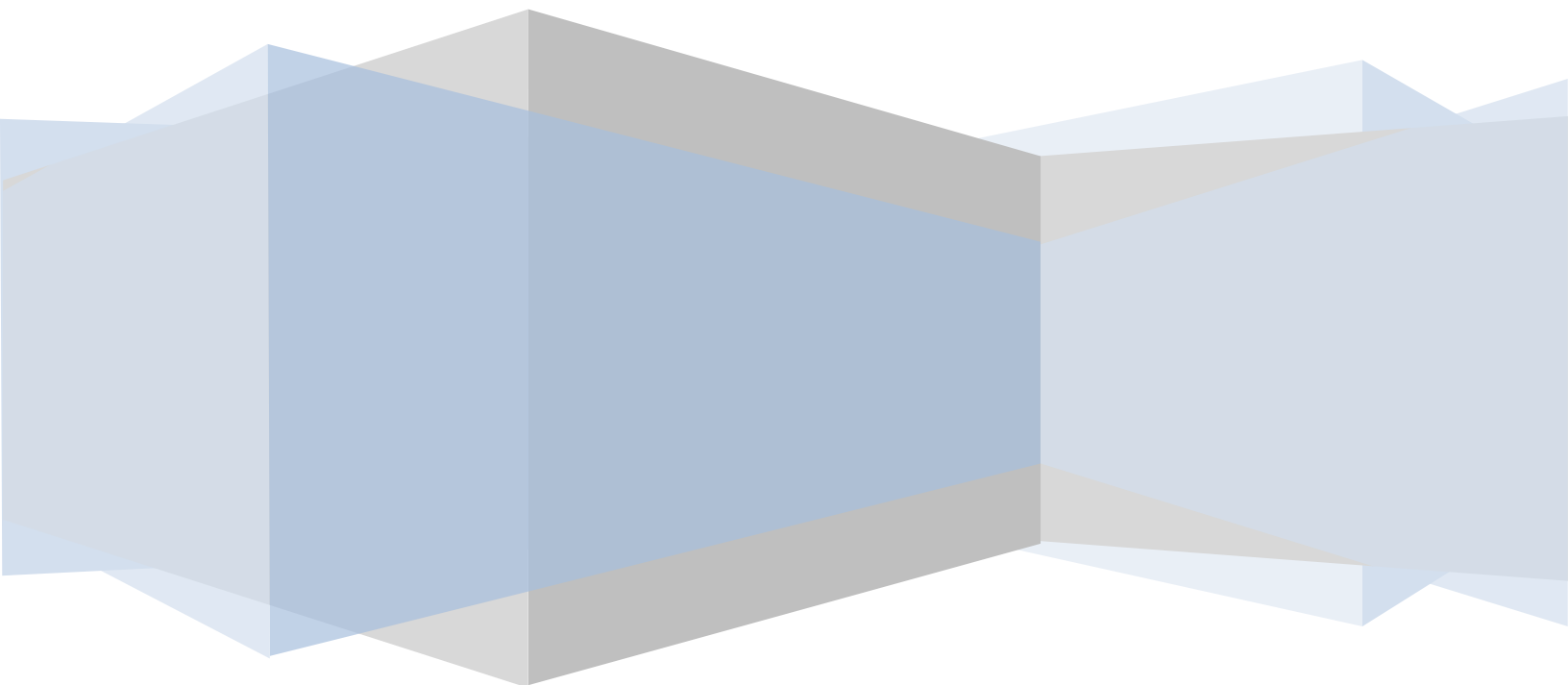


# IOWA AUTISM COUNCIL

## 2011 PRIORITIES

Moving Iowa Forward

Iowa Autism Council



# Iowa Autism Council

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To the Governor and the Legislators of Iowa:

The Iowa Autism Council continues our second year of work with an ongoing evaluation on how to bridge the gaps for people living with Autism Spectrum Disorders (ASD) in Iowa. According to a recent study “The societal costs for each individual with ASD across the lifespan is estimated at 3.2 million dollars” (Ganz, 2007), furthermore “with effective treatment, the lifetime costs can be reduced by 65% (Jarbrink & Knapp 2001).” While many policy makers talk about cutting services to “entitlements”, we would argue that proper investment in appropriate services, programs, and trainings will save the state millions of dollars in aggregated costs. This report will outline specific areas that the executive and legislative branches can immediately help the ASD community.

