

*GROWING THE FIELDS OF OPPORTUNITY
FOR
CHILDREN AND ADULTS WITH AUTISM IN IOWA*

*Iowa Autism Council
Recommendations*



2009-2010



IOWA AUTISM COUNCIL

To the Office of the Governor:

Many would argue that the dramatic rise in autism has reached critical mass, and this council echoes that statement. Iowa, like many states in the nation, is currently ill equipped to handle the large influx of children and adults with autism. When this council was initially formed we were facing diagnosis rates of 1 in 150 and currently the diagnosis rate is 1 in 91. Current resource strains in education, qualified trained professionals, access to care, and financial services are rapidly deteriorating Iowa's ability to deliver quality services to children, adults, and families affected by autism.

If Iowa leadership fails to act quickly the already strained system will face a breaking point in the following areas: financing, coordination of care, educational resources, early identification, adult services, and access to service delivery - just to name a few. This council has taken the past 12 plus months hearing testimony from state officials, providers, and caregivers to ensure that care for those with autism is effective, cost efficient, and accessible. This council will be making recommendations on three major areas; early identification, seamless support/coordination of care, and financing of care. While these areas will be highlighted in this first annual report it in no way minimizes other areas that need to be addressed such as early intervention, special education, training, in-home support services, financing options, and data collection. Implementing the initial recommendations of this council will lay foundational support for the areas mentioned above.

Often those in position to help ask what can be done to help families in Iowa. This council has provided a roadmap to help facilitate effective and proven treatments to children and adults with autism.

In closing, I would like to thank the private citizens and public officials who have come together to build a roadmap to improve the currently fractured system. Merely reading these recommendations is not enough. Lawmakers must take action to increase the accessibility and efficiency in the current system.

Sincerely,

*Joshua Cobbs
Chairperson Iowa Autism Council*

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Executive Summary

Iowa needs a statewide coordinated autism early identification system. Such a system would be child and family centered with care coordinated at the individual level. A statewide system will require training a wide variety of professionals who regularly interact with children at very young ages. This will not only ensure early identification but will help Iowa families access services early which increases the likelihood of positive outcomes for Iowa children. Finally, Iowa must commit resources for the development, implementation, and evaluation of a coordinated autism early identification system. There needs to be an interagency agreement created amongst state agencies including IDPH, DHS, Dept of Ed (Early ACCESS), CHSC, DVR, and University of IA Center for Excellence for ASD to plan, implement, and evaluate a coordinated system of care.

Currently Iowa lacks a standardized early identification system for autism and lacks a standardized approach to training professionals to implement an early identification system specific to Autism Spectrum Disorders. Autism Spectrum Disorder screening is not a basic part of well child care in Iowa. Training efforts do not meet the definition of a comprehensive system. Data reveal that children and families in Iowa benefit when and early diagnosis is made. Data also reveal that the most benefit is gained when the early identification system consistently leads the family to coordinated care after diagnosis. Unfortunately, there is great disparity in knowledge and skill levels across the state. This needs to be remedied.

Resources at community and state levels have not been committed to develop, implement, and evaluate an early identification system. When an early identification system is developed and implemented throughout Iowa, a network of trained professionals who mentor and communicate will develop. This network will also provide a vehicle for data collection and evaluation of an early identification system, including the efficacy of training and the individual coordination of care post diagnosis.

The issues outlined above are not unique to early identification services. Individuals with Autism Spectrum Disorders (ASD) require a coordinated system of care that includes both public and private sector solutions. The necessities of people with ASD require a long-lasting solution to address needs as the individual's needs change; this currently cannot be obtained due to the lack of coordination in the public and private sectors. The current system in Iowa places the burden on families to seek out information on autism, learn what services are available, apply for those services, and once receiving them, coordinate services from different sources. At the same time, it provides few resources to assist families in doing so. Although there may be pockets of quality services, as a whole, the state is ill prepared to meet current and future demands. State programs are currently underfunded, scattered, and exclusionary by not allowing access to proven treatments. Furthermore, private services are often unobtainable due to cost and distance. Exacerbating the current lack of coordination is a rural landscape, a deficit of trained professionals, and an exploding autism population. Iowa needs to act quickly to enhance current systems. Iowa needs to create new programs that will allow data collection, resource pooling, collaboration, and a coordinated care system that includes private and public partnerships.

One of the greatest barriers to a comprehensive treatment plan is how to ensure a balanced approach to financing treatments for caregivers. It is our responsibility to ensure that a proper balance and financing options are set between public, private, and personal responsibility. Currently a majority of Iowans finance what care they can afford and not necessarily the best care available. This does not always lead to the best outcome for independence for those with ASD. In addition to lack of financing options, a lack of adequate reimbursement to providers currently providing services hampers delivery of service by creating unnecessary waiting lists.

The 2008 legislative session saw the introduction of SF1/HF1 to bridge the gap between quality care and the ability to access care due to lack of coverage in the private sector. This council urges the Executive Branch to work with the Legislative Branch to pass this legislation for Iowa's families in the 2010 session. Last year the Legislative Branch required the Iowa Autism Council to investigate the creation of an Autism Specific Waiver Program. The Iowa Autism Council does not recommend the creation of a separate Autism Waiver at this time. Rather, we make specific recommendations to improve the existing Intellectual Disability (ID) and Ill & Handicapped Waivers. Lastly this council recommends the Executive Branch, in partnership with this council look at utilizing alternative financing options to get programs started. Financing options such as utilization of Race to the Top Funds to implement a data collection system, if the State of Iowa is awarded such funds, or using Investing in Innovation Funds are funds that the Iowa Department of Education will be issuing through an RFP for school districts, LEAs and non-profits.

Recommendations Needing Immediate Action

While every recommendation listed in this report is needed sooner rather than later, the council felt that these five recommendations are immediate needs that need to be accomplished during this legislative session. This will take a strong effort from the executive and legislative branches, but this council has full confidence in the ability of both branches to move swiftly.

- 1) Designate an entity and appropriate funding to create a data tracking system to ensure reliable and valid data collection methods. Without accurate data collection Iowa will continue to be stifled in delivering equitable services efficiently. There could be opportunities to get this data collection system running by utilizing stimulus dollars.*
- 2) Immediate passage of SF/HF1 to end insurance discrimination for the autism spectrum population in Iowa. While some may object to these bills for philosophical reasons such as not supporting mandates or not recommending coverage for a specific population the time to enact this is now. Many of our neighboring states have enacted or are very far along in enacting similar legislation. The fact of the matter is that autism is currently not being treated appropriately under medical provisions or mental health parity provisions. Iowa has a chance to rectify this for their citizens.*
 - Include all state regulated insurance plans in Iowa. This would include self-funded and self-insured plans.
 - Disallow discrimination based on pre-existing condition policies.
 - Coverage must include evidenced based approaches to treatment such as Applied Behavioral Analysis (ABA), Speech Therapy, Occupational Therapy, and other effective treatments.
 - Treat Autism Spectrum Disorder like any other neurological disorders under the policy when applicable.
 - "Autism spectrum disorders" means any of the neurobiological conditions including autistic disorder, Asperger's Disorder, Rhett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorders not otherwise specified.
 - "Diagnostic assessment of autism spectrum disorders" means medically necessary assessment, evaluations, or tests including genetic tests, allergy tests, and necessary labs performed by a licensed physician, licensed physician assistant, licensed psychologist, or licensed registered nurse practitioner to diagnose autism spectrum disorders.

- Coverage will be limited to \$36,000 annually for evidence-based treatments and are not subject to a lifetime cap. Benefits for autism treatments should not be applied to general benefits caps or restrictions.
 - A review of the treatment plan can be performed by the insurance company once every six months.
- 3) *Last year the legislative branch asked this council to research with the Department of Human Services the need for an autism specific waiver. The Iowa Autism Council does not recommend the creation of a separate Autism Waiver at this time. However, we make the following recommendations to improve the existing Intellectual Disability (ID) and Ill & Handicapped Waivers:*
- Amend the ID 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.
 - Change the financial management of the waiver from a monthly cap to the annualized average cap. This would provide greater flexibility resulting in the ability of families to keep their children at home, in school, and out of residential placements, while maintaining cost neutrality. This would allow individualized plans of care to be reviewed periodically and ensure services are based on an individualized clinical or medical need according to best practices for children and adults with ASD.
 - Continue to meet with DHS/IME/MHDS to study what services should be added or amended to existing waivers.
- 4) *Iowa needs to obtain equitable services for individuals with autism from diagnosis to adulthood.*
- Counties have an obligation to fund a portion of services for Medicaid eligible people. The Iowa Autism Council recommends that legislators take action to 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.
 - All adults with ASD should immediately receive services under the county management plan.
 - Address disparities to access county funded adult services. Currently counties have the option to determine what services are paid for under current ID waiver. This means that adults with ASD are provided with different levels of access to services across the state.
 - Iowa must move toward an equitable system of funding in which county of legal settlement is not the determining factor on who can access adult services and which services they access.
 - Opportunities for real work and sufficient income to move away from Medicaid funded programs should continue to be reviewed by the Iowa Autism Council and state agencies.
 - Iowa spends money to support people with disabilities (including ASD) in institutional settings. Currently there is lack of equality in the reimbursement rate between institutional providers and community based providers. The funding is based on placement and not on services provided. This is an archaic concept of services that must be replaced with community based supports. The Iowa

legislature should direct Resource Centers in Iowa to utilize existing resources to support individuals with ASD in the community following the 1999 Olmstead vs. LC decision.

