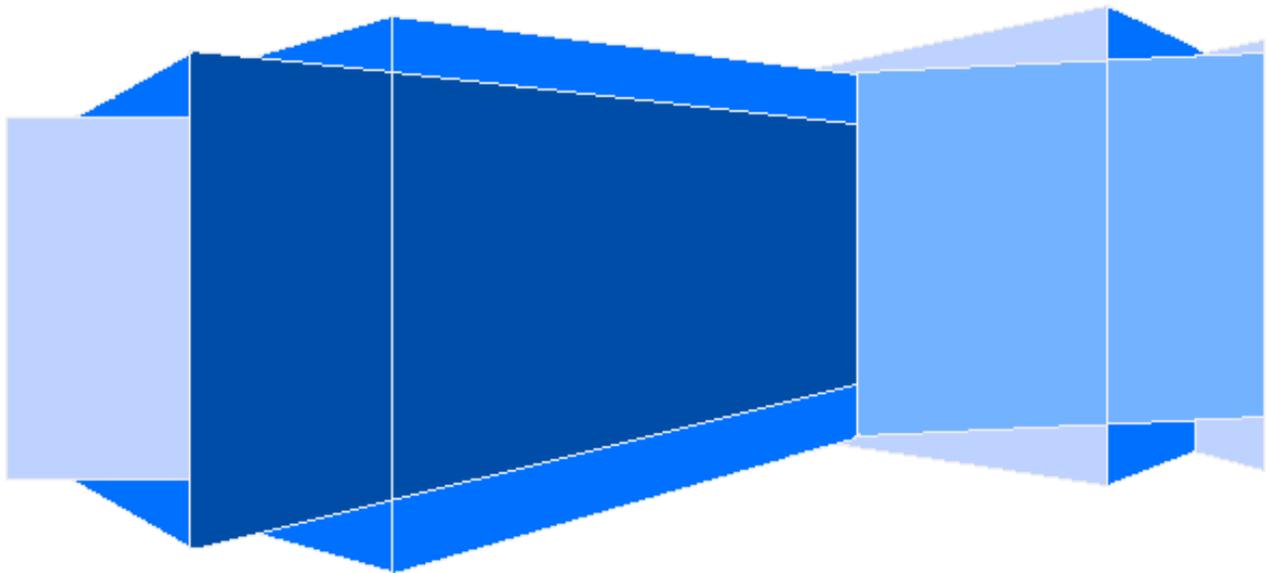


IOWA AUTISM COUNCIL 2014 PRIORITIES

Moving Iowa Forward

Iowa Autism Council



To the Governor and the Legislators of Iowa:

Iowa has made progress this past year in supporting children and adults with autism:

- A. The state employee insurance benefit includes ABA for young children. Payment to providers has improved following the state insurance commissioner's directive to the carrier to pay for services provided under the supervision of Board Certified Behavior Analysts.
- B. The state created \$2 million in new funding for early intervention for children with autism seeking intensive ABA treatment effective January 1, 2014.
- C. We are seeing an expansion of ABA services available to more parts of the state.
- D. The Department of Education hired a full time autism specialist to help coordinate educational responses to this unique disability.
- E. Several conferences and community events have helped expand the discussion of the best way to serve the needs of a growing and aging autism population in Iowa.

There is still more we can do:

- A. The Legislature has stated it will not consider any insurance mandates in the coming Legislative session. However, if the State of Iowa is to make real progress in its current efforts to support individuals and families affected by ASD, meaningful insurance reform is needed in both Medicaid and non-Medicaid programs to continue to provide access to medically necessary care and to expand the provider network in Iowa.
- B. The process required to implement rules to administer the \$2 million Autism Support Fund resulted in a shortened window for submitting eligible claims. The Council feels that the current age limit restricts the fund to mainly reimbursing services related to early skill acquisition which has contributed to underutilization of the fund. The Council would encourage the Governor and the Legislature to consider amending the age limit for the Autism Support Fund.
- C. Transition Services will continue to be an area of concern for individuals on the autism spectrum as they age out of the education system. These services will assist individuals with autism in additional education, career or vocational training and placement as well as support once placement is achieved.
- D. Iowa needs to invest in community and residential housing options that will allow individuals with autism to be as independent as possible. At the same time, we need to ensure that appropriate alternatives and resources are available to support individuals who may require intervention not available in the individual's chosen setting, rather than institutionalization or out-of-state placement.
- E. While services are becoming available in more areas, there is still a lack of Autism Service Providers to deliver those services. Establishing funding to expand the infrastructure available to support tele-medicine may help in the delivery of autism services to those rural areas where Autism Service Providers are not physically present.