Iowa will continue to face deficits related to adult services that will only be exacerbated as more children age out of school programs. If stakeholders do not work proactively to take proper action, families and individuals will continue to suffer from a lack of quality placement or support options. Educationally it is important that the Department of Education understand the population of people who are receiving services for ASD. The lack of quality data could continue to hamper appropriate and meaningful educational services for students with ASD. The Iowa Autism Council considers parental training an essential component of any successful intervention program for children with ASD. Parent and family training is a worthwhile investment that has the potential to save financial hardships for not only the families, but the state as well. Lastly, this council recognizes the need for a website to help

navigate the systems of care for families, providers, educators, and others affected by ASD in Iowa. The council is currently working towards a website launch date during the first half of 2011.

We look forward to meaningful action to improve the lives of Iowa's ASD community in the upcoming year. While these are focused priorities for the upcoming year, it is important to note that we are still working with stakeholders on the recommendations from the previous year. Merely reading these priorities will not accomplish the change that is needed to move Iowa forward. The change that is needed will come about by taking action and working with stakeholders.

Thank you,



Joshua Cobbs  
Chairperson Iowa Autism Council

## **LEGISLATIVE PRIORITIES**

- ❖ Require Department of Human Services (DHS) to amend the Intellectual Disabilities waiver to add Autism Spectrum Disorders (ASD) as an eligible group and determine eligibility through an individual clinical assessment that is based upon need and functional impairment criteria.
- ❖ Require DHS to amend the Intellectual Disabilities and Ill and Handicap Waivers to allow behavioral treatments such as Applied Behavior Analysis be covered treatments.
- ❖ Replace the dollar cap on county property tax levies with a levy rate cap and allow counties flexibility in determining which base year to use as the capitation rate. We believe that if this legislation was introduced as a “stand alone” bill it would have bi-partisan support and support from counties.
- ❖ Increase choice for Iowans with autism to live in their community through the expansion of Home and Community Based Services (HCBS) certified homes and Intermediate Care Facilities-Mental Retardation (ICF-MR) licensed homes of 4 persons or less.
- ❖ Amend the Hawkeye Healthcare plan to ensure that behavioral treatments such as Applied Behavior Analysis are covered treatments.
- ❖ Expand the coverage that was passed for state employees last year for ASD treatments to all insurance plans regulated by state insurance rules.
- ❖ Require 100 percent of the area education agencies (AEAs) to offer sibling training for siblings of people with ASD by Fall 2011.

## **AGENCY RECOMMENDATIONS**

### **1. Ensure Parent Training for all families living with a child with autism spectrum disorders (ASD).**

**STATEMENT:** Individuals living with ASD have a right to information and training. The Iowa Autism Council considers parental training an essential component of any successful intervention program for children with ASD. The impact on families of having a child with autism is well known, and includes significant parental stress, anxiety, depression and emotional exhaustion. Family stress also impacts the child's siblings, as well as grandparents and other relatives, who often give assistance with caretaking, moral support, finances and advocacy. Most importantly, any investment into parent training will ultimately decrease short and long term state and federal resources for the child with ASD.

Based on Iowa Autism Council research there are limited training resources available in Iowa that address family needs, however families are not aware of them, they are lacking coordination as a system, and parents aren't able to determine which of the resources provide quality (evidence-based) information. Finally, some of the educational components are blended with other disability groups, and therefore don't provide a deep enough scope to address the needs of families living with a child with autism.

**STRATEGY:** Create access to quality parent training about autism based on the child's needs, including in-home and/or school based training. Training content should include knowledge of the disorder and its implications for education/behavior, individualized communication strategies, and positive behavioral approaches. This training will improve parents' ability to support their family and the child, as well as to improve the parents' own coping strategies. Parents need access to training in navigating the social and educational system. This includes parent participation in the treatment choices designed for their child, participation in the IFSP/IEP process, and learning advocacy strategies.

