

STATE OF IOWA DEPARTMENT OF
Health AND **Human**
SERVICES

AUTISM SUPPORT PROGRAM REPORT

DECEMBER 2023

AUTISM SUPPORT PROGRAM ANNUAL REPORT

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 on the autism spectrum 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 fill a service gap to children with autism who do not have access to ABA services through Medicaid coverage or through a private insurance benefit. In 2016, the Legislature expanded program eligibility criteria for age and income to increase access for families in need. Since the inception of the program in 2014 it has provided funding for 84 children who would not otherwise have been able to access this critical early intervention treatment.

In 2017, the passage of House File 215 required more group insurance carriers in Iowa to cover ABA for children with autism spectrum disorder (ASD), and many families previously without ABA insurance coverage have benefited from that expansion. There are, however, families who gained an ABA benefit only to learn that the high out-of-pocket cost share for deductibles and co-pays is unaffordable. In addition, the number of ABA providers are limited in Iowa, and some insurance companies do not have in network providers who are geographically close enough to provide ABA, as it is a time-intensive service that may require sessions several times each week. If the family must pay out-of-network rates to obtain the service, that also reduces their ability to access services.

Stakeholders express strong support and appreciation for the program as a sound investment in improving functional skills and 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 and lead to greater independence, community integration, and economic productivity.

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INTRODUCTION

The Iowa Department of Health and Human Services (Iowa HHS) 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 2023 (SFY23) 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 agency to:

- Implement an autism support program 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 SFYs 2018-2022, the legislature annually appropriated \$573,000 to be credited to the Autism Support Program Fund. The funding for FY23 was reduced to \$188,000 due to lower program expenditures during SFY20 and SFY21. This was, in part, attributable to the COVID-19 Public Health Emergency (PHE). Total ASP expenditures for SFY22 were \$236,021 and for SFY23 were \$259,489. Program utilization is currently increasing, partially due to the end of the PHE, which was announced in March 2023. This means that Medicaid member eligibility needs to be reviewed and, through that process, some families find they are no longer income eligible for Medicaid and have sought assistance. Some of these families then seek to fund their child's ABA treatment through the Autism Support Program.

Each annual ASP appropriation further provided that Iowa HHS must use \$25,000 of the total amount 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 supports an after-school and summer social skills building program for children and youth with ASD. The program was initially operated by Four Oaks and has been operated by Tanager Place since July 1, 2018.

APPLIED BEHAVIOR ANALYSIS (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 helping children with autism:

- Improve their social and communication skills.
- Reduce behaviors that are harmful or affect learning negatively.
- Learn new functional skills.
- Generalize behaviors and skills across settings and individuals.

ABA programs for autism are not "one size fits all." A treatment program is written to meet the unique needs of each 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 work on skills that will help each individual served to become more independent and successful in the short term and cumulatively over time. With continued practice, a child will be able to replace inappropriate or interfering behaviors with ones that are more constructive.

ABA services are most often delivered for a limited period of months or years when a child is young, although they can be helpful for older individuals as well. The nature of the service often requires treatment to be intensive (in the range of 10 to 40 hours per week). Fifteen to 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 by state law to individuals who meet specific 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 program was revised 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 through ASP if:

- The child is under the age of fourteen (14) at the time of application.
- The child has a diagnosis of autism spectrum disorder made by a child psychiatrist, developmental pediatrician, or a clinical psychologist made or affirmed 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.
- The child's family has a household income at or below 500% of the federal poverty level (FPL) (as an example, effective January 2023, 500% of FPL for a family of four is \$150,000).

STATE FISCAL YEAR 2023 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.

- There were 14 applications received for the ASP during SFY23 (up from nine in SFY22).

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

- Nine (64%) of the 14 applications received during SFY23 were approved. Three applications were denied because the child had a private insurance benefit for ABA (with a high out-of-pocket cost share) and two were denied because the child was eligible for Medicaid coverage.
- A total of \$259,489 was expended during SFY23 for ABA service reimbursements to providers. This represents an increase of 10% over SFY22. Expenditures increased 88% from SFY21 to SFY22, and 92% from SFY20 to SFY21. SFY20 and SFY21 expenditures were unusually low due to the public health emergency (PHE).
- Applications to the program continue to increase.
- For each of the years 2014 through 2017, an average of 28 applications for assistance through ASP were received. For the first four years since the insurance mandate for ABA coverage went into effect in January 2018, that number had gone down to an average of 10 per year, but now shows an uptick. Inquiries from families to the program manager also indicate an increase in private insurance coverage has limited 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 ABA Services*,” pages 8-9.)
- The average amount of ASP funds expended per month during SFY23 was \$21,624.
- The average monthly cost for ABA services paid from the ASP fund per participant for SFY23 (after the family cost share is applied) is \$2,883.
- The average monthly service cost share paid by families is \$130 (which represents 4.50% of the monthly cost).

