

December 14, 2018

Charles Smithson
Secretary of Senate
State Capitol Building
LOCAL

Carmine Boal
Chief Clerk of the House
State Capitol Building
LOCAL

Dear Ms. Boal and Mr. Smithson:

Enclosed please find copies of reports to the General Assembly relative to the Autism Support Program Annual Report.

This report was prepared pursuant to the directive contained in Iowa Code §225D.2(5)(d).

Please feel free to contact me if you need additional information.

Sincerely,



Mikki Stier
Deputy Director

Enclosure

cc: Kim Reynolds, Governor
Senator Amanda Ragan
Senator Mark Costello
Representative David Heaton
Representative Lisa Heddens
Legislative Service Agency
Kris Bell, Senate Democrat Caucus
Josh Bronsink, Senate Republican Caucus
Natalie Ginty, House Republican Caucus
Kelsey Thien, House Democrat Caucus



Department of
HUMAN SERVICES

***Autism Support Program
Annual Report***

December, 2018

Autism Support Program Annual Report

Executive Summary

The Autism Support Program (ASP) was created by the Iowa Legislature in 2013 to provide funding for applied behavioral analysis (ABA) services to children who meet certain age, diagnostic and financial eligibility criteria. The program funds services to children with autism who are not covered by Medicaid and do not have a private insurance benefit for ABA services. Eligibility criteria for age and income were expanded in 2016 to increase accessibility to families in need. The program has served 55 children who would not otherwise have been able to access this critical early intervention treatment. Stakeholders express strong support and appreciation for the program as a sound investment in improving life outcomes for children with autism. The Department believes that ASP funds a valuable and cost-effective service for children in the program and their families.

Introduction

The Department is required by Iowa Code §225D.2(5)(d) to submit an annual report no later than January 1 of each year regarding implementation of the Autism Support Program. Included in this report is a summary of the services provided in State Fiscal Year 2018 (SFY18) by the ASP and recommendations for continued operation of the program.

Program Overview

Background: The Iowa Legislature created the Autism Support Program in 2013 Iowa Acts, Chapter 138, Sections 82-85, (Iowa Code section 225D.2).

The legislation directed the Department to:

- implement an autism support program beginning January 1, 2014, to provide payment for the provision of applied behavioral analysis treatment for eligible individuals
- adopt rules, including standards and guidelines pursuant to chapter 17A to implement and administer the program
- consult with and incorporate the recommendations of an expert panel convened by the regional autism assistance program to provide expert opinion on clinically relevant practices and guidance on program implementation and administration in adopting the rules, standards, and guidelines for the program
- implement and administer the program in a manner so that payment for services is available throughout the state, including in rural and under-resourced areas

Funding: For State Fiscal Year 2016-2017, the legislature appropriated two million dollars to be credited to the Autism Support Program Fund. The appropriation further provided that of the \$2 million dollar total, the following allocations would be made:

- \$250,000 to the Board Certified Behavior Analyst (BCBA) and Board Certified Assistant Behavior Analyst (BCaBA) Grants Program Fund
- \$25,000 to be used to continue a grant to a child welfare services provider serving children with autism spectrum disorder (ASD) and their families
- \$25,000 to be used to continue a grant to a hospital-based provider for the continuation of a pilot project to determine the necessary support service for children with autism spectrum disorders

For State Fiscal Year 2017-2018, the legislature appropriated \$950,000 to be credited to the Autism Support Program Fund. The appropriation further provided that of the \$950,000 total, the following allocations would be made:

- \$25,000 to be used to continue a grant to a child welfare services provider serving children with autism spectrum disorder (ASD) and their families
- \$25,000 to be used to continue a grant to a hospital-based provider for the continuation of a pilot project to determine the necessary support service for children with autism spectrum disorders

For State Fiscal Year 2018-2019, the legislature appropriated \$573,000 to be credited to the Autism Support Program Fund. The appropriation further provided that of the \$573,000 total, the following allocation would be made:

- \$25,000 to be used to continue a grant to a child welfare services provider serving children with autism spectrum disorder (ASD) and their families

The BCBA and BCaBA grants program is discussed under the “Workforce” heading later in this report. The continuing grant to a child welfare services provider, which has supported a summer social skills building program for children and youth with ASD operated by Four Oaks through SFY18, will be used during SFY19 to fund a similar after-school program operated by Tanager Place. The hospital-based pilot project was operated by Mercy Medical Center Dubuque through SFY16. Mercy Medical Center declined to accept the SFY17 and SFY18 allocations due to programming and staff changes. Mercy Dubuque no longer directly provides specialized autism services and no longer has the staff capacity to continue the pilot program.

Eligibility: The use of ASP funds is limited to individuals who meet a specific set of criteria. These criteria include limitations based on diagnosis, diagnostician qualifications, age of applicant, and financial status of the applicant’s family. Services must be provided by a qualified Applied Behavior Analyst (ABA) provider. The Iowa Legislature made revisions to the Autism Support Program in 2016 that expanded the criteria for age and family income and made the program accessible to more families.

