

Report to the Health and Human Services Interim Committee

H.B 184 Medicaid Autism Waiver Service Options Report

Prepared by the Division of Medicaid and Health Financing
in collaboration with the Autism Waiver Consultation Group

September 30, 2010



Table of Contents

Introduction 1

Defining Autism Spectrum Disorders (ASDs) 1

Prevalence..... 3

Guiding Principles 3

Overview of Home and Community Based Services (HCBS) Waiver Programs..... 4

Administrative Costs 6

Service Information – Core and Adjunct Services 9

Service Information – Service Delivery and Provider Types 11

HCBS Waiver Service Package Options 12

“Option One - Group Recommended Option” Based on Providing Intensive Individual Supports to Children with ASD Ages 2 – 6 Years..... 13

“Option Two - ABA Option” Based on Providing Applied Behavioral Analysis to Children with ASD Ages 0 – 9 Years 14

“Option Three - Maryland Option” Based on Maryland’s Waiver for Children with Autism Spectrum Disorder 15

Waiver Option Comparison..... 16

Total Program Costs 17

Recommendations..... 19

Conclusion 21

Appendix A..... 22

H.B. 184, Medicaid Autism Waiver

Service Options Report

Introduction

H.B. 184 was passed during the 2010 Legislative General Session. The legislation required the Medicaid agency to develop a range of options to serve individuals with autism. The range of options was to be developed in consultation with key stakeholders with specialized knowledge of autism and reported to the Health and Human Services Interim Committee before October 1, 2010.

In compliance with H.B. 184, the Utah Department of Health, Division of Medicaid and Health Financing (Department) convened a group of families, providers and others with specialized knowledge of autism to participate in the development of a range of service options for persons with autism.

The group, known as the “Autism Waiver Consultation Group” (Group) met on a monthly basis from April through August 2010. The individuals in this group provided thoughtful commentary and meaningful recommendations to the Department and were directly involved in the preparation of *The H.B.184, Medicaid Autism Waiver Service Options Report* (the Report). The Department wishes to acknowledge and express gratitude for the contributions made by the Group. The list of Group members is attached. (*Appendix A*)

H.B. 184 required the Department to develop information on two specific options:

- The Maryland Waiver for Children with Autism Spectrum Disorder; and
- Applied Behavioral Analysis for Children Ages 0 – 9

The Report provides detailed information about these options. In addition, another option was developed for the Legislature’s consideration:

- Intensive Individual Supports to Children with ASD Ages 2-6

Along with the detailed information about the specific options, the Report provides contextual information about Autism Spectrum Disorders, the prevalence of autism, general information about Medicaid home and community based waivers, associated administrative costs, and proposed services. The Report concludes with a *Recommendations* section.

Defining Autism Spectrum Disorders (ASDs)

Rather than using the specific term *autism*, the Report utilizes the term *Autism Spectrum Disorders* or *ASDs* to characterize the condition for which services would be designed. The following information was obtained from the Centers for Disease Control and Prevention (CDC), *Autism Spectrum Disorders, Fact Sheet*. The Fact Sheet information provides a broad overview that may not be inclusive of all detailed information related to ASDs.

More information is available online at: <http://www.cdc.gov/ncbddd/autism/facts.html>

“Autism Spectrum Disorders are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. People with ASDs handle information in their brain differently than other people.

ASDs are “spectrum disorders.” That means ASDs affect each person in different ways, and can range from very mild to severe. People with ASDs share some similar symptoms, such as problems with social interaction. But there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms.

There are three different types of ASDs:

- **Autistic Disorder** (also called “classic” autism)
This is what most people think of when hearing the word “autism.” People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.
- **Asperger Syndrome**
People with Asperger syndrome usually have some milder symptoms of autistic disorder. They might have social challenges and unusual behaviors and interests. However, they typically do not have problems with language or intellectual disability.
- **Pervasive Developmental Disorder – Not Otherwise Specified** (PDD-NOS; also called “atypical autism”)
People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all, may be diagnosed with PDD-NOS. People with PDD-NOS usually have fewer and milder symptoms than those with autistic disorder. The symptoms might cause only social and communication challenges.

Signs and Symptoms

ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time. Some children with an ASD show hints of future problems within the first few months of life. In others, symptoms might not show up until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had.

A person with an ASD might:

- Not respond to their name by 12 months
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play “pretend” games (pretend to “feed” a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel”

Prevalence

The national data released by the Centers for Disease Control from 2006 shows that approximately 1 in 110 children has an ASD¹. The CDC will be releasing 2008 data in the near future. State specific data produced by the CDC in 2002 showed approximately 1 in 130 children in Utah have an ASD. The Utah Registry for Autism and Developmental Disabilities (URADD) is in the process of finalizing 2008 data for prevalence of ASD in Utah. Preliminary review suggests that the rate will be greater than 1 in 130.