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 Iowa HHS staff directly 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 2023:

- Iowa HHS has received and processed a total of 146 applications.
- A total of 84 children have received ABA services through the program.
- 16% of applicants have been female and 84% have been male.
- The average age of an ASP applicant is 4.50 years.
- The average income of an ASP applicant's family is 285% FPL.
- The average length of time a child receives ASP services is 14 months (well below the program maximum benefit period of 24 months).
- The average total amount of ASP funds spent for each child served is \$32,408 (well below the program maximum of \$72,000).

SNAPSHOT OF THE AVERAGE PROGRAM PARTICIPANT: The average ASP participant for FY23 is a 4-and-a-half-year-old boy, who has one sibling and comes from a family with an annual income of about \$81,500 (or a gross income of \$6792 per month). Usually only one parent in the household works full time as they have young children and the child with autism requires extra care and attention and is often difficult to place in daycare. The family has often spent two years or more getting a diagnosis for their child, finding a provider who is willing and able to provide ABA services in their area, and finding a source of funding. The total cost of ABA services pursuant to a professional treatment plan to the child averages nearly \$4000 per month.

PROGRAM UTILIZATION: The program has been operating for nearly ten years. While a few of the 84 actively enrolled children have remained in services for the full 24-month eligibility period (only 16 children to date), or used the full \$72,000 of funding (only 9 children to date), the majority utilize less than the full benefit for a variety of reasons, including:

- The child makes significant gains, meet their treatment goals, and ABA services are no longer needed.
- The child becomes eligible for ABA funding through Medicaid.
- The child becomes eligible for ABA funding through a private insurer.
- The family moves out of state or other life circumstances change.
- ABA services are discontinued because they are deemed ineffective for that particular child and other types of treatment are pursued instead.

Consistency and continuity are critical 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.
- When a child is enrolled in HAWK-i (Healthy and Well Kids in Iowa), Iowa’s low-cost Children’s Health Insurance Plan (CHIP), which offers basic health insurance coverage but does not include an ABA benefit. Many ASP participants are enrolled with HAWK-i and do not have affordable access to other health insurance coverage.

WORKFORCE: Board Certified Behavior Analysts (BCBAs) are a vital component of the ABA treatment team. They are in high demand and short supply in Iowa. The Behavior Analyst Certification Board (BACB) currently reports a total of 234 (up from 204 last year) active BCBAs and 5 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.

PROVIDER NETWORK: The availability of providers in the ASP network is constantly growing, but continues to be limited, due to the limited numbers of BCBAs and ABA providers in Iowa. The ASP provider network includes 20 provider agencies, serving families from 51 locations in the following cities:

• Altoona	• Clinton	• Harlan	• Sioux Center
• Ames	• Clive (2)	• Hiawatha	• Sioux City (2)
• Ankeny (2)	• Coralville (2)	• Iowa City (2)	• Spencer
• Bellevue	• Council Bluffs	• Johnston (2)	• Urbandale (2)
• Bettendorf (2)	• Davenport (3)	• Maquoketa	• Waterloo
• Burlington	• Clinton	• Muscatine	• Waukee
• Cedar Falls	• Dubuque (5)	• Omaha, NE (2)	• West Des Moines
• Cedar Rapids (3)	• Dyersville	• Rock Valley	
• Clear Lake	• Fort Dodge	• Pleasant Hill	

Several ASP providers began offering sessions via telehealth during the pandemic. Any provider of ABA services that is enrolled with Iowa Medicaid to provide ABA services can also provide ABA through the Autism Support Program.

STATEWIDE ACCESS: The geographic distribution of ABA providers within the state continues to be uneven and most operate clinics in metropolitan locations, making distance and travel time difficult or prohibitive for rural families. 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 can 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.

Iowa HHS will continue to encourage providers to use all resources available to them to serve children outside of their local geographical areas. The global 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 were relaxed temporarily as a result. Experiences have been positive, and some of the proven, yet more flexible service delivery standards are now being adopted permanently. Rural families in particular, benefit from the availability of telehealth to deliver ABA services.

ADDRESSING REMAINING GAPS IN ACCESS TO ABA SERVICES: 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 for many Iowa families. This measure mandated an ABA benefit to be included in all health insurance plans subject to state insurance commission rules and that serve businesses with 50 or more employees.

Insurance plans with prohibitively high out-of-pocket costs: Since January 2018, ASP has received several applications each year 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 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.

