

Survey and Comparison of Disability Waivers
That Provide Services To
Children With Autism

Prepared for

The New Mexico Legislative
Disabilities Concerns Subcommittee
Senator Nancy Rodriguez, Chair

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In response to testimony provided to the New Mexico Legislative Disability Concerns Subcommittee (DCS) regarding the provision of services to children with autism by the New Mexico Department of Health and the New Mexico Human Services Department a survey was conducted to find out how other states provide services to this group of individuals.

New Mexico serves most of its intellectually and developmentally disabled (IDD) population through waiver programs allowed by the federal Centers for Medicaid and Medicare Services (CMS). These programs allow the state to serve the needs of these individuals in the community as opposed to placing them in institutions and are known as Home and Community Based Service Waivers (HCBS).

On August 4, 2016 the Department of Health provided documents and testimony to the DCS that indicated that millions of dollars of state general fund money was being spent on Autism services. The committee and those present were left with the understanding that this money was not matched by the federal government either through the state plan program or any disability waiver program.

In order to answer questions from legislators, advocates and families this survey was undertaken. Data was derived from the federal Centers for Medicaid (CMS) website which included a review of approximately four hundred and fifty different waiver programs approved by CMS for the fifty states and the District of Columbia. The waiver descriptions in this report are copied verbatim from the website.

The cost data was also copied from *the "Cost Neutrality"* sections of the respective waiver applications on file with CMS. It should be noted that these figures are cost projections and not necessarily actual expenditures. However CMS requires a certain degree of accuracy and the use of actual rates for each service and estimate of the number of users. Actual cost data is available but the most recent is about four years old. Thus it was determined that the projected data was more current and reasonable the intended use of this report.

The survey indicated that fourteen states had waivers specifically for autism services. Thirteen are for children with autism. A table is provided on the following page. There is a wide range of costs and services provided under the various waivers. Total program costs range from around 33 million to 337 thousand. Number of participants range from 47 to 1500 and average costs per person range from \$1,474 to \$161,039. Maximum ages tend to be mostly for minors and minimum ages tend more to a range from 0 to 3 years old.

The costs shown do not reflect the state's share of costs which can range from 50% to around 70% depending on the relative wealth of the state. New Mexico's share is about 30%. Thus to create a waiver similar to the 3 million spent by Connecticut, our states share would be \$ 900,000.

The data shows that about one fourth of the states have chosen to leverage state money to get the federal match for an autism waiver. A number of states that have done so are small states with relatively smaller populations. It is not solely large wealthy states that are taking this approach.

The total costs in most of the states appear to be in line with what New Mexico is purportedly spending with unmatched money. However at the lowest federal Medicaid match they would only be paying half the cost.

States with Separate Autism Waivers	Minimum age	Maximum age	Total program cost	Number of Participants	Average cost
Arkansas	1	6	\$4,978,940	150	\$33,193
Colorado	0	5	\$1,589,844	144	\$11,040
Connecticut	3	no max	\$3,104,867	136	\$22,829
Kansas	0	5	\$1,606,250	150	\$10,708
Massachusetts	0	8	\$4,963,597	325	\$15,272
Maryland	1	21	\$45,263,352	1500	\$30,175
Maine	5	21	\$12,883,175	80	\$161,039
Missouri	3	18	\$2,949,421	175	\$16,853
Montana	1	4	\$2,580,766	60	\$43,012
Nebraska	0	17	\$2,515,080	85	\$29,589
North Dakota	0	4	\$2,426,037	47	\$51,617
Pennsylvania	21	no max	\$29,348,017	596	\$49,241
South Carolina	3	10	\$33,618,931	1025	\$32,798
Utah	2	6	\$337,550	229	\$1,474

The survey showed that specific autism waivers were not the only way the states were providing autism services to children. A number of states have “Children’s Waivers” where participation is usually limited to minors. An investigation of the states children’s waivers was carried out to determine if autism services were included in the waiver.

Seven states had children’s waivers that provided specialized services to children with autism. The data did not provide a method to easily extract the specific costs in the waivers however the waiver descriptions illustrate the services that are made available and are included in the addendum.

