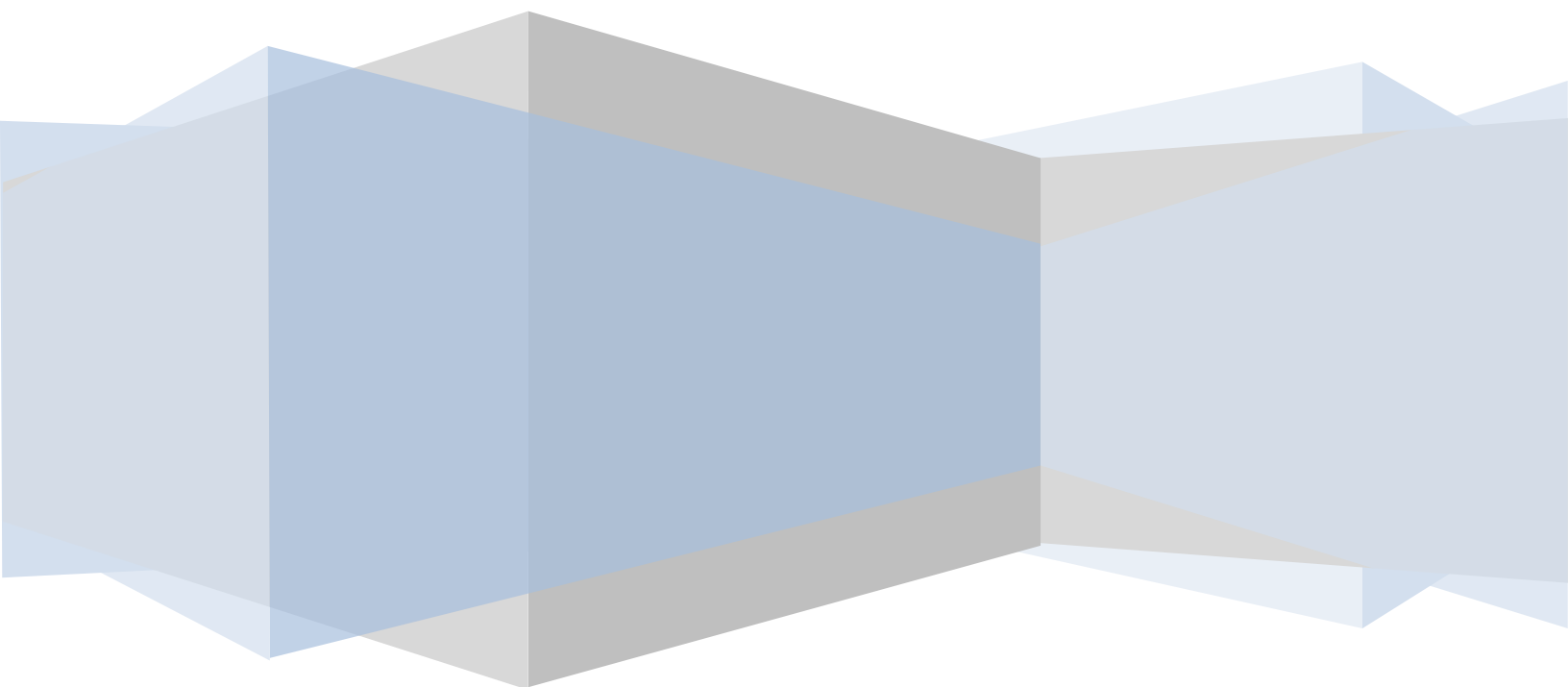


IOWA AUTISM COUNCIL

2012 PRIORITIES

Moving Iowa Forward

Iowa Autism Council



Iowa Autism Council

To the Governor and the Legislators of Iowa:

The Iowa Autism Council continues our work with ongoing evaluations on how to bridge the gaps for people living with Autism Spectrum Disorders (ASD) in Iowa. Studies state that “The societal costs for each individual with ASD across the lifespan is estimated at 3.2 million dollars” (Ganz, 2007).

