$9,092,730	\$24,247
16-21	121	\$2,311,754	\$19,105	157	\$3,274,122	\$20,854	211	\$5,139,130	\$24,356	262	\$6,778,948	\$25,874
Total	715	\$13,363,351	\$18,690	754	\$15,634,438	\$20,735	790	\$17,903,055	\$22,668	827	\$20,353,014	\$24,611

Source: DSS.

Intensive individual support is the most widely used Autism Waiver service. From FY 2006 to FY 2009, the total number of Autism Waiver participants using intensive individual support services increased 16%.

The number of users aged 16-21 more than doubled from FY 2006 to FY 2009. However, among participants aged 6-10, the number of users decreased 37% during this same period.

In FY 2009, average expenditures per user increased with age.

Figure 16. Intensive Residential Habilitation Users and Expenditures, by Age Group

Age Group	Fiscal Year											
	FY 06			FY 07			FY 08			FY 09		
	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User
1-5	0	\$0	\$0	0	\$0	\$0	0	\$0	\$0	0	\$0	\$0
6-10	1	\$19,255	\$19,255	2	\$37,004	\$18,502	2	\$160,657	\$80,329	1	\$49,862	\$49,862
11-15	8	\$433,939	\$54,242	8	\$522,910	\$65,364	6	\$413,865	\$68,978	4	\$456,638	\$114,160
16-21	12	\$708,859	\$59,072	14	\$881,161	\$62,940	21	\$2,459,811	\$117,134	22	\$2,497,834	\$113,538
Total	21	\$1,162,053	\$55,336	24	\$1,441,105	\$60,046	29	\$3,034,332	\$104,632	27	\$3,004,335	\$111,272

Source: DSS.

Residential habilitation services are community-based, residential placements for those waiver participants who cannot live at home because they require a highly supervised and supportive environment. Only 27 (3% of) Autism Waiver participants used intensive residential habilitation in FY 2009. Average expenditures per person were \$111,272; total expenditures were more than \$3 million. From FY 2006 to FY 2009, total expenditures for this service increased 158%.

Figure 17. Respite Care Users and Expenditures, by Age Group

Fiscal Year												
Age Group	FY 06			FY 07			FY 08			FY 09		
	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User
1-5	10	\$24,900	\$2,490	1	\$883	\$883	1	\$588	\$588	0	\$0	\$0
6-10	231	\$378,731	\$1,640	210	\$340,646	\$1,622	199	\$370,465	\$1,862	165	\$407,426	\$2,469
11-15	204	\$357,286	\$1,751	237	\$437,364	\$1,845	254	\$493,187	\$1,942	316	\$748,639	\$2,369
16-21	101	\$210,725	\$2,086	128	\$257,711	\$2,013	164	\$380,466	\$2,32	217	\$580,741	\$2,676
Total	546	\$971,643	\$1,780	576	\$1,036,604	\$1,800	618	\$1,244,706	\$2,014	698	\$1,736,806	\$2,488

Source: DSS.

From FY 2006 to FY 2009, the number of respite care users in the 6-10 age group steadily decreased, while the number of respite care users in the 11-15 and 16-21 age groups steadily increased. In each fiscal year, waiver participants in the 16-21 age group had the highest expenditures per user.

Figure 18. Therapeutic Integration Services Users and Expenditures, by Age Group

Fiscal Year												
Age Group	FY 06			FY 07			FY 08			FY 09		
	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User	Users	Expenditures	Expenditures Per User
1-5	0	\$0	\$0	0	\$0	\$0	0	\$0	\$0	0	\$0	\$0
6-10	76	\$397,077	\$5,225	76	\$428,873	\$5,643	76	\$519,256	\$6,832	59	\$398,888	\$6,761
11-15	72	\$328,017	\$4,556	94	\$536,520	\$5,708	113	\$692,636	\$6,130	142	\$1,183,852	\$8,337
16-21	31	\$183,548	\$5,921	44	\$253,588	\$5,763	70	\$522,428	\$7,463	100	\$789,279	\$7,893
Total	179	\$908,642	\$5,076	214	\$1,218,981	\$5,696	259	\$1,734,320	\$6,696	301	\$2,372,020	\$7,880

Source: DSS.

The number of therapeutic integration services users in the 11-15 and 16-21 age groups steadily increased from FY 2006 to FY 2009. In these same age groups, there was an 83% and 33% increase in expenditures per user, respectively.



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