



# Iowa Department of Human Services

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Terry E. Branstad  
Governor

Kim Reynolds  
Lt. Governor

Charles M. Palmer  
Director

December 28, 2016

Michael Marshall  
Secretary of Senate  
State Capitol Building  
LOCAL

Carmine Boal  
Chief Clerk of the House  
State Capitol Building  
LOCAL

Dear Mr. Marshall and Ms. Boal:

Enclosed please find a copy of a report to the General Assembly relative to the Autism Support Program Fund Report, pursuant to the directive contained in 2013 Iowa Acts, Chapter 138.83.

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

Sincerely,

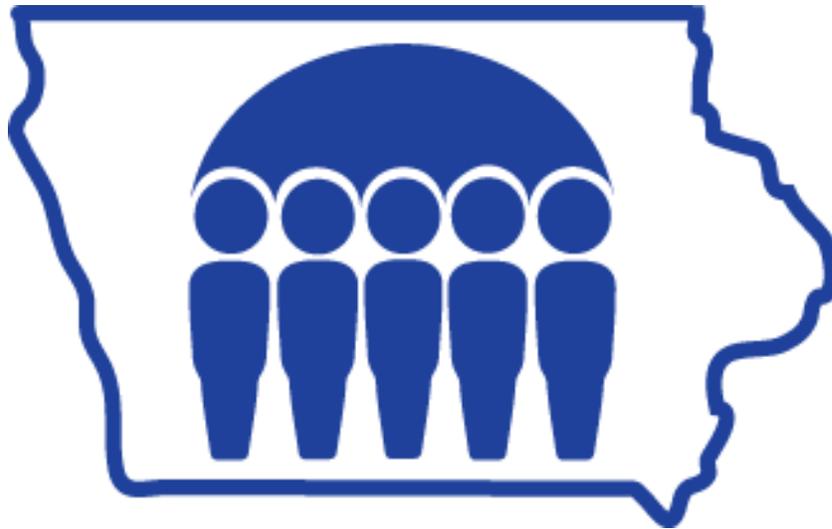
Sally Titus  
Deputy Director

ST/tam

Enclosure

cc: Terry E. Branstad, Governor

# Iowa Department of Human Services



## *Autism Support Program Annual Report*

December 2016

# 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 for 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. The ASP has served 33 children who would not otherwise have been able to access this critical early intervention treatment. Eligibility criteria for age and income were recently expanded to increase accessibility to families in need. Stakeholders express strong support and appreciation for the program as an investment in improving the life outcomes for children with autism. The Department believes the ASP funds a valuable 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 2016 (SFY16) 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

The remainder, \$1,700,000, was available to fund applied behavior analysis services to children through the Autism Support Program.

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 has supported a summer camp program for children and youth with ADS operated by Four Oaks. The hospital-based pilot project was operated by Mercy Medical Center Dubuque through SFY16. Mercy Medical Center declined to accept the SFY17 allocation due to program and staff changes. The program no longer directly provides autism services and does not have 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, source of diagnosis, age of applicant, financial status of the applicant’s family, and services provided by an eligible Applied Behavior Analyst (ABA) provider.

The Iowa Legislature made revisions to the Autism Support Program in 2016 Iowa Acts, Chapter 1139, Sections 59-60, (Iowa Code sections 225D.1 and 225D.2) to:

- raise the age of eligibility for the program from children under the age of nine at the time of application to children under the age of 14 at the time of application
- raise the maximum household income limitation from 400% of FPL (federal poverty level) to 500% FPL
- increase the maximum cost share from 10% of service costs to 15% of service costs for families with incomes between 400% and 500% FPL

During the six months since these changes to the eligibility criteria went into effect on July 1, 2016, three applicants with family incomes between 400% and 500% have been approved for ASP funding, and two applicants over age 8 have been approved, resulting in access to applied behavior analysis services for five children who did not previously qualify for ASP funding.

**Administration:** Magellan of Iowa (Magellan) administered the program through a contract with DHS from April 1, 2014 through December 31, 2015. The Autism Support Program has been managed by the DHS Division of Mental Health and Disability Services since January 1, 2016. Responsibility for administration of the ASP was included in the RFP for the Iowa High Quality Healthcare Initiative and plans are underway to transition most management functions of the program to the Iowa

Health Link managed care organizations that have been contracted with to administer the Medicaid program.

