

Report to:

Utah Department of Health Executive Director
Health and Human Services Interim Committee
Social Services Appropriations Subcommittee

Autism Treatment Account Pilot Program

Prepared by the:

Utah Department of Health, Autism Treatment Account Advisory Committee

November 2014



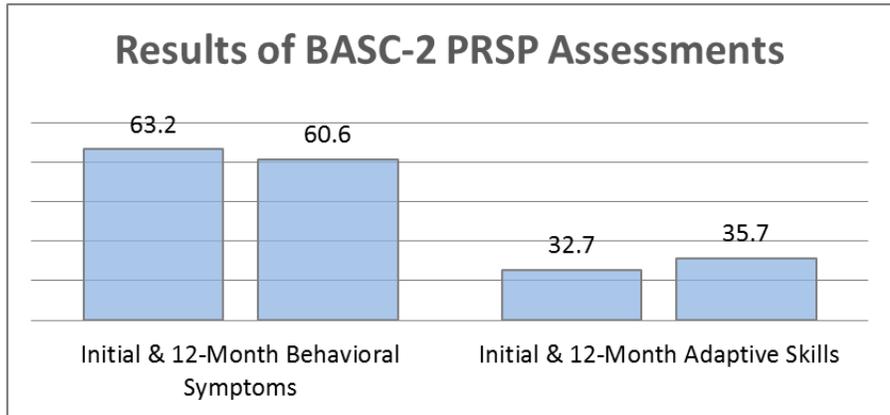
Executive Summary

With the passage of HB272 in the 2012 Legislative Session, a pilot program was created to provide intensive behavioral services to children with autism spectrum disorder (ASD). The pilot was divided into three sub-pilots. The Autism Treatment Account (ATA), one of the sub-pilots, provided children with ASD, 2 to 7 years of age with access to intensive behavioral services using an evidence-based therapy known as applied behavioral analysis (ABA). Through the ATA, the Utah Department of Health contracted with four ABA providers. A total of 49 children received services during the pilot program.

Outcomes and Effectiveness

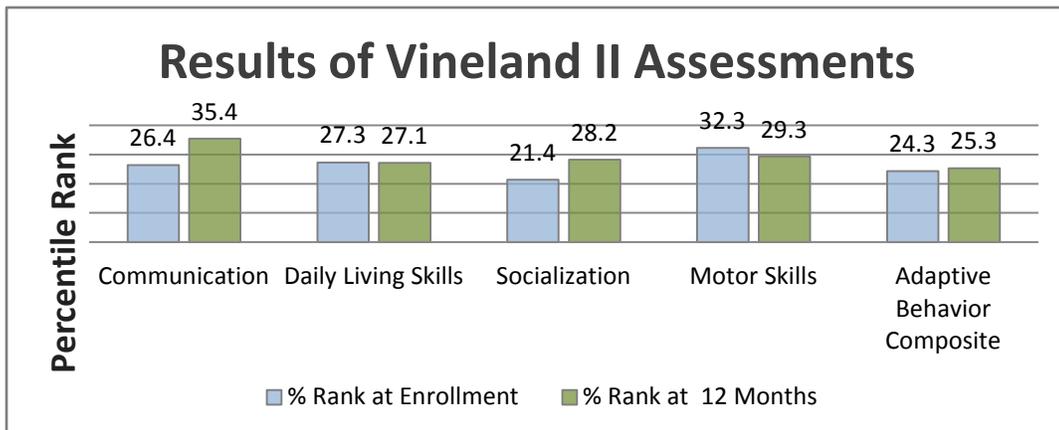
Participating children were assessed at enrollment prior to services being initiated and again every six months of services.

The Behavioral Assessment System for Children, Second Edition, Parent Rating Scale (BASC-2 PRSP) was used to assess the social, emotional, behavioral, and adaptive functioning of participating children. The results of the initial and the 12-month measures, presented in the accompanying table,



indicate a reduction in maladaptive behaviors. (Scores below 60 are considered average.) The Adaptive (self-help) skill scores also denote an increase in positive behaviors. (A score above 40 is considered average.) The changes in both measures indicate improvement.

The Vineland II, a parent/caregiver questionnaire, was used to assess the communication, daily living skills, socialization, motor skills, and adaptive behavioral functioning of participating children. A comparison of the baseline and 12 month scores indicate that participating children made gains in communication, socialization, and adaptive behavior functioning.



