To the Governor and Legislators of Iowa:

The Iowa Autism Council was formed four years ago with the charge to improve the lives of Iowa families living with autism spectrum disorders (ASD) by making recommendations for system improvements. Moderate progress is happening in understanding the educational needs of this population and with the passage of the state employee healthcare benefit for applied behavior analysis (ABA); unfortunately there are still countless families that struggle to find appropriate services.

The recent diagnosis rate of 1 in 88 (Center for Disease Control and Prevention, March, 2012) will mean more individuals accessing education, health, vocational, and other public/private services putting additional strain on these systems. The increase in diagnosis rate is important to note, but individuals currently navigating the system are facing funding and service deficits right now. Iowa leaders need to continue to look at how to fund sustainable programs for individuals with ASD in all areas of the state. The Iowa Autism Council Members look forward to having a consistent dialogue with policy makers to share ideas that will better support Iowa’s ASD population. Lastly, we encourage the executive and legislative branches to look at past recommendations; many of the recommendations still need to be implemented or studied further to complete a more comprehensive system of care. Sincerely,

Joshua R. Cobbs
Financing of Care Recommendations

Narrative:
As diagnosis rates continue to rise at an alarming rate, caregivers are turning to private and public options to finance the necessary care for their individual with autism spectrum disorders (ASD). It is imperative that private and public partners all contribute to this state and national crisis. Last legislative year, the Iowa Senate voted in a bipartisan effort to expand coverage that is currently available for state employees to all state regulated insurance plans. The measure fell short in the house and was unable to exit the second funnel week. If Iowa is to remain a place for all individuals to prosper, the Governor’s Council on Autism strongly urges Governor Branstad and Director Palmer of the Department of Human Services to work with the legislature to pass private insurance reform for individuals with ASD.

1. Expand the coverage that was passed for state employees for ASD treatments to all insurance plans regulated by state insurance rules.
2. Ensure that Hawk-I insurance plans have access to behavioral treatments for individuals with ASD, including Applied Behavior Analysis (ABA).
3. Require Department of Human Services (DHS) to amend the Intellectual Disabilities waiver to add ASD as an eligible group and determine eligibility through an individual clinical assessment that is based upon need and functional impairment criteria.
Narrative:
DHS is in progress of a major overhaul of statewide systems that will have a direct impact on individuals diagnosed with ASD and their families. Up to this point, this population has been largely left out of the conversations when redesigning a system that should be responsive and flexible to better fit the needs of this population. When the Governor’s Council on Autism was formed, the purpose was to improve the lives of Iowan’s with ASD by providing recommendations for system improvements. We want to alert Director Palmer that he has an established work group that can provide him a portfolio of recommendations for the redesign process specifically for individuals on the spectrum. The Governor’s Council on Autism will reach out to any outlying individuals or organizations to provide a comprehensive review of state and national best practices.

1. Establish a workgroup from the Iowa Autism Council that will provide action items to Director Palmer
2. Set clear expectations and timelines for completion of recommendations
Current Action Items in Development

1. Adult Services Committee
   a. Review programs and services offered in other states
   b. Review what employment opportunities are currently available
   c. Review what employment opportunities are working in other states (e.g. King County Washington)

2. Education Committee
   a. What is the preparative curriculum identified by institutes of higher education (IHE) and how does it relate to the results of DOE autism study
      i. How are new teachers prepared
      ii. How are current teachers able to access established and emerging practices
   b. Develop follow up surveys as outlined in DOE Autism Report

3. Network of Professionals
   a. The goal of the regionalized network would be to have a clearinghouse of information that can help provide care navigation for healthcare providers, educational institutions, social workers, and other identified groups, and to develop timelines and commitments to complete the work.
IOWA AUTISM COUNCIL MEMBERS

Voting Members
Chairperson – Josh Cobbs
Vice-Chair – Steve Muller
Danielle Sharpe
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Rachel Heiss
Karn Johansen
Robin Sampson
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Rick Schults (Designee- Laura Larkin) – Division of Mental Health and Disability Services
Kathy Levine - Iowa Vocational Rehabilitation
Open (Superintendent) – Board of Regents
Becky Harker (Executive Director) – Governor’s Developmental Disabilities Council
Jim Mumford (1st Deputy) – Iowa Insurance Division
Dr. Debra Waldron (Co-Director/Chief) – Department of Public Health
Toni Merfe (Co-Facilitator) – Department of Education

Panel Members
Beth Buehler-Sapp (Panel Secretary) – 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
Steve Muller - Vice-Chair Iowa Autism Council at SMuller@thehomestead.org
Sue Baker - Facilitator Iowa Autism Council at sue-baker@uiowa.edu