

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 2013



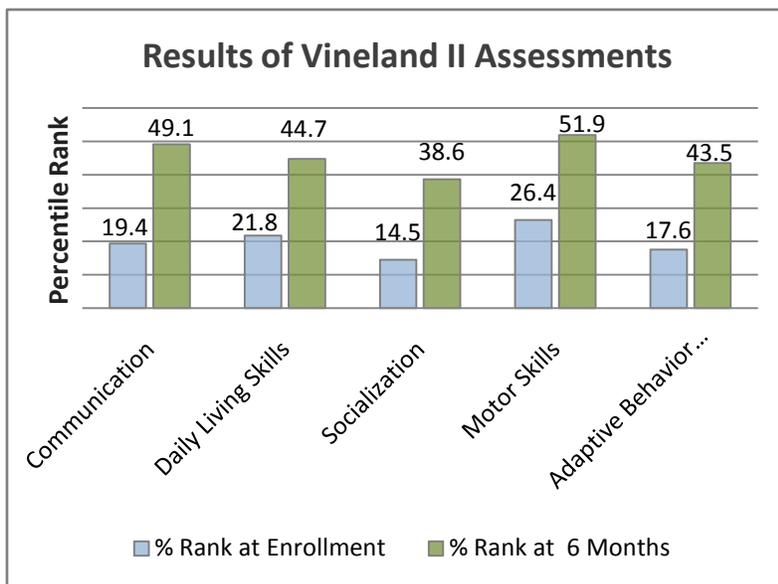
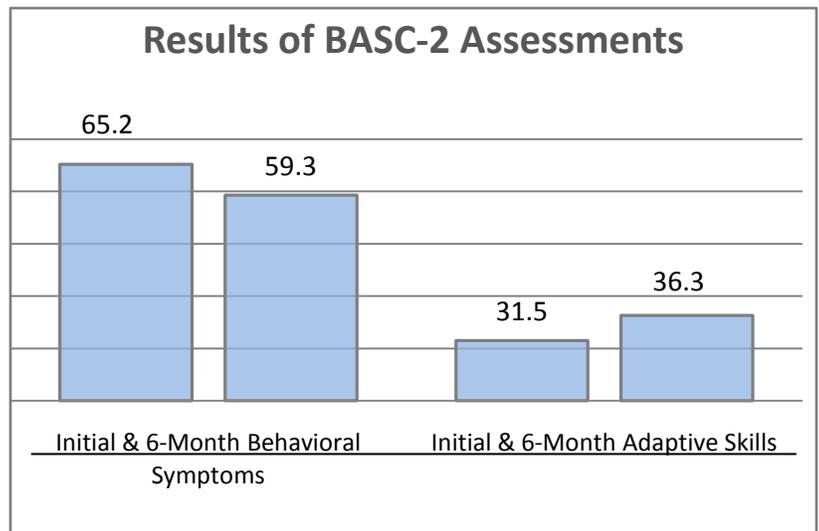
Executive Summary

With the passage of HB272 in the 2012 Legislative Session, an autism-services pilot was created. The pilot was divided into three sub-pilots. The Autism Treatment Account (ATA) is one of the sub-pilots. The ATA serves children with autism spectrum disorders, 2 to 7 years of age. Through the ATA, the Utah Department of Health contracts with four Applied Behavioral Analysis (ABA) providers. A total of 35 children received services during the first year of the pilot. Assessment data are available for 28 children who received at least six months of continuous therapy.

Outcomes and Effectiveness

Participating children were assessed at enrollment prior to services being initiated and again after receiving 6 months of services.

The Behavioral Assessment System for Children, Second Edition (BASC-2) was used to assess the social, emotional, behavioral, and adaptive functioning of participating children. The outcomes for children receiving services demonstrate that ATA funded therapy resulted in positive decreases in behavioral problems (Behavioral Symptoms, where a score above 60 is a concern) and increases in positive behaviors (Adaptive Skills, where a score below 40 is a concern). The change in both measures indicates improvement.



The Vineland II: Parent/Caregiver Survey Interview (Vineland II) was used to assess the communication, daily living skills, socialization, motor skills, and adaptive behavioral functioning of participating children. The outcomes for children receiving services were positive and demonstrate that services provided resulted in positive increases in all domains.

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) have been 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.

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 during the first year of the pilot program:

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

Cheryl Smith is the current chair as selected by the ATA Advisory Committee. The committee members serve on a rotation and 2 new members were appointed in November 2013 by the Governor to replace Peter Nicholas and Leeann Whiffen. The new members are Natalie Roth, PhD and Melanie Hall, mom of a child with autism.

Autism Treatment Account: FY2013 Activities

The ATA Advisory Committee was charged with creating a rule to govern administration of the funds.

This rule includes:

- qualification criteria and procedures for selecting children who may qualify for assistance from the account,
- qualifications, criteria, and procedures for evaluating the services and providers to include in the program, and
- provisions to address and avoid conflicts of interest that may arise in relation to the committee's work.

The proposed rule went through the rulemaking process and became effective July 30, 2012.

The ATA Advisory Committee and the Utah Department of Health determined that the most efficient and effective way to provide therapy for children under HB272 was to issue a request for grant application (RFA).