### **Action(s) to be taken:**

#### **AEA:**

- It is recommended that the AEA Special Education Directors study the reorganization of the Autism Resource Teams in order to develop and implement quality parent training by spring of 2011.
- The ratio for children served with ASD by an AEA Autism Resource Team member should be 10 children to one member.
- Require 100 percent of the AEA's to offer sibling training by Fall 2011.

**Department of Human Services:**

- DHS should include expanded parent training supports in their Remedial service option and increase necessary staff development training by spring 2011. This will provide quality training to family members in the home setting as they are supporting interventions with their own child.

**Health Care Facilities** that care for individuals with ASD conditions:

- Existing health care facilities (oral health, physical health and mental health care) should provide ASD awareness and advocacy training to parents and siblings. This training should address initial understanding of this disorder and link the family to specific support services in their local community to create a seamless system of family centered care. The following are quality parent resources:
  - Sound Advice on Autism at <http://www.aap.org/audio/autism>
  - The Autism Society of America at [www.autism-society.org](http://www.autism-society.org)
  - Family voices at [www.familyvoices.org](http://www.familyvoices.org)
  - Iowa Resources at <http://www.autismspeaks.org>
  - *Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians* (American Academy of Pediatrics )

**Family to Family Iowa**

It is recommended that the Navigator positions associated with the Family to Family Iowa Grant serve as links in the coordinated system of resource sharing, as families are not aware of training resources and have difficulty accessing existing quality resources. Future results of this grant effort will determine the need for legislative action to support sustainability.

**Establish greater access to available resources for families that address sibling adjustment and family functioning via sibling training.**

- Increase the number of opportunities for sibling training in community provider service agencies by Fall 2012.
- Provide a comprehensive autism website for experienced community providers to share their curriculum and models that are currently available.

**2. Ensure the basic needs of adult Iowans with ASD.**

**STATEMENT:** Iowa must ensure that individuals with ASD currently living in community based settings and those moving to integrated settings are provided with appropriate supports, well trained and compensated support professionals, and a focus on achieving meaningful real lives versus an emphasis that quality supports are measured by paperwork compliance.

## Action(s) to be taken:

- The state of Iowa should review the process of determining quality services for providers of HCBS services. This should include actual face to face person centered interviews with people served and less focus on documentation that is often duplicated among providers and case management organizations.
- When rule changes to HCBS waivers are proposed which could negatively impact members and their families, a minimum of 30 days notice should be given to allow for public comment. All members receiving services should be made aware of the proposed changes in a format that is understandable and clearly outlines the reason for the proposal, the changes, and timeframe for implementation. DHS and Iowa Medicaid staff must work in a cooperative fashion with families to determine appropriate options that will help keep children and adults with ASD in their home communities.
- “A Life in the Community for Everyone” is the Iowa Department of Services Olmstead Plan with the MH/DS Division. This plan has several bold initiatives that will positively impact people with ASD. The Iowa legislature must adequately fund the priorities within this plan to maintain compliance with the Olmstead decision.
- Iowa should review compensation levels and training requirements for Direct Support Professionals who work in community based settings with children and adults with ASD and other developmental disabilities. A statewide recruitment and retention plan that brings together existing initiatives of the Department of Public Health and DHS should be enacted.
- Expand the Iowa Program Assistance Response Team (I-PART) to more regional sites in Iowa which will build provider and families’ capacity to better serve individuals with ASD who display significant emotional challenges.

### **3. Continued improvement for financing of care options for individuals with ASD**

**STATEMENT:** Iowans deserve a stable financial support system for care.

## Action(s) to be taken:

- In 2009, the state legislators approved the creation of a new Medicaid funded alternative to support children with autism using intensive Applied Behavior Analysis. The Department should complete the steps to implement this program. Further delaying full implementation of this program is a detriment to people with ASD and could result in out of state placement or increased institutional placement for people with ASD.

## **RECOMMENDATIONS IN DEVELOPMENT**

### **1. Work in partnership with stakeholders to develop an accurate mechanism to determine prevalence rate, location and service levels of students with ASD.**

**STATEMENT:** There currently is not an accurate way to collect data on school age students who have ASD; this would include location, number of students, and what services those students are receiving. Without this data it becomes increasingly difficult to not only understand the population, but the services those students receive.