- 5) *This council would strongly recommend looking at stimulus dollars to set up some of the recommended programs in this document. Furthermore, should it be needed this council is willing to help in the search.*
- Utilization of Race to the Top Funds to implement a data collection system if the State of Iowa is awarded such funds.
 - Apply for investing in Innovation Funds. These are funds that the Iowa Department of Education will be issuing through an RFP for school districts, LEAs and non-profits.
 - Appoint a representative from the Governor's office to work with the Iowa Autism Council to pursue additional federal funding for programs to continue to move Iowa forward in diagnosis and service delivery.

Report Breakdown

The compilation of this report took about a year with the help of dozens of private and public participants.

The report is divided into three large categories; Early Identification, Seamless Support/Coordination of Care, and Financing of Care. Three separate subcommittees made up of council members and members from the public (when needed) compiled data and recommendations that will be outlined in this report.

Reading the Report

To make this report as comprehensive as possible it was necessary to provide documentation to support our recommendations. However, this council also recognizes that the data needed to be quick and easy to read. With this in mind you will see a breakdown by Subcommittee with bulleted recommendations. Directly under the Subcommittee title there will be a corresponding page number for the detailed findings and reference material that helped formulate the recommendations.

Early Identification Recommendations

1) A state-wide coordinated autism early identification system should be adopted and should include:

- Surveillance, screening, and evaluation.
- Information provided in a simple, standardized format that will serve both professionals and families.
- Patient and family centered and delivered in a culturally competent manner.

2) Early identification system should include these essential components:

- Participation by health, education, social service, child care, family support agencies, mental health and disability services, and professional clinical associations in the system design.
- Training to increase awareness, knowledge and skills of healthcare and mental healthcare providers involved in the Early Identification System.
- Care coordination at the individual level.
- Communication between levels of early identification.
- Data collection and evaluation of the Early Identification system for ASD.

3) Adequate resources must be committed at the state and community level to ensure the development, continuous improvement, and evaluation of the early identification system including:

- Support for training in early identification strategies and family resources for health care and mental healthcare providers.
- Support for a creation of competent network of practitioners to help families access early identification resources.
- Support for a state level interagency committee to implement and direct the early identification system.

Members of the Early Identification Subcommittee:

Chair:

Sue Baker

Committee members:

John Kohles

Lana Michelson

Pamela Parker

Grace Percival

Dr. Deb Waldron

Early Identification Findings

1. ***Iowa needs a statewide standardized, coordinated system addressing care coordination needs, and culturally competent services, and covering surveillance, screening, and evaluation.***
 - Policy and technical information for pediatricians and a specific algorithm to support the development of a strategy for early identification is now available. The field has not only developed strong guiding resources to standardize an early identification system but also substantiates the need for skill development for healthcare providers. Iowa does not have a standardized approach to train and implement this system despite guidance resources being available.
 - Iowa's early identification system is not a coordinated system from the medical provider's standpoint; training for medical professionals is very limited and is not comprehensive in meeting screening, diagnosis, and referral needs of the ASD population. AAP resources and other articles provide guidance regarding care coordination needs of the ASD population as well as supporting the multiple component levels in such a coordinated system. These informational tools should be a primary resource for all pediatricians to complement their practice to support families and children on the autism spectrum.
 - Family support needs were identified by a statewide group of stakeholders who drafted a document for a *call for action* in Iowa not long ago. This document, "Autism in Iowa: Shaping the Future for Iowa's Children September 2008," supports screening to identify young children at risk for ASDs that should be a basic part of well-child care for children 18-24 months of age. Access to Family-Centered Services is another focus of this Iowa document stressing the need for "medical home" and a range of family support resources. The totality of services provided for families of children with autism has been articulated by many other states but is lacking such documentation and access in Iowa.
 - There are well designed reference resources to enhance the training needed for health care providers that articulate what information and resources medical professionals should be sharing with families to ensure a family centered and culturally competent system of services. Training is a need identified for Iowa to address a statewide coordinated system of early identification for the ASD population.
 - Findings from research articles in the field do identify the M-CHAT as the most promising screening tool for 16 to 36 month toddlers for pediatricians to use at Level 1 to identify children at risk for autism. Other diagnostic tools for comprehensive medical professionals include the ADI-R and ADOS at Level II. To date, Child Health and Specialty Clinics (CHSC) have established training efforts and universal autism screening procedures to the patients they serve. The training efforts to date have not reached the level of being adopted by all family practice, other pediatric offices, or residency training programs, but suggest promising outcomes via use of these tools in training.
 - An informal survey of selected parents living with ASD and adults on the spectrum in Iowa conducted by members of this committee provided additional information regarding how an early autism diagnosis made a difference in their

lives. Responses from parents described how an early diagnosis was beneficial for their child even before they were old enough to go to school. These responses supported the need for early identification that leads to the best outcomes due to early intervention. This survey identified there was some level of confidence in medical and mental health professionals having knowledge of the ASD condition, while others provided a perspective of further expertise needs to be developed in the area of mental health concerns that often combine with autism. Mental health providers may be difficult to find, especially given the geographic nature of our state, and their need for additional care coordination was noted.

2. System Components: national data impetus, state lacks prevalence data system, need for training in evaluating and diagnosing at comprehensive level for health care providers, need for training at awareness level for local providers, communication between levels, knowledge and skills have been outlined in resources, and need to develop care coordination post diagnosis.

- Centers for Diseases Control and Prevention (CDC) joins with Health Resources and Services Administration (HRSA) in recognizing that ASDs are conditions of urgent public health concern and recent preliminary data, approximately 1% of children are affected with an ASD, affirm that a concerted and substantial national response is warranted. The rise in data nationally should raise awareness and help improve early identification and services nationally.
- According to the TWENTY-FOURTH ANNUAL REPORT to Congress on the Implementation of the Individuals with Disabilities Education Act, 17% of children under the age of 18 are affected by a developmental, behavioral, or learning disability. The special kind of developmental disability called autism spectrum disorders does not have an accurate data collection system to monitor prevalence in Iowa. Knowing the accurate numbers of those individuals impacts the financial status to address the needed services for the increasing numbers perceived in Iowa and nationally. The only identified official state system, Iowa Department of Education, looks promising yet it identified only 1,100 school students in need of ASD supports but unofficial estimates range above 4,500.
- *The call for action* announced in the document “Autism in Iowa: Shaping the Future for Iowa’s Children *September 2008*,” supports training for professionals. It indicated that an accurate diagnosis will be possible only if there are sufficient numbers of professionals trained in evaluating and diagnosing children with ASDs. Training to reduce under- and over-diagnosis is especially critical. Training also focused on the needs of parents, early childhood educators, and child care workers in addition to health care professionals to respond to problems in social communication and atypical behavior of this population.
- The American Academy of Pediatrics Resource Toolkit provides guidance regarding care coordination needs of the ASD population as well as supporting the multiple component levels in such a system. This resource directs the primary care pediatricians to make referrals to intervention programs like Early ACCESS before the diagnosis is confirmed, enhancing the concept of a coordinated system for Iowa. Resources like these need to be a part of all the offices of all primary

health care professionals to enhance the infrastructure of early identification services and supports for families.

3. Adequate resources for training, network of practitioners, continuous improvement and evaluation of system, and position/committee to oversee.

- Adequate resources at the state and community level need to be committed to develop, implement, and evaluate the early identification system being described as a need for Iowa. Reliable training resources have been developed nationally to target both the primary level of screening and the comprehensive evaluation training that is being proposed in this system.
- Such development of a coordinated early identification system would identify a network of providers which is the cornerstone of collaborative mentoring and communication among providers needed for a successful system.
- The newly developed collaboration between state agencies, each represented on the Iowa Autism Council, will result in each agency's improved commitment to provide support, direction, and implementation of their part in the system.
- Any system being developed needs a continuous improvement cycle to survive and be sustained. It needs a way to evaluate if what is being implemented is responsible for the positive changes and improvements that are planned. A practical example includes the development of an implementation checklist to review compliance to training recommendations, use of screening tools in practice, and signal the need for additional support from other providers.

Seamless Support/Coordination of Care Recommendations

1. Develop a Coordinated System of Care for individuals with ASD living in Iowa.

- Needed services and supports are organized to work together to provide care.
- The needs of the family and the individual are addressed in a comprehensive and efficient manner throughout life.
- The goal is to improve functional outcomes in social, educational, vocational, and familial domains.

2. Create an interagency agreement amongst state agencies to plan, implement, and evaluate a coordinated system of care, and identify one agency to be the lead agency.