Autism Treatment Account Pilot Program Report

Purpose of Report

This report is submitted in response to the following language from HB272 passed by the 2012 Legislature:

“Not later than November 30 of each year, the [Autism Treatment Account Advisory] committee shall provide a written report summarizing the activities of the committee to:

- (i) the executive director of the department;
 - (ii) the Legislature's Health and Human Services Interim Committee; and
 - (iii) the Legislature's Social Services Appropriations Subcommittee.
- (b) The report under Subsection (8)(a) shall include:
- (i) the number of children diagnosed with autism spectrum disorder who are receiving services under this chapter;
 - (ii) the types of services provided to children under this chapter; and
 - (iii) results of any evaluations on the effectiveness of treatments and services provided under this chapter.”

Overview

The Autism Treatment Account (ATA):

- Established in March 2010 by the Utah Legislature with the passage of House Bill 311.
- Revised during the 2012 legislative session.
 - o HB 272 created a pilot program to provide services for children ages 2 to 7 years through three mechanisms;
 - 1) a Medicaid Waiver,
 - 2) PEHP insured, eligible children, and
 - 3) the Autism Treatment Account.
- A restricted special revenue account for the receipt and expenditure of funds to be used for assistance in funding services and therapy to eligible Utah children less than seven years of age with Autism Spectrum Disorders (ASD).
 - o Funding was appropriated by the state to the ATA for \$1M for the 2 year pilot program.
- The account may also accept “gifts, grants, donations, and bequests of real property, personal property, or services, from any source, or any other conveyance that may be made to the account from private sources, interest and other earnings derived from the account money.”
 - o Private donations of \$750,000 from Intermountain Healthcare (\$500,000) and Zions Bank (\$250,000) were received
- Administered by the Executive Director of the Utah Department of Health
 - o Staff support from the Bureau of Children with Special Health Care Needs (CSHCN), in the Division of Family Health and Preparedness.
- During the 2014 General Session, the Legislature passed HB88 which makes technical and conforming changes to the language of the law. However, no funding was allocated and the ATA Pilot Program ended June 30, 2014.

Autism Treatment Account Advisory Committee

The legislation established the Autism Treatment Account Advisory Committee

- Purpose of committee is to recommend how funds should be managed and expended.

The six Governor-appointed members serving on the committee currently include:

- Harper Randall, MD (representing Utah Department of Health),
- Natalie Roth, PhD (providing expertise in treatment of ASD),
- Paul Carbone, MD (pediatrician specializing in ASD),
- Melanie Hall (family member),
- Cheryl Smith (family advocate/president of the Autism Council of Utah), and
- Jeffrey Skibitsky (a board certified behavioral analyst).

Cheryl Smith served as chair until April 2014. Jeff Skibitsky succeeded Ms. Smith and is the current chair.

Autism Treatment Account: FY2014 Activities

The ATA Advisory Committee and the Utah Department of Health continued to oversee the pilot program to provide therapy for children.

- Account monies were used to provide a child who had a diagnosis of ASD, and who was at least two years of age but younger than seven years, with services that utilized applied behavior analysis (ABA) and other proven effective therapies per national standards.
- All services provided included at least:
 1. ABA therapy provided by or supervised by a board certified behavior analyst or a licensed psychologist with equivalent university training and supervised experience who is working toward board certification in applied behavior analysis;
 2. Ability to reach children in rural and underserved areas of the state through use of telehealth; and
 3. Methods to engage family members in the treatment process.

The ATA services were provided by four ASD therapy providers selected through a competitive solicitation process and included: Alternative Behavior Strategies, Inc.; Amy Peters Therapy Services, LLC; Autism Therapy Services LLC; and Kids on the Move, Inc.

Number of children with ASD who are receiving services

Forty-nine children were enrolled during the pilot program. Eighty-four percent (83.7%) of the participants are male (8 female participants) with a mean age of nearly four years (46.7 months) at the time of application. Eighty-eight percent (88.1%) of the participants indicated their child's race as white with 11.9% of these identifying their ethnicity as Hispanic, and 4.8% African-American. About forty-three percent (42.6%) of the participants reside in rural counties, or are similarly underserved, with a mean household size of roughly five (4.6).

Types of services provided to children

All children received a baseline assessment prior to beginning services and had a treatment plan developed which was updated regularly. The treatment plans consisted of the identified problems/concerns, a statement of the treatment goals or objectives, a strategy by which the goal was addressed and the criteria used to measure progress. The parents actively collaborated in the development of the treatment plan and in monitoring progress. The plans were reviewed at least every three months or sooner if appropriate. Progress or lack of progress was recorded and resulting plan revisions. After every six months of services, the assessments were repeated to evaluate progress and identify directions for next steps in the ABA services. Properly certified and/ or supervised personnel who were employees or

contractors of the provider provide the ABA services. The progress documented by achievement of goals on the treatment plan cannot be compared across children as each child's treatment plan contained unique goals designed to address the behavioral needs of the individual child.