Furthermore “with effective treatment, the lifetime costs can be reduced by 65% (Jarbrink & Knapp 2001).” Policymakers’ talk about cutting services to “entitlements”; we would argue that proper investment in appropriate services, programs, and trainings will save the state millions of dollars in aggregated costs. The current redesign of the Iowa mental health and disability system should continue to ensure that the system is responsive and robust to meet the needs of individuals with ASD in Iowa. Shortsighted cuts in programs could reverse several years of progress of keeping individuals with ASD in the community. The council is disappointed that state agencies continue to move slowly on recommendations made for basic improvements in the diagnosis and treatments for individuals with ASD. Having the proper diagnosis and treatments available within the state waiver and hawk-i systems would not only improve the lives of Iowans, but also could potentially lower costs over time.

The council in partnership with the Department of Education is closer to understanding the population of individuals who are receiving services for ASD. However, until quality student data is ascertained, program effectiveness is challenging to measure. Furthermore as students’ transition throughout milestone years, the council would strongly urge that private/public partnerships are formed to ensure that students are receiving: vocational tools to foster employment; community skill

building; and proper evaluations for life after school.

Iowa, like many states is facing a dramatic increase in the number of individuals with ASD accessing support systems. As individuals continue to access education, health, vocational, and other public/private services, appropriations need to ensure the systems are fully funded. Funding proper programs help ensure the best possible outcomes for individuals with ASD in Iowa. If Iowa leaders fail to take serious thoughtful actions, Iowans with ASD could potentially find themselves consistently behind the nation in emerging treatments and vital supports needed for a life in the community. We look forward to having a consistent dialog with the governor and legislature to provide leadership, vision, and support for Iowans.

Sincerely,

A handwritten signature in black ink, appearing to read 'Josh Cobbs', with a long horizontal line extending to the right.

Joshua Cobbs
Chairperson Iowa Autism Council

Financing of Care Recommendations

1. Amend the hawk-i Healthcare plan to ensure that behavioral treatments including Applied Behavior Analysis are covered treatments.
2. Expand the coverage that was passed for state employees for ASD treatments to all insurance plans regulated by state insurance rules.
3. Require Department of Human Services (DHS) to amend the Intellectual Disabilities (ID) waiver to add Autism Spectrum Disorders (ASD) as an eligible group and determine eligibility through an individual clinical assessment that is based upon need and functional impairment criteria.
4. Require DHS to amend the Intellectual Disabilities and Ill and Handicap Waivers to allow behavioral treatments including Applied Behavior Analysis be covered treatments. This should include the location and eligibility for services.
5. Replace the dollar cap on county property tax levies with a levy rate cap and allow counties flexibility in determining which base year to use as the capitation rate. We believe that if this legislation was introduced as a “stand alone” bill it would have bi-partisan support and support from counties.
6. Integrated and community based services are a matter of function, not funding. In Iowa we have heard the debate framed in the context of rules and licensure. Currently there is criticism that Intermediate Care Facilities for Mental Retardation (ICF/MR) funding is institutional and that Home and Community Based Services (HCBS) is community based. This connection is not accurate. A person can reside in an ICF/MR and live in a small setting, in an integrated community with a strong network of personal relationships and experiences that engage that person successfully in their environment. While another person can reside in an HCBS funded program and live in an isolated, segregated environment with little or no opportunity for meaningful relationships with the non-disabled community. Iowa should offer its citizens both options as part of the continuum of services while defining standards within each that promote full inclusion in communities.

Iowa Autism Council's Adult Subcommittee

1. HCBS service providers' annual performance measures should include on-site visits to the location(s) where services are provided to ensure consistency with provider documentation and data collection. Site visits by state Quality Assurance Specialists should also include face to face discussions with consumers of services and their families to further validate consumer satisfaction.
 2. "A Life in the Community for Everyone" is the Iowa Department of Services Olmstead Plan with the Mental Health and Disability Services (MHDS) Division. This plan has several bold initiatives that will positively impact people with ASD. The Iowa legislature must adequately fund the priorities within this plan to maintain compliance with the Olmstead decision.
 3. The State of Iowa should provide financial incentives for direct support staff and providers who achieve approved competency based training in caring for individuals with Autism Spectrum Disorders.
 4. Iowa providers who employ direct support staff should be allowed to bill training costs as a direct expense rather than an indirect cost.
 5. Support I-PART in providing 1) crisis intervention and prevention services for all people with autism spectrum disorders, regardless of their residential setting, and 2) also trainings for direct support staff, family caregivers and provider agencies to increase the capacity of communities to meet the needs of people with autism spectrum disorders.
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Iowa Autism Council's Education Subcommittee Recommendations

Department of Education should continue data collection regarding quality educational services for ASD students in Iowa. The council requires adequate data to continue to make sound recommendations on system improvements for Iowa students.