- Agencies should include but not be limited to those defined in code 256.35A: The Department of Education, The Division of Vocational Rehabilitation of the Department of Education, The Department of Public Health, The Department of Human Services, The Governor's Developmental Disabilities Council, The Division of Insurance of the Department of Commerce, and The State Board of Regents, for example Child Health Specialty Clinics (CHSC.)
- Identify seamless support system to plan and implement a tailored set of services for each individual's physical, emotional, social, educational, and family needs.
- Develop State Best Practice Guidelines specific to ASD.
- Implement professional development specific to ASD.
- Organize and support a system of electronic communication as a resource to provide current information on ASD and ASD related services to parents, caretakers, and professionals statewide.
- Report to the Iowa Autism Council on a quarterly basis.

3. Establish regionalized centers of care for community based care coordination and service delivery.

- Expand Child Health Specialty Clinics' Regional Autism Spectrum Disorder in conjunction with Center for Disabilities and Development (CDD) to include adults.
- Implement Care Coordination based on the chronic care model.
- Establish a proactive team approach including collaboration of the medical home, early intervention and education systems, family support organizations, other health care providers, and other community based organizations.
- Due to the diverse needs of individuals with ASD and multiple agency involvement, the autism program should be unique and separate from other CHSC Disability Programs.

4. Designate an entity and appropriate funding to create a data tracking system to ensure reliable and valid data collection methods.

***Members of the Seamless Support/Coordination of Care
Subcommittee***

Chair

Dr. Danielle Sharpe

Committee Members

Cathy Young

Dr. Debra Waldron

Pam Alger

Barb Stineman

Toni Merfeld

Seamless Support/Coordination of Care Findings

- Autism Spectrum Disorders are reaching epidemic numbers in every state and Iowa is not an exception. On October 5, 2009, the CDC announced the number of individuals living with autism has increased from 1:150 to 1:91 children (1:58 boys.)
- Iowa has no centralized entity to coordinate services and promote cooperation among the various agencies involved with serving the autism community.
- Caregivers often experience extreme difficulty and frustration gaining access to services, and maybe unsure of where to get assistance.
- There is a lack of reliable and valid data on ASD being collected in Iowa. Without the necessary data collection to warrant funding, there will continue to be inadequate services provided for the ASD population.
- Diverse populations may face disparities in diagnosis and treatment.
- The limited numbers of services that are available in Iowa are mostly restricted to individuals under the age of 21. This leaves adults living with ASD without access to needed services. Adults with ASD could greatly benefit from improvements in vocational, educational, life skills training, and supported housing arrangements.
- Due to the diverse needs of each individual, care coordinators need to be adequately trained on all programs available to those with ASD.
- Many of the services offered are not specific to autism spectrum disorders.
- Eligibility is based on another disability group. This means individuals with autism would qualify only if they had another co-occurring disability and the other co-occurring diagnosis/disability was considered “primary” for a particular service. This is particularly true of the services that can be provided in the home, community and other “typical” locations – a critical aspect of the service delivery for individuals with ASD to live successfully in home and community services.
- Coordination of all facets of treatment is needed to truly have a well defined program and treatment. This can be accomplished with a proactive team approach.
- There is no system that ensures timely delivery of services. The road between the diagnosis of autism, description of the need for services, and actual delivery of services is often long and “bumpy.” Without appropriate early intervention, many individuals that could become independent adults end up requiring dependent adult services.
- There is no funding mechanism for services in the community for the uninsured or the underinsured. At the same time, there may be public funding for certain facility-based and/or institutional types of services. A community based system for service delivery is far more cost effective.
- Currently, services across Iowa are delivered in an inconsistent fashion.
- Not all state agencies in Iowa have developed Best Practice Guidelines specific for Autism Spectrum Disorders. Where guidelines may exist, the enforcement is not uniformly ensured.

- State agencies may communicate in an uncoordinated manner. This often results in inefficiencies in the system and lack of coordination in services.
- There is a crisis in ASD, not just because the rates and trends in prevalence have increased, but because the service system lacks an adequate number of trained professionals at all levels. The service system is fragmented/broken and needs to be restructured to provide quality services in Iowa.

Financing of Care Recommendations

1) *The Iowa Legislator is strongly encouraged to pass SF1 & HF1 introduced in the 2009 legislative session. These bills would end insurance discrimination for families covered under Iowa statute. SF1 & HF would need to include the following provisions.*

- Include all state regulated insurance plans in Iowa. This would include self-funded and self-insured plans.
- Disallow discrimination based on pre-existing condition policies.
- Coverage must include evidenced based approaches to treatment such as Applied Behavioral Analysis (ABA), Speech Therapy, Occupational Therapy, and other effective treatments.
- Treat Autism Spectrum Disorder like any other neurological disorders under the policy when applicable.
- "Autism spectrum disorders" means any of the neurobiological conditions including autistic disorder, Asperger's Disorder, Rhetts Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorders not otherwise specified.
- "Diagnostic assessment of autism spectrum disorders" means medically necessary assessment, evaluations, or tests including genetic tests, allergy tests, and necessary labs performed by a licensed physician, licensed physician assistant, licensed psychologist, or licensed registered nurse practitioner to diagnose autism spectrum disorders.
- Coverage will be limited to \$36,000 annually for evidence-based treatments and are not subject to a lifetime cap. Benefits for autism treatments should not be applied to general benefits caps or restrictions.
- A review of the treatment plan can be performed by the insurance company once every six months.

Medicaid Recommendations:

2) *Iowa Medicaid State Plan*

- Implementation of Applied Behavior Analysis services for children through Medicaid that was amended to take place July 1st, 2010 as amended by DHS and approved by the Federal Center for Medicaid and Medicare Services.
- Care Coordination should also become a service for individuals with ASDs under Medicaid.
- Medicaid service eligibility be determined by an individualized assessment that determines a need for services versus denying access based upon diagnosis or IQ level.
- Work with DHS/IME/MHDS on the creation of standards and a reimbursement model for autism spectrum services delivered via telehealth or interactive video.

3) ***The Iowa Autism Council does not recommend the creation of a separate Autism Waiver at this time. However, we make the following recommendations to improve the existing Intellectual Disability (ID) and Ill & Handicapped Waivers:***

- Amend the ID 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.
- Change the financial management of the waiver from a monthly cap to the annualized average cap. This would provide greater flexibility resulting in the ability of families to keep their children at home, in school, and out of residential placements, while maintaining cost neutrality. This would allow individualized plans of care to be reviewed periodically and ensure services are based on an individualized clinical or medical need according to best practices for children and adults with ASD.
- Continue to meet with DHS/IME/MHDS to study what services should be added or amended to existing waivers.

4) ***Equitable services for individuals with autism***

- Counties have an obligation to fund a portion of services for Medicaid eligible people. The Iowa Autism Council recommends that legislators take action to 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.
- All adults with ASD should immediately receive services under the county management plan.
- Address disparities to access county funded adult services. Currently counties have the option to determine what services are paid for under current ID waiver. This means that adults with ASD are provided with different levels of access to services across the state.
- Iowa must move toward an equitable system of funding in which county of legal settlement is not the determining factor on who can access adult services and which services they access.
- Opportunities for real work and sufficient income to move away from Medicaid funded programs should continue to be reviewed by Iowa Autism Council and state agencies.
- Iowa spends money to support people with disabilities (including ASD) in institutional settings. Currently there is lack of equality in the reimbursement rate between institutional providers and community based providers. The funding is based on placement and not on services provided. This is an archaic concept of services that must be replaced with community based supports. The Iowa legislature should direct Resource Centers in Iowa to utilize existing resources to support individuals with ASDs in the community following the 1999 Olmstead vs. LC decision.

5) ***Review of alternative financing***

- Utilization of Race to the Top Funds to implement a data collection system if the State of Iowa is awarded such funds.

- Apply for investing in Innovation Funds. These are funds that the Iowa Department of Education will be issuing through an RFP for school districts, LEAs and non-profits.
- Appoint a representative from the Governor's office to work with the Iowa Autism Council to pursue additional federal funding for programs to continue to move Iowa forward in diagnosis and service delivery.