National CDC prevalence data was used in conjunction with the 2009 census information obtained from Utah's Indicator-Based Information System for Public Health (IBIS-PH)ⁱ to derive the estimated number of people with ASD in a particular age group, and is included in the *HCBS Waiver Service Package Options* section of the Report.

Guiding Principles

At the onset of this project, the following guiding principles were agreed upon by the Group:

1. The provision of services to persons with ASD should result in improved outcomes for the individuals served. Improved outcomes should be reflected in improved quality of life for individuals with ASD and their families and in many cases should reduce the need for, or intensity of, ongoing services throughout the individual's lifetime. ***The Group recommends that a set of outcome indicators be developed and measured to demonstrate the efficacy of the any program that may be developed to provide services to children with ASD. The measurement process should be conducted by an entity independent from the treatment providers to prevent bias.***
2. Parental involvement and responsibility are crucial to achieving positive outcomes for the child and for the successful utilization of Home and Community Based program services. ***The Group recommends specific levels of parental involvement be required as a component of eligibility for the program.*** (Implementation of this concept would be contingent upon approval from the Centers for Medicare and Medicaid Services (CMS)).
3. A waiting list for services should not be created. ***The Group recommends that enrollment should be managed through an open-enrollment period process rather than creating and managing an ongoing waiting list for services.***
4. The intent of the program is to improve outcomes for as many Utah children with ASD as possible. While there are many services that could possibly be recommended for inclusion in a program, the service package recommended should stay true to the idea of providing services that meet program participants' "needs" rather than "wants". ***The Group will only recommend inclusion of services that are determined to meet a specific need.***

¹ CDC data showed a range of between 1 in 80 up to 1 in 240 across the nation, with a national average of 1 in 110.

Overview of Home and Community Based Services (HCBS) Waiver Programs

H.B. 184 directs the state to explore HCBS waiver programs as a means of providing services to individuals with ASD.

To provide additional context related to this Medicaid waiver authority, general characteristics of HCBS waivers and associated administrative requirements are described in this section.

History

In 1981, Section 1915(c) of the Social Security Act was enacted. *This legislation was the advent of Home and Community Based Services waiver programs, often referred to as HCBS waivers or 1915(c) waivers.* 1915(c) waivers were instituted to provide Medicaid recipients who, but for the provision of these newly available home and community based services, would have received their long term care services in facility based settings. In other words, HCBS waiver programs were provided as an alternative to facility based (institutional) care.

Waiver Authority

1915(c) waiver authority allows state Medicaid programs to “waive” some of the requirements that are otherwise mandatory throughout the general Medicaid program, including the ability to:

- limit the number of people served in the program;
- describe a target population to be served;
- provide the service in a limited geographical area rather than statewide; and
- consider the individual’s income rather than the total family income when determining financial eligibility.

Waiver Assurances

States must apply to CMS for authorization to operate HCBS waivers. The state must make some assurances to CMS in order to receive waiver approval, including:

- Waiver recipients must meet institutional level of care. This means that the clinical eligibility requirements for home and community based care must be the same as the requirements for facility based care. A person who qualifies for participation in an HCBS waiver must also qualify for admission into a nursing facility or an intermediate care facility for individuals with intellectual disabilities (mental retardation) (ICF/MR) as defined in state rule R414-502 (UAC); and
- Waiver services must be cost-neutral. This means the state must demonstrate the costs of providing waiver services to individuals in the community cannot exceed what the costs would have been had the individuals received the services in a facility.
 - To perform the cost-neutrality calculation, the state must consider the cost of HCBS waiver services plus the cost of *State Plan Benefits* (*State Plan Benefits* are the array of services available to any person on Medicaid – things a person would be eligible for by using their Medicaid card). These costs are then compared to the cost of either nursing facility or ICF/MR services plus the State Plan Benefits for a comparable population residing in facility based care.

Waiver Administration

As part of the waiver application process, states must describe how the program will be administered at the state level.