**STRATEGIES:** Iowa needs a mechanism for understanding who the children with a valid Autism Spectrum Disorder diagnosis are, where those children live, and the kinds of services those children are receiving. Information is needed to understand in more detail what type of therapies, strategies, and supports are being delivered to students with ASD. In addition, the Autism Council is interested in understanding parents' perceptions of service delivery, and the training provided to education and support staff, and how progress is being measured pertaining to IEP goals.

### **Action(s) to be taken:**

- Develop and institute an educational survey establishing a mechanism for understanding the ASD school population. Participants might be asked questions as they relate to their educational experience with teachers, paraprofessionals, administrators, support staff, location, diagnosis, and other relative educational information. The council anticipates initial results the spring of 2011, next step actions will be determined from results.

### **2. Iowans with ASD deserve the opportunity to meaningful employment opportunities.**

**STATEMENT:** Successful high school and secondary education transitions to competitive employment could bestow opportunity for meaningful, paid employment that utilizes the individual's unique skills, knowledge and abilities, meets the labor market needs of the region, and result in adults with autism moving away from Medicaid funded programs.

### **Action(s) to be taken:**

- Hold an Autism Spectrum Disorder (ASD) work symposium during the first half of the year 2011. Participants will include people with ASD in the work place, law makers, business leaders, Iowa



Autism Council members, autism service providers, Department of Education, Vocational Rehabilitation, Governor's Developmental Disability Council, I-PART, and other key members.

- 3. Create a centralized website where individuals, families, providers, government officials, and others are able to understand what is available for ASD resources.**

**STATEMENT:** Currently it is difficult if not impossible to understand what resources are available for families or individuals living with ASD in Iowa.

## Action(s) to be taken:

- Develop an online website for ASD services that are available in Iowa. This will allow families, educators, professionals, and others to have a place to research available options. The council anticipates having an initial site available by first half of 2011.

## **IOWA AUTISM COUNCIL MEMBERS**

### ***Voting Members***

*Chairperson – Josh Cobbs*  
*Co-Chair – Danielle Sharpe*  
*Katie Byers*  
*Keith Gatrost*  
*Dr. Linda J. Louko*  
*Steve Muller*  
*Karn Johansen*  
*Pamela Parker*  
*Susan Smith*  
*Barbara Stineman*  
*Dr. Charles Wadle*  
*Patrick Westhoff*

### ***Ex-Officio Members***

*Marty Ikeda – Department of Education (Lead Agency)*  
*Jeanne Nesbit – Division of Mental Health and Disability Services*  
*Kenda Jochimsen (Chief of Rehab Services) - Iowa Vocational Rehabilitation*  
*Dr. Jeanne Prickett (Superintendent) – Board of Regents*  
*Becky Harker (Executive Director) – Governor’s Developmental Disabilities Council*  
*Jim Mumford (1<sup>st</sup> Deputy) – Iowa Insurance Division*  
*Dr. Debra Waldron (Co-Director/Chief) – Department of Public Health*  
*Toni Merfeld (Co-Facilitator) – Department of Education*

### ***Panel Members***

*Sonia Lewis – Department of Education*  
*Frank Forcucci (Administrative Consultant) – Department of Education*  
*Sue Baker (Facilitator) – Department of Education*

### October 2010 Draft of Findings

#### Training for Educators, Parents, Siblings, & Other Family Members

**Subcommittee: Co-leaders Linda Louko and Sue Baker, Members: Karn Johansen and Barb Stineman**

1. There are a number of training resources that address the needs of families with ASD; however, families are not aware of them, they are lacking in being coordinated as a system, and parents don't know how to access what quality training resources exist. Iowa has some autism specific training available to families. There are also trainings blended with other disability groups, but they don't provide a deep enough scope to address behavioral needs of the child living with autism. See the list below illustrating statewide examples.