ATA providers indicated that 26.5% of the enrolled applicants live in areas of the state that do not have access to Applied Behavioral Analysis (ABA) service providers. Video-conferencing was used to provide Board Certified Behavior Analyst (BCBA) supervision; supporting to 25 ABA tutors and 1 BCBA candidate. Supervision was provided according to the Behavior Analyst Certification Board (BACB) guidelines at a rate of 1 hour of supervision for every 10 hours of treatment. The cost effective method of supervision increased access to ABA services for 18 ATA children participants.

During the 18 months of the ATA pilot, participating children received 35,963 hours in direct services (one-on-one ABA instruction). The average number of direct service hours (per child) in a month is 54 hours, with an average of 13.5 hours per week.

Results of evaluations on the effectiveness of treatment and services provided

The Utah Department of Health issued a request for proposals using the Utah State Purchasing system. Utah State University (USU) Center for Persons with Disabilities was selected to conduct the evaluation of the ATA. All providers submitted data to USU as required in their contract. Complete results of the evaluation are available upon request. Participating children were assessed when services were initiated and again after receiving six and twelve months of services. The results are presented separately for those who received six months of services and those who received at least twelve months of services. Ten children received less than six months of services (parent withdrawal, moved out of service area) and are excluded from the presented results. Seventeen (17) children received more than six months of services but less than twelve months and twelve (12) children received 12 months or more of services.

Each of the four ATA providers submitted copies of the Vineland II Adaptive Behavior Scales (Vineland II) and Behavioral Assessment System for Children, Second Edition (BASC-2) instruments as they were completed during the initial assessment and after six and twelve months of ABA services to the evaluation team. Paired-samples *t* tests were used to evaluate whether the difference between the enrollment and six-month and twelve-month scores were significantly different.

The Vineland II is an assessment of an individual's daily functioning that may be used in educational and clinical diagnostic evaluations of developmental delays, in developmental evaluations of young children, for progress monitoring, and for program planning.

- The outcomes for children receiving services were positive and demonstrate that treatments resulted in positive increases in the communication, socialization and maladaptive behavior domains.
- Children receiving at least 12 months of services had a significant change ($t(12)=2.521$, $p=.027$) in their maladaptive behaviors domain that includes subdomains for

internalizing, externalizing, and other types of undesirable behavior. These children demonstrated fewer maladaptive behaviors at 12 months.

The BASC-2 (completed by parents and preschool/elementary classroom teachers, when available) indicated the efficacy of ATA funded services in improving social, emotional, behavioral, and adaptive functioning outcomes for children with ASD.

- The preschool/elementary classroom teacher rated outcomes for children receiving six months of services were positive with a decrease in behavioral problems (Behavioral Symptoms Index, where a score above 60 is a concern) as well as a positive increase in Adaptive Skills Composite (where a score below 40 is a concern). On individual measures teachers indicate significant decreases in the child's hyperactivity, depression, and atypicality (Atypicality is a term used to describe when a person performs behaviors that differ from their peers.) for those receiving at least six months of services, as well as a positive increase in the child's adaptability.

The evaluation results indicate the delivery of ABA services through ATA is associated with positive behavioral and developmental outcomes in children with ASD.

Family involvement and perception. At the end of their ATA services all participating families were asked to respond to a brief online survey regarding their experience in the ATA program and the impact of the ATA for their child. The evaluation team designed the survey which was reviewed and revised by the ATA Advisory Committee and the ABA providers. To ensure confidentiality, the link to the electronic survey was distributed by each provider to each family with their own confidential identifier. As a result, the evaluation team did not have access to participants' names. The participating families were informed that their individual responses would not be shared with their ABA provider. Twenty-one families responded to the survey and 20 completed it.

