Department of
HUMAN SERVICES

AUTISM SUPPORT PROGRAM ANNUAL REPORT

DECEMBER 2020

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EXECUTIVE SUMMARY

The Iowa Legislature created the Autism Support Program (ASP) in 2013 to provide funding for the provision of applied behavioral analysis (ABA) services to children who meet certain age, diagnostic and financial eligibility criteria. ABA services are individually designed to help each child work on communication, social and behavioral skills that will help them become more successful in learning and more independent as they grow to adulthood. The program funds services to children with autism who do not have access to ABA services through Medicaid coverage or through a private insurance benefit. The Legislature expanded program eligibility criteria for age and income in 2016 to increase access for families in need. The program has served 64 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. Gains in communication and social skills during the early years have been shown to reduce the level of supportive services a child will need over his or her lifetime.

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 ASP. Included in this report is a summary of the services provided in State Fiscal Year 2020 (SFY20) by 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; and
- 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 SFYs 2018-2019 and 2019-2020, the legislature has annually appropriated $573,000 to be credited to the Autism Support Program Fund. Each annual appropriation further provided that of the $573,000 total, the Department must $25,000 to continue a grant to a child welfare services provider serving children with autism spectrum disorder (ASD) and their families.

The continuing grant to a child welfare services provider has supported an after-school and summer social skills building program for children and youth with ASD. The program was formerly operated by Four Oaks, and has been operated by Tanager Place since July 1, 2018.

ABA SERVICES:
ABA is a highly researched and scientifically validated approach to understanding behavior and how it is affected by the environment, and then using this knowledge to bring about meaningful and positive change in behavior that helps improve how a child functions within the home and community. ABA has been shown to be effective in:

- Improving social and communication skills;
- Reducing behaviors that are harmful or affect learning negatively;
- Teaching new functional skills; and
- Generalizing behavior and skills across settings and individuals.

ABA programs for autism are not "one size fits all." Each treatment program is written to meet the needs of the individual child. A qualified and trained Board Certified Behavior Analyst (BCBA) designs and directly oversees the program based on the age and ability level of the person with ASD. The BCBA customizes the ABA program to each child's skills, needs, interests, preferences and family situation. The goal of any ABA program is to help each child work on skills that will help them become more independent and successful in the short term as well as in the future. With continued practice, the child will be able to replace an inappropriate behavior with one that is more helpful.

ABA services are most often delivered for a limited period of months or years when a child is young, but the nature of the service requires treatment to be intensive (in the range of 10 to 40 hours per week). Twenty hours per week of ABA would be typical. The individualized and time intensive character of the service make it significantly more expensive than other types of therapies such as speech, occupational or physical therapy.

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 ABA provider. The Iowa Legislature made revisions to the program in 2016 to expand the criteria for age and family income and make 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 24 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; and
- The child's family has a household income at or below 500% of the federal poverty level (FPL) (as an example, effective Jan. 31, 2020, 500% of FPL for a family of four is $131,000).

SFY20 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 7 applications for the ASP during SFY20.

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 6 (86%) of the 7 applications received during SFY20. The remaining application was denied because the family income exceeded the 500% FPL requirement.

    - A total of $65,135 was expended during SFY20 for ABA service reimbursements to providers. This represents a decrease from the $164,700 amount expended during SFY19. A significant factor in this decrease in spending is the increased number of private insurance plans that have been required to offer coverage for ABA, beginning in January 2018. (See *Expansion of Private Insurance Coverage*, page 6.)

    For each of the years 2014 through 2017, the Department received an average of 28 applications for assistance through ASP. For the three years since the insurance mandate went into effect, that number has been reduced to an average of 10 per year. Inquiries from families to the program manager also indicate an increase in private insurance coverage is limiting application numbers, although the new private insurance benefit available is sometimes insufficient to effectively provide access to needed services. (See *Remaining Gaps in Access to Services*, page 7.)

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 Department staff managed the program.

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:

For the period from the start of the program in April 2014 through June 2020:

- The Department received and processed a total of 106 applications.
- A total of 64 children received ABA services through the program.
- 15% of applicants have been female and 85% have been male.
- The average age of an ASP applicant is 5.0 years.
- The average income of an ASP applicant's family is 312% FPL.
- The average monthly cost for ABA services paid from the ASP fund per participant (after the family cost share is applied) is $1,862.
- The average amount of ASP funds expended per month is $21,302 ($1,597,681 over 75 months).
- The average monthly service cost share paid by families is $108 (which represents 5.8% of the monthly cost).
- The average length of time a child receives ASP services is 12 months (the program maximum is 24 months).
- The average total amount of ASP funds spent for each child served is $25,422 (the program maximum is $72,000).