- State Medicaid Agency - *Final Administrative Authority* – As is the case with all Medicaid programs the State Medicaid Agency is required to maintain final administrative oversight of the program. Elements of this authority include the responsibility to:
 - draft and submit the waiver application and any subsequent amendments and identify a waiver liaison within the state with whom CMS will interact. The authorization period for a new HCBS waiver is three years. If the state chooses to renew that waiver, the renewal period is every five years thereafter;
 - monitor and track waiver expenses and complete comprehensive quality assurance activities;
 - report to CMS on an annual basis confirmation of cost-neutrality and other quality assurance activities;
 - enroll waiver providers and process waiver claims through the state’s Medicaid Management Information System (MMIS);
 - oversee the day-to-day operations of the waiver or delegate the day-to-day administration to an *Operating Agency*.
- Operating Agency (*Day-to-Day Operations*) – There are many responsibilities associated with running a HCBS waiver program including:
 - developing and managing the open enrollment period process (this was referred to in the Guiding Principles section regarding the recommendation that the state not create or maintain a waiting list);
 - determining eligibility for enrollment in the HCBS waiver by reviewing applications for admission into the waiver program, including reviewing clinical assessments and/or completing assessments to:
 - assure the child had a diagnosis of an ASD
 - assure the child meets the criteria for admission into an ICF/MR
 - assure parents and families are willing to commit to participation in service provision (this was referred to in the Guiding Principles section regarding the recommendation that only children whose parents/family are willing to commit to providing a specified level of services themselves will be eligible for the waiver)
 - upon determining eligibility, completing the needs assessment, identifying service providers and being involved in the care planning process;
 - educating families about the program;
 - cultivating a provider infrastructure sufficient for the needs of waiver recipients;
 - contracting with and monitoring waiver services providers;
 - monitoring program expenditures to assure they do not exceed amounts appropriated by the legislature;
 - monitoring the quality of services provided; and
 - collaborating and seeking authorization from the State Medicaid Agency on any policies or procedures that pertain to the waiver program.

Administrative Costs

General Waiver Administration

- State Medicaid Agency - To perform the administrative functions described under the *Overview of Home and Community Based Services Programs* section above, with exception of performing the Operating Agency functions directly, it would be necessary for the Division of Medicaid and Health Financing to hire the equivalent of one full-time employee:
 - one half-time Health Program Specialist III to complete the functions related to developing and implementing the waiver and performing the liaison function with both CMS and the waiver Operating Agency; and
 - one half-time Quality Assurance Specialist to complete the required cost reporting and quality assurance functions.

State Medicaid Agency Administrative Cost			
Waiver Year	Number of Employees	Total Annual Salary and Benefits Cost	50/50 Match State Share Amount
1	2 Half-Time Employees	\$64,000	\$32,000
2	2 Half-Time Employees	\$64,000	\$32,000
3	2 Half-Time Employees	\$64,000	\$32,000
Three Year Totals:		\$192,000	\$96,000

- Operating Agency - To perform the administrative functions described under the *Overview of Home and Community Based Services Programs, Operating Agency* section above, it would be necessary for the designated Operating Agency to hire 1.5 full-time employees:
 - one half-time Program Administrator I - \$40,000 approximate total costs; and
 - one full time Caseworker II to process intake/open enrollment and program eligibility determinations at the approximate total cost of \$55,000.

Operating Agency Administrative Cost			
Waiver Year	Number of Employees	Total Annual Salary and Benefits Cost	50/50 Match State Share Amount
1	1.5 Full-Time Employees	\$95,000	\$47,500
2	1.5 Full-Time Employees	\$95,000	\$47,500
3	1.5 Full-Time Employees	\$95,000	\$47,500
Three Year Totals:		\$285,000	\$142,500

Costs of Developing and Implementing Outcome Indicators

As stated in the *Guiding Principles* section, the Group recommends developing and monitoring a set of outcome indicators to demonstrate the efficacy of the program. For the purposes of the initial HCBS waiver authorization period (three years), the Group recommends that outcome assessment and testing be completed prior to the delivery of services in order to establish a base-line, then annually thereafter.

At the conclusion of the three year period, the Group recommends the outcome data be reported to the legislature to evaluate program effectiveness and to assist policy makers in determining whether the state should renew the HCBS waiver program for subsequent 5 year renewal periods.

If a decision is made to renew the HCBS waiver after the initial authorization period, the Group recommends that outcome assessment and testing be completed prior to the delivery of services in order to establish a base-line, then one additional time as the child is preparing to discharge from the HCBS waiver program.

One of the Group’s recommendations is to “phase-in” the waiver by allowing enrollment of up to 33 individuals per year up to maximum waiver capacity of 100 individuals. Based on this implementation methodology, the costs associated with the testing during the initial, three year authorization period would be estimated as follows:

- Baseline Assessment: (intellectual assessment and autism specific testing): Cost is approximately \$800 per child
- Annual Outcome Assessment: (Repeat measures in baseline assessment): Cost is approximately \$800 per child

Costs associated with conducting data analysis, aggregation and reporting would be approximately \$100 per hour. It is estimated that the time needed to conduct the evaluation and reporting is four hours per child.