## SFY16 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.

- MHDS received 31 applications during SFY16.

2. The number of applications approved and the total amount of funding expended for reimbursements under the program in the immediately preceding fiscal year.

- MHDS approved 15 of the applications received during SFY16. The remaining 16 applications were denied for the following reasons:
  - 10 were over income guidelines
  - 4 did not supply a diagnosis meeting the program eligibility requirements
  - 1 did not supply evidence of denial by third-party insurance
  - 1 was found to be Medicaid eligible

Three of the ten applicants that were denied as over income prior to July 1, reapplied and were enrolled in ASP after the income eligibility ceiling was raised to 500% FPL.

- A total of \$356,440.55 was expended during SFY16 for reimbursement to ABA service providers. This represents an increase of 295% from \$120,875.88 expended during SFY15.

3. The cost of administering the program in the immediately preceding fiscal year.

- Magellan received a 10% administrative cost fee totaling \$16,586.32 for the first half of SFY16. No administrative costs were charged to the program during the second half of the fiscal year because it was managed by staff within the DHS Division of Mental Health and Disability Services.

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 funding. 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:**

- 33 children have received ABA services through the program
- 2 children have completed their full 24 months of eligibility
- 20 children are actively enrolled
- 10% of applicants are female and 90% are male
- the average age of ASP applicants is 4.7 years
- the average income of ASP applicant families is 364% FPL
- the average monthly service cost paid from the ASP fund per participant (after the family cost share is applied) is \$2592

**Workforce:** The Behavior Analyst Certification Board currently reports 88 BCBA's and 11 BCaBA's in Iowa. A significant portion of these professionals are employed as educators 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 other behavioral challenges is unmet in Iowa and continues to grow.

To help address this workforce shortage, SFY16 and SFY17 appropriations legislation designated \$250,000 of the two million dollar annual appropriation to be used to fund a board-certified behavior analyst (BCBA) and board-certified assistant behavior analyst (BCaBA) grants program administered by the Iowa Department of Public Health (IDPH). The program will provide 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, with priority in the awarding of grants 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, has developed and adopted administrative rules for the grant program (641 Iowa Administrative Code Chapter 107). An RFP for the BCBA and BCaBA grants program was released by IDPH on October 3, 2016. Proposals were due November 28, and notice of intent to award will be made on December 21.

**Provider Network:** The availability of providers in the ASP network is growing, but continues to be limited, as is the general availability of BCBA's and ABA providers in Iowa. One new ABA provider located in Rock Valley has recently enrolled an ASP participant and two other new ABA providers, located in Clear Lake and the Sioux City and Spencer areas, expect to begin serving ASP participants in the next few months. The addition of these providers to the ASP network brings the total number of provider sites utilizing ASP funding to 15.

**Statewide Access:** The geographic distribution of ABA providers within the state is uneven. Services in certain parts of the state and have proposed increased access to telehealth services as one way to address geographic gaps. Providers will continue to

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

**Coordination and Outreach:** The University of Iowa Regional Autism Assistance Program (RAP), funded by a separate state appropriation, 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.

**Stakeholder Input:** The Department has routine contact and holds regular meetings with 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 2017 Priorities: Moving Iowa Forward," is available at: <https://www.educateiowa.gov/sites/files/ed/documents/iowa%20Autism%20Council%20Legis%20Report.pdf>

Both groups have expressed their support for continuation of the Autism Support Program and their appreciation for the Legislature's expansion of the age and income eligibility criteria, as well as for the creation and funding of 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 or because provider capacity is limited.

## **Recommendations**

Many families are unable to access private insurance coverage for intensive interventions such as ABA for their children with autism, and those who do not qualify for Medicaid have few options. The Autism Support Program is an important safety net for them and represents an investment in relatively short-term early interventions that can dramatically reduce a child's lifelong dependence on publicly funded services.

The Department believes the ASP funds a valuable service for children in the program and their families. The number of applications and enrolled participants continue to grow. 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, or are at risk of, a diagnosis of autism to ensure that Iowans with ASD have the opportunity to reach their potential and live meaningful and productive lives in their communities.