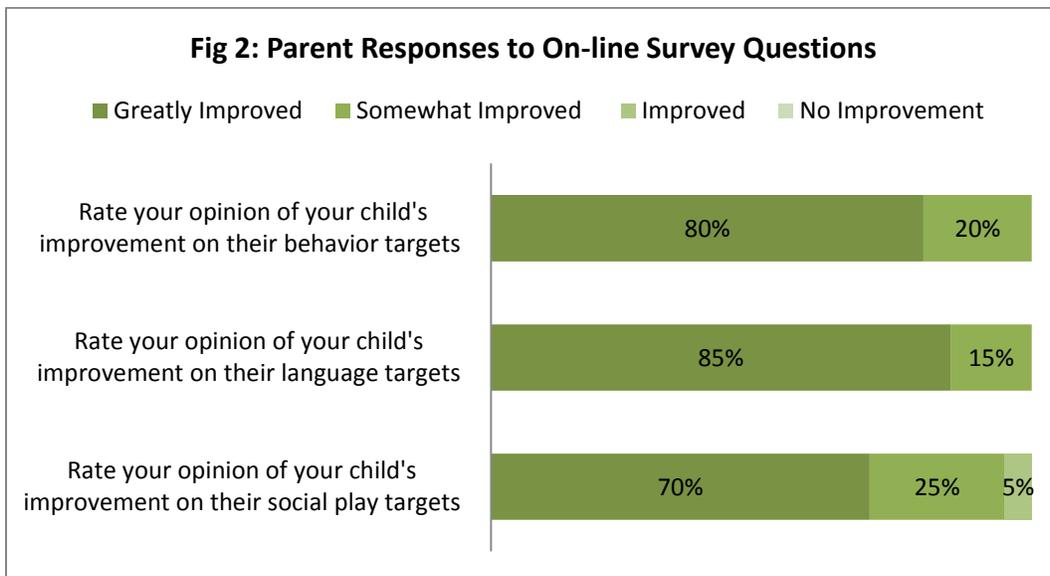
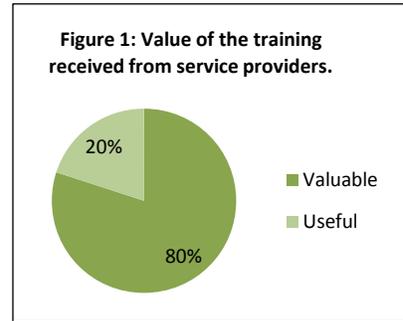
Family involvement is a critical component of the ATA program. Families responding to the survey indicated that they observed their child's treatment/therapy an average of 9 hours per week and had participated in training sessions an average of 2.3 hours per week and in meetings with the provider team 1.3 hours per week. Participation in parent training sessions averaged 2 hours per week and working independently with their child averaged 16.5 hours per week. Although not all providers offered each of these elements, these data indicate that families seemed to be actively engaged.

Family perceptions of child change.

All or nearly all of participating families strongly agreed or agreed: that the provided services are making a significant difference in their child's development (100%); that their understanding of how to support and interact with their child is improving (100%); that their child's ability to interact with other children is improving (94%); and that their child's ability to be successful in their home (100%), school (95%), and community (95%) is improving. Specifically, 100% of the families rated their child's improvement on behavior and language

targets as improved or greatly improved. In the area of social play, 70% of the families noted greatly improved, 25% as improved, and 5% as somewhat improved.

Participating families rated the value of the information that they had received from their service provider as useful (5%) or valuable (95%). Figure 1 represents the value of the training received from the provider: valuable by 80% of the families and useful by 20%. All families indicated that they were comfortable or very comfortable in participating in the treatment of their child. Figure 2 further summarizes portions of the online survey. All parents indicated some level of improvement.



Family comments

When given the opportunity to provide their thoughts regarding the strengths and weakness of their child’s ATA program, families said:

Strengths:

- *“The therapists all had extensive experience with ABA therapy and children with special needs/Autism. They showed a deep understanding and caring nature towards our son and his individual issues. The therapists had an incredible amount of insight and detailed planning went into our son's programs.”*
- *“Our child has grown in leaps and bounds in many aspects. She has gained many new skills based on the programs ran in her ABA program. We only have seen strengths in her program and no real weaknesses.”*
- *“We have seen nothing but strengths build with our son over the last 2 years. Apart from our son going to full days of school then coming home for about an hour and*

starting ABA (which towards the end of the week he was getting tired) it fit well in our schedule. We will surely miss not having the program and tutors in our lives anymore.

- *“HUGE progress in ALL areas of my son's deficits.”*
- *“Gave me the tools to help my child, and it has also eased stress on my marriage. there are no weaknesses, it has been nothing but positive.”*
- *“My child has learned how to do so many things through the ABA program. He now has eye contact, good behavior, receptive and expressive vocabulary, play and social skills, and academics. All of these things he really did not have when he first started the program 2 years ago!”*

Weakness:

- “The only weakness I can think of is time, a year is not enough. He need more help still.”
- “And there have been no weaknesses.”
- “I really can't think of a negative thing about having the therapy. The only thing I can think of is that I am really sad that our program didn't get any funding to continue. We have to try to pay for it ourselves, and it is extremely expensive! But there is no way that we can stop the therapy since our son's results have been amazing.”