Members of the Financing of Care Subcommittee

Chair

Casey Westhoff

Committee Members

Joshua Cobbs

Steve Muller

Katie Byers

Jim Mumford

Dr. Charles Wadle

Financing of Care Findings

- Currently families that have private insurance under Iowa Statute are excluded from evidenced base treatment plans.
- Cost analysis for the mandated coverage for Iowa resulted in a premium impact of .46% or \$1.83 per member per month. This information was published in a report provided by Jim Boudier and is consistent with his findings in other states that have passed insurance mandates. The report is enclosed.
- Discriminating against policy holders allow insurance companies to pass costs onto the public sector while accepting premiums from customers.
- The US government's military health insurance system, TriCare, now offers coverage for vital Autism services, including evidence-based behavioral interventions.
- As of 2009, there are 15 states that require coverage for Autism under a specific mandate.
- Early and Intensive treatments allow the greatest chance at success and reduction of costs for all financing sectors.
- Many of the services offered are not specific to autism spectrum disorders. Eligibility is based off another disability group. This means individuals with autism would qualify only if they had another co-occurring disability and the other co-occurring diagnosis/disability was considered "primary" for a particular service. This is particularly true of the services that can be provided in the home, community and other "typical" locations – a critical aspect of the service delivery for individuals with ASD to live successfully in home and community services.
- Although a MHM (Medical Model Home) has been discussed for autism and been developed, there is limited implementation of this model in primary and behavioral care. Coordination of all facets of treatment is needed to truly have a well defined program and treatment.
- There is no system that ensures timely delivery of services. The road between identification of disability, description of the need for services, and actual delivery of services is often long and "bumpy."
- Individuals with ASD (or any disability) who need services may end up requiring higher end care in the absence of less restrictive services that are accessible in a timely manner.
- There is no funding mechanism for services in the community for the uninsured or the underinsured. At the same time, there may be public funding for certain facility-based and/or institutional types of services.
- Although a number of services for individuals with autism are available in Iowa, access to specialized services does not exist on a consistent statewide basis, and individuals with autism spectrum disorders often wait to obtain appropriate services or go without services all together.
- Intensive care coordination/case management is needed to assist families in obtaining comprehensive and integrated services.
- Many services are subject to waiting lists (e.g., HCBS Waivers, Habilitation) or "first come first serve" (Children at Home and Family Support Subsidy.)

- Adult services are hugely underfunded and waiver supports need to extend to the life of some with ASD that can continue to show progress and quality of life gains allowing a home or home type setting.
- States that currently have coverage mandated for autism: Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Montana, Nevada, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, and Wisconsin. Of those that have mandated coverage a handful of others have safeguards in place for the insured and are working towards mandated coverage for Autism Spectrum Disorders.

Autism in Iowa: Shaping the Future for Iowa's Children

September 2008

Autism is a serious neurodevelopmental disorder that results in marked difficulties in social interaction, communication, and repetitive behavior. With a prevalence as high as 1 in 150 children (Centers for Disease Control and Prevention, 2007), autism spectrum disorders (ASD) affect as many as 4,700 Iowa children. Although a number of services for children with autism are available in Iowa, access to specialized services is inconsistent, and children must often wait to obtain appropriate services or go without services altogether.

Children and families coping with autism deserve better! It is time for Iowa to create a system of care that recognizes the comprehensive needs of children with autism and ensures that all Iowa children receive the services and support they need. The following principles reflect the current status of autism services in Iowa and recognition of the actions that are needed to create a coordinated “system of care” for people with autism spectrum disorders.

1. Early Identification – Consistent with the CDC’s *Learn the Signs – Act Early* program, screening to identify children at risk for ASDs should be a basic part of well-child care for children 18-24 months of age. Parents, health care professionals, early childhood educators, and child care workers should be educated in the early signs of ASDs and in how to obtain appropriate services for children with problems in social communication and atypical behavior.

2. Assessment and Diagnosis – All children at risk for ASDs should have access to timely and high-quality assessment and diagnostic services. Accurate diagnosis will be possible only if there are sufficient numbers of professionals trained in evaluating and diagnosing children with ASDs. Training to reduce under- and over-diagnosis is especially critical.

3. Early Intervention – Providing intensive intervention as early as possible is a key factor in improving long-term life outcomes for children with ASDs.

- Intervention programs should use evidence-based practices to provide individualized services matched to each child’s needs.
- Programs should teach children skills in communication, social interaction, and cognitive development while reducing rigid and repetitive behaviors.
- Systematic instruction using applied behavior analysis and structured teaching strategies must be provided at a level of sufficient frequency and intensity (a

minimum of 25 hours/week, 12 months a year) to produce gains in learning skills and social behavior.

4. Intensive Behavioral Intervention – Applied behavior analysis (ABA) has become widely accepted as an effective treatment for ASDs (National Institute of Mental Health, 2007). A coordinated system of care for young children with ASDs must ensure that early intensive behavioral interventions are provided at an appropriate level of frequency and intensity throughout the year. This will require a trained workforce and sufficient funding to support these interventions.

5. Access to Family-Centered Services – Families should have access to a range of services to support them in raising a child with an ASD.

- Every child with an ASD should have a “medical home” that can ensure that comprehensive, individualized care is provided and that there is appropriate coordination of care across different providers and agencies.
- Decisions about medical, behavioral, and educational interventions should be family-centered and based on the unique needs of each child.
- Family support should include respite care, advocacy support, counseling, and access to clear and practical information about ASDs and associated services.
- Comprehensive autism services should be available to all children in the state, regardless of their geographic location.
- Services should be provided for individuals with ASD as they transition to adulthood and as they seek to achieve success in working and living in their communities.

6. Workforce Development – Iowa currently has a severe shortage of professionals trained to assess, diagnose, and treat ASDs. There is also a significant shortage of paraprofessionals and direct care workers with the skills and experience needed to serve children with ASDs. Workforce development initiatives should target training for child psychiatrists, child psychologists, developmental-behavioral pediatricians, speech-language pathologists, behavior specialists, in-home therapists, and direct care workers in both home and school settings.

7. Research – There is a critical need for empirical research on the genetic, environmental, and neurodevelopmental causes of autism and on evidence-based practices that will improve the lives of people with ASD. Translating research findings to clinical practice must occur rapidly but responsibly.

8. Funding – Sustained funding is needed to support:

- *Educational programming*, including autism training for educators.
- *Behavioral interventions*, including both direct care and consultation to parents and educators.
- *Speech-language therapy* and other therapeutic interventions.

- *Health care services* for diagnosis, treatment, and care coordination -- with access to private insurance, public health care plans, and/or HCBS Medicaid waivers. Access may require that insurance plans prohibit exclusions for ASDs and that current waiver or service programs be supplemented, modified, or enhanced.

9. Interagency Collaboration – A clear commitment from all Iowa stakeholders is needed to create a coordinated system of care for ASDs. Iowa state agencies and organizations must identify the responsibilities and actions that each will take in working together to combat autism. This effort will require establishing clearly defined areas of expertise and commitment of resources. Enhanced public-private partnerships should be part of this initiative.

Prepared by the *Iowa Act Early Autism Coalition*, with support from the *Association of University Centers on Disabilities* and the *National Center on Birth Defects and Developmental Disabilities* at the *Centers for Disease Control and Prevention*.

Insurance Statutes Review

Arizona - Coverage for Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorders "not otherwise specified" (PDD-NOS). Policies cannot exclude or deny coverage for a treatment or impose dollar limits, deductibles and coinsurance provisions based solely on the diagnosis of Autism Spectrum Disorder. Treatment includes diagnosis, assessment and services. Requires coverage for services provided outside the state. Behavioral therapy is considered medically necessary. *"Behavioral therapy" means interactive therapies derived from evidence based research, including Applied Behavioral Analysis, which includes discrete trial training, pivotal response training, intensive intervention programs and early intensive behavioral intervention.* To be eligible for coverage, behavioral therapy services shall be provided or supervised by a licensed or certified provider. Coverage for behavioral therapy is subject to a fifty thousand dollar maximum benefit per year for an eligible person up to the age of nine; a twenty-five thousand dollar maximum benefit per year for an eligible person who is between the ages of nine and sixteen. (Az. Code A.R.S. § 20-826.04).

Colorado - Requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Coverage of treatments will be provided when prescribed, or ordered for an individual diagnosed with autism by a licensed physician or a licensed psychologist who determines the care to be medically necessary. The bill includes coverage of the following treatments: Diagnosis, Habilitative or rehabilitative care, Pharmacy care, Psychiatric care, Psychological care, Therapeutic care, Applied Behavior Analysis (ABA). The bill defines "medically necessary" as any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist that will, or is reasonably expected to prevent the onset of an illness, condition, injury, or disability; reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for individuals of the same age. (Co. § 09-244)

Connecticut - Requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Coverage of treatments will be provided when prescribed, provided, or ordered for an individual diagnosed with autism by a licensed physician or a licensed psychologist who determines the care to be medically necessary. The bill includes coverage of the following treatments: diagnosis, Habilitative or rehabilitative care, pharmacy care, psychiatric care, therapeutic care, counseling services, and applied behavior analysis (ABA). The bill limits coverage for behavioral therapy to a yearly benefit of \$50,000 for a child who is less than nine years of age, \$35,000 for a child who is at least nine years of age and less than thirteen years of age, and \$25,000 for a child that is at least thirteen years of age and less than fifteen years of age. The bill applies only to fully-funded group health plans governed by state law. (Ct. § SB-301)