Outcome Assessment Administrative Cost					
Waiver Year	Number of Recipients	Total Testing Cost	Analysis and Reporting Cost	Total Cost (State and Federal Funds)	50/50 Match State Share Amount
1	33	\$26,400	\$13,200	\$39,600	\$19,800
2	66	\$52,800	\$26,400	\$79,200	\$39,600
3	100	\$80,000	\$40,000	\$120,000	\$60,000
Three Year Totals:				\$238,800	\$119,400

Total Administrative Cost						
Waiver Year	Number of Recipients	Total State Medicaid Agency Admin Cost	Total Operating Agency Admin Cost	Outcome Assessment Admin Cost	Total Admin Cost (State and Federal Funds)	Total Admin Cost State Only Share (50/50 Match)
1	33	\$64,000	\$95,000	\$39,600	\$198,600	\$99,300
2	66	\$64,000	\$95,000	\$79,200	\$238,200	\$119,100
3	100	\$64,000	\$95,000	\$120,000	\$279,000	\$139,500
Three Year Totals:		\$192,000	\$285,000	\$238,800	\$715,800	\$357,900

Service Information – Core and Adjunct Services

Core Services

In 2009, the National Autism Center released the *National Standards Report –The National Standards Project—addressing the need for evidence based practice guidelines for autism spectrum disorders*ⁱⁱ

This report describes service modalities in which efficacy have been established through the review of scientific evidence.

The types of practice guidelines described in the National Standards Report are the core services the Group recommends for inclusion in a Medicaid ASD waiver that may be developed for children in Utah.

These services are known broadly as **Intensive Individual Supports** but there are a variety of different terms used to describe sub-component models including:

- **Applied Behavioral Analysis (ABA)**, also known as **Comprehensive Behavioral Treatment for Young Children**, is described as a research-based treatment approach that can be individualized to a child’s strengths and needs. Key principles of ABA include discrimination, motivation, and reinforcement. Discrimination is the ability to consistently behave differently when given different instruction. Adequate motivation ensures that a child is more likely to participate in a given activity. Reinforcement is maximized for appropriate, desirable behaviors and minimized for inappropriate behaviors. ASDs do not follow a common developmental pattern therefore children with ASDs are likely to have very different needs. Children with ASDs may be similar to their typically developing peers (e.g. appearance, fine and gross motor abilities, physical development) yet often have behavior repertoires that include atypical excesses and deficits that do not align with typical developmental patterns. ABA-based programs are designed to use the principles of learning to assess and individualize programs based on a child’s specific motivation and skills. ABA treatment can include but is not limited to several established teaching tools: discrete trial teaching, incidental teaching, pivotal response training, fluency building, and verbal behavior. *The ABA approach can be used by a trained, non-paid provider such as a parent, or by a paid provider such as a trained college student, sibling or other family member, counselor, or certified behavior analyst and can include web-based treatment platforms.*
- **Intensive Developmental Intervention (IDI) Models for Young Children with Autism –** Including but not limited to the following:
 - developmental, individualized and relationship-oriented (DIR) model
 - the Play and Language for Autistic Youngsters (PLAY) Project Home Consulting model; and
 - the Early Start Denver Model.

These approaches are described as comprehensive, empirically tested interventions specifically designed for toddlers and preschoolers with ASD. Supported by the principles of developmental psychology and applied behavior analysis, the models' intensive teaching interventions are delivered within play-based, relationship-focused routines. The models promote development in such key domains as imitation; communication; social, cognitive, and motor skills; adaptive behavior; and play.

The IDI model is typically provided by an occupational therapist, speech-language pathologist or other professional trained in the models.

As has been emphasized previously, when parents and families are highly involved in the provision of these services, positive outcomes are much more likely to be experienced. The Group recommends that a condition of participation in the waiver program would require a minimum of five hours per week of *Intensive Individual Supports* be provided by the trained parent or family member at no cost to the waiver program. The provision of this service by trained, non-paid caregivers will assure the involvement of the family in the child's treatment and result in cost savings to the waiver program.

Non-Paid Provider Cost Savings					
Waiver Year	Number of Recipients	Total Non-Paid Provider Hours per Week	Total Non-Paid Provider Hours per Year	Savings per Hour	Total Annual Savings
1	33	5	260	\$18	\$154,440
2	66	5	260	\$18	\$308,880
3	100	5	260	\$18	\$468,000
Three Year Totals:					\$931,320

- **Case Management Service**

This service is considered a core service of an HCBS waiver program in order to assure compliance with key waiver components. For example the case manager is responsible to:

- review the assessed needs of the participant and develop and assure implementation of the care plan;
- assure service providers, including parents and families are providing the level of services agreed upon in the care plan;
- assist the family in accessing necessary services regardless of the funding source;
- assure the child's health and welfare needs are met;
- collaborate with the Operating Agency to assure the child is receiving the needed waiver services on an ongoing basis; and
- assist with discharge planning activities required as the child ages- out of the program.