PROGRAM UTILIZATION:

The program has been operating for nearly seven years. While a few children have remained in services for the full 24-month eligibility period (only 11 children to date), and only two of those children have used the full $72,000 of funding, 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 that particular child.

Consistency and continuity are important factors in the delivery of ABA services. It is noteworthy that ASP 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 (receiving a slot initiates Medicaid eligibility).
- When a child loses Medicaid coverage due to an increase in family income.
- 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 (BACB) currently reports 149 (up from 129 last year) active BCBAs and 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 ABA and behavior analytic services for individuals with autism as well as children and adults with other behavioral challenges continues to grow more rapidly than the increase in qualified professionals available to provide the services.

For each of SFYs 2016 and 2017, the ASP Fund annual appropriation provided that $250,000 of the total be allocated to the BCBA and BCaBA Grants Program Fund to help address the statewide workforce shortage of these behavioral health professionals. No additional funds were appropriated in subsequent years because the $500,000 funding from the SFY16 and SFY17 appropriations has not fully been expended and funds remain available for use.

The program, administered by the Iowa Department of Public Health (IDPH), pays up to half of the tuition and fees for qualified students during each semester or quarter of their accredited BCBA or BCaBA college or online program. Awardees must become board certified upon graduation and fulfill a two-year employment commitment in Iowa to complete the program requirements. If an awardee does not meet those obligations, they must repay the funds. Applicants who are residents of Iowa receive priority in awarding grants. Both the University of Iowa and Drake University currently offer BCBA programs.

Four rounds of requests for applications have been offered. Since program inception, 59 applications have been received and 31 awards have been made, totaling $210,148. For SFY20, 22 applications were received and 10 awards totaling $114,993 were made. Twelve applications for SFY21 are under review as of the writing of this report and are expected to be awarded before the end of December.

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 18 provider agencies, serving families from 31 locations: Altoona,

Ankeny, Bellevue, Bettendorf (2), Burlington, Cedar Falls, Cedar Rapids, Clear Lake, Clinton, Clive, Davenport, Dubuque (5), Dyersville, Hiawatha, Iowa City (2), Johnston, Maquoketa, Muscatine, Omaha (NE), Plattsmouth (NE), Rock Valley, Sheldon, Sioux City, Spencer, and Urbandale.

STATEWIDE ACCESS:

The geographic distribution of ABA providers within the state continues to be uneven and most operate clinics in metropolitan locations, so travel distance and time for rural families can be difficult or prohibitive. Several providers use 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 protected health care information provisions.

The Department will continue to encourage providers to use all resources available to them to serve children outside of their local geographical areas. The COVID-19 pandemic has resulted in a greater emphasis on providing "face-to-face" services remotely and some of the stringent site requirements for service delivery via telehealth have been relaxed temporarily as a result. Experiences have been positive and many families would benefit from consideration of adopting some of the proven, yet more flexible service delivery standards after the pandemic is resolved.

EXPANSION OF PRIVATE INSURANCE COVERAGE:

From 2010 through 2017, only state employee health insurance plans in Iowa were required to provide an ABA 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 2018, ASP has received 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 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 local providers may not have openings. Most plans require families to pay a significantly higher share to access "out of network" providers.

REMAINING GAPS IN ACCESS TO SERVICES:

This unintended consequence of expanding private insurance coverage has resulted in some families who previously had no ABA benefit and therefore qualified for ASP, now no longer qualify to access ASP because they "have coverage" and yet they 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, supports children with ASD, and works with health care professionals who see and diagnose young children with autism to encourage them to make referrals to RAP so that they can be connected with ASP or other appropriate services. RAP does not receive funding from the autism support program fund.

STAKEHOLDER INPUT:
The Department maintains routine contact with and attends regular meetings of the RAP Expert Stakeholder Panel to discuss issues related to serving individuals with autism in Iowa, including the implementation of 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 2021 Priorities: Moving Iowa Forward," is available on the Iowa Department of Education website.

Both groups have expressed their appreciation and support for continuation of ASP and the BCBA and BCaBA grants program. The groups continue to have concerns about families who cannot access ABA services because they do not meet the eligibility criteria for funding, but who cannot afford the out-of-pocket costs required by private insurers, or who cannot find a local provider with the capacity to deliver the needed services.

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, few affordable options exist. ASP has demonstrated that the costs per child served are considerably less than initially estimated and more children could be served without increased funding if program eligibility requirements allowed. ASP remains an important safety net for 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 continued operation of ASP 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 Iowans with ASD have the opportunity to reach their potential and live meaningful and productive lives alongside their fellow Iowans.