Florida - Requires health insurance plans and health maintenance contracts issued or renewed on or after April 1, 2009, to cover the following: Well-baby and well-child screening for diagnosing the presence of autism; and treatment of autism through speech therapy, occupational therapy, physical therapy, and applied behavior analysis provided by certified behavior analysts, psychologists, clinical social workers, and others. Covers the following autism spectrum disorders: Autistic disorder; Asperger's syndrome; and Pervasive developmental disorder not otherwise specified. Benefits children under 18 years of age or in high school who have been diagnosed as having a developmental disability at 8 years of age or younger. Limits coverage as follows: coverage is limited to treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. Coverage is limited to \$36,000 annually and may not exceed \$200,000 in total lifetime benefits. Beginning January 1, 2011, these maximum benefits will be adjusted for inflation. Coverage may be subject to other general exclusions and limitations, including coordination of benefits, participating provider requirements, restrictions on services provided by family members, and utilization review, including the review of medical necessity, case management, and other managed care provisions. Coverage, however, may not be denied on the basis that services are habilitative in nature. Coverage may not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles, or coinsurance provisions that apply to physical illnesses, except as provided in above. Prohibits insurers from denying or refusing to issue coverage for medically necessary services or for refusing to contract with, renew, or reissue coverage, or for terminating or restricting coverage for an individual because the individual is developmentally disabled. The autism mandate does not limit benefits and coverage otherwise available to an insured under a health insurance plan. The autism mandate applies to the state group insurance program and other group health policies, health benefit plans, and health maintenance contracts. It does not apply to individual market contracts or individually underwritten contracts, or to contracts provided to small employers (having 50 or fewer employees). The Office of Insurance Regulation may not enforce the autism mandate against an insurer or health maintenance organization that signs the developmental disabilities compact by April 1, 2009. The Office of Insurance Regulation must, however, enforce the mandate against an insurer that signs the developmental disabilities compact but does not by April 1, 2010, comply with the terms of the compact for all health insurance plans or health maintenance contracts. (Fl. SB-2654)

Illinois - Requires a group or individual health insurance policy, or managed care plan to provide coverage for the diagnosis and treatment of autism spectrum disorders. Coverage will be provided for a treatment for an autism spectrum disorder will include care prescribed, provided, or ordered for an individual with an autism spectrum disorder by a licensed physician, licensed psychologist, or certified registered nurse practitioner if the care is determined to be medically necessary. Including: Psychiatric care, Psychological care, Rehabilitative care, Therapeutic care, including speech, occupational, and physical

therapy, Pharmacy care, Applied behavior analysis therapy, or any care, treatment, intervention, service or item for individuals with an autism spectrum disorder which is determined by the Department of Health Care and Family Services, based upon its review of best practices or evidenced-based research, to be medically necessary. Coverage must be provided for an eligible beneficiary under the age of 21. Coverage must be provided up to a maximum benefit of \$36,000 per year (will be adjusted for inflation after December 30, 2009). Coverage is not subject to limits on the number of visits to an autism service provider. (Il. Public Law 095-1005)

Indiana – Policies must include coverage for pervasive developmental disorders, including Autism. Coverage may not be subject to dollar limits, deductibles, co-payments, or coinsurance provisions that are less favorable to an insured than those that apply to a physical illness. Insurers and HMOs cannot deny or refuse to issue coverage on, refuse to contract with, refuse to renew or reissue, or otherwise terminate or restrict coverage on an individual because of a pervasive developmental disorder diagnosis (Ind. Code §§ 27-13-7-14.7 and 27-18-14.2-1 through 27-8-14.2-5).

Louisiana - Requires health insurance coverage from a group health insurance plan or the Office of Group Benefits programs to provide coverage of the diagnosis and treatment of autism spectrum disorders. Coverage applies to individuals under 17 years old. Coverage is not subject to limits on the number of visits an individual may make to an autism services provider. Coverage is subject to a maximum benefit of \$36,000 per year (adjusted for inflation on an annual basis) with a lifetime limit of \$144,000. Coverage is required for treatment of autism spectrum disorders, including: Habilitative or rehabilitative care, Pharmacy care, Psychiatric care, Psychological care, and Therapeutic care. Law does not apply to an employer with 50 or fewer employees. (La. Act.648 HB958)

Montana - Requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Coverage under this bill is subject to a maximum benefit of \$50,000 annually for a child with autism 8 years of age or younger and \$20,000 annually for a child between the ages of 9 and 18. Coverage of treatments will be provided when prescribed, provided, or ordered for an individual diagnosed with autism by a licensed physician or a licensed psychologist. The bill includes coverage of the following treatments: diagnosis, habilitative or rehabilitative care, pharmacy care, psychiatric care, psychological care, therapeutic care, and Applied Behavior Analysis (ABA). The bill applies only to fully-funded health plans governed by state, to the state employee group insurance program, the state university system employee group insurance program, and to any employee group insurance program of a city, town, school district or any other political subdivision of the state. (Mt. SB 234)

Nevada - Requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Coverage of treatments will be provided when prescribed, provided, or ordered for an individual diagnosed with autism by a licensed physician or a licensed psychologist who determines the care to be medically appropriate. Coverage will be provided to individuals under the age of 18, or under the age of 21 if the individual is enrolled in high school. Coverage under this bill

is subject to a maximum benefit of \$36,000 annually for Applied Behavior Analysis (ABA) therapy. The bill defines "medically appropriate" as any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist that will, or is reasonably expected to prevent the onset of an illness, condition, injury, or disability; reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for individuals of the same age. The bill includes coverage of the following treatments: Diagnosis, Habilitative or rehabilitative care, Pharmacy care, Psychiatric care, Psychological care, Therapeutic care, and Applied Behavior Analysis (ABA), and behavioral therapies. The bill defines "behavioral therapy" as "any interactive therapy derived from evidence-based research, including, without limitation, discrete trial training, early intensive behavioral intervention, intensive intervention programs, pivotal response training and verbal behavior". The bill applies only to fully-funded group health plans governed by state law and to state, county, and school district health plans offered to public employees (Nv AB 162)

New Jersey - Requires health insurers to provide health benefits coverage for expenses incurred for certain treatments when prescribed as medically necessary by the covered person's physician upon a diagnosis of autism. Coverage will be provided to an individual with autism until the age of 21. Covered treatments include physical therapy, speech therapy, occupations therapy, and evidence-based behavioral interventions. Coverage of evidence-based behavioral interventions is subject to a maximum of \$36,000 per year. This bill applies to group health insurance plans governed by state law, Small employer health plans, and the State Health Benefits Program. (Nj. S.1651)

New Mexico - Requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Coverage will be provided to individuals under the age of 19, or age 22 if the individual is enrolled in high school. Coverage under this bill is subject to an inflation adjusted maximum benefit of \$36,000 annually with a lifetime maximum of \$200,000. Coverage of treatments will be provided when prescribed by the individual's treating physician in accordance with a treatment plan. A treatment plan includes all elements necessary for the health insurance to pay claims appropriately, including: the diagnosis, the proposed treatment by types, the frequency and duration of treatment, the anticipated outcomes states as goals, the frequency with which the treatment plan will be updated, the signature of the treating physician. The bill includes coverage of the following treatments: Diagnosis, Habilitative or rehabilitative care (includes speech therapy, occupational therapy and physical therapy), Pharmacy care, Psychiatric care, Psychological care, Therapeutic care, Applied Behavior Analysis (ABA). The bill applies only to fully-funded health plans governed by state.

Pennsylvania - Law goes into effect on July 1, 2009. Requires health insurance policies and the medical assistance program to cover the diagnosis and treatment of autism spectrum disorders in individuals less than 21 years of age. Applies to policies offered, issued, or renewed on or after July 1, 2009, to groups of 51 or more employees. Benefit limits -- Coverage is subject to a maximum yearly benefit of \$36,000 but no lifetime benefit caps or visit limits. After December 31, 2011, the maximum yearly benefit will be adjusted for inflation. Coverage is subject to co-payment, deductible, coinsurance provisions, and general policy or program limitations and exclusions to the same extent as other medical services. Authorized treatment -- The treatment of autism spectrum disorders includes the following medically necessary care identified in a treatment plan: Prescribed medications and any test needed to determine their effectiveness; Psychiatric care; Psychological care; Rehabilitative care, including applied behavior analysis; and Speech therapy, occupational therapy, and physical therapy. A physician or psychologist must develop the treatment plan for autism spectrum disorders. An insurer may review the treatment plan once every six months, unless the insurer and physician or psychologist agree that more or less frequent review is necessary. Providers -- The State Board of Regulation, in consultation with the Department of Public Welfare, will set standards for behavior specialists, a newly recognized group of service providers. Insurers are required to contract with and accept as participating providers autism service providers enrolled in the Commonwealth's medical assistance program who agree to accept the payment terms and conditions that apply to the insurer's other participating providers. Review -- If an insurer denies a claim for diagnosis or treatment of autism spectrum disorders, an insured can seek an expedited internal review followed by an expedited independent external review. An insurer or an insured may appeal to a court an order of an expedited independent external review. While the appeal is pending, an insurer must pay for services that have been authorized or ordered. (Pa HB 1150)