The survey indicated that 31 states in the country have Supports Waivers. Four states are like Arizona and have only one “Demonstration Waiver” for everything. This is the exception rather than the norm. Most states operate a number of waivers and the average is 8.5 per state.

An investigation was conducted into the “Supports Waivers” of states that did not have an Autism waiver or covered Autism under their “Children’s Waiver.” The data revealed that 21 states served children with autism under their supports waiver.

The conclusion regarding which waivers are being used to serve children with autism is as follows. 13 are using a separate autism waiver, 7 are using a children’s waiver and 21 states are

using a supports waiver. Thus a total of 41 states are leveraging state money with waivers to serve this population. The table below illustrates the use of the various waivers.

State	Serves Children With Autism Under Childrens Waiver	Autism Waiver	Serves Children with Autism Under Supports Waiver		State	Serves Children with Autism Under Childrens Waiver	Autism Waiver	Serves Children with Autism Under Supports Waiver
Alaska			yes		Nebraska		yes	
Alabama			yes		Nevada			yes
Arkansas		yes			New Hampshire	yes		yes
Colorado		yes			New Mexico	no	no	no
Connecticut		yes			New York	yes		
Delaware			yes		North Carolina			yes
Florida			yes		North Dakota		yes	
Iowa			yes		Ohio			yes
Idaho	yes				Oklahoma			yes
Illinois	yes				Oregon	yes		
Indiana			yes		Pennsylvania		yes	yes
Kansas		yes			South Carolina		yes	
Louisiana			yes		South Dakota			yes
Massachusetts		yes			Tennessee			yes
Maryland		yes			Texas			yes
Maine		yes			Utah		yes	
Michigan	yes				Virginia			yes
Minnesota			yes		Washington			yes
Missouri		yes			West Virginia			yes
Mississippi			yes		Wisconsin	yes		
Montana		yes			Wyoming			yes

It is clear that New Mexico is not following the norm in regard to serving children with Autism or providing services to them with a supports waiver.

In order to illustrate why the other states are leveraging money; let us assume that New Mexico spent a figure of 10 million per year since 2010 on Autism services totaling 60 million dollars. Had that money been matched at our current match rate of about 70/30 it could have provided 200 million dollars' worth of services. Conversely the same services that were provided for 60 million should have only cost 18 million and there should still be 42 million left on reserve for budget short falls.

The handout provided to the subcommittee on August 4, 2016 states a number of figures under the heading FY 2017 STATE GENERAL FUND (SFG) Programs. A copy is included in the addendum. The items were placed in a table and analyzed.

FY 2017 STATE GENERAL FUND PROGRAMS	COST
Adult Residential Services	\$2,546,956
Adult Habilitation/ Vocational Services	\$2,802,287
Autism Spectrum Disorder	\$3,614,461
UNM Autism Services	\$2,929,040
Recreational Respite for Children With Autism	\$124,000
Autism Flexible Services	\$409,969
Assistive Technology	\$25,000
Behavioral Support Services	\$65,000
Flexible Supports	\$500,000
Parenting Skills Training	\$72,000
Prader-Willi Syndrome Project	\$121,994
Respite Services Children	\$1,260,693
Respite Services Adults	\$251,028
Self-advocacy Training	\$26,500
Special Olympics	\$310,000
Total	\$15,058,928

It appears that at least two thirds of these services or expenditures are items that are covered in other states waiver programs. Each of the expenditures needs to be examined and a comprehensive study needs to be done of all of DDSD's non matched expenditures to insure that the state is not in the position of cutting disability budgets solely because they failed to take the reasonable and necessary steps virtually all other states have taken to insure their funds are properly leveraged with federal money.

Further, any monies that are spent on administration at a match of 50% that could be saved, should be spent on services at a 70% match. For each state dollar we can save on administration we can get three and a third dollars' worth of services for our most disabled population.