Adjunct Services

The *HCBS Waiver Service Package Options* section includes a description of adjunct services. For example, the “Maryland Model” includes a wide array of services including *Residential Services*, *Environmental Accessibility Adaptations* for the child’s home and *Family Training*. Each of these services will be described briefly under each option.

As described in the Guiding Principles section, the Group is committed to recommending only those serves intended to meet crucial needs. The one adjunct service the Group recommends for inclusion is *Respite Care*.

- **Respite Care**

This service can be defined as the provision of temporary care for a person who requires specialized or intensive care or supervision that is normally provided by his or her family at home. Respite care provides the family with relief from demands of the child's care. Respite care can be provided in the child’s home or in other settings.

The Group recommends inclusion of this service in any prospective HCBS program for children with ASD. Because of the complex needs of children with ASD, many parents and families’ time is consumed with the care of a child with ASD. The provision of minimal amounts of Respite Care can prevent parent burn-out, allow for time to be spent with other children in the family and serves to preserve the family unit as a whole by reducing the stress families of children with ASD typically encounter.

Service Information – Service Delivery and Provider Types

Traditional Provider Method

This method of providing services is the typical way in which a person accesses waiver services. Through this method, the service needs of the child are identified and the parent is provided with a list of companies that are available to provide the service. To receive the services, the parent chooses from among the enrolled providers.

Self-Administered Provider Method

This method of providing services allows parents to hire individuals of their choosing to be providers of some services. The individuals must meet the quality standards and qualifications established in the waiver program. ABA has been identified as a service that can be provided by a parent, other family member or a college student. Allowing a parent to hire the employee directly rather than choosing a company to provide the service is the *Self-Administered Provider Method*.

The state has experience utilizing this service method in some of the other waiver programs currently operating. The Group recommends this methodology be provided as an option to allow for greater flexibility in finding providers due to personal preference of the parents, but also to help address the lack of direct-care work force that is often experienced in these sectors. When this method is used, the state requires the use of a financial management services agent to assure that payroll and other employment requirements are adhered to.

HCBS Waiver Service Package Options

To develop the HCBS waiver service package options, the Group met monthly, reviewed other states' ASD waivers and did extensive research and investigation. The Group learned a great deal throughout this process and respects the varied approaches states have taken to best serve their citizens with ASD. It is the strong intent of the Group to recommend the option which is believed to best serve the needs of Utah's children with ASD.

In this section, three options are described:

1. Option One is based on providing Intensive Individual Supports to children with ASD, ages two through six years and is the recommended option of the Group.
 - a.** Option One targets the age group of two years through six years for ***three very important reasons:***
 - i.** The diagnosis of ASD can reliably be made by the time the child is two years old;
 - ii.** Intensive early individualized intervention results in improved outcome which lead to reduced ongoing need for services, hardship to families and reduced costs; and
 - iii.** Intensive Individual Supports (ABA or similar) training is most effective when provided prior to the age of six.
2. Option Two would provide ABA therapy for children from birth through nine years of age. A review of this option was specifically required in the legislation. The group strongly believes the expenditure of services to those less than two years and older than six years would not result in as great of an improvement in outcomes which are likely to occur in Option One. In addition, as individualizing therapy is believed to be an essential part of providing appropriate therapy to children with ASD, this option was limited in that it only offered one form of therapy.
3. Option Three would replicate the Maryland HCBS waiver which targets the age group of one through twenty-one years. A review of this option was specifically required by the legislation. As with Option Two, this third option offered services to those beyond the maximal opportunity for improvement window.

It should be noted that all members voiced their awareness that there is no age when a person with ASD could not benefit from services. It was the Group's task to define how best to spend limited resources and maximally benefit those receiving these services.

Each option describes the estimated number of people with ASD in the identified age group. In addition, each option describes a sub-group that is an estimate of the number of people with ASD who would meet the requirements for admission into an ICF/MR. As described previously, the state must assure that waiver participants meet the medical eligibility requirements for admission into an ICF/MR.

“Option One - Group Recommended Option” Based on Providing Intensive Individual Supports to Children with ASD Ages 2 – 6 Years

Targeting Criteria

- Two years old through six years old
- Has a confirmed ASD diagnosis
- Meets ICF/MR level of care

Covered Services

- **Intensive Individual Support Services** – Training of Direct Care Workers to provide ABA or similar supports.
- **Intensive Individual Support Services (ABA or similar)** provide intensive one-to-one assistance based on the child’s need for intervention and support. Service is limited to 15 hours of paid services per week. (In addition to the 15 hours of paid services, parents and family are required to complete a minimum of 5 hours of one-on-one intervention- ABA or similar).
- **Case Management Services**– assures the development and implementation of a care plan that meets the assessed needs of the child and assists the family in accessing needed services regardless of the funding source, and assists with discharge planning when the child ages out of the program.
- **Respite Care Services** are provided for the temporary care for a person who requires specialized or intensive care or supervision that is normally provided by his or her family at home. Respite care provides the family with relief from demands of the child's care.
- **Financial Management Services (To allow parents to hire direct care staff)** are offered in support of the self-administered services delivery option and include, provider qualification verification, completion of employer-related activities including federal, state, and local tax withholding/payments, unemployment compensation fees, wage settlements, fiscal accounting and expenditure reports and Medicaid claims process and reimbursement distribution.