South Carolina - Includes: Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified. Requires health insurance plans to provide coverage for the treatment of autism spectrum disorder in accordance with a treatment plan as specified by a treating medical doctor. To be eligible for coverage, an individual must be diagnosed at age 8 or younger. An individual is eligible for coverage up to 16 years old. Coverage for behavioral therapies is subject to a \$50,000 maximum per year. (SC Section 38-71-10 Title 38)

Texas - Includes: Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified. Requires health insurance plans to provide coverage for generally recognized services prescribed in relation to autism spectrum disorder by a primary care physician. The law requires health insurance plans to provide coverage for individuals with autism who are younger than 10 years old. Coverage for behavioral therapies is subject to a \$50,000 maximum per year. Covered services include: Evaluation and assessment services, Applied Behavior Analysis (ABA), Behavior training and behavior management, Speech therapy, Occupational therapy, Physical therapy, Medication or nutritional supplements used to address symptoms of autism spectrum disorder. (Tx HB1919 and HB 451)

Wisconsin - Requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder. Under this bill an insured individual can receive coverage of *at least* \$50,000 annually for intensive-level services (with a minimum of 30-35 hours of care) per week for four years. The bill defines "Intensive-level services" as "evidence-based behavioral therapy that is designed to help an individual with autism spectrum disorder overcome the cognitive, social, and behavioral deficits associated with that disorder" - this included Applied Behavior Analysis (ABA) therapy. After the four year intensive-level services period is up, an insured can receive coverage of *at least* \$25,000 annually for post-intensive-level services. The bill defines "Post-intensive-level services" as "therapy that occurs after the completion of treatment with intensive-level services and that is designed to sustain and maximize gains made during treatment with intensive-level services or, for an individual who has not and will not receive intensive-level services, therapy that will improve the individual's condition". Under this bill, the commissioner must further define "intensive-level services" and "post-intensive-level services". Coverage of treatments will be provided when prescribed by a licensed physician and provided, to an individual diagnosed with autism by a licensed psychiatrist, psychologist, or social worker, or a paraprofessional working under the supervision of any of these three types of providers. Coverage will also be provided for the services of a professional working under the supervision of an outpatient mental health clinic, a speech-language pathologist, or an occupational therapist. The bill applies only to fully-funded individual and group health plans governed by state law and to state, county, city, town, village, and school district health plans offered to public employees . (WI AB 75)

Cost Analysis of SF1/HF1

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March 5, 2009

The Honorable Tom Rielly

VIA ELECTRONIC MAIL

The Honorable David Hartsuch

Iowa State Capitol
Des Moines, IA 50319

RE: Increased Claims Cost re Iowa Senate File 1 pertaining to Insurance Coverage for Autism Diagnosis and Treatment

Dear Senators:

I am writing in response to your request for additional information regarding increased claims-related costs associated with mandating private insurance coverage in Iowa. For the expected claims related costs Iowans could expect, I direct you to Exhibit "A" of the Cost Analysis I provided you on February 3, 2009. My cost analysis forecasts that premiums could experience an average increase of 0.46% once an adequate provider network is in place to meet the demands for services by children likely to require and seek treatment for their condition. In summary, my analysis determined that the said total dollar costs would likely be as follows:

Scenario #1: Claims in Dollars – Provider Network in Place during First Year

	Year 1
Low Estimate	15,089,228
Mid Estimate	23,345,420
High Estimate	30,088,638

Again, the scenario summarized above assumes that a provider network capable of meeting the needs of all children with autism who require and seek treatment is prepared to deliver services during the first year of implementation of Senate File 1. As a practical matter, however, it takes time for providers to recruit, train, and deploy professionals, especially in markets that lack a pre-existing provider base like Florida and Pennsylvania, which the Behavior Analyst Certification Board ("BACB") reports have approximately 1,800 and 300 Board Certified Behavior Analysts ("BCBA"). By comparison, the BACB reports that the State of Iowa has nine (9) BCBA's. The existence of alternative funding streams in the former two states encouraged the aggressive proliferation of Behavior Analysts, and the same can be expected in Iowa once a reliable funding stream is established. In order to provide you with a more

realistic picture of incremental claims-related costs associated with SF1, please note the following two scenarios with one- and two-year ramp-ups (50%/100% and 33%/67%/100%, respectively) to allow for the provider network to respond to the availability of private insurance reimbursement for their services.

Scenario #2: Provider Network in Place after One-Year Ramp Up

	Year 1	Year 2
Low Estimate	7,544,614	15,089,228
Mid Estimate	11,672,710	23,345,420
High Estimate	15,044,312	30,088,638

Scenario #3: Provider Network in Place after Two-Year Ramp Up

	Year 1	Year 2	Year 3
Low Estimate	5,029,743	10,059,485	15,089,228
Mid Estimate	7,781,807	15,563,613	23,345,420
High Estimate	10,029,546	20,059,092	30,088,638

It is important to note that other factors may further reduce first year claims. SF 1 is currently written to require coverage for plans delivered, issued for delivery, continued, or renewed in Iowa on or after January 1, 2010. Assuming open enrollment trends in Iowa are similar to those in other states, approximately 80% of health plans renew on January 1. This could translate into a lower claims experience during the first year of implementation in all three scenarios presented above.

I hope you find this information useful. If you have any questions or would like additional information, please feel free to contact me at (717) 808-9910 or by email at jbouder@ptd.net.

With Kind Regards,

James N. Bouder, MPA

Cc: The Honorable Daryl Beall

HF1 & SF1 as amended to meet family needs

HOUSE FILE

BY ZIRKELBACH

Passed House, Date Passed Senate, Date

Vote: Ayes Nays Vote: Ayes Nays

Approved

A BILL FOR

1 An Act requiring certain group health insurance policies,
2 contracts or plans to provide coverage for autism spectrum
3 disorders for certain persons, requiring certification of
4 behavior specialists and providing applicability date.

5 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

6 TLSB 1118HH 83

7 av/rj/14

1 1 Section 1. **NEW SECTION.** 514C.24 AUTISM SPECTRUM

1 2 DISORDERS COVERAGE.

1 3 1. Notwithstanding the uniformity of treatment

1 4 requirements of section 514C.6, a group policy, contract, or

1 5 plan providing for third-party payment or prepayment of

1 6 health, medical, and surgical coverage benefits shall provide

1 7 coverage benefits to covered individuals under twenty-one

1 8 years of age for the diagnostic assessment of autism spectrum

1 9 disorders and for the treatment of autism spectrum disorders

1 10 if the policy, contract, or plan is either of the following:

1 11 a. A policy, contract, or plan issued by a carrier, as

1 12 defined in section 513B.2, or an organized delivery system

1 13 authorized under 1993 Iowa Acts, chapter 158, to an employer

1 14 who on at least fifty percent of the employer's working days

1 15 during the preceding calendar year employed more than fifty

1 16 full-time equivalent employees. In determining the number of

1 17 full-time equivalent employees of an employer, employers who

1 18 are affiliated or who are able to file a consolidated tax

1 19 return for purposes of state taxation shall be considered one

1 20 employer.

1 21 b. A plan established pursuant to chapter 509A for public

1 22 employees.

1 23 2. As used in this section, unless the context otherwise

1 24 requires:

1 25 a. "Applied behavioral analysis" means the design,

1 26 implementation, and evaluation of environmental modifications,

1 27 using behavioral stimuli and consequences, to produce socially

1 28 significant improvement in human behavior or to prevent loss

1 29 of attained skill or function, including the use of direct

1 30 observation, measurement, and functional analysis of the

1 31 relations between environment and behavior.

1 32 b. "Autism service provider" means a person, entity, or

1 33 group providing treatment of autism spectrum disorders,

1 34 pursuant to a treatment plan.

1 35 c. "Autism spectrum disorders" means any of the neurobiological conditions including autistic disorder,

2 2 Asperger's disorder, Rett syndrome, CDD, and pervasive developmental disorders not 2 3 otherwise specified. The commissioner, by rule, shall define

2 4 "autism spectrum disorders" consistent with definitions

2 5 provided in the most recent edition of the American

2 6 psychiatric association's diagnostic and statistical manual of

2 7 mental disorders, as such definitions may be amended from time

2 8 to time. The commissioner may adopt the definitions provided

2 9 in such manual by reference.

2 10 d. "Behavior specialist, behavior analyst, assistant behavior analysts" means an individual, certified by

2 11 the commissioner, or a nationally recognized certification board for behavior and assistant behavior analysts who designs, implements, or evaluates a

2 12 behavior modification intervention component of a treatment

2 13 plan, including those based on applied behavioral analysis, to

2 14 produce socially significant improvements in human behavior or

2 15 to prevent loss of attained skill or function, through skill

2 16 acquisition and the reduction of problematic behavior.

2 17 e. "Diagnostic assessment of autism spectrum disorders"

2 18 means medically necessary assessment, evaluations, or tests, including genetic tests, allergy tests, and necessary labs.

2 19 performed by a licensed physician, licensed physician

2 20 assistant, licensed psychologist, or licensed registered nurse

2 21 practitioner to diagnose whether an individual has an autism

2 22 spectrum disorder.