ADDENDUM

AUTISM WAIVER INFORMATION

ARKANSAS AUTISM WAIVER - AR Autism (0936.R00.00) Provides consultative clinical and therapeutic services, individual assessment/treatment development, lead therapy intervention, line therapy intervention, plan implementation and monitoring of intervention effectiveness, provision of therapeutic aides and behavioral reinforcers for children w/autism ages 1-6

COLORADO AUTISM WAIVER - CO HCBS Children w/Autism (0434.R02.00) Provides behavioral therapy, ongoing treatment evaluation, post service evaluation for children w/autism ages 0-5

CONNECTICUT AUTISM WAIVER- CT Home and Community Supports Waiver for Persons with Autism (0993.R00.00) Provides community companion homes, live-in companion, respite, assistive technology, clinical behavioral support, community mentor, individuals good and services, interpreter, job coaching, life skills coach, non-medical transportation, PERS, social skills group, specialized driving assessment for individuals w/autism ages 3 – no max age

KANSAS AUTISM WAIVER - KS Autism (0476.R01.00) Provides intensive individual supports, respite, consultative clinical & therapeutic services (autism specialist), family adjustment counseling, interpersonal communication therapy, parent support & training (peer-to-peer) for individual w/autism ages 0-5 yrs

MASSACHUSETTS AUTISM WIAVER- MA Children's Autism Spectrum Disorder (MA.40207.R02.00) Provides community integration, expanded habilitation/education, homemaker, respite, assistive technology, behavioral supports and consultation, family training, home modifications and adaptations, individual

MARYLAND AUTISM WAIVER - MD Waivers for Children w/Autism Spectrum Disorder (0339.R03.00) Provides residential hab, respite, adult life planning, environmental accessibility adaptations, family consultation, intensive individual support, therapeutic integration for individuals w/autism ages 1 – 21

MAINE AUTISM WAIVER - ME Services for Children w/ID and/or Pervasive Developmental Disorders (0864.R00.00) Provides home support, respite, communication aids, consultation, home accessibility adaptations, transportation for individuals w/autism, IID ages 5 – 21

MISSOURI AUTISM WAIVER - MO Autism (0698.R01.00) Provides in-home respite, personal assistant, assistive technology, behavior analysis, community specialist services, environmental accessibility adaptations-vehicle mods, out of home respite, person centered strategies consultation, professional assessment and monitoring, specialized medical equipment and supplies (adaptive equipment), support broker, transportation for individuals w/autism ages 3-18

MONTANA AUTISM WAIVER - MT Children's Autism Waiver (0667.R01.00) Provides children's autism training, respite, waiver funded children's case management, adaptive equipment/environmental mods, OT, PT, speech therapy, transportation, individual goods and services, program design & monitoring for children w/autism ages 1-4

NEBRASKA AUTISM WAIVER - NE Autism (40660.R00.00) Provides early intensive behavioral intervention to children /autism ages 0 – 17

NORTH DAKOTA AUTISM WAIVER - ND Autism Spectrum Disorder Birth through Four (0842.R01.00) Provides environmental mods, equipment and supplies, in home supports, intervention coordination for children w/autism ages 0 – 4

PENNSYLVANNIA AUTISM WAIVER - PA Adult Autism (0593.R02.00) Provides day habilitation, residential habilitation, respite, supported employment, supports coordination, therapies, assistive technology, career planning, community transition services, family support, home modifications, nutritional consultation, specialized skill development, temporary supplemental services, transitional work services, vehicle modifications for individuals w/autism ages 21 - no max age

SOUTH CAROLINA AUTISM WAIVER - SC Pervasive Developmental Disorder (0456.R01.00) Provides case management, EIBI assessment, EIBI plan implementation, EIBI program development and training, lead therapy, line therapy, self-directed line therapy for children w/autism ages 3 – 10

UTAH AUTISM WAIVER - UT Autism (1029.R01.00) Provides respite, FMS for children w/autism ages 2-6