Option One - Group Recommended Option	
Approximate Number of People with ASD in this Age Group	2,668
Approximate Number of People with ASD who would meet ICF/MR Level of Care and be Eligible for the Waiver	993 ²
Per Person Average Total Annual Cost (State and Federal Funds)	\$33,588 per person for waiver and state plan services ³
Total Non-Federal Share per Person- State Share ~30 percent of total	\$10,076 per person for waiver and state plan services

² Based on Arizona data related to number of individuals with ASD who have a co-occurring intellectual disability

³ Waiver Costs = \$25,548 and State Plan Costs = \$8,040 = \$33,588

“Option Two - ABA Option” Based on Providing Applied Behavioral Analysis to Children with ASD Ages 0 – 9 Years

Targeting Criteria

- One year old through nine years old
- Has a confirmed ASD diagnosis
- Meets ICF/MR level of care

Covered Services

- **Intensive Individual Support Services** – Training of Direct Care Workers to provide ABA or similar supports.
- **Intensive Individual Support Services (ABA or similar)** provide intensive one-to-one assistance based on the child’s need for intervention and support. Service is limited to 25 hours per week.
- **Case Management Services**– assures the development and implementation of a care plan that meets the assessed needs of the child and assists the family in accessing needed services regardless of the funding source, and assists with discharge planning when the child ages out of the program.

Option Two - ABA Option	
Approximate Number of People with ASD in this Age Group	5,295
Approximate Number of People with ASD who would meet ICF/MR Level of Care and be Eligible for the Waiver	1,970 ⁴
Per Person Average Total Annual Cost (State and Federal Funds)	\$36,320 per person for waiver and state plan services ⁵
Total Non-Federal Share per Person- State Share ~30 percent of total	\$10,896 per person for waiver and state plan services

⁴ Based on Arizona data related to number of individuals with ASD who have a co-occurring intellectual disability

⁵ Waiver Costs = \$28,280 and State Plan Costs = \$8,040 = \$36,320

“Option Three - Maryland Option” Based on Maryland’s Waiver for Children with Autism Spectrum Disorder

Targeting Criteria

- One year old through the end of the school year in which the individual turns twenty-one
- Has a confirmed ASD diagnosis
- Receives services in a Special Education setting or Early Intervention
- Meets ICF/MR level of care

Covered Services

- **Residential Habilitation Services** are for individuals who cannot live in the family home because the individuals require highly supervised and supportive environments.
- **Respite Care Services** are provided for the temporary care for a person who requires specialized or intensive care or supervision that is normally provided by his or her family at home. Respite care provides the family with relief from demands of the child's care.
- are provided on a short-term basis because of the absence or need for relief of those persons normally providing care to the child.
- **Adult Life Planning Services** are services intended to assist individuals who are aging out of the school based services.
- **Environmental Accessibility Adaptation Services** are physical adaptations to the child’s home which are necessary to ensure health, welfare and safety of the child and which enable the child to function with greater independence in the home.
- **Family Training Services** are available to families of children served on the waiver for the purpose of training the family to support the child in the home, including explanation of treatment regimens or instruction on the use of special equipment. “Family” does not include individuals who are employed to provide services to this child.
- **Intensive Individual Support Services (ABA or similar)** provide intensive one-to-one assistance based on the child’s need for intervention and support. Service is limited to 25 hours per week.
- **Therapeutic Integration Services** are structured programs of therapeutic activities which focus heavily on expressive therapies and therapeutic recreational activities.
- **Case Management Services** (In Maryland rather than being a waiver service, this services is provided as a State Plan Service - Targeted Case Management)

Option Three - Maryland Option	
Approximate Number of People with ASD in this Age Group	10,077
Approximate Number of People with ASD who would meet ICF/MR Level of Care and be Eligible for the Waiver	3,750 ⁶
Per Person Average Total Annual Cost (State and Federal Funds)	\$53,602 per person for waiver and state plan services ⁷
Total Non-Federal Share per Person- State Share ~30 percent of total	\$16,081 per person for waiver and state plan services

⁶ Based on Arizona data related to number of individuals with ASD who have a co-occurring intellectual disability