"Medically necessary" means any care, treatment, intervention, genetic testing, allergy testing, vitamins & nutritional supplements, service or item which will or is reasonably expected to do any of the following: (i) prevent the onset of an illness, condition, injury, disease or disability; (ii) reduce or ameliorate the physical, mental or developmental effects of an illness, condition, injury, disease or disability; or (iii) assist to achieve or maintain maximum functional activity in performing daily activities.

2 23 f. "Pharmacy care" means medications, vitamins & nutritional supplements prescribed by a

2 24 licensed physician, licensed physician assistant, or licensed

2 25 registered nurse practitioner and any assessment, evaluation,

2 26 or test prescribed or ordered by a licensed physician,

2 27 licensed physician assistant, or licensed registered nurse

2 28 practitioner to determine the need for or effectiveness of

2 29 such medications.

2 30 g. "Psychiatric care" means direct or consultative

2 31 services provided by a licensed physician who specializes in

2 32 psychiatry.

2 33 h. "Psychological care" means direct or consultative

2 34 services provided by a licensed psychologist.

2 35 i. "Rehabilitative and Habilitative care" means professional services and

3 1 treatment programs, including applied behavioral analysis,
3 2 provided by an autism service provider to produce socially
3 3 significant improvement in human behavior or to prevent loss
3 4 of attained skill or function.

3 5 j. "Therapeutic care" means services provided by a
3 6 licensed speech pathologist, licensed occupational therapist,
3 7 or licensed physical therapist.

3 8 k. "Treatment of autism spectrum disorders" means
3 9 treatment that is identified in a treatment plan and includes
3 10 medically necessary pharmacy care, psychiatric care,
3 11 psychological care, Rehabilitative and habilitative care, and therapeutic care
3 12 that is one of the following:

3 13 (1) Prescribed, ordered, or provided by a licensed
3 14 physician, licensed physician assistant, licensed
3 15 psychologist, nationally certified behavior analyst or assistant behavior analyst, licensed
social worker, or licensed registered
3 16 nurse practitioner.

3 17 (2) Provided by an autism service provider.

3 18 (3) Provided by a person, entity, or group that works
3 19 under the direction of an autism service provider.

3 20 l. "Treatment plan" means a plan for the treatment of
3 21 autism spectrum disorders developed by a licensed physician or
3 22 licensed psychologist, nationally certified behavior analyst or assistant behavior analyst,
pursuant to a comprehensive evaluation
3 23 or reevaluation performed in a manner consistent with the most
3 24 recent clinical report or recommendations of the American
3 25 academy of pediatrics, as determined by the commissioner by
3 26 rule.

3 27 3. Coverage is required pursuant to this section in a
3 28 maximum benefit amount of not less than thirty=six thousand
3 29 dollars per year but shall not be subject to any limits on the
3 30 number of visits to an autism service provider for treatment
3 31 of autism spectrum disorders. Beginning in 2013, the
3 32 commissioner shall, on or before April 1 of each calendar
3 33 year, publish an adjustment to the maximum benefit required
3 34 equal to the percentage change in the United States department
3 35 of labor consumer price index for all urban consumers in the
4 1 preceding year, and the published adjusted maximum benefit
4 2 shall be applicable to group policies, contracts, or plans
4 3 subject to this section that are issued or renewed on or after
4 4 January 1 of the following calendar year. Payments made under
4 5 a group policy, contract, or plan subject to this section on
4 6 behalf of a covered individual for treatment of a health
4 7 condition unrelated to or distinguishable from the
4 8 individual's autism spectrum disorder shall not be applied
4 9 toward any maximum benefit established under this subsection.

4 10 4. Coverage required pursuant to this section shall be
4 11 subject to copayment, deductible, and coinsurance provisions,
4 12 and any other general exclusions or limitations of a group
4 13 policy, contract, or plan to the same extent as other medical
4 14 or surgical services covered by the group policy, contract, or
4 15 plan.

4 16 5. Coverage required by this section shall be provided in
4 17 coordination with coverage required for the treatment of
4 18 autistic disorders pursuant to section 514C.22.

4 19 6. This section shall not be construed to limit benefits
4 20 which are otherwise available to an individual under a group
4 21 policy, contract, or plan.

4 22 7. This section shall not be construed to require coverage
4 23 by a group policy, contract, or plan of any service solely
4 24 based on inclusion of the service in an individualized
4 25 education program. Consistent with federal or state law and
4 26 upon consent of the parent or guardian of a covered
4 27 individual, the treatment of autism spectrum disorders may be
4 28 coordinated with any services included in an individualized
4 29 education program. However, coverage for the treatment of
4 30 autism spectrum disorders shall not be contingent upon
4 31 coordination of services with an individualized education
4 32 program.

4 33 8. This section shall not apply to accident-only,
4 34 specified disease, short-term hospital or medical, hospital
4 35 confinement indemnity, credit, dental, vision, Medicare
5 1 supplement, long-term care, basic hospital and
5 2 medical-surgical expense coverage as defined by the
5 3 commissioner, disability income insurance coverage, coverage
5 4 issued as a supplement to liability insurance, workers'
5 5 compensation or similar insurance, or automobile medical
5 6 payment insurance, or individual accident and sickness
5 7 policies issued to individuals or to individual members of a
5 8 member association.

5 9 9. A carrier, organized delivery system, or plan
5 10 established pursuant to chapter 509A may manage the benefits
5 11 provided through common methods including but not limited to
5 12 providing payment of benefits or providing care and treatment
5 13 under a capitated payment system, prospective reimbursement
5 14 rate system, utilization control system, incentive system for
5 15 the use of least restrictive and costly levels of care, a
5 16 preferred provider contract limiting choice of specific
5 17 providers, or any other system, method, or organization
5 18 designed to assure services are medically necessary and
5 19 clinically appropriate.

5 20 10. An insurer may review a treatment plan for treatment

5 21 of autism spectrum disorders once every six months, subject to
5 22 its utilization review requirements, including case
5 23 management, concurrent review, and other managed care
5 24 provisions. A more or less frequent review may be agreed upon
5 25 by the insured and the licensed physician, licensed
5 26 psychologist, or a nationally certified behavior analyst or assistant behavior analyst,
developing the treatment plan.

5 27 11. For the purposes of this section, the results of a
5 28 diagnostic assessment of autism spectrum disorder shall be
5 29 valid for a period of not less than twelve months, unless a
5 30 licensed physician, licensed psychologist or nationally certified behavior analyst or assistant
behavior analyst, determines that a
5 31 more frequent assessment is necessary.

5 32 12. The commissioner, in consultation with the board of
5 33 medicine, and a nationally recognized certification board for behavior analysts and assistant
behavior analyst shall adopt rules providing for the certification of
5 34 behavior specialists.

5 35 a. An applicant for a certificate as a behavior specialist
6 1 shall submit a written application on forms provided by the
6 2 commissioner evidencing and insuring that the applicant meets
6 3 all of the following requirements:

6 4 (1) Is of good moral character.

6 5 (2) Has received a master's or higher degree from a
6 6 board=approved, accredited college or university, including a
6 7 major course of study in school, clinical, or counseling
6 8 psychology, special education, social work, speech therapy,
6 9 occupational therapy, or another related field.

6 10 (3) Has at least one year of experience involving
6 11 functional behavior assessments, including the development and
6 12 implementation of behavioral supports or treatment plans.

6 13 (4) Has completed at least one thousand hours in direct
6 14 clinical experience with individuals with behavioral
6 15 challenges or at least one thousand hours experience in a
6 16 related field with individuals with autism spectrum disorders.

6 17 (5) Has completed relevant training programs, including
6 18 professional ethics, autism=specific training, assessments
6 19 training, instructional strategies and best practices, crisis
6 20 intervention, co morbidity and medications, family
6 21 collaboration, and addressing specific skill deficits
6 22 training.

Certification by a nationally recognized board of behavior analysts will be considered sufficient
to meet (1) through (5) above and have the ability to administer a behavior plan.

6 23 b. The commissioner shall not issue a certificate to an
6 24 applicant who has been convicted of a felony, of a controlled
6 25 substance=related offense under chapter 124 or of the laws of
6 26 another jurisdiction unless all of the following requirements

6 27 have been met:

6 28 (1) At least ten years have elapsed from the date of
6 29 conviction of such an offense.

6 30 (2) The applicant satisfactorily demonstrates to the
6 31 commissioner that the applicant has made significant progress
6 32 in personal rehabilitation since the conviction such that
6 33 certification of the applicant would not be expected to create
6 34 a substantial risk of harm to the health and safety of
6 35 patients or the public, or a substantial risk of further
7 1 criminal violations.

7 2 (3) The applicant otherwise satisfies the requirements of
7 3 this subsection.

7 4 13. The commissioner shall adopt rules pursuant to chapter
7 5 17A to implement and administer this section.

7 6 14. This section applies to third-party payment provider
7 7 policies, contracts, or plans, and to plans established
7 8 pursuant to chapter 509A that are delivered, issued for
7 9 delivery, continued, or renewed in this state on or after
7 10 January 1, 2010.