Currently a child is eligible to receive assistance under ASP if:

- the child is under the age of fourteen (14) at the time of application
- the child has a diagnosis on the Autism spectrum made by a child psychiatrist, developmental pediatrician, or a clinical psychologist within twenty-four months of the date of application
- the child does not qualify for Medicaid or any other public funding for ABA services
- the child does not have coverage available for ABA services under any private insurance carrier
- the child's family has a household income at or below 500% of the federal poverty level (FPL) (as an example, effective Jan. 31, 2018, 500% of FPL for a family of four is \$125,500)

SFY18 Data

Iowa Code section 225D.2(5)(d) requires this annual report to address the following items for the preceding fiscal year:

1. The total number of applications received under the program for the immediately preceding fiscal year.
 - The Department received 23 applications for the ASP during SFY18.
2. The number of applications approved and the total amount of funding expended for reimbursements under the program in the immediately preceding fiscal year.
 - The Department approved 17 (74%) of the applications received during SFY18. The remaining 6 applications were denied for the following reasons:
 - 2 were over income guidelines
 - 3 was found to have access to ABA through a private insurance benefit
 - 1 was found to be Medicaid eligible
 - A total of \$359,557 was expended during SFY18 for ABA service reimbursements to providers. This represents a decrease of 4.3% from the \$474,194 amount expended during SFY17.
3. The cost of administering the program in the immediately preceding fiscal year.
 - No administrative costs were charged to the program funds during the fiscal year because the program was managed by Department staff.
4. The number of eligible individuals on a waiting list, if any, and amount of funding necessary to reduce the existing waiting list.

- No individuals have been placed on a waiting list due to program funding constraints. Individuals who have been found eligible for ASP funding are sometimes placed on waiting lists with provider agencies due to lack of provider capacity. ASP funding has been sufficient to serve all eligible individuals to date.

Additional Information:

- Twenty-four children have been actively enrolled in ASP during SFY18.
- About 11 to 15 children are actively receiving ASP services each month. For the period from the start of the program in April 2014 through June 2018:
- A total of 55 children received ABA services through the program.
- 14% of applicants were female and 86% were male.
- The average age of ASP applicants is 4.75 years.
- The average income of ASP applicant families is 362% FPL.
- The average monthly service cost paid from the ASP fund per participant (after the family cost share is applied) is \$2,360.
- The average amount of ASP funds expended per month is \$27,441.
- The average monthly service cost share paid by families is \$110 (which represents 4.3% of the cost).
- The average length of time a child receives ASP services is 10 months (the program maximum is 24 months).
- The average total amount of ASP funds spent for each child served is \$26,174 (the program maximum is \$72,000).

Program Utilization: The program has been operating for nearly five years. While a few children have remained in services for the full 24-month eligibility period (only 10 children to date), the majority utilize less than the full benefit for a variety of reasons, including:

- They make significant gains, meet their treatment goals, and ABA services are no longer needed.
- They become eligible for ABA funding through Medicaid.
- They become eligible for ABA funding through a private insurer.
- Families move out of state or other life circumstances change.
- ABA services are discontinued because they are deemed ineffective for the child.

Consistency and continuity are important factors in the delivery of ABA services. It is noteworthy that the Autism Support Program has been instrumental in “bridging the gap” so that the continuity of ABA services can be maintained when family circumstances are in flux, for example:

- ASP has provided support while a child is on the waiting list for a Medicaid Home and Community Based Services (HCBS) Waiver slot.
- ASP has provided support when a child loses Medicaid coverage due to an increase in family income.
- ASP has provided support when families lose private insurance coverage because of a job layoff or have a waiting period for coverage when starting a new job, as well as when their policies do not offer an ABA benefit.

Workforce: The Behavior Analyst Certification Board currently reports 118 Board-Certified Behavior Analysts (BCBAs) and three Board-Certified Assistant Behavior Analysts (BCaBAs) in Iowa. A significant portion of these professionals are employed in the educational system or in consultative roles and are not available to directly provide ABA services to individual clients on an ongoing basis. The demand for applied behavior analysis and behavior analytic services for individuals with autism as well as children and adults with other behavioral challenges continues to grow.

To help address this workforce shortage, appropriations legislation for SFY16 and SFY17 designated \$250,000 of the annual appropriation to the autism support fund be allocated to establish a BCBA and BCaBA grants program. No additional funds were appropriated in SFY18 and SFY19 because funding from the SFY16 and SFY17 appropriations has not fully been expended and remains available for use.

The program, administered by the Iowa Department of Public Health (IDPH), provides educational grants to applicants who have been accepted for admission or are enrolled in an accredited college or online program to become eligible for board certification as a behavior analyst or assistant behavior analyst, and demonstrate financial need. Priority in awarding grants is given to applicants who are residents of Iowa. Qualifying students make a commitment to obtain certification as a BCBA or BCaBA and practice in Iowa for a specified period of time.