⁷ Waiver Costs = \$45,562 and State Plan Costs = \$8,040 = \$53,602

Waiver Option Comparison

Autism Waiver Options Comparison			
Waiver Characteristic	Recommended Option	ABA 0-9 Option	Maryland Option
Target Age in Years	2 - 6	0 - 9	1 - 21
Number of People with ASD in the Age Group	2,668	5,295	10,077
Estimated Number Eligible for the Waiver	993	1,970	3,750
Number of Services	5	3	8
Self-Administered Services Option	Yes	No	No
Parent/Family Participation Requirement	Yes	No	No
Annual Total Cost per Person	\$33,588	\$36,320	\$53,602
Annual State Share per Person	\$10,076	\$10,896	\$16,081

Total Program Costs

Option One - Group Recommended Option- Intensive Individual Supports for Children 2 through 6 Years				
Total Program Cost (State and Federal Funds)				
Waiver Year	Number of Recipients	Total Annual Service Cost (State and Federal Funds)	Total Annual Admin Cost (State and Federal Funds)	Total Annual Program Cost (State and Federal Funds)
1	33	\$1,108,404	\$198,600	\$1,307,004
2	66	\$2,216,808	\$238,200	\$2,455,008
3	100	\$3,358,800	\$279,000	\$3,637,800
Three Year Totals:		\$6,684,012	\$715,800	\$7,399,812
Total Program Cost (State Funds Only)				
Waiver Year	Number of Recipients	Total Annual Service Cost (State Funds Only ~30 % of total)	Total Annual Admin Cost (State Funds Only 50/50 Match)	Total Annual Program Cost (State Funds Only)
1	33	\$332,521	\$99,300	\$431,821
2	66	\$665,042	\$119,100	\$784,142
3	100	\$1,007,640	\$139,500	\$1,147,140
Three Year Totals:		\$2,005,204	\$357,900	\$2,363,104

Option Two - ABA Option for Children 0 through 9 Years				
Total Program Cost (State and Federal Funds)				
Waiver Year	Number of Recipients	Total Annual Service Cost (State and Federal Funds)	Total Annual Admin Cost (State and Federal Funds)	Total Annual Program Cost (State and Federal Funds)
1	33	\$1,198,560	\$198,600	\$1,397,160
2	66	\$2,397,120	\$238,200	\$2,635,320
3	100	\$3,632,000	\$279,000	\$3,911,000
Three Year Totals:		\$7,227,680	\$715,800	\$7,943,480
Total Program Cost (State Funds Only)				
Waiver Year	Number of Recipients	Total Annual Service Cost (State Funds Only ~30 % of total)	Total Annual Admin Cost (State Funds Only)	Total Annual Program Cost (State Funds Only)
1	33	\$359,568	\$99,300	\$458,868
2	66	\$719,136	\$119,100	\$838,236
3	100	\$1,089,600	\$139,500	\$1,229,100
Three Year Totals:		\$2,168,304	\$357,900	\$2,526,204

Option Three - Maryland Option				
Total Program Cost (State and Federal Funds)				
Waiver Year	Number of Recipients	Total Annual Service Cost (State and Federal Funds)	Total Annual Admin Cost (State and Federal Funds)	Total Annual Program Cost (State and Federal Funds)
1	33	\$1,768,866	\$198,600	\$1,967,466
2	66	\$3,537,732	\$238,200	\$3,775,932
3	100	\$5,360,200	\$279,000	\$5,639,200
Three Year Totals:		\$10,666,798	\$715,800	\$11,382,598
Total Program Cost (State Funds Only)				
Waiver Year	Number of Recipients	Total Annual Service Cost (State Funds Only ~30 % of total)	Total Annual Admin Cost (State Funds Only)	Total Annual Program Cost (State Funds Only)
1	33	\$530,660	\$99,300	\$629,960
2	66	\$1,061,320	\$119,100	\$1,180,420
3	100	\$1,608,060	\$139,500	\$1,747,560
Three Year Totals:		\$3,200,039	\$357,900	\$3,557,939

Recommendations

Based on the comprehensive review completed by the Group, the Department recommends:

1. The Guiding Principles outlined in the report should be incorporated into any prospective HCBS program developed for children with ASD.

Outcome Measurement – The Outcome Measurement Project should be implemented for the initial 3-year waiver authorization period. At the end of the period, the data should be reported to the Legislature and other policy makers to assist in determining the effectiveness of the program and to determine whether the state should pursue renewal of the HCBS waiver program for subsequent authorization periods. Although there are administrative costs involved with implementing this recommendation, decisions about continuing the waiver program should be based on empirical data.