Developmental Disabilities Supports Division Programs and Services

FY17 - STATE GENERAL FUND (SGF) Programs

- **Adult Residential Services, \$2,546,965** – Services to a limited number of individuals who meet the state definition of developmental delay ages 22 and older. Provides the necessary assistance and support to meet the daily living and safety needs of individuals with developmental disabilities. Staff support is available as needed from 10 hours per week to 24-hour care. Rate: **\$1530/ month**.
- **Adult Habilitation/ Vocational Services, \$2,802,287** – “Day services” including skill building, personal care and supported employment to a limited number of individuals who meet the state definition of developmental disability ages 22 and older. Rate: **\$739/month**.
 - **Autism Spectrum Disorder (ASD) Services, \$3,614,461** - DDSD is funding a variety of supports specifically for individuals (ages vary by service) with ASD and their families;
 - **UNM Autism Services, \$2,929,040** - University of New Mexico Center for Development and Disability provides a number of infrastructure supports for autism including: diagnostic evaluations; training and technical assistance; family support; parent in-home training; direct Applied Behavior Analysis and other intervention with children with challenging behaviors.
 - **Recreational Respite for children with Autism, \$124,000** – Contracts with several providers to provide community based recreational services to children, while at the same time, giving a break to caregiving parents.
- **Autism Flexible Services, \$490,969** - Up to \$2,500 per year of service to meet the needs of children, up to age 21, with ASD, who are not Medicaid eligible, and their families, including but not limited to: respite; Applied Behavioral Analysis; recreational and social skills development; other therapeutic services.
- **Assistive Technology, \$25,000** - Allows for the purchase of Assistive Technology equipment not covered by other payment sources. This support is available to individuals in State Funded Adult Services and DD Waiver programs based on a therapist assessment and recommendation.
- **Behavioral Support and Consultation Services, \$65,000** - Service to persons of all ages, who are on the waiting list or are currently receiving services through State General Funds (SGF). SGF Behavioral Supports is a service provided in each DDSD region to individuals with Intellectual/Developmental Disabilities experiencing behavioral challenges in their homes, workplace, and/or communities that interrupt their ability to form and/or maintain relationships and activities that are meaningful to them.

- **Flexible Supports, \$500,000** – (Developed from work of Senate Memorial 20 Task Force) supports people on the DD waiver waiting list with \$3,500 per year to purchase services or goods to accommodate their needs related to their disability.
- **Parenting Skills Training Project, \$72,000** - Provides targeted training and supports to parents with developmental disabilities in order for them to provide a nurturing, caring and safe environment for their children. Services are to be provided in the individual's home and other community settings (e.g. store, medical office, recreation center, child's school, etc.) as appropriate. The child of the parent with a developmental disability may be of any age.
- **Prader-Willi Syndrome Project, \$121,994.40** - The State General Fund helps to support the Prader-Willi project. This project provides support and guidance to individuals with Prader-Willi Syndrome and developmental disabilities, increasing the use of natural and generic supports, increasing the individual's ability and decreasing the need for paid supports. The project includes outreach and referral, along with professional expertise in the management of Prader-Willi Syndrome to include identification, information and referral, behavior support, nutrition, health, service coordination, resource development, public awareness, and family support including respite services. The project addresses both routine and emergency out-of-home respite needs and placements and includes technical assistance, consultation, and staff development for professionals, service providers and families.
- **Respite Services** – Respite Services offer a short term relief from day to day caregiving duties and are provided to families of children (Birth – 21 yrs.) **\$1,260,693** and adults **\$251,028** who have intellectual/developmental disability up to 200 hours per year (additional hours may be provided if there is no waiting list). Respite provides a critical break to care giving to parents. Respite services are administered through the newly formed Child and Family Supports Bureau. A respite house in Albuquerque is also funded for adults living at home, so that families can get an overnight break
- **Self-Advocacy Training, \$26,500** - Provide oversight and assistance to local People's First Chapters Statewide, including developing and providing training and technical assistance to local People's First Chapters, and recruiting individual participant self-advocates. Also, developing multi-media materials to promote collaboration between local chapters and the national self-advocacy movement. Support Individual and family participation in People First and other advocacy meetings.
- **Special Olympics, \$310,000** - Flow through funding to NM Special Olympics for games and team building activities for athletes of all abilities and their families, coaches, school systems and community organizations.