- The purpose of the RFA was to enter into contracts with qualified providers or organizations to provide services eligible under UCA 26-52 (<http://le.utah.gov/UtahCode/section.jsp?code=26-52>).
- Account monies are used to provide a child who has a diagnosis of ASD, and who is at least two years of age but younger than seven years, with services that utilize applied behavior analysis (ABA) and other proven effective therapies per national standards.
- All services provided include 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 RFA resulted in contracts with four ASD therapy providers. Providers selected:: 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

A total of 35 children have been served during the first year of the pilot. After initial enrollment, five children discontinued services (parents moved out of state, child near typical development, parent withdrew) and 9 new children were enrolled, including some that have been in the program for less than 6 months. The time period for service duration needed to assess outcomes was determined to be at least six months. Assessment data are available for 28 children who received at least 6 months of continuous service. Enrolled children met the established criteria: family is a resident of Utah; child is between 2 and 6 years of age (this was amended to 7 years of age); can receive at least 6 months of service; has a diagnosis of Autism Spectrum Disorder; and family agrees to the provision of ABA services and family involvement activities.

The 28 children included:

- 92% male
- Mean age at time of enrollment: 45.6 months (3.8 years)
- 72% received services in-home setting, 4% used videoconferencing
- Videoconferencing was used in 18% of homes to provide treatment supervision by a BCBA
- 21% rural

Types of services provided to children

All children received a baseline assessment prior to beginning services and had a treatment plan developed which is updated regularly. The treatment plans generally consist of the identification of the problems/concerns, a statement of the treatment goal or objective, a strategy by which the goal will be achieved and the criteria to be used to measure progress. The parents actively collaborated in the development of the treatment plan and in monitoring progress. The plans are reviewed at least every three months or sooner if appropriate. Progress or lack of progress is recorded, and the plan is revised as necessary. After receiving six months of services, the assessments were repeated to determine progress and identify directions for next steps in the ABA services. Properly certified and / or supervised personnel who are employees or contractors of the provider provide the ABA services. The amount of progress cannot be compared across children as each child's treatment plan contains unique goals designed to address the behavioral needs of the individual child. Videoconferencing (Skype, Facetime, Telehealth) was used to provide Board Certified Behavior Analyst (BCBA) supervision and support to 22 ABA tutors and 1 BCBA candidate. The cost effective method of supervision increased access to ABA services for 15 ATA children.

To August 31, 2013, participating children have received 14,038 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.

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 receiving six months of ABA services to the evaluation team.

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.

- Results from the Vineland II indicate significant improvements in ATA participants' communication, daily living skills, socialization, motor skills, and adaptive behaviors.

The BASC-2 (completed by both parents and teachers) indicates the efficacy of ATA-funded services in improving social, emotional, behavioral, and adaptive functioning outcomes for children with ASD.

- Both parents and teachers indicated a decrease (an improvement) in the Behavioral Symptoms Index (BSI), or overall score, which measures the level of behavioral problems. Teachers indicated an increase in the Adaptive Skills Composite, indicating more positive behaviors. The change in both measures indicates improvement.
- On individual measures, both parents and teachers indicate a decrease in the child's atypicality. (Atypicality is a term used to describe when a person performs behaviors that differ from their peers.) Parents indicated positive changes, indicating improvement, in hyperactivity, depression, attention problems, social skills, activities of daily living, and functional communication. Teachers also noted a decrease in aggressive behaviors.
- These results indicate the delivery of ABA services through ATA is leading to positive behavioral outcomes in children with ASD.

Family involvement and perception. After approximately 6 months of service, all families participating in the ATA program were asked to respond to a brief online survey regarding their experience in the ATA program and the impact of the ABA services 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 families responded to the survey and 16 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 6.73 hours per week and had participated in training sessions an average of 2 hours per week and 2.95 hours per week in meetings with the provider team. Participation in parent training sessions averaged 4.47 hours per week. Parents working independently with their child averaged 11.2

hours per week. Although not all providers offered each of these elements, families were actively engaged in the ABA process.

Family perceptions of child change.

Are services provided making a difference with:

	Strongly disagree	Disagree	Agree	Strongly agree
Your understanding of how to support and interact with your child?	0%	0%	44%	56%
Your child's development?	0%	0%	12.5%	87.5%

Please rate your opinion of your child's improvement on:

	No improvement	Somewhat improved	Improved	Greatly improved
Language development	0%	12.5%	25%	62.5%
Behavior targets	0%	0%	18.75%	81.25%

The families rated the value of the information that they had received from their service provider as valuable (87.5%) or useful (12.5%). The training they received from their provider was rated as valuable by 87.5% of the families; useful by 7% and not useful by 7%. All families indicated that they were comfortable or very comfortable in participating in the treatment of their child.