Cost of providing ABA services through ATA:

Average cost of providing services to each child by the contracted providers was \$2,673 per month with an average of 61 hours of direct service hours per child per month. Utah Department of Health administrative costs, including personnel and the evaluation contract amounted to 9% of all total program costs.

Resulting system improvements

In June 2014, at the conclusion of the ATA program, the four ATA providers described the changes they had seen in expanding the state's capacity to serve young children with ASD:

- Established BCBA candidates in Price, St. George, two in Ogden, Park City, Lehi.
- New direct service staff (35) all enrolled in Board Certification programs in Salt Lake, Summit, Weber, Davis, Utah, Carbon, Tooele.
- Families that applied for the ATA and had insurance were identified. Their insurance coverage was discussed and some of the families already had benefits for ABA
- The commencement of the U of U BCBA credentialing program.
- Established professional groups for behavior analysts (two groups within the state; one research oriented and the other practice oriented).

In addition, three of the ATA service providers also responded to a brief electronic survey in June 2014 regarding the impact of the ATA on their community and other programs. The complete survey responses are contained in Attachment D. They indicated that the program has benefited families and enhanced the capacity of communities and systems. Comments include:

Benefits for families

- Access to services not readily available in rural areas. Greatly reduced financial burden.
- Most children have shown dramatic improvements in many developmental areas. Having such a large number of hours made for very effective treatment. The coverage for parent training time, which isn't covered under other funding sources, also enabled us to provide high quality training. Many parents really valued this, and implemented in outside of therapy time. Anecdotally, these are the children that showed the best progress. We have one client who, clinically, we feel like is no longer in need of any specialized services at all, and thus will be mainstreamed in his neighborhood school district, which is the ultimate success.
- Increased skills in children in areas of language, self-help, behavior, play, and social skills increased skills in parents and siblings in their ability to teach and manage behavior of their children. Children performed better in school settings

Benefits for service providers

- We have been able to gain, and now retain, many new clients. With this grant in place, we were able to cover our costs enough that we were able to expand services quickly and efficiently.
- Increased number of families we were able to serve in our community. Increased number of trained staff we were able to bring on Increased number of professional contacts we had in the ABA community

Feedback for the system of care/community

- Greatly reduced burden on the schools which has traditionally been only option for services. Additionally, we are able to focus on skills that are difficult to accomplish during the traditional 2.5 hours, four day a week special education preschool service pattern such as toilet training. Additionally, we were able to target behavior and skills in areas where the schools would not be able to provide services such as dance class, behavior in public etc.
- Thank you for this amazing opportunity to provide services to families within our State. I wish that families would have been able to continue with the Medicaid Waiver when this program was discontinued. Many of them applied, but have not been accepted so now their children will move from receiving intensive services to receiving nothing.
- In the future for other grants or waivers, it should be mandatory that a transition plan for clients be put into place. This would be relevant for children who are aging out, or for all clients when the grant/waiver ends. Dealing with these transition issues was by far the most difficult part of this grant.

Evaluation team comments on the overall impact of the ATA on children, families, and the system of services:

The ATA Project was not developed to meet research criteria (e.g. no control group was established) but rather was evaluated through a behavioral science approach. The purpose of the Autism Treatment Account Project was to evaluate the impact of intensive behavioral home-based services with children with ASD and their families.

Individuals with ASD have core deficits in social communication and display repetitive behaviors and restricted interests. These core deficits were positively impacted by the ATA services. The children receiving ATA services demonstrated improvement in the areas of social skills, adaptability, atypicality, (a term used to describe when a person performs behaviors that differ

from their peers) and attention problems as demonstrated by the BASC. The BASC scores also indicated that, In general, the children in the program displayed increases in behaviors such as eye-to-eye gaze, facial expression, and gestures to regulate social interactions. Expressive and receptive communication, as measured by the Vineland II, showed positive developmental trends; as did the areas of daily living skills (personal care) and socialization (interpersonal relationships, play and leisure time, coping skills). The ATA model led to positive behavioral and developmental outcomes in the lives of children with ASD and their families.

The Department of Health is encouraged to continue to systematically evaluate the impact of ASD related services to the children and families in Utah that are supported by the department.