7 11 EXPLANATION

7 12 This bill creates new Code section 514C.24 which requires
7 13 certain group health insurance policies, contracts, or plans
7 14 to provide coverage benefits for the diagnosis and treatment
7 15 of autism spectrum disorders. The new provision is applicable
7 16 to group health policies, contracts, or plans issued to
7 17 employers with more than 50 employees and to health plans
7 18 established under Code chapter 509A for public employees.
7 19 Coverage benefits are required for covered individuals under
7 20 21 years of age.

7 21 "Autism spectrum disorders" any of the neurobiological conditions includes autistic
disorder,

7 22 Asperger's disorder, Rett syndrome, CDD, and pervasive developmental disorder not
7 23 otherwise specified, as defined by the commissioner of

7 24 insurance by rule consistent with definitions provided in the
7 25 most recent edition of the American psychiatric association's
7 26 diagnostic and statistical manual of mental disorders7 27 Required coverage for the

diagnosis and treatment of autism

7 28 spectrum disorders must be not less than \$36,000 per year and

7 29 without limits on the number of visits to an autism service

7 30 provider. Beginning in 2013, the commissioner is required to

7 31 make annual adjustments to the maximum benefit required equal

7 32 to the change in the United States department of labor

7 33 consumer price index. Payments made on behalf of a covered

7 34 individual that are unrelated to or distinguishable from the

7 35 individual's autism spectrum disorder cannot be applied toward

8 1 this maximum benefit.

8 2 Coverage of autism spectrum disorders under the new Code
8 3 section is to be provided in coordination with coverage
8 4 required for the treatment of autistic disorders pursuant to
8 5 Code section 514C.22. The section shall not be construed to
8 6 limit benefits otherwise available to an individual under a
8 7 group health policy, contract, or plan.
8 8 The commissioner, in consultation with the board of
8 9 medicine, and a nationally recognized certification review board for behavior analysts and
assistant behavior analyst is required to adopt rules for the certification of
8 10 behavior specialists who design, implement, or evaluate
8 11 behavior modification intervention components of treatment
8 12 plans for autism spectrum disorders that are developed by a
8 13 licensed physician, licensed psychologist, or nationally certified behavior analysts or
assistant behavior analyst.
8 14 The new Code section applies to third=party payment
8 15 provider policies, contracts, or plans, and to plans
8 16 established pursuant to Code chapter 509A that are delivered,
8 17 issued for delivery, continued, or renewed in this state on or
8 18 after January 1, 2010.
8 19 LSB 1118HH 83
8 20 av/rj/14

Additional Insurance Conclusions

1. The Iowa Legislature is strongly encouraged to pass SF1 & HF1 introduced in the 2009 legislative session. These bills would end insurance discrimination for families covered under Iowa statute. A few of the major provisions are listed below.

- Include all state regulated insurance plans in Iowa. This would include self-funded and self-insured plans.
- Disallow discrimination based on pre-existing condition policies.
- Coverage must include evidenced based approaches to treatment such as Applied Behavioral Analysis (ABA), Speech Therapy, Occupational Therapy, and other effective treatments.
- Treat Autism Spectrum Disorder like any other neurological disorders under the policy when applicable.
- "Autism spectrum disorders" means any of the neurobiological conditions including autistic disorder, Asperger's disorder, Rett syndrome, CDD, and pervasive developmental disorders.
- "Diagnostic assessment of autism spectrum disorders" means medically necessary assessment, evaluations, or tests including genetic tests, allergy tests, and necessary labs performed by a licensed registered nurse practitioner to diagnose whether an individual has an autism spectrum disorder.
- Coverage will be limited to \$36,000 annually for evidence-based treatments and are not subject to a lifetime cap. Benefits for autism treatments should not be applied to general benefits caps or restrictions.
- A review of the treatment plan can be performed by the insurance company once every six months.

2. Barriers to coverage and recommendations to relieve coverage gaps

- When the insurance mandate is passed most individuals will still face barriers to qualified professionals. Service providers may not be available in network especially given Iowa's rural landscape and current waiting lists at metro facilities.
- Limitation of qualified professionals in most disciplines including Speech Therapy, Occupational Therapy, Behavior Therapy, Psychology, and others.
- Look at public reimbursement rates for providers.
- Work with Drake University and the University of Iowa to provide additional staffing needs to complete undergraduate Behavioral Science Program.
- Allow licensed professionals to provide treatment programs using Interactive Video Systems if the provider has the ability to meet with client face to face for initial treatment evaluation.

Additional Medicaid and Funding Conclusions

For people with Autism or on the Autism Spectrum Disorder (ASD), Medicaid is the major funding source for community and facility based supports and services. The number of people with ASD receiving Medicaid funding is undetermined in Iowa, however we do assume that a significant amount of people with ASD do qualify for Medicaid. Often people with ASD in Iowa are supported through a HCBS waiver program (Intellectual Disability or Ill & Handicapped Waiver) or within state operated or community based intermediate care facilities for the mentally retarded (ICF/MR). Depending upon the age of the individual, the state of Iowa (for children) and the county of legal settlement (over age 18) must participate in the funding of support services for eligible participants.

The Iowa Autism Council worked with The Iowa Department of Human Services on exploring options of support for Iowans with ASD. These included enhancing services available to through the Medicaid state plan, coordinating the system of care within the existing state plan, amending an existing HCBS Waiver or the creation and application of a separate HCBS waiver specific to people with ASD.

The Council also studied the existing state of Medicaid funds available in Iowa and reviewed forecasting estimates of potential significant deficits by year 2011. Other states were researched along with questions to persons with ASDs and their families on what currently works within the system of support and what improvements should be made.

Medicaid Recommendations: The Iowa Autism Council thinks that people with ASDs could benefit from services currently available through Medicaid including **Remedial** Services, **Habilitation** Services, and services under the **Iowa Plan** such as Community Support Services, Joint Treatment Planning, Wrap Around Services for children, and Crisis Services Development (mobile crisis, crisis stabilization and sub-acute services) for individuals of all ages.

Furthermore, the Iowa Medicaid State Plan should be **enhanced** for individuals with ASD by offering a state approved Applied Behavior Analysis service for children. **Care Coordination** should also become a service for individuals with ASD under Medicaid. This could follow a similar model to that of the existing Children's System of Care project in Iowa that has proved successful. Understanding and navigating the 'system of support' for families is very challenging and fragmented in Iowa. Too often many children and adults with ASD 'fall through the cracks' of being eligible for services and the Autism Council strongly recommends that eligibility for Medicaid be determined by an **individualized assessment** that determines a need for services versus denying access based upon diagnosis or IQ level.

The Iowa Autism Council **does not** recommend the creation of a separate Autism Waiver at this time. However, we make the following recommendations to **improve** the existing Intellectual Disability (ID) and Ill & Handicapped Waivers:

- Amend the ID waiver to add ASDs as an eligible group and determine eligibility through an individual clinical assessment that is based upon need and functional impairment criteria. **Remove** the individual monthly cap on waiver services for children to provide

flexibility and support the ability of families to keep their children at home, in school, and out of residential placements.

- The Iowa Autism Council and DHS/IME should continue to meet and **study regularly** what services should be added to existing waivers to improve the lives of individuals with ASDs.
- Given the projection of a significant deficit (potentially 150 million) with the Iowa Medicaid program by 2011, Iowa must **consider options** to manage existing funds within the waivers in different ways to allow for effective use of limited dollars among a greater numbers of people. Based upon the latest estimates, 1:91 children will be diagnosed with an ASD. This existing crisis of limited funds available within Medicaid will only increase unless Iowa takes swift action to manage utilization and address waiting lists and those individuals who don't currently qualify for services.

Other recommendations to the **funding** of services to individuals with ASD:

- As stated, a significant number of adults with ASD receive support services throughout Iowa. Counties have an obligation to fund a portion of services for Medicaid eligible people-often within residential, vocational, and transportation services. The Iowa Autism Council recommends that legislators **take action to 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.
- Counties can determine if they have the funds and are willing to support individuals with ASDs who do not qualify for Medicaid. This means that adults with ASDs are provided with different levels of access to services across the state. Iowa **should move** toward a system of funding in which county of legal settlement is not the determining factor on who can access adult services and who cannot.
- The Iowa DHS, working in partnership with The Autism Council and key public and private partners, should **strategize and focus** efforts on community capacity and asset development building for individuals with ASD. Individuals with ASD should have opportunities for real work and sufficient income to move away from Medicaid funded programs.
- Iowa has decided to spend a significant amount of state money to support people with disabilities (including ASD) in institutional settings. This is an archaic concept of services that must be replaced with community based supports. The Iowa Legislature should **direct** Resource Centers in Iowa to utilize existing professional expertise to support individuals with ASD in the community.

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Toni Merfeld – Department of Education Ex Officio
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Keith Gatrost – Service Provider
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Steve Muller – Service Provider
Pamela Parker – Parent
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