Data Questions

**Once data is collected by the Department of Education the Iowa Autism Council would like to see the following information provided by January 2012 when applicable.*

1. Randomly sample the minutes on IEPs to determine the percentage of services that are consultative versus direct instruction.
2. Review IEP data to determine if students are making progress in areas of consultative services.
3. Randomly sample IEPs to determine if provider minutes on caseload match up with provider minutes available.
4. Randomly sample data to determine if IEP minutes reflect enough time spent for children to make appropriate grade level progress in a year's time in the areas of social competencies, communication, academics, and behaviors
5. •Utilize F page services from IEPs to determine if services offered are evidence based
 - a. From services offered on F page of IEP is the staff appropriately trained to deliver services in such a way for students to make adequate progress in a years' time?
6. Provide a comparison utilizing the density map from the Department of Education to determine the disbursement ratio of teacher and paraprofessional training. The report should contain the hours of training provided and the type of training facilitated.
7. Randomly sample IEPs to determine if staff is appropriately trained to understand and perform progress monitoring, data collection, and instructional decision making rules.
8. Conduct a follow up parent survey by randomly sampling parents identified through the Department of Education's data. The survey should inquire about family satisfaction with their child's services and time allotted in minutes. Determine family knowledge on how to interpret an IEP.
9. Provide data on the readiness of students preparing to leave high school. The council wants to obtain what percentage of students are ready for college according to their readiness scores.

Secondarily if students are not able to attend college what plan is being put in place for post high school activity?

10. Provide data on post-secondary outcomes for students with ASD. What portion of students that were identified as having ASD completed college or obtained employment?
11. Randomly sample current student IEP's to ensure that transitional meetings are occurring and track the proposed outcomes suggested in the meetings.

Iowa Autism Council Progress

Recommendation in progress: Amend the current Department of Education (DE) website for the Iowa Autism Council to include:

- a) How parents, professionals, and adults on the Autism Spectrum can apply for open positions on the Council
- b) Links to current resources for families and professionals to support the individual and family living with an ASD condition.

Statement on Need: Several comprehensive sites currently exist in Iowa, the subcommittee will provide links to those statewide resources to enhance the DE site to include a feedback source to include a voice of the public about current recommendations and activities.

Action to be taken: Amend the current DE site to include resources and an opportunity for the public to respond to activities and recommendations made to the Governor's office. Amendments to the DE site should be completed by spring 2012.

IOWA AUTISM COUNCIL MEMBERS

Voting Members

Chairperson – Josh Cobbs

Co-Chair – Danielle Sharpe

Katie Byers

Jeff Gitchel

Rachel Heiss

Steve Muller

Karn Johansen

Robin Sampson

Susan Smith

Barbara Stineman

Jan Turbes

Dr. Charles Wadle

Patrick Westhoff

Ex-Officio Members

Marty Ikeda – Department of Education (Lead Agency)

Open – Division of Mental Health and Disability Services

Ruth Allison - Iowa Vocational Rehabilitation

Dr. Jeanne Prickett (Superintendent) – Board of Regents

Becky Harker (Executive Director) – Governor’s Developmental Disabilities Council

Jim Mumford (1st Deputy) – Iowa Insurance Division

Dr. Debra Waldron (Director and Chief Medical Officer) – Department of Public Health

Toni Merfeld (Co-Facilitator) – Department of Education

Panel Members

Beth Buehler-Sapp – Department of Education

Frank Forcucci (Administrative Consultant) – Department of Education

Sue Baker (Facilitator) – 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:

Josh Cobbs - Chairperson Iowa Autism Council at Joshua.cobbs@gmail.com

Danielle Sharpe - Co-Chair Iowa Autism Council at hki2thdrs@hotmail.com

Sue Baker - Facilitator Iowa Autism Council at sue-baker@uiowa.edu