For example, a family of four with a qualifying child on the autism spectrum, a family income of \$100,000, and no private insurance ABA benefit can receive assistance through the Autism Support Program and be responsible for paying a cost share equal to 10% of the cost of the ABA services. Typical costs of ABA services are in the range of \$3000 to \$4000 per month. That means the out-of-pocket cost to the family in this example would be \$300 to \$400 a month (10% of the total) during the duration of the ABA therapy. That’s \$3600 to \$4800 a year. For many families, that cost is a difficult stretch, but one they can usually find a way to manage.

If the same family has a private insurance benefit and therefore does not qualify for assistance through the autism support program, their insurance plan may require them to pay an annual deductible of \$10,000 and then a 50% co-pay for ABA services, meaning they would have to spend \$10,000 out of pocket before they receive any reimbursement from their private insurer and then continue to be responsible for as much as half of the per-session cost. Assuming their ABA costs were at the low end, or \$3000 per month (\$36,000 per year) they would have to cover \$23,000 of that cost each year while their insurer would pay \$13,000. For families of four

living on \$100,000 or less, that \$23,000 price tag is out of reach and leaves them unable able to access the ABA services their child needs, and this is especially cost prohibitive for families with multiple children on the autism spectrum. Several families in this situation have applied for assistance through the autism support program during the last few years and had to be denied because, technically, they had insurance coverage for ABA.

A flexible funding option for ASP eligibility could allow ASP funds to be used to help “fill the gap” between the cost of ABA and the insurance benefit by reimbursing families for high co-pays and/or deductibles that are spent for ABA services. Specifically, the eligibility standards for ASP could be expanded to add individuals with private insurance coverage that has an ABA benefit requiring high out-of-pocket costs if the family meets all other existing eligibility requirements for the program, including the 500% FPL ceiling. Once determined eligible for ASP, they would be able to apply for reimbursement of their out-of-pocket costs, less their ASP cost share. If their out-of-pocket costs are less than the ASP cost-share (zero to 15%, depending on income), they would receive no ASP assistance. Such a modification would put these families with very limited insurance benefits on the same footing as families with no insurance benefit and require the same rate of cost participation to utilize the Autism Support Program. Since ASP services are required to be managed within the state appropriation, such a change would necessarily be managed within the dollars appropriated.

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 now have “coverage” and yet they cannot afford to use their newly acquired private insurance benefit, so many have been forced to terminate the ABA services their child needs.

Greater flexibility in program benefit limits: As previously noted, most children do not make use of the entire 24 months of services or the entire amount of funding available to them through the ASP program for a variety of reasons. This has meant that the program has been able to serve all applicants who have been determined eligible well within the fund allocated for the program and has successfully operated at a considerably lower cost than initially estimated. At the same time, there are a small number of children who need to continue their ABA treatment beyond 24 months and have no other source of funding after their ASP eligibility has been exhausted. In these cases, the need goes unmet, even though ASP has funds available to continue to serve the child for a longer period, as well as serving new applicants.

When the original ASP legislation was passed, there were concerns that offering such a program would open the doors to unknown large numbers of families requesting ABA funding. That has not been the reality. Since the program began, it has served all eligible applicants at an annual cost of less than \$500,000 and without waiting lists. Allowing some flexibility in the program limitations on the number of months and total funding available per child could fill in service gaps for that small number of children. It would be possible to make program changes that could allow ASP to make exceptions to the time and funding limitations when program funds are available that would

provide greater flexibility in meeting the needs of children with autism at a critical time in their development, without expanding the cost of the program beyond its historic funding level of about \$500,000 annually.

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: Iowa HHS 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 panel continues to provide expert opinions on clinically relevant practices and guidance on program implementation. Iowa HHS also participates in an ex-officio capacity on the Iowa Autism Council. The Council's annual report, "Moving Iowa Forward, A Summary of Accomplishments in 2023 and Priorities and Recommendations for 2024" is available on the Iowa Department of Education website.

Both groups have expressed their appreciation and support for continuation of ASP and continue to have concerns about families who cannot access ABA services because they do not meet the eligibility criteria for funding yet 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

Iowa's Autism Support Program is an important support for families and represents a sound investment in relatively short-term early intervention that can dramatically reduce a child's lifelong dependence on publicly funded services, increase productivity, and enhance community integration and quality of life. ASP has demonstrated that the costs per child served are considerably less than initially estimated and more children could be served without increased funding.

Iowa HHS recommends continuation of the ASP program; however program requirements need to be reviewed in light of shifts in the insurance marketplace since the program's inception. Consideration should be given to both expanding access to insured families who are unable to afford the out-of-pocket expense and greater flexibility in benefit limitations to maximize utilization of available resources. Iowa HHS will continue to work to increase awareness of the program for families of children with a diagnosis of autism and 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.