Family comments

Families were given the opportunity to provide their thoughts, both positive and negative, regarding their child's ATA program. Selected representative comments include the following:

- “We are very proud of the progress our son has made since he’s been in the ABA program. We see continuous improvement from him and this program has given us hope for the future. This program has been a dream come true and we are very blessed to be a part of this program. “
- “The ABA program has been life changing for us and especially our son! He is now communicating, answering simple questions and requests, he doesn't run away, he has great behavior and is now teachable! I honestly didn't know if we would ever reach him, but we have, and his chances of being integrated into society as an adult if he keeps doing ABA are way higher, and we are so happy about this! We now have hope!”

- “Our child's program is doing an excellent job. We have seen so much progress in just a little over six months. When our child began the program, he could say less than ten words and would go weeks without saying anything. We could not take him to public places, like restaurants or shopping, and we would often have to intervene to stop him from attacking others. He could not sit in a chair or be still. Now, we cannot even count the words he can say and sign. He is fine in public places and his attacks on others have decreased significantly. He can even sit still for several minutes. Our child's program is working miracles with our son.”

Several challenges were noted which included:

- “One thing I wish the program had was peer interaction, because that is one of my son's greatest weaknesses. But luckily my son will be starting preschool for kids with special needs through the school district, along with his ABA, and this should hopefully help that tremendously. Also I think the program should continue longer than 2 years. I know it would be tremendously helpful if it at least continued until the child is 7 or 8 years old.”
- “The downside of in-home therapy has been that the personal and professional lines were blurred and often overstepped by the tutor, as well as me (the mother), out of politeness. Although the benefits have been good for my autistic son, there were too many downsides in the end and I would only continue the therapy in an out-of-home setting.”

Cost of providing ABA services through ATA:

From July 2012 through August 31, 2013, the total expenditures of the ATA Program:

Total expenditures:	\$719,836
Contractual costs to ABA providers:	\$663,224 (comprise 92% of all funds expended)
UDOH administrative costs:	\$ 56,612 (comprise 8% of all funds expended)

Of the \$663,224 contractual costs to ABA providers, direct service expenses comprised \$430,027, or approximately 65%. Clinical administrative (non-direct) costs (Assessments/Coordination/Supervision/Tools) account for \$233,197, or approximately 35% of the contractual costs.

Resulting system improvements

In February 2013, following the implementation of the ATA program, the 4 ABA providers noted early changes in expanding the state’s capacity to serve young children with ASD:

- New BCBA candidates in Price, St. George, two each in Ogden, Park City, Lehi
- New direct care staff (35) all enrolled in Board Certification programs in Salt Lake, Summit, Weber, Davis, Utah, Carbon, Tooele
- The U of U opened a BCBA credentialing program
- A new professional group for behavior analysts was established
- The number of direct care providers increased, thereby increasing access to ABA services

The four ATA service providers also responded to an electronic survey, in August 2013, regarding the impact of the ATA on their community and other programs. They indicated that the program has opened a dialogue with communities and increased capacity of the systems to provide care. Quotes included:

“Care has transitioned and generalized across community members and stakeholders.”

“The program has provided a treatment option that was previously not available in the community. This program has also led to collaborative relationships with schools and clinics. Several agencies have asked us to come and present information to their staff. The longer the program has gone the more communication there has been between school programs and home programs.”

“Some of the benefits of the ATA within our organization are an increased capacity to serve kids in our area. I hired more staff and can now not only serve the ATA well kids but also others who come along. Through collaboration with other ATA providers we have learned how to better utilize video supervision. This has improved the amount of dose supervision we can provide to some of our clients who are more distant.”

“The ability to supervise tutors using virtual technology has allowed us to work with more clients. Using virtual technology has also enabled us to reach clients in rural areas who otherwise have no ability to access specialized services.”

“We have also been able to reach out to families in need in rural communities when this wasn't an option before. As we've opened up therapy in a specific rural area. We have been able to train 2 ABA tutors who are now in that area.”

Lessons learned:

- 1) Children enrolled were older than the recommended treatment start age of 2-3 years. The average age of ATA children being 45.6 months.
- 2) The stipulation in provider contract for number of hours of therapy per child needs to be evaluated. Hours of treatment should be based on results of assessment. In the current system, each provider estimated the number of hours that a child would receive services and then found they were limited if the child required therapy beyond the estimated projection.
- 3) To increase usability of evaluation data submitted by the providers, a standard protocol and training should be developed for each evaluation instrument for providers.
- 4) Families engaged in the ABA process to a much greater degree than nationally recommended level of 20%.
- 5) Families may be unaware of coverage by their insurance plans. A few families that applied for the ATA were identified to already have insurance coverage for ABA

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

The evaluation team from USU reviewed, aggregated, and analyzed the child data and the treatment plans. Based on the 6-month results, the children participating in the ATA program made noticeable progress as indicated by scores on the Vineland II and the BASC-2. Treatment plans also documented achieved goals.

Families are clearly pleased with the changes they have seen in their child's behavior, social skills, and language development. Their comments are almost entirely positive in nature, and are supported by the analysis of the outcome measures. It is the opinion of the evaluation team that the ATA program is having a positive impact on the enrolled families including their ability to participate with their child in community activities and interact with family and friends.

The ATA program has already made positive changes to the service systems in Utah. The use of virtual technology for supervision purposes, training more direct service personnel, extending services into rural areas, and reaching underserved populations are all enhancing the capacity of the service systems.