**Iowa Department of Education:** [www.iowa.gov/educate](http://www.iowa.gov/educate)

a. Parent and Educator Connection (PEC) provides service between parent and AEA educator to work on child's IEP

<http://www.iowa.gov/educate/index.php?option=comcontent&view=article&id=601&Itemid=1601>

b. Parents as Presenters: yearly workshop to train parent's to tell "your story"

<http://www.iowa.gov/educate/index.php?option=comcontent&view=article&id=926&Itemid=1602>

c. Parent and Educator Connection Annual Conference providing information on early childhood and secondary transition services and supports.

d. Early ACCESS [www.earlyaccessiowa.org](http://www.earlyaccessiowa.org)

e. All 9 AEA Special Education Directors have committed resources to study and improve access to autism training. These resources include:

- Autism Program Quality Indicators
- Family Involvement and Support components

**Part D of IDEA and ESEA (NCLB) - Federal Service:**

a. Iowa's Parent Training and Information Center of Iowa (PTI) <http://www.askresource.org/pti.html>

b. ASK - Access for Special Kids - Family Resource Center <http://www.askresource.org/> (Teams with PEC to provide Annual Conference and Parents as Presenters.)

c. Iowa Parent Information and Resource Center <http://www.iowaparents.org> (Works jointly with PTI and PEC)

d. University of Iowa: Regional Autism Services Program/ Iowa Dept. of Education: <http://www.medicine.uiowa.edu/autismservices/> (Iowa Autism Services Consultant-Sue Baker; Moodle Site-Social Skills Training)

**Iowa Dept of Human Services** <http://www.dhs.state.ia.us/index.html> I-PART- Iowa Program Assistance Response Team assists families and providers in Iowa to manage serious and challenging behaviors of autism.

**Autism Society of Iowa** [www.autismia.org](http://www.autismia.org) (Parent Resource Document and Free Parent Packet: [http://www.autism-society.org/site/Clubs?club\\_id=1164&pg=docs](http://www.autism-society.org/site/Clubs?club_id=1164&pg=docs))

**NAMI of Iowa** <http://www.namiiowa.com/about.htm> (Autism is one of several disorders covered.)

**Family to Family Iowa (includes Family 2 Family and Family 360)** Federal grants focusing on a System of Care resource in Iowa for families who have children and youth with special needs (including autism). It includes (a plan for) up to 70 “navigators” skilled in training, advocating, and educating, who are mentors for families and a Family Governance Council made up of over 15 different family support organizations.

**Sibshops:** A recognized sibling training curriculum (*Sibshops: Workshops for Children with Special Needs*, Meye & Vadasy, 2008) however, there are limited community or school programs that provide regular training for siblings of children with ASD conditions.

2. It is recognized that there is significantly more parental stress, anxiety, depression and emotional exhaustion living with a child with autism than with those of other conditions (Rao and Beidel, 2010; Mori, Ujiie, Smith, and Howlin, 2009). Other published national surveys, from IAN, mimic this degree of impact on family lives; one recent study indicated that 72% of respondents reported that difficult child behaviors had a moderate or great negative impact on their lives.
3. This family stress also impacts the child's grandparents and other relatives. Grandparents also often give assistance with caretaking, moral support, finances and advocacy and perceive this stress and anxiety as well.
4. As a result of this concern for families, the field of Autism Spectrum Disorders considers parental training an essential component of successful intervention program for children with ASD.
  - Goals of Parent training have been identified in research and include: building rapport, teaching and modeling techniques, providing feedback and building independence (Ingersoll, Dvortcsak, 2008).
  - Evidence shows that parent training has been shown to be a very effective method for promoting generalization and maintenance of skills in children with autism.
  - Case studies offer validity and recognize the importance of consistency in training especially regarding Positive Behavioral Support parental training in young children.
  - Parent Training has also been shown to make improvements in decreasing severe behavioral problems when compared to medication use alone (Aman, 2009).

In summary, there is a need in Iowa for parent education models that can be easily accessed and implemented (improve behavior, generalization, maintenance, and skill acquisition). In addition, there is a need for preparation of special educators to address parent education strategies and for sibling education/support.

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

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

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Danielle Sharpe - Co-Chair Iowa Autism Council at [hki2thdrs@hotmail.com](mailto:hki2thdrs@hotmail.com)

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