Required Parental/Family Involvement – While this provision will be subject to the approval of CMS, the Group believes that 1.) outcomes for children with highly involved families are significantly better than those with less family involvement; 2.) personal accountability and responsibility are principles that are widely held by the people of Utah and should be incorporated into this program; and 3.) requiring a minimum of 5 hours of ABA or similar training to be provided by the family will result in greatly enhanced outcomes and substantial savings. Approximately \$931,000 in state and Federal Medicaid funds could be saved over the three year waiver authorization period by having families provide a minimum of 5 hours of non-paid services per week rather than having the services rendered by a paid provider.

Open Enrollment Periods to Manage Entrance onto the Waiver -

The prevalence of ASD is going to be a problem facing this country and our state for decades to come. It is unlikely that the state will have sufficient resources to serve all those who might potentially be eligible for services. Rather than creating a waiting list, the Group recommends managing enrollment through limited open enrollment periods. There will be some administrative work involved in developing and implementing this process, but it is preferable to the work of managing an ongoing waiting list.

Only include Needed Services – While there are many services that could be of potential benefit to children with ASD, the Group recommends that the service package should not include items that would be desirable but not necessary and should only include those services that have been determined to be needed.

2. The Division of Services for People with Disabilities (DSPD) should be the state agency selected to perform the Operating Agency functions.

This is a natural fit because DSPD is the agency with statutory authority to provide services to people with disabilities. DSPD is the designated Operating Agency for several other HCBS waivers currently operating in the state and possesses considerable experience and a thorough understanding of the HCBS waiver requirements. DSPD already has established relationships and contracts with service providers in this field and would be able to rapidly enlist their existing base of contracted and qualified providers to serve the children in this prospective waiver.

3. The Self-Administered Service delivery method should be permitted in any HCBS waiver program that is developed.

This service delivery method will allow for greater flexibility in finding providers not only due to personal preference of parents, but also to help address the lack of direct-care work force that is often experienced in these sectors, especially in rural and frontier area of the state. When this method is used, the state requires the use of a Financial Management Services provider to assure that payroll and other employment requirements are adhered to. Financial Management Services should be included to support the Self-Administered Service delivery method.

4. Option One – Based on Providing Intensive Individual Supports to Children with ASD Ages Two through Six Years should be implemented.

Providing services to children from ages two to six provides the best opportunity to experience positive outcomes for the child and family. Recent studies show that the diagnosis of ASD can reliably be made by the time the child is two years old; other studies reinforce that intensive early individualized interventions produce lasting results if conducted prior to the age of seven. Improved outcomes lead to reduced ongoing needs for service, hardship to families and reduced costs.

In addition, providing services to this age group allows for the best natural when determining whether applicants meet the required ICF/MR eligibility as defined in State rule R414-502 (UAC).

While there are many services that could be of potential benefit to children with ASD, the service package should not include items that may be desirable but not necessary and should only include those services that have been determined to be needed. This will allow the state the opportunity to serve as many children as possible with appropriated funds.

5. The waiver should be phased-in over the 3-year waiver authorization period, with a maximum initial enrollment of 100 children (33 children per year).

Utilizing a phase-in process will allow state administrative staff the opportunity to perform all the required functions related to participant enrollment, provider enrollment, and implementation oversight with a manageable population that grows over time rather than suddenly. Phased implementation will also permit deliberative development of quality assurance monitoring and cost reporting processes. The phase-in process will allow the outcome measurements to be monitored systematically as new participants enter the waiver during each of the waiver years.

Conclusion

The Department would like to express its appreciation for the opportunity to perform a comprehensive review of service options for children with ASD and to report and submit recommendations to the Legislature.

ⁱ Indicator-Based Information System for Public Health, <http://ibis.health.utah.gov>

ⁱⁱ National Autism Center released the “*National Standards Report –The National Standards Project—addressing the need for evidence based practice guidelines for autism spectrum disorder*” Copyright © 2009 National Autism Center

AUTISM WAIVER CONSULTATION GROUP CONTACT INFORMATION	
NAME	REPRESENTING
Laura Anderson	Participants/Families
Chuck Bruder	DSPD
Josette Dorius	Home Program
Tonya Hales	DMHF/HCBS Waivers
Susan Ord	Early Intervention
Alan Ormsby	DSPD Director
Harper Randall	CSHCN
Gail Rapp	DMHF/Assistant Division Director
Cheryl Smith	Participants/Families
Jason Stewart	DMHF/HCBS Waivers
Jocelyn Taylor	Utah Office of Education
Dinah Weldon	DHS/Substance Abuse/Mental Health
LeeAnn Whiffen	Participants/Families
Judith Zimmerman	Utah Registry of Autism

Acronym Key:

- DSPD - Division of Services for People with Disabilities
- DMHF - Division of Medicaid and Health Financing
- HCBS - Home and Community-Based Services
- CSHCN - Children with Special Health Care Needs
- DHS - Department of Human Services