IDPH, with consultation from DHS and the Department of Education, developed and adopted administrative rules for the grants program (641 Iowa Administrative Code Chapter 107). An initial Request for Proposals (RFP) for the BCBA and BCaBA grants program was released by IDPH on October 3, 2016. Eleven grants were awarded in early 2017, for a total amount of \$41,399. A second RFP was released in January 2018. Six more grants were awarded and approved for funding in the amount of \$53,575. Funds remain available for additional grants, and a third RFP is scheduled to be released early in 2019.

Provider Network: The availability of providers in the ASP network is growing, but continues to be limited, due to the limited numbers of BCBAs and ABA providers in Iowa. The ASP provider network includes 14 provider agencies, serving families from 19 locations: Altoona, Bellevue, Bettendorf, Burlington, Cedar Falls, Cedar Rapids, Clear Lake, Clive, Davenport, Dubuque (2), Hiawatha, Iowa City, Omaha (NE), Rock Valley, Sheldon, Sioux City, and Spencer.

Statewide Access: The geographic distribution of ABA providers within the state continues to be uneven. Several providers have begun using telehealth to expand the scope of their service areas. Providers report that new software technologies allow them to connect with families in their own homes, without any specialized equipment needed by the family. Families are able to use their own personal computers or tablets to connect with a provider's system and communicate securely in compliance with HIPPA protected health care information provisions. Providers will continue to be

encouraged to use all resources available to them to serve children outside of their local geographical areas.

Expansion of Private Insurance Coverage: From 2010 through 2017, only state employee health insurance plans in Iowa were required to provide an applied behavior analysis benefit for children with autism. 2017 Iowa Acts Chapter 18, expanded private insurance coverage for applied behavior analysis, effective January 1, 2018. This measure extended ABA coverage to all health insurance plans subject to state insurance commission rules that have 50 or more employees.

Since January, the Autism Support Program has received several applications submitted by families who gained an ABA benefit pursuant to the new requirement, only to learn that the out-of-pocket cost share they would have to pay is beyond their resources. Since these families technically have private insurance coverage for ABA services, they are not eligible for assistance through ASP, yet the cost to the family makes the use of the ABA benefit out of their reach for several reasons:

- The family may be required to meet a high deductible before any benefit is paid.
- Even after a deductible is met, the family may be required to meet a high co-pay or co-insurance for each ABA session.
- Insurance companies may have only a very small number of ABA “in network” providers and may not have any that are located geographically close enough to provide services, or may not have openings. Most plans require families to pay a significantly higher share to access “out of network” providers.

This unintended consequence of expanding private insurance coverage means that some families who previously had no ABA benefit and qualified for ASP, now no longer qualify to access ASP and yet cannot afford to use their newly acquired private insurance benefit.

Coordination and Outreach: The University of Iowa Regional Autism Assistance Program (RAP) supports care coordinators located at Child Health Specialty Clinics across the state to assist families with access to services and supports children with autism spectrum disorders, and works with health care professionals who see and diagnose young children with autism to encourage them to make referrals to the RAP program so that they can be connected with the ASP or other appropriate services. The RAP program does not receive funding from the autism support program fund.

Stakeholder Input: The Department has routine contact with and attends regular meetings of the University of Iowa Regional Autism Program (RAP) Expert Stakeholder Panel to discuss the implementation of the ASP. The expert panel consists of families of individuals with autism; educational, medical, and human services specialists, professionals, and providers; and others with interest in or expertise related to autism. The Department also participates in an ex-officio capacity on the Iowa Autism Council. The Council’s annual report, “Iowa Autism 2019 Priorities: Moving Iowa Forward,” is available on the Iowa Department of Education website.

Both groups have expressed their appreciation and their support for continuation of the Autism Support Program and the BCBA and BCaBA grants program, although they continue to have concerns about families who cannot access ABA services either because they do not meet the eligibility criteria for funding, cannot afford the out-of-pocket costs required by private insurers, or because provider capacity is limited.

Recommendations

A significant number of families continue to be unable to access private insurance coverage for intensive interventions such as ABA for their children with autism. For children who do not qualify for Medicaid there are few affordable options. Indeed, the program has demonstrated that the costs per child served are considerably less than initially estimated. The Autism Support Program remains an important safety net for these families and represents a sound investment in relatively short-term early interventions that can dramatically reduce a child's lifelong dependence on publicly funded services and increase productivity and quality of life.

The Department recommends that the Autism Support Program continues to operate under its current structure. The Department continues to work with stakeholders to publicize the program to families of children with a diagnosis of autism and to professionals who work with children who have a diagnosis of autism, or are suspected of having autism, to ensure that lowans with ASD have the opportunity to reach their potential and live meaningful and productive lives alongside their fellow lowans.