For the Council,

James Curry
Chairperson

Iowa Autism Council

General

One of the Iowa Autism Council's (Council) responsibilities is to apprise the Governor and Legislature of goals and recommendations for the upcoming year. Matters submitted in previous sessions remain concerns and in addition to those, the Council intends to follow up on the needs assessment conducted by the Department of Education (DE). The goal will be to collect data to quantify the needs identified in the surveys received by the DE and develop strategies for addressing those needs. In developing those strategies, the Council will look to the many groups statewide doing important work that will benefit the entire autism community including, but not limited to, the Regional Autism Assistance Program (RAP) Expert Panel, the team utilizing a Health Resources and Services Administration (HRSA) grant at the University of Iowa and the Challenging Behavior workgroup.

The Council will continue to monitor changes, originating from the Center for Medicaid Services (CMS) as well as the forthcoming State Plan Amendment (SPA), regarding Autism funding and services.

The Council feels that two emerging long-term issues are:

1. Transition services and supports for young adults exiting the education system and moving into postsecondary education and/or the workforce; and
2. Community treatment and residential options for individuals with autism including those who exhibit challenging behaviors.

Funding ABA Transition Services through the Autism Support Program

The Council recommends that the age limit for treatment funded by the Autism Support program be amended to age 21. The administrative reality surrounding the launch of the Autism Support Program did not put Autism Service Providers or those who would utilize the services provided by the fund, in a position to show that the Fund is successful in fulfilling its purpose. The Council believes one reason the fund is not being fully utilized is the age limit for services that are covered by the fund. Currently, the fund only authorizes ABA services up to age 9. There is data to support that ABA services show the greatest effect on early skill acquisition prior to age 9 but there is no data that supports an arbitrary age cutoff for ABA services. ABA services are not just applicable to early skill acquisition and can be utilized throughout the life of the individual.

Iowa's educational system serves individuals with developmental delays until age 21 and allowing ABA funding to follow other Medicaid funding models, also to age 21, increases the chances that

individuals will be able to continue to acquire skills to address behavioral and social deficits, some of which may not be present at the time the individual becomes ineligible for services at age 9. Developing skills related to the transition to young adulthood may decrease challenging behaviors that negatively impact individuals' ability to gain and maintain employment and navigate social interactions as adults as well as decrease the need for out of state residential placement due to the challenging behaviors.

Continued funding for the next fiscal year and beyond, as well as allowing individuals up to age 21 to receive funding for covered services, will permit the fund to be utilized to the fullest extent possible as well as ensure access to services for those who can benefit from them, when the services are appropriate. This, in turn, will increase opportunities for individuals on the autism spectrum to achieve their goals and allow them to become and remain as independent as possible.

Services for Adults with Autism and challenging behavior in community and residential settings

Presently, there is simply an insufficient number of community and residential options for adults with autism and challenging behaviors. Currently, one option is an Intermediate Care Facility for individuals with intellectual disabilities (ICF-ID). However, if an individual at an ICF-ID exhibits challenging behavior beyond what the facility is staffed to handle, it may be necessary to discharge the individual from the ICF-ID. This situation can also occur for persons residing in home and community-based settings. Unfortunately, with no suitable alternative readily available, such individuals have ended up in psychiatric units and remain there far beyond what is feasible or desirable. The Council intends to research community based treatment options in order to develop a model for crisis-level intervention without institutionalization.

Additionally, the Council will be researching residential and home and community-based options for adults with challenging behaviors. For example, Hills and Dales in Dubuque operates a community-based program that successfully serves adults with a diagnosis of autism and who exhibit challenging behavior. The goal is to see more residential or home and community-based options available statewide, funded so as to attract and retain professional staff trained to address challenging behaviors and reduce the need for out of state residential placements due to lack of availability and training in Iowa.

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University of Northern Iowa

Iowa Insurance Commission

Child Health Specialty Clinics

Iowa Department of Education

Iowa Department of Education

Iowa Department of Education

Further findings are available with previous year's recommendations located at:

Iowa Department of Education located under the Iowa Autism Council you may also contact: