

Members

Rep. Robert Heaton, Chairperson
Rep. Kathleen Heuer
Rep. Vanessa Summers
Rep. Michael White
Sen. Randall Head
Sen. Brent Waltz
Sen. Jean Breaux
Sen. Timothy Skinner
John Taylor
Dr. Robin Murphy
Mary Rosswurm
Hugh Beebe
Michael Carmin
Kylee Bassett Hope



INDIANA COMMISSION ON AUTISM

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MEETING MINUTES¹

Meeting Date: August 8, 2012
Meeting Time: 9:30 A.M.
Meeting Place: State House, 200 W. Washington St.,
House Chambers
Meeting City: Indianapolis, Indiana
Meeting Number: 1

Members Present: Rep. Robert Heaton, Chairperson; Rep. Kathleen Heuer; Rep. Vanessa Summers; Rep. Michael White; Sen. Randall Head; Sen. Brent Waltz; Sen. Jean Breaux; Mary Rosswurm; Hugh Beebe; Kylee Bassett Hope.

Members Absent: Sen. Timothy Skinner; John Taylor; Dr. Robin Murphy; Michael Carmin.

With a quorum present, Chairman Representative Robert Heaton called the first meeting of the Commission to order at 9:40 AM.

Following introductions by the Commission members, Chairman Heaton directed LSA staff to read the charge of the Commission. Chairman Heaton then recognized the following persons to testify.

Dr. Candace Joles, EdD, Associate Director, Blumberg Center for Interdisciplinary Studies in Special Education, Indiana State University.

Dr. Joles testified on the importance of autism awareness training of first responders (firefighters, EMTs, police, etc.). She referred to a handout that provided information on first responder training (See Exhibit A).

¹ These minutes, exhibits, and other materials referenced in the minutes can be viewed electronically at <http://www.in.gov/legislative>. Hard copies can be obtained in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for hard copies may be mailed to the Legislative Information Center, Legislative Services Agency, West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for hard copies.

Dr. Joles described the current training that first responders receive in autism. She pointed out the need for more awareness in particularly high stress situations where first responders have interaction with persons with autism. She said the coping skills of persons with autism in an emergency situation can lead to reactions of a particularly aggressive nature to first responders trying to help them. She continued that difficult rescue situations can be compounded by the tendency of persons with autism hiding in closets or other areas. She added that the lack of autism awareness can increase the amount of time a first responder can expend to locate and assist a person with autism in an emergency situation.

Dr. Joles stated that efforts are being made to coordinate 911 dispatchers with first responders in emergency situations that involve persons with autism to have a more proactive rather than reactive approach. She discussed the continued need for workshops for first responders.

She spoke on the need to prepare emergency shelter personnel to receive persons with autism (for example flood and fire victims). She said that Blumberg Center is collaborating with first responder agencies in the Wabash Valley on how to be more proactive on uniforms, sirens, and flashing lights that can be viewed as more highly disturbing to individuals with autism.

Ms. Kylee Bassett Hope, Commission member, asked about the frequency of first responder training.

Dr. Joles answered that they are working to increase the training cycle frequency with first responders and that she would like to see training introduced to first responder recruiting classes. She said dialog is ongoing with instructors of courses to incorporate more autism awareness training.

Dr. Cathy Pratt Ph.D., Indiana Resource Center for Autism (IRCA), Indiana University Bloomington.

Dr. Pratt's presentation centered around a handout (See Exhibit B) that included various reports and statistics concerning autism incidence. She stated that Indiana's incidence rate for autism is currently 1 in 83 persons. She said that the Indiana incidence ratio has increased steadily in her time at the IRCA and that there are currently states with higher ratios. She said that the IRCA is engaged in increasing university course support, particularly with medical students on recognizing the signs of autism.

Dr. Pratt said that the use of social networking, such as Facebook and Twitter, has increased autism awareness and has enabled her to connect with more persons affected by autism.

She talked about the Act Early program in partnership with the Centers for Disease Control with the goal to identify and increase awareness of autism at an earlier age so treatments can begin earlier. Dr. Pratt said the average age at the time of initial diagnosis is four years. She continued that often parents will notice signs at an earlier age but do not have the resources to seek an earlier diagnosis. She stated that an effort is underway with the Indiana University Medical Center and other organizations such as Easter Seals and the Logan Center in order to get the word out to medical providers. She said the goal of this cooperation is to educate more primary care physicians for earlier diagnosis of autism in their young patients.

Dr. Pratt reported some results from the mandatory needs survey. She said that contacting families through the survey has provided demographic information on the incidence of autism, including the percentage of families with multiple children with autism. She reported, with respect to education, 82% of children with autism attend public schools, 4% attend private school, 3% are in college, 3% are in a special education program, and the remainder are in

other programs such as home schooling.

Dr. Pratt reported that 51% of the survey respondents were satisfied or very satisfied with their child's education experience. She stated to the Commission that mental health issues such as anxiety, obsessive compulsive, and bipolar disorders are prevalent among persons with autism. She said that a prevalent denominator in the diagnosis of mental disorders is a result of in-school bullying. She indicated that often persons that have both autism and a mental illness are left in a gap between the two treatment communities.

Dr. Pratt reported that the employment rate of persons with autism is around 26%. She said the largest reason for the low employment rate among persons with autism is the lack of adequate social skills needed for an employment setting.

Dr. Pratt praised the General Assembly for allowing Indiana to become one of the first states to have an insurance mandate. She said that even with the insurance mandate, many families face over \$1,000 per month of out-of-pocket expense to provide treatment and services to a family member with autism. She also applauded the General Assembly for passing legislation mandating first responder training for autism and Asperger's syndrome.

Dr. Pratt argued that the waiting list for a waiver from the Division of Disability and Rehabilitative Services (DDARS) has increased in her tenure at IRCA. She concluded her testimony with a list of topics that she would wish the General Assembly to address in the next legislative session for persons with autism, including bullying, early identification and awareness of autism, bridging the gap for treatment of persons with both mental health issues and autism, and seclusion and restraint as a means of discipline in schools.

Representative Summers, Commission member, asked why doctors are hesitant to diagnose autism early.

Dr. Pratt replied that the physicians may screen a child for 5 or 10 minutes and in their professional opinion may want to refer the child for more formal testing with a specialist. She said that primary care physicians are hesitant to do this when they see neither the sources nor services to refer the child. She said this is the 'big rock' the autism awareness community is chipping at. She continued to say that a key area in the fight against autism is to increase the awareness of primary care physicians that there are resources out there. She referred to the First Steps program as an example of existing services for families that have children with autism.

Dr. Pratt continued that in order for a family to access the First Steps program, a diagnosis of autism is not needed. She concluded that before a formal diagnosis is made by a referral specialist, perhaps much later, physicians could at least inform the parents of a child that exhibits signs of autism about these services.

Representative Summers asked what can be done with older adults with autism.

Dr. Pratt answered that at least on the employment side, there are good corporation initiation models out there that Indiana should make available to help combat high unemployment among persons with autism.

Chairman Heaton expressed his appreciation to Dr. Pratt for all of her good work with the IRCA. He added that he had a conversation with a lady recently divorced with a son that has autism. He said sometimes we do not realize the strains that having a child with autism can place on families, including the problems brought on by school bullies.

Senator Head, Commission member, was recognized to speak by Chairman Heaton. The Senator suggested that the Commission should look at the policies of schools with respect to seclusion and restraint regarding students with autism. He shared some statistics he had researched on seclusion and restraint in Indiana schools. He said that the schools should be proactive and that there should be a stronger law governing school policies on seclusion and restraint. He cited a case law example where the parents of a child with autism had sued their school corporation for taping their child to a chair and placing the chair with the child on it on its back. He wondered if that incident could have been prevented if the child's parents had been notified by the school sooner.

Chairman Heaton said he would like the LSA to look into a potential bill draft that would establish stronger school policies regarding seclusion and restraint.

Shane Spotts, Director DDARS, Indiana Family & Social Services Agency.

Mr. Spotts distributed a handout (Exhibit C) and referred to it for the majority of his testimony.

He said that DDARS is attempting to re-brand and add services to the existing DDARS waiver. He said that the goal is to allow persons with autism to continue on the DDARS waiver without the need to apply for the autism waiver. He said that the hope of the FSSA is that the DDARS waiver cap will be increased to \$20,000 in the near future.

Mr. Spotts said that there are three times as many persons with a DDARS waiver as there are with an autism waiver.

Mr. Spotts said that when he became director, the waiver wait list had approximately 20,000 persons. He then stated that he thought that number may have been a bit high. He said he had DDARS send out a survey to all 20,000 persons on the wait list. He said there was an overwhelming response to the survey, and as a result, DDARS was able to trim about 7,000 persons no longer in need of services from the wait list.

Mr. Spotts said that consolidating the waivers on a needs-based criterion should reduce the wait list to under 10,000 persons. He stated the goal is to eliminate the wait list in four to five years. He said that generally the survey responders were anxious for a waiver streamlining effort.

Chairman Heaton said to Mr. Spotts that going from 20,000 to 13,000 on the waiver list in around six months time (Mr. Spotts indicated that the time between the survey results and the list reduction was about six months) seemed to be a pretty big jump in such a short period of time.

Mr. Spotts replied that such a statement works on the assumption that the list at 20,000 waiting individuals was accurate. He continued that there were thousands of persons that no longer were in need of the services. He said the reasons included the services were no longer wanted by the person, the person had moved out of Indiana, or the person currently receives services, yet was still on the wait list.

Mr. Spotts reported that the survey had a 40% return rate. He said that 60% of the replies no longer wanted the services they were waiting for. He continued that those no longer on the list could return to the wait list at the same entry date.

The Chairman asked about the current length of time on the wait list before receiving services.

Mr. Spotts said that those on the list since 1999 are currently being served. He said staying with the status quo would only make the length of wait longer. He equated the current situation to keeping their head above water. He continued that the current cost to serve everyone that is on the waiting list would be \$1 B, the funds for which are not available.

Ms. Hope asked Mr. Spotts what the due diligence criteria was for those persons that the survey could not find.

Mr. Spotts said that second or subsequent addresses were checked and new surveys were sent to those addresses. He said those persons were checked against Medicaid addresses for them as well. He stated that all persons for whom an address could not be located were put into a subgroup.

Ms. Rosswurm, Commission member, asked about the differences between the waivers and if anyone eliminated from the list could lose eligibility for services.

Mr. Spotts described the waiver differences and then said that those removed from the list could request to be put back on and could have their positions restored on the wait list at the click of a button.

Ms. Rosswurm asked how to find information on the new waiver format. She said there used to be a booklet that described the old waivers and asked if it had been updated.

Mr. Spotts said the website for DDARS contained manuals on the waivers. He said a person could literally become an expert by referring to the information on the DDARS website.

Following the testimony, Chairman Heaton asked if there was any more business to come before the Commission. Finding none, the Chairman briefly posed to the Commission the possibility of shifting the time of the next meeting from 9:30 AM to 1 PM. A few members indicated that a shift may make it easier for them to attend the September meeting.

Chairman Heaton said he would consider the time change and would let members know of his decision.

The meeting was adjourned at 10:41 AM.



Plan Your Response for an Autism Emergency Dennis Debbaudt 2012

Thoughts about personal safety and risk are found high on the list of concerns expressed by the global autism community. So, just what can we do to increase security and lower the risks? Beyond educating law enforcers, three approaches come to mind. One is to be prepared for an autism emergency. The second is to develop the ability to disclose our need for an accommodation. We can then display our resiliency to address these risks and share our autism spectrum knowledge with those that need to know now. All are proactive options that, with a little effort, can become part of our daily routines.

To help ensure safety and lower risk for a child or adult with autism, parents and care providers will need to become proactive and prepare an informational handout. A leading cause for concern are children and adults who run away or wander from parents and care providers. Tragically, children and adults with autism are often attracted to water sources such as pools, ponds, and lakes. Drowning is a leading cause of death for a child or adult who has autism. Wandering can also lead to high-risk field contacts with law enforcement or members of the general public.

Preparing for a wandering incident may seem extreme for some families. After all, their child or adult hasn't wandered or bolted. Yet, for many other families, addressing wandering the first time can be the worst time. These preparations will also become invaluable before, during and after a natural or manmade emergency situation. For example, when a parent or care provider has their own medical emergency and becomes quickly incapacitated.

Securing the home & anti-wandering technology

For many families, securing their home to prevent access to dangerous materials and also to address wandering is the first order of preparedness. These efforts may include installing locking systems for cupboards, closets, appliances and utility rooms to prevent access to the items of everyday households: medicines, cleaning materials, foods and beverages, lawn and garden products, tools, plug-in electronics, and, of course, firearms, knives, matches, lighters and other combustible materials.

Interior and exterior doors and windows are a favorite escape route for the child or adult who is prone to bolting and wandering. Everything from double key, chain and window locks, electronic alarms that alert to door or window openings, to personal tracking systems, have been used with success. However, there are no 100% fixes. What works for one may not work for another.

Everyone considering home safety should consider consulting with professional home security and burglar alarm, locksmiths, and home improvement companies who are familiar with 21st century technology that can prevent a disaster.

Whenever and wherever either high or low technology is used to secure a home against wandering, fail safes must be in place such as automatic shut off of electronic key and lock systems and additional fire and CO 2 alarms.



Keep Records

Always keep a record of your anti-wandering efforts. You may need to prove to authorities that you are not neglectful parents or care providers. There may be little or no awareness of wandering and autism as an issue among the general public, law enforcement and social service professionals. Equating autism with Alzheimer's disease and dementia as a wandering population analogy can be a quick fix for immediate understanding.

Contacting 911 Call Centers

In the U.S., some law enforcement, fire rescue, and emergency 911 call centers are willing and able to proactively place this information into their data base. Although not every system or agency is able to provide this service, it is certainly worthy of inquiring about.

If wandering is a concern, ask your local 911 Call Center to red flag this information in their 911 computer data base. When a call comes in for response to Alzheimer's, autism, or medically fragile families who participate--911 telecommunicators can alert the first responder before they arrive with key information that you provided. When we provide law enforcement with information before an incident occurs, we can expect better responses.

Autism groups can partner with Alzheimer's disease advocacy organizations to approach local 911 Emergency Call Centers. Single family approaches can also be made for families in more rural areas. Remember that you are volunteering this information and privacy may be a concern. This will be your choice to make.

There are model programs. Take Me Home, developed by the Pensacola, Florida Police Department is one example (see web site contact information at <http://autismriskmanagement.com>). Cite these examples when you make your approach. You may need to be persistent, but these are reasonable requests.

When a wandering incident occurs, and you are listed in a 911 special needs database, please be aware that the information is typically linked to your home--to help assist during an emergency at your home---and may not automatically transfer to identify a person who has wandered away from home and is now out in the community. Before searching, it will be your responsibility to call 911 and inform them that a family member is missing and needs assistance in the community. Be ready and willing to provide information about the person who is missing, either proactively or on-the-spot, to 911 telecommunicators or field officers. This can make a positive critical difference for the the field response.

Emergency planning checklist:

- Prepare and copy your Autism Emergency information handout (model below)
- Keep a copy on your refrigerator and near your phone
- If wandering has occurred, call 911 before you go off to search
- Alert the 911 telecommunicator if you are listed in the 911 Special needs directory
- If not, be prepared to share with the telecommunicator the information from your Autism emergency information handout
- Plan and practice your response in the event of a wandering incident
- Plan a mock event and your response as you would plan and practice your response for escape from a fire in your home
- Practice the 911 call with a friend
- Keep a written record of your efforts



An Autism Emergency Contact Form should be developed, copied and carried with you at all times--at home, in your car, purse or wallet. Also circulate this handout to family members, trusted neighbors, friends and co-workers. The handout will also come in handy if you are in an area other than your neighborhood and are approached by the police.

Consider Autism Icons

When traveling in vehicles, consider prominently placing disclosure tools and icons such as autism car magnets, autism alert decals, autism puzzle ribbon magnets, "I Love Someone With Autism" bumper stickers, at home on the front door and on vehicle bumpers and windows. Law enforcement and first response professionals are being trained to look for these icons and search for autism handouts based on this information. Also consider using autism awareness specialty license plates that are now becoming available in the U.S. As a precaution, always check appropriate laws regarding decal placement on vehicle windows and bumpers.

Autism Emergency Contact Form Model

- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for elopement and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Likes, dislikes--approach and de-escalation techniques
- Method of communication, if non-verbal sign language, picture boards, written word
- ID wear jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted
- Blueprint or drawing of home, with bedrooms of individual highlighted (Debbaudt, 2004-07)

ID Options

Some type of ID wear is essential for those with autism, especially if they are non-verbal or are unable or become unable to respond to questions about their identity if they are found.

- MedicAlert style bracelet or necklace
- Joggers shoe tags
- ID information laminated card: on belt loops and belt, sewn into pants, sewn into jackets
- hang from zippers
- silk screened into undergarments
- non permanent tattoos



Bracelets, anklets, necklaces, shoe or jacket tags, ID cards, clothing labels or permanent ink ID on t-shirts or undergarments are all good options. The problem with some of these is they may be removed by the person with autism who has sensory issues. An innovative option is the use of prepared, washable tattoos that bear ID information (tattooswithapurpose.com). If ID wear is used, first responders may not know what autism is. More specific language should be considered in addition to name, address and phone number, such as, non-verbal, sensitive to light, sound or touch, possible seizure activity, or may not seek help. (Debbaudt, 2002).

Alert Your Neighbors

The behaviors and characteristics of autism have the potential to attract attention from the public. Law enforcement professionals suggest that you reach out and get to know your neighbors.

- Decide what information to present to neighbors
- Plan a brief visit to your neighbors
- Introduce your child or adult or a photograph
- Give your neighbor a simple handout with your name, address, and phone number
- Ask them to call you immediately if they see your son or daughter outside the home

This approach may be a good way to avoid problems down the road and will let your neighbors:

- Know the reason for unusual behaviors
- Know that you are approachable
- Have the opportunity to call you before they call 911

Knowing your neighbors can lead to better social interactions for your loved ones with autism. (Debbaudt, 2004)

NOTE: This article recommends reaching out to and alerting neighbors about a child or adult. Parents have expressed their concerns about doing this. The fear, not unfounded, is stranger abductions or abuse. While these incidents can and do occur, physical and sexual abuse is oftentimes perpetrated by persons well known to the victim families.

Below is a link to information that parents can become familiar with in the area of victim selection and modes of operation of child abusers. Risks are dealt with best when we know about them. I interviewed Ken Lanning for my 1994 booklet, *Avoiding Unfortunate Situations*. His advice and information is essential for every parent to know.

[Child Molesters: A Behavioral Analysis](#)

Authored by Kenneth V. Lanning and produced in cooperation with the FBI, the fourth edition of this book is an investigative tool for law enforcement officers and child-protection professionals handling cases of children who are sexually exploited. It provides investigative strategies, the characteristics of a pedophile, and the difficulties often encountered in cases of sexual exploitation. It introduces a typology that places sex offenders on a continuum, from preferential to situational. 160 pp.

Whether we develop an Autism Emergency Plan ourselves or use a template, what's important is our ability, willingness and preparation to use it during an emergency.



For Persons Who Have Autism? Make safety a part of the daily routine!

Learning to recognize that men and women in uniform are people you can go to and stay with during an emergency is a lesson we all learn. Persons who have autism can learn these lessons when we teach these safety skills at home, reinforce them at school and practice them in the community. They are learned best when they are delivered early and often, and are suited to a child or adult's age and ability levels.

Plan cross educational opportunities for students with autism and law enforcement professionals. Provide them in a safe, non-threatening environment. These opportunities can result in improved field interactions and develop skills that will last throughout careers and lifetimes for both populations. Students with autism will learn that law enforcers in uniform are safe "go to" people in times of emergency. This can help demystify police in uniform, and teach that inside the uniform are good people who are also neighbors and friends. Law enforcers who have had a basic training about autism can learn for themselves, for example, what communications in the field with persons who have autism will look and sound like and when to use the specialized autism-related tactics they learned during training. Most importantly, police officers will get the opportunity to meet the children and adults who have autism that live in their community. Best of all, the initial contact will be in a safe, relaxed, controlled environment, not during the oftentimes emotionally charged atmosphere of a sudden field contact.

Building skills for children and less independent adults

To establish these life skills education for children or less independent adults who have autism, form partnerships with teachers and law enforcement professionals to help develop a simple curriculum that helps expand skills that will enhance their safety in the community and build personal resilience to risk. Formally or informally, invite a variety of law enforcers to sit among, not stand in front of, the students. The session should be designed to last about ten minutes, be delivered as frequently as possible, and by as many different officers as possible. Rotation of officers reinforces the message to students that police officers can and will look and sound differently. Rotation also makes the skill easier to generalize for the student and will allow more officers to participate without generating extraordinary time constraints for one particular officer. Officers can be asked to talk in their own words about the life skill that is being taught at the time.

For example:

1. Recognize and respond as best they can to law enforcers, their uniforms, badges and vehicles
2. Stay with--not run from--safe, "go to" police or other uniformed first responders
3. Keep an appropriate distance when interacting with a law enforcer--or anyone else
4. To avoid making sudden movements, i.e. hands into pockets
5. Carry and safely produce an ID card
6. Disclose their autism, carry and/or produce an autism information card
7. Recognize inappropriate touching or sexual come-ons directed at them
8. Effectively report bullying or other incidents
9. Tell someone they need help, or use the phone to request it (Debbaudt and Coles, 2004 b)



Further, officers can participate in mock interviews, for example, by asking the student what their name is and if they have an ID card. With permission from all involved, consider videotaping the visits then using the videotape as a learning tool whenever possible. These life skills lessons will be learned best when they become part of our daily routine. Augment the skills by practicing them at school and at home. Ultimately, plan field tests in the community to gauge progress.

Building skills for the more independent adolescent or adult who has autism or Asperger Syndrome

Persons with autism who are able to navigate the community without assistance should strongly consider developing a personal handout for the police and develop the skills and resiliency to risk necessary to appropriately disclose their need for an accommodation. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome.

What can and should the independent person living on the autism spectrum expect during sudden or even expected interactions with law enforcement, customs and immigration, first responders such as fire rescue, paramedics, hospital emergency room professionals or other security professionals?

With few exceptions, law enforcers and other first responders will have had little or no training about how to recognize, communicate and respond well when they interact during field contacts with a person on the spectrum. There may be little understanding of the significance of the words Asperger Syndrome, or autism when they hear them. You can expect a higher level scrutiny from law enforcement and security personnel when traveling in the 21st century community.

Expect public or private sector scrutiny at:

- Security checkpoints such as airports, government buildings, schools, any secured facility
- Drive-up or walk-up guard shacks
- Building entrances
- Campus, shopping malls and districts

In these days of heightened security? Anywhere!

So, what are the best options for the independent spectrum person during a sudden interaction with a law enforcer during an emergency or non emergency situation? Should you disclose your autism or AS? When? To whom?

Disclosure tools and options

What's the best tool to use when you make the decision to disclose your autism or Asperger syndrome to a police officer? A handout card.



- 1) Develop a handout card that can be easily copied and laminated
- 2) The handout is replaceable. You can give it away to the officer on the scene
- 3) Carry several at all times
- 4) The handout card can be generic or specific to you
- 5) Work with an AS support organization to develop a generic handout
- 6) Work with persons whose opinions you trust and value to develop a person specific handout

What are the best ways to tell the officer that you have a handout? One is to verbally let the officer know you have AS and have an information card for them to read. If nonverbal, or if sudden interactions render you nonverbal or mute, consider using a medical alert bracelet for an officer to read that alerts them to your condition of AS and the fact that you have an information card.

Avoid making sudden movements to reach for the handout card. Obtain permission or signal your intentions before reaching into coat or pants pockets, briefcases or bags, or in to glove compartments of vehicles

Disclosure to a police officer

The decision to disclose will always be yours to make. If you have learned through experience that disclosure would be helpful, you may decide to disclose to a police officer. Law enforcers report that they make their best decisions when they have their best information. A good, strong AS disclosure that includes the use of an information card, contact information for an objective AS professional, and proof of diagnosis should be considered (Debbaudt, 2006 b).

Plan and practice disclosure techniques

Plan your response and practice with others for a sudden encounter. They will happen to all of us. Your preparation is your best chance to have a successful interaction with law enforcement.

1. Discuss these risks with people that you trust
2. Develop a hard person specific disclosure handout
3. Develop a personal plan of how you will use the handout
4. Practice through role playing with people you know and trust
5. Develop disclosure handouts and role play when, where and how you would use them.
6. Adapt and amend disclosure handouts. It's only paper. They're not written in stone.

Further suggestions for you to consider during sudden interactions with police:

- (1) Do not attempt to flee
- (2) Do not make sudden movements
- (3) Try to remain calm
- (4) Verbally let officer know you have autism. If nonverbal, use alternative communication tools, such as a simple sign language card, that indicates the need to write
- (5) Obtain permission or signal intentions before reaching into a coat or pants pocket, or reaching into a car glove box



- (6) If unable to answer questions, consider use of a generic or person-specific autism information card
- (7) If you lose the ability to speak when under stress, consider wearing an alert bracelet or necklace that is easy to see--one that lets the reader know you have an information card
- (8) Ask officer to contact an advocate, if necessary and possible
- (9) If you are a victim or are reporting a crime, you may want the police to contact a family member, advocate or friend who can help you through the interview process
- (10) Carry the phone number of an advocacy organization or personal advocate, relative or friend (Debbaudt, 2006 b)

Avoiding victimization

Everyone should take precautions to avoid becoming victims of criminal activity. Unfortunately, persons with autism may need to take extra precautions. In order to avoid detection, arrest, and prosecution, criminally bent individuals become skilled at picking out easy victims. Robbers and con artists will notice unusual behavior when they select their next victim. An unarmed robber or con artist will operate in public places. Anywhere there's regular pedestrian traffic or large public gatherings will afford a criminal the chance to identify or mark victims. If you are threatened or asked to give up money or valuables, do not resist. Give them what they want. These things can be replaced. Once in a safe area, call the police.

- To avoid victimization from street crimes or abusers: Avoid areas that are unfamiliar to you
- Consider carrying a cell phone
- Travel in groups if possible or walk with the crowd
- Do not dawdle or appear rushed in a crowd
- Park in a secure area
- Keep car doors locked
- Take a look around the parking lot before unlocking doors and exiting vehicle
- Arrive with the crowd to work, school, events
- Avoid gawking
- Do not maintain eye contact
- Let someone know of your travel plans
- Do not carry large amounts of cash
- Dress to suit the area
- Stay in well lit areas
- Do not wander or explore off well traveled pedestrian walkways or vehicular avenues

Contact your local autism advocacy organization and suggest that they help you to become involved in developing a partnership with police for ongoing law enforcement training sessions.

Ask your support group to assist you in the development a generic handout for law enforcement Also ask for help to distribute the handout to law enforcement agencies, and develop an approved training program for law enforcers.



Encourage your advocacy organizations and persons of trust to create opportunities where you and other persons with autism or Asperger Syndrome can interact with law enforcers in a safe, structured, non threatening and low anxiety environment. You can then learn from each other how to best interact. These educational opportunities will need to be discussed, planned and carried out. Advocacy groups should be encouraged to embrace these issues and help you form partnerships with law enforcers. Mutual education and information sharing will always be the keys to successful resolution of autism related contacts. (Debbaudt, 2003)

Conclusion

We practice our risk management skills every time we lock a door or put on a car seat belt. Heck, we don't quit wearing seat belts because we don't get into an everyday auto accident. Taking these precautions becomes part of our daily routine. While developing the resiliency to address the risks of autism and make safety part of our daily routines may not stop an emergency from happening, it becomes our best defense when one does occur. Be Proactive!

(Author, Dennis Debbaudt, is the parent of a young man who has autism, an author, law enforcement trainer and producer of autism-related videos and curriculum for law enforcement agencies. His materials are in use by law enforcement agencies in the U.S., Canada and United Kingdom.

Dennis can be reached via his web site: <http://autismriskmanagement.com> email at ddpi@flash.net or call 772-398-9756.

References:

Debbaudt, D. (2002) *Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders*, London-Philadelphia, Jessica Kingsley Publishers

Debbaudt, D. (2003) *Safety Issues for Adolescents with Asperger Syndrome*. In Liane Holliday Willey (ed) *Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between*. London-Philadelphia: Jessica Kingsley Publishers

Debbaudt, D. (2004 a) *Are You Prepared for an Autism Emergency?* Autism Risk & Safety Newsletter. Port St. Lucie, Florida

Debbaudt, D. and Coles, W. (2004 b) *The Role of the Family-School Liaison Counselor: Safety & Risk Support for Students with ASD*. Autism Spectrum Quarterly

Debbaudt, D. (2006 a) *Autism Spectrum Risk and Safety*. ASA The Autism Advocate newsletter. Bethesda, Maryland. January-February 2006 edition

Debbaudt, D. (2006 b) *'Disclosing to the Authorities'* In Dinah Murray (ed) *Coming Out Asperger: Diagnosis, Disclosure and Self-Confidence* London-Philadelphia: Jessica Kingsley Publishers

Debbaudt, D. (2007) *Plan Your Response to an Autism Emergency*. Autism Risk & Safety Newsletter. Port St. Lucie, Florida



Autism Emergency Contact Form

PHOTO HERE

Name of Child/Adult with Autism Nickname (if any)

Date of Birth Height Weight Eye Color Hair Color

Medical Conditions Scars or Identifying Marks

Address City, State, Zip Home Phone Other Phone

Method of Communication, if non-verbal: sign language, picture boards, written word, etc.

Identification Worn: (ex. Jewelry/Medic Alert®, clothing tags, ID card, tracking monitor, etc.)

Current Prescriptions (include dosage):

Sensory/Medical/Dietary issues and requirements, if any:

Inclination for wandering behaviors or characteristics that may attract attention:

Favorite attractions or locations where person may be found, if missing:

Likes/Dislikes (Include approach and de-escalation techniques:

Emergency Contact Names/Phone

Autism & Emergency Preparedness: Tips and Information for Emergency Shelter Staff and Trainers by Dennis Debbaudt © 2006

Emergency preparedness in the 21st century is very diverse service. You will meet people and families from all walks of life. People with autism are part of that diversity.

Autism is America's fastest growing developmental disability. Children and adults with autism are now living, going to school, working, and enjoying recreational opportunities everywhere in our communities. During and after an emergency, natural or manmade disaster, you may meet children and adults with autism and their families. The information below will provide tips and options on how to safely and effectively interact with individuals with autism, their family members and care providers.

Definition:

Autism is a neurologically-based developmental disability that seriously affects a person's ability to communicate, socialize, and make judgments. Autism also affects the person's sensory responses to even normal levels of lights, sounds, touches, odors, and tastes. It is typically observed by age three, and is more common in males than females. It is not caused by the way parents raise their children. Despite ongoing research, there is no known cause or cure, although people with autism can make remarkable gains. Autism is referred to as a spectrum disorder. It affects each person differently and ranges from mild to severe. Other terms for autism may include: Asperger Syndrome, High Functioning Autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Parents and professionals have learned through experience and education how to recognize the common traits of autism. Autism may or may not be physically obvious--there may be no particular physical marker. No one expects an emergency responder to be able to diagnose autism, but there are some diagnostic behaviors and characteristics you may observe.

A person who has autism may:

- Be non-verbal or have limited speech;
- Avoid eye contact;
- Prefer to be alone;
- Lack fear of real danger;
- Demonstrate apparent insensitivity or high tolerance for pain;
- Have difficulty in expressing needs; does not use gestures;

- Unusual responses to lights, sounds, or other sensory input;
- Seek sensory stimulation, including heavy pressure;
- Have difficulty interacting with others;
- Exhibit avoidance of touch;
- Demonstrate sustained unusual repetitive actions;
- Display inappropriate laughing or giggling;
- Have inappropriate attachment to objects;
- Spin or twirl objects and exhibit finger, arm, or wrist flicking;
- If verbal, may have trouble with correct speech volume (i.e., loud to whisper, and/or monotone, computer-like vocal intonation);
- Appear as if deaf, cover their ears and look away;
- Display clumsiness, toe-walk or have difficulty running;
- Rock back and forth;
- Talk to themselves or no one in particular;
- Echo words and phrases; and
- Display fascination with water, lights, reflections and shiny objects.

People with autism are as different from each other as we all are. They may inherently present autism spectrum-based behaviors and characteristics in different combinations and degrees. Each person will have a different level of independence as well. Some persons with autism will have a caregiver with them at all times. Others will live semi or fully independent lives. You will hear terms such as low functioning autism, high functioning autism, and Asperger syndrome to describe the condition. In most cases, the person will have difficulties following your verbal commands, reading your body language, and will have deficits in social understanding. As with Alzheimer's patients, a person who has autism may attempt to bolt and wander from care provider or shelter.

They may be dangerously attracted to water sources, roadways, or disaster debris and emergency vehicles. They may also attempt to enter occupied dwellings.

A good training program can be designed to allow responders to better serve the public, and make the best use of valuable time and resources. (Contact author below to inquire about training and training tools.) Training designed to inform responders about the risks associated with autism and offer suggestions and options about how to address those risks is highly recommended.

Included in those risks are:

- Behaviors that draw attention
- A misinterpretation of those behaviors by others
- Person may lack fear of real dangers

- Person may not recognize authority figures or know what is expected of them if they do
- Inherent condition may present as misleading indicators of guilt such as a lack of eye contact, an apparent aloof and indifferent manner, will change topic of conversation
- Responders not being aware of associated medical conditions such as seizure disorder, asthma, or low muscle tone
- Sensory sensitivity issues that may produce fight or flight reaction
- Basic verbal and nonverbal communication difficulties
- Issues such as hypotonia-low muscle tone, high tolerance for pain and mechanical/positional asphyxia will require alternate restraint options and techniques

Communication

The person you are interacting with:

- May be non verbal or have limited verbal skills
- May not respond to your commands or questions
- May repeat or mimic your words & phrases; your body language or emotional state
- May have difficulty expressing their needs

Behavior

- May display tantrums or extreme distress for no apparent reason
- May ignore your presence
- May be extremely sensitive to lights, words, aromas or touch
- May display a lack of eye contact
- May bolt away from emergency personnel
- May have no fear of real danger
- May may not feel pain or discomfort
- May exhibit self-stimulating behavior; hand flapping. body rocking or unusual attachment to objects. If these behaviors are *not* presenting as a danger to themselves or others it is in your best interest not to interfere with it.

Attempts to stop the behaviors may increase anxiety and cause the individual to act out aggressively.

Tips for Interactions with Persons with Autism

- Display calming body language; give person extra personal space
- Use simple language
- Speak slowly; repeat and rephrase questions
- Allow extra time for response
- Give praise and encouragement
- Consider use of pictures, written phrases and commands, and sign language
- Use low gestures for attention; avoid rapid pointing or waving
- Examine for presence of medical alert jewelry or tags, and ask for an autism handout card
- Model calming body language (such as slow breathing and keeping hands low)
- Model the behavior you want the person to display.
- Exercise caution if restraint is indicated. The person may have seizure disorder and low muscle tone.

Avoid positional asphyxia. Keep airway clear. Turn person on side often.
Given time and space person may deescalate their behavior.

Autism Emergency Contact Questions/Triage Model

- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for wandering and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Likes and dislikes, for example, food, toys, topics of conversation, music, animals
- Approach and de-escalation techniques
- Method of communication, if non-verbal - sign language, picture boards, written word
- ID wear - jewelry, tags on clothes, printed handout card

Autism and Access to Shelters

- Minimize waiting time
- Talk with parent or caregiver to determine person's unique needs

- Allow patient to tour facility, as appropriate in order to become familiar with new surroundings
- Praise or reward for cooperative behavior
- If verbal, patient may produce false complaints or misleading statements
- Consider that a child or adult with autism may need more than one personal care provider
- Offer family the most sensory free environment possible
- Allow family to bring in items that they know will help the individual be calm

Special considerations may need to be made in order for the individual to reset the sensory bombardment and drastic changes an emergency situation can create.

Shelters should make sure that space for sensory quiet time is available for person with an autism spectrum disorder. This may be accomplished by several means. Access to less used or even staff-only, authorized areas may need to be considered. Two versions of Special Needs shelters may need to be considered when individual needs are at odds with each other. For example, when a person with sensitivity to sound is in proximity with a person who needs life-saving technology that emits sound. Creative use of space will be difficult under emergency situations but making every effort to accommodate individuals with autism will add to the effectiveness of the shelter as well as the shelter staff's ability to provide services to other refugees.

Remember: Each individual with autism is unique and may act or react differently during an emergency!

The parent or caregiver is your **best resource** of information on how to effectively interact with the person who has autism. Ask how to specifically address the following needs: communication, behavior, sensory issues, anxiety responses, and rewards.

References:

Debbaudt, D. and Rothman, D. (2001) *Contact With Individuals With Autism: Effective Resolutions*. FBI Law Enforcement Bulletin, 7, 4, 20-24.

Debbaudt, D. (2002) *Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders*. London: Jessica Kingsley Publishers.

Debbaudt D., *Are You Prepared for an Autism Emergency?* 2004, Autism Risk & Safety Newsletter. Port St. Lucie, FL

Autism

Risk & Safety
Management

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www.autismriskmanagement.com

Disaster Preparedness

Debbaudt D. and Legacy. D *Autism & Law Enforcement Video*. Appendix. 2004,

Debbaudt Legacy Productions, LLC. Port St. Lucie, FL

Acknowledgments:

Dr. Mark Yeager, Ph. D. Together Enhancing Autism Awareness in Mississippi
www.teeam.org

Vickie Nettles, President of the Acadian Society for Autistic Citizens,
Lafayette, Louisiana www.lastateautism.org/acadian/index.htm

Susan Rzucidlo, member of board of directors of the Greater Philadelphia
chapter of the Autism Society of America and creator of the non-profit Silent
No More--autism emergency communication boards www.dol.net/~srz

For more information visit:

Autism Society of America (search for emergency preparedness tips and Safe
and Sound campaign)
www.autism-society.org

Autism Risk & Safety
www.autismriskmanagement.com

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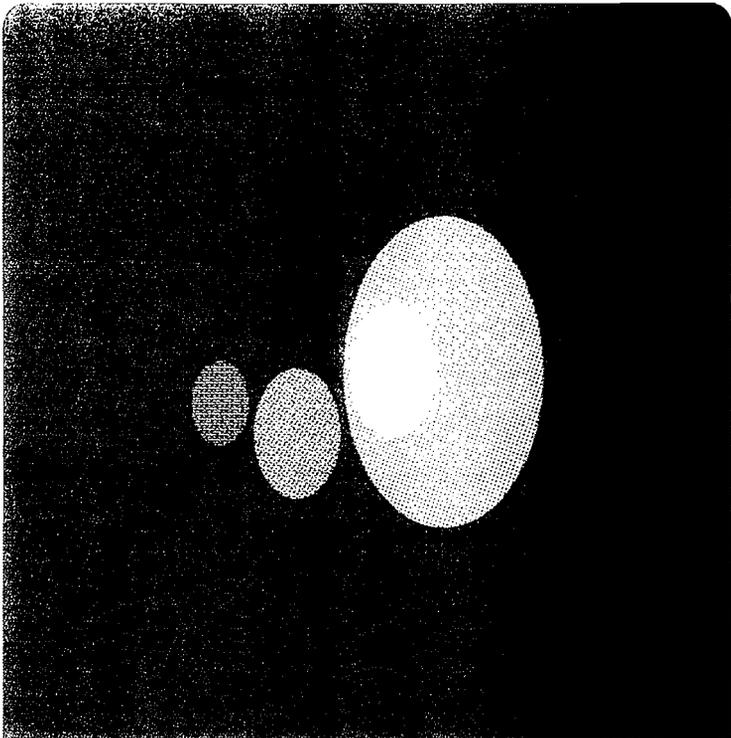
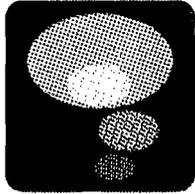


Exhibit C
Indiana Commission on Autism
Meeting #1, August 8, 2012



Family Supports Waiver (FSW)

DD Waiver =
Developmental
Disabilities Waiver

ASD Waiver = Autism
Spectrum Disorder
Waiver

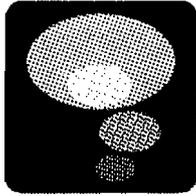
**Participant
Assistance / Care
Service =** staffing for
personal assistance and
care in the home

First Point of Entry
= No longer a need to be
on three waiting lists

- The Family Supports Waiver is the new first point of entry into the Medicaid Waiver system in Indiana.
- The Family Supports Waiver provides waiver services to 5 times more people than either the DD or the ASD waiver can serve.
- The amount of funding for individuals receiving the FSW will be increased from \$13,500 to \$16,250 each year.
- The FSW now offers Participant Assistance and Care Service (which it hadn't in the past)



**Division of Disability and
Rehabilitative Services**



Autism and Developmental Disability Waivers

Did you know...

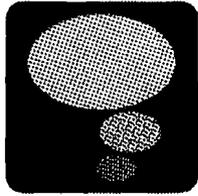
The Autism Waiver and the DD Waiver provide exactly the same benefits

In fact, the DD Waiver provided more services until recent modifications to the Autism waiver were implemented.

- Many people are on both the Autism and the DD Waivers and Waiting Lists.
- 1,257 individuals on the DD waiver have a diagnosis on the autism spectrum
- 1,337 individuals on the Support Services waiver have a diagnosis on the autism spectrum
- 5,938 individuals on the DD waiver waiting list have a diagnosis on the autism spectrum



**Division of Disability and
Rehabilitative Services**



ATTENTION...

You will NOT lose your "spot" on the waiting list.

Your spot will be determined by earliest date of application.

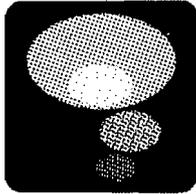
So...if you applied for the DD waiver on January 1, 2001 and applied for the Autism waiver on March 3, 2001...your spot will be based on the January 1, 2001 (earlier than March 3, 2001).

Community Integration and Habilitation Waiver

- In order to effectively reduce the number of individuals on all waiver waiting lists, DDRS feels it is important to make some serious changes.
- DDRS will replace the Autism and DD waivers with the new Community Integration and Habilitation Waiver.
- This will NOT have a negative impact for anyone with an autism spectrum disorder
- This WILL have a positive impact, as the administrative focus will be on issues affecting the entire community affected by Intellectual and Developmental Disabilities.



Division of Disability and Rehabilitative Services



ATTENTION...

We recognize that emergencies are different for everyone. There are many resources available to help guide you through them including:

Your local BDDS office
ASI
IRCA
Arc of Indiana
Family Voices
About Special Kids

Emergency Situations

- Loss of primary caregiver
- Caregivers over the age of 80
- Evidence of abuse or neglect in current institutional or home placement
- Extraordinary health & safety risk



**Division of Disability and
Rehabilitative Services**



Increasing Incidence of Autism Spectrum Disorders Continues in Indiana

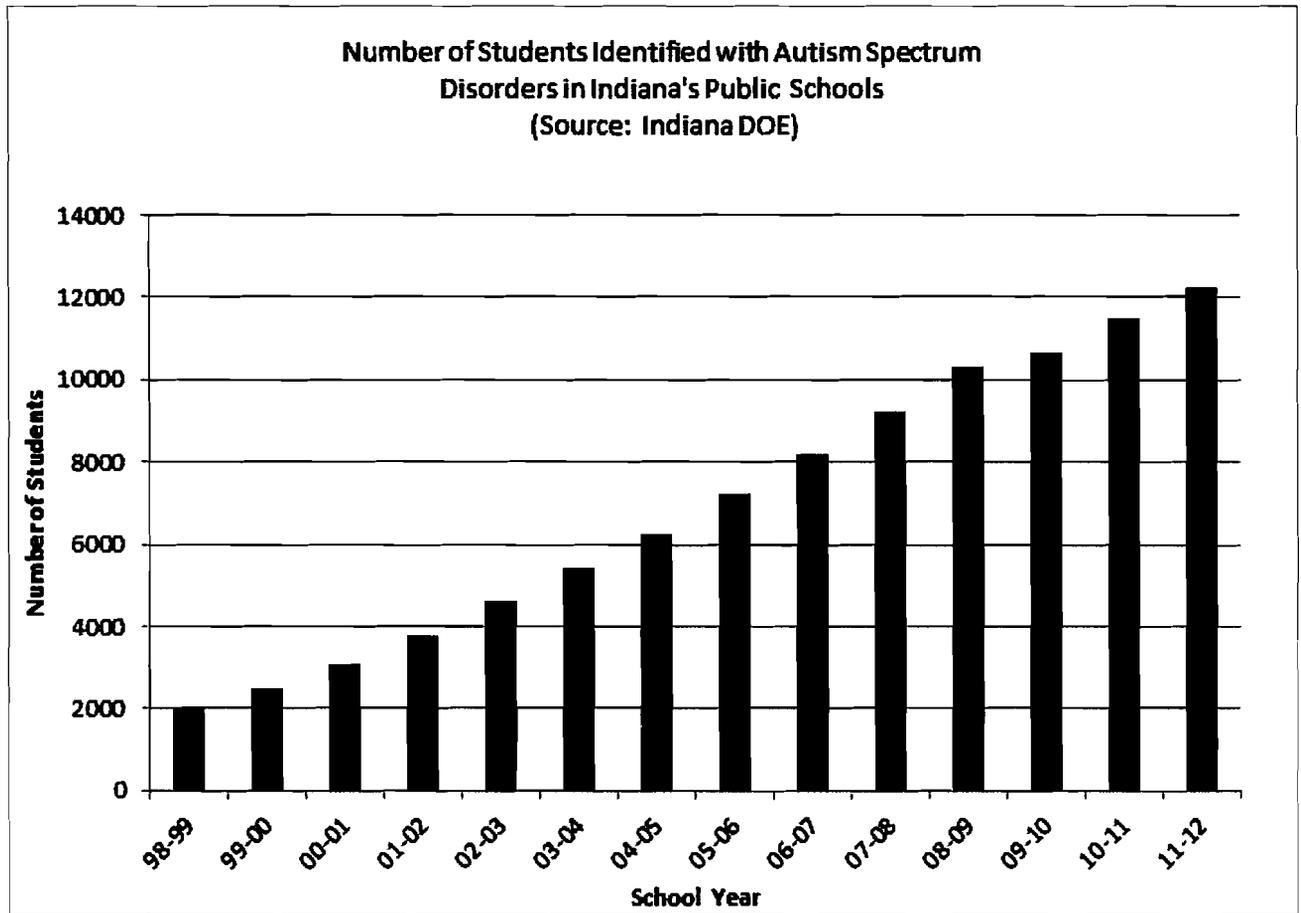
Contributed by Dr. Cathy Pratt, BCBA-D
Director, Indiana Resource Center for Autism

In February 2007, the Centers for Disease Control issued a report based on a sample of 8 year olds, and concluded that the prevalence of autism had risen to 1 in 150 in American children and almost 1 in 94 among boys. By 2009, based on a similar sample, that incidence had increased to 1 in 110. And in 2012, using a similar sample, it was announced that the incidence had climbed to 1 in 88. Based on these latest numbers, 1 in 54 boys and 1 in 252 girls are being diagnosed with an autism spectrum disorder.

If the projected incidence rates are accurate, what does this mean for Indiana? Based on the estimated census data from 2011, Indiana is home to 6,516,922 citizens. At an estimated rate of 1 in 110, there are potentially 59,245 individuals with a diagnosis on the autism spectrum. Remember these numbers are projected and only estimate the real occurrence of autism spectrum disorders in Indiana. No database exists in Indiana of the actual numbers of people on the autism spectrum.

Another example of the increase of those diagnosed with ASD is the child count data collected by the Indiana Department of Education, Department of Special Education. These data are collected from school districts across Indiana. According to the December 1 child count data, the number of students identified in 2009 was 10,643. During that year, the incidence rate was 1 in 101. By December 2010, that number had increased to 11,514 and as of December 2011 that count is 12,226. The number of students enrolled in Indiana's public schools during the 2011-2012 school year is approximately 1,041,196. Using that data and the incidence data from December 2011, approximately 12 in 1,000 students in Indiana have a diagnosis of an autism spectrum disorder. This year's identification rate is 1 in 83. The child count data does not include children who are not on special education service plans, and are homeschooled or educated in non-public schools. All who have either an IEP or special education service plan are counted.

While there is a general belief and awareness that autism spectrum disorders are on the rise, it is unclear why. Some believe that more children are being identified because the medical community and other professionals have a better understanding of autism spectrum disorders, and because the definition of autism has been expanded to encompass more individuals. Others believe that the increase is real and are advocating for research to investigate the potential causes of autism. Whether we believe the growth is because of increases in ASD or the result of changes in diagnosis, or both, the reality is that more Indiana citizens are being served under the eligibility category of Autism Spectrum Disorders. The other reality is that many of these children come with complex issues and support needs. The potential impact on our schools and other service delivery systems is tremendous. The strain on families is very real and significant.



Pratt, C. (2012). Increasing incidence of autism spectrum disorders continues in Indiana.

What to Do If You Suspect Your Son/Daughter Might Have an Autism Spectrum Disorder

Contributed by:

Dr. Cathy Pratt, BCBA: Indiana Resource Center for Autism

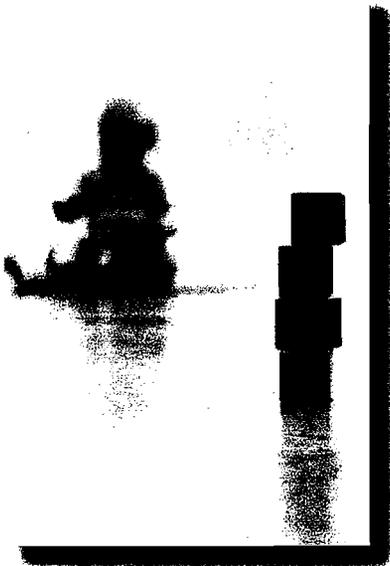
Dr. Angie Tomlin: Riley Child Development LEND Program

Dr. Noha Minshawi: Christian Sarkine Autism Treatment Center

Dana Renay: Autism Society of Indiana

During the last decade, there has been much attention on the increasing incidence of autism spectrum disorders (ASD). As a result, parents and professionals may be more likely to recognize developmental differences that could signal autism than in the past. Despite this increased awareness, knowing how to get an accurate diagnosis and what to do after a diagnosis is made, can be confusing and overwhelming. Our goal is to help clarify options, highlight characteristics, and suggest next steps.

Often times, primary care physicians such as family practice doctors and pediatricians are the first professionals that family members will ask for guidance. Doctors can ask parents or guardians specific questions about developmental milestones or behaviors, and may even screen your son or daughter for an autism spectrum diagnosis using a standardized tool. As a result of this process, your child may be given a diagnosis of autism. However, best practice guidelines require a more extensive assessment process that includes a combination of parent interview and direct observation completed by a multi-disciplinary team of professionals who are experienced in working with individuals with autism spectrum disorders.



If you wish to pursue a more thorough medical diagnosis, a list of professionals who can diagnose/assess is available on the website for the Indiana Resource Center for Autism at <http://www.iidc.indiana.edu/index.php?pageId=269>. This list includes individual providers, such as licensed psychologists, specialty physicians, and diagnostic teams including the Riley Child Development Center LEND Program. These organizations are able to conduct evaluations that may lead to medical diagnoses. When you contact these clinics, ask about waiting lists, whether you need a referral, and the types of payments/insurance they will accept.

While you are waiting for an assessment or diagnosis, **DO NOT** wait to pursue services. If your child is younger than age three, and you are concerned about behaviors or delays, contact Indiana's Early Intervention System, First Steps at <http://www.in.gov/fssa/ddrs/2633.htm> or by calling 1-800-441-7837. Your child can receive a professional assessment and if eligible, may receive early intervention services with providers such as a developmental therapist, physical therapist, speech clinician and/or occupational therapist in your home or other community settings. There is no charge to you for the evaluation although there may be some charge for services. The Autism Resource Network of Indiana (<http://www.arnionline.org>) can be used to locate First Steps therapists and providers in your area.

If your child is three years of age or older, contact your local special education planning district. They will probably need to evaluate your son/daughter using a team approach that includes a speech clinician, educators, occupational therapist, psychologist, and other professionals.

You will also have the chance to provide input. Even if your child has an autism spectrum disorder diagnosis provided by a physician or psychologist, he or she will still need to be evaluated by the school to show they meet educational eligibility to receive services. In other words, a medical diagnosis does not mean that a child is eligible for educational services.

Autism spectrum disorders are referred to as a 'spectrum' to demonstrate that while individuals share common characteristics, how these characteristics are manifested can be quite different. In other words, no two individuals are the same. The characteristics of autism spectrum disorders present themselves differently in each child. Some children with an autism spectrum disorder show hints of future problems within the first few months of life. In others, symptoms might not appear until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had. For example, a child with an ASD might:

- Not respond to their name by 12 months
- Not point at objects to show interest (example: point at an airplane flying over) by 14 months
- Not play "pretend" games (example: pretend to "feed" a doll) by 18 months
- Avoid eye contact and wants to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests (example: lining toys up repeatedly, talking in great depth about only one subject)
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look or feel

For more information about characteristics and normal developmental milestones, visit the website for the Centers for Disease Control at <http://www.cdc.gov/ncbddd/autism/facts.html>.

If your son or daughter is given an autism spectrum disorder diagnosis either by a medical provider or by the school, you will have many questions. There is much information on the web and via the media. Your challenge will be discerning what is useful and what strategies have a proven record. Each child on the autism spectrum will need a different intervention, and the decision about what is right for your child and family is a hard one. There are many services and options in Indiana. Contact one of the following organizations and they can help you navigate the service delivery system, as well as provide support, resources, and referrals within your area.



Riley
**Child
Development**
Center



AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Indiana

Indiana Resource Center for Autism at 1-812-855-6508,
<http://www.iidc.indiana.edu/irca> or via email at prattc@indiana.edu

Riley Child Development Center LEND Program at
1-317-944-8167, <http://www.child-dev.com/page.cfm?id=25>

Autism Society of Indiana at 1-800-609-8449,
<http://www.inautism.org> or via email at info@inautism.org

INDIANA UNIVERSITY



**Indiana
Resource
Center for
Autism**



**Supporting
Individuals
with Autism,
Asperger's
Syndrome,
and Pervasive
Developmental
Disorders**

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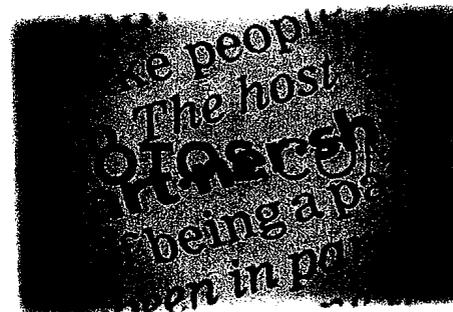
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Research



Education



Service

...in Schools and



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**INDIANA UNIVERSITY
BLOOMINGTON**

**Exhibit B
Indiana Commission on Autism
Meeting #1, August 8, 2012**



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Exhibit B
Indiana Commission on Autism
Meeting #1, August 8, 2012

Cathy Pratt, Ph.D., BCBA-D
Director



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2012 Indiana Parent/Family Needs Assessment Survey

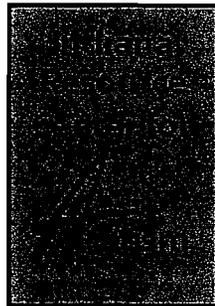
Conducted By:

Cathy Pratt, Ph.D., BCBA-D

Director

Scott Bellini, Ph.D.

Professor, School of Education



Indiana Resource Center for Autism

Indiana Institute on Disability and Community

Indiana University, Bloomington

2853 East Tenth Street ♦ Bloomington IN ♦ 47408

Indiana's University Center for Excellence on Disabilities

www.iidc.indiana.edu

Participants

- **237 Families Participated**
 - **Respondents**
 - **Parents- 94%**
 - **Grandparents- 4%**
 - **Other- 2%**
 - **65 Counties Represented**
 - **15% of families have multiple children with an autism spectrum disorder**
 - **87% of children live at home with parents**
 - **15% have more than one child on the autism spectrum (up to 5)**

- **The Children**
 - **Gender of Child**
 - **Male-79%**
 - **Female- 21%**
 - **Mean Age- 13.3**
 - **Age Range- 2 to 43**
 - **Primary Disability**

	<u>In 2009</u>	<u>In 2006</u>
▪ Autism- 51%	59 %	57%
▪ Asperger Syndrome- 21%	22%	25 %
▪ Pervasive Developmental Disorder-Not Otherwise Specified- 27%	14%	15 %
• Other- 4%	5%	4%
○ 60 % of the Children had a Co-Morbid Disability		77%
▪ ADHD- 35%		
▪ Mental Retardation- 15%		
▪ Learning Disability- 14%		
▪ Obsessive Compulsive Disorder- 16%		
▪ Anxiety Disorder- 27%		
▪ Seizure Disorder- 11%		
▪ Depression- 15%		
▪ Bi-Polar Disorder- 5%		
▪ Other- 23% (e.g., medical, neurological, genetic, and sensory disabilities)		

Sources for Autism Related Information

• **Information Sources for Families**

- **Indiana Resource Center for Autism- 75%**
- **Books- 89%**
- **Internet- 87%**
- **Newspaper/Magazines- 52%**
- **Journal Articles- 53%**
- **Television- 31%**
- **Conferences/Workshops- 63%**
- **Autism Society of America- 40%**
- **Autism Society of Indiana- 51%**
- **Local School District Autism Consultant- 26%**
- **Private Therapists- 47%**
- **School Personnel- 43%**
- **Autism Support Group- 52%**
- **Pediatrician- 44%**
- **Other- 17% (Easter Seals Crossroad, Logan Center)**

• **Primary Information Source**

	<u>In 2009</u>
▪ Internet- 31%	35 %
▪ Books- 16%	15 %
▪ Indiana Resource Center for Autism- 11%	11 %
▪ Conferences/Workshops-7%	6 %
▪ School Personnel- 3%	4 %
▪ Autism Society of America- 1%	1 %
▪ Autism Society of Indiana – 3%	
▪ Autism Support Group- 9%	5 %
▪ Newspaper/Magazines- 3%	1%
▪ Journal Articles-1%	3 %
▪ Pediatricians-5%	4 %
▪ Television- 0%	1%
▪ Other- 5%	1%

School Issues

School Placement

	<u>In 2009</u>	<u>In 2006</u>	<u>In 2003</u>
○ 82 % were in Public School (Charter)	78%	81%	74%
○ 4 % were in Private School	4%	5%	13%
○ 3 % were in College or at a University	1%	2%	4%
○ 3 % were in Separate, Special Needs School	3%	4%	3%
○ 3 % were in Home School	4%	4%	3%
○ 1 % were in a Residential Program	4%	1%	2%
● Classroom Placement			
○ 32 % were in Full-time General Education Classes	27%	26%	25%
○ 14 % were in Full-time Self-Contained Classes	19%	24%	26%
○ 1 % were in Full-time Resource Rooms	3%	2%	2%
○ 40 % were in Combined Placements	37%	48%	48%
● Discipline			
○ 8 % had been Suspended in the Last Year	8%	9%	8%
○ 7 % had been Expelled	3%	2%	4%
● Parental Satisfaction with Educational Programming			
○ 33% were Dissatisfied or Very Dissatisfied	23%	26%	26%
○ 51% % were Satisfied or Very Satisfied	62%	56%	51%
● “What additional service does your child need to be successful at school?”			
○ Social Skills Training - 64%			
○ Occupational Therapy/Sensory Integration - 57%			
○ Behavior Consultation - 49%			
○ One-On-One Paraprofessional - 24%			
○ Counseling - 23%			
○ Speech Therapy - 9%			
○ Intensive Early Intervention Behavior Therapy - 15%			

Mental Health and Legal Issues

• **Mental Health**

	<u>In 2009</u>	<u>In 2006</u>	<u>In 2003</u>
○ 5 % of the Children had Received a Short-term Crisis Management intervention at a Hospital in the Past Three Years	5%	6%	7%

• **Legal**

○ 1 % of the Children had been Arrested or Charged With a Crime in the Past Three Years	1%	1%	2%
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Employment Issues

	<u>In 2006</u>	<u>In 2003</u>
• Employment		
○ 81% of the Children (age 18 and older) were Unemployed	69%	61%
○ 5 % Work in Sheltered Workshops	11%	14%
○ 26 % Work in Community Jobs	20%	25%
○ Those who work, work an average of 17 hours per week	21%	21%
○ Median Annual Income was \$7,957	\$7687	\$6,516
• “Does your son receive services through Vocational Rehabilitation? 44%		
• “How would you rate the quality of VR services for your son/daughter? 30% Good or Very Good. 41% Neutral. 29% Poor or Very Poor.		
• “What supports or services does your child need in finding and keeping a job?”		
○ One-on-One Job Coach-74%		
○ Social Skills Training- 66%		
○ Behavior Consultation- 36%		
○ Vocational Training- 52%		
○ Occupational Therapy- 10%		
○ Counseling- 26%		
○ Speech Therapy- 7%		
○ Physical Therapy- 3%		

Insurance and Expenses

- **General Expenses and Insurance Coverage**

	<u>In 2009</u>	<u>In 2006</u>	<u>In 2003</u>
○ 18% had been Denied Insurance Coverage for their Child with ASD in the Past Three Years	19%	23%	27 %
○ 67 % of the Families Purchased Private Services in the Past Three Years	58%	57%	57%
○ “What do you estimate as the monthly cost of services that you need to successfully support your son or daughter at home?” \$1005 (Mean)			

- **Insurance Coverage for Specific Services:**

<u>Service</u>	<u>Full Coverage</u>	<u>Partial</u>	<u>No Coverage</u>
Speech Therapy	11%	52%	37%
Occupational Therapy	10%	56%	33%
Social Skills Training	8%	19%	73%
Physical Therapy	11%	44%	44%
Counseling	12%	55%	33%
Behavior Consultation	18%	32%	50%
Assessment/Evaluation	21%	29%	50%
Medical Treatment	16%	59%	25%
Medications	15%	66%	19%
In-Home Behavior Therapy	18%	29%	53%
Sensory Integration	8%	15%	77%
Psychiatric/Medications	7%	75%	18%

Most have difficulty with accessing and paying for quality psychiatrists, behavior consultants, and occupational therapists.

Medicaid Waiver

• **Applying**

	<u>In 2009</u>	<u>In 2006</u>	<u>In 2003</u>
○ 80 % of Families were Aware of Medicaid Waivers	88%	82%	84 %
○ 80 % of the Families who Applied were on the Waiting List	66%	50%	72 %
○ 20 % of the Families who Applied are Currently Receiving Waivered Services (32 Families)	50%	28 %	33 %
▪ Autism Waiver- 34%			
▪ Developmental Disability- 13%			
▪ Support Service Waiver- 53%			

• **Length of Time on Waiting List**

○ Families on the Waiting List have been Waiting an Average of 66 Months (up to 264 months).	53 mo.	44 mo.	27 mo.
○ Families Currently Receiving Waivered Services were on the Waiting List an Average of 69 Months. Max was 15 years.	45 mo.	38 mo.	24 mo.

• **Satisfaction with Waivered Services**

○ 35 % were Satisfied with the “Availability and Quality of Waivered Services”	45%	46%	50 %
○ 35 % Stated that “Sufficient Funds are Available through Waivered Services to Purchase Needed Services” for Their Child with ASD	44%	41%	63 %
○ 39 % Stated That There Were a “Sufficient Number of Service Providers in Their Area”	46%	46%	N/A

• **Perceived Outcomes of Waiver**

	<u>In 2009</u>	<u>In 2006</u>
<i>“As a Direct Result of the Waiver, our Son/Daughter...”</i>		
○ “Is Doing Better at Home”		
▪ 72 % Agree or Strongly Agree	2%	70 %
▪ 16% Disagree or Strongly Disagree	15%	11 %
○ “Is Doing Better at School”		
▪ 23 % Agree or Strongly Agree	35%	55 %
▪ 31 % Disagree or Strongly Disagree	24%	18 %
○ “Behaviors Have Improved”		
▪ 60 % Agree or Strongly Agree	51%	66 %
▪ 19 % Disagree or Strongly Disagree	18%	12 %
○ “Communication Has Improved”		
▪ 47 % Agree or Strongly Agree	45%	58 %
▪ 25 % Disagree or Strongly Disagree	18%	13 %
○ “Is Doing Better in Social Situations”		
▪ 57 % Agree or Strongly Agree	54%	63 %
▪ 16 % Disagree or Strongly Disagree	16%	14 %
○ “Is Better Able to Deal with Problems”		
▪ 40 % Agree or Strongly Agree	40%	54 %
▪ 12 % Disagree or Strongly Disagree	21%	16 %
<i>“As a Direct Result of the Waiver, our Family...”</i>		
○ “Has More Time for ourselves”		
▪ 62 % Agree or Strongly Agree	49%	62 %
▪ 31 % Disagree or Strongly Disagree	24%	23 %
○ “Has More Time for Recreational Activities ”		
▪ 44 % Agree or Strongly Agree	49%	52 %
▪ 28 % Disagree or Strongly Disagree	22%	24 %
○ “Has More Time for Friends and Other Relatives”		
▪ 38 % Agree or Strongly Agree	38%	48 %
▪ 31 % Disagree or Strongly Disagree	27%	25 %
○ “Has Been Better Able to Take Vacations”		
▪ 18 % Agree or Strongly Agree	32%	34 %
▪ 47 % Disagree or Strongly Disagree	31%	39 %

	<u>In 2009</u>	<u>In 2006</u>
○ “Has More Time to Spend on Own Work and Chores”		
▪ 55 % Agree or Strongly Agree	49%	50 %
▪ 25 % Disagree or Strongly Disagree	26%	27 %
○ “Has Experienced Less Overall Stress”		
▪ 53 % Agree or Strongly Agree	46%	58 %
▪ 22 % Disagree or Strongly Disagree	26%	26 %
○ “Has Experienced Less Financial Worry”		
▪ 55 % Agree or Strongly Agree	52%	53 %
▪ 21 % Disagree or Strongly Disagree	25%	23 %

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

My husband is a computer analyst at one of the Indianapolis universities. Because of his good income, I have been able to be the primary support person for our son, and have something like a life of my own, but it is still stressful. The tax tables, which I am told were prepared in the 1970s, have us as among the near rich, but we are not. We do not accumulate debt. We were unable to afford speech therapy for our son until he got SSI at age 18. The 40 minutes a week he was getting at school, now 20 minutes, is a joke for someone with his severe needs. He should have been having much more all along. This would have possibly enabled him to support himself, as he is underneath and behind the challenges a bright enough young man. Valerie, Marion County

The hardest challenge for us is that we don't make enough money to pay for the cost of private therapies and we make too much money to qualify for other assistance. Our insurance only pays for typical therapy such as PT, OT, Speech, etc. But even then they don't fully pay for anything so we are left with the rest which becomes overwhelming too. We have had to cancel all therapies for our son due to financial hardship and claim bankruptcy.

Angie
Fishers
Hamilton County

My son attended North Grove Elementary School (Center Grove) from k-5 and he will be attending Center Grove Middle School North 6-8 grades. I have always been extremely happy with the special education teachers and aids that helped my son and my family. He has made big improvements and a lot of it is thanks to the teachers! They DO make a world of difference in not only the lives of the children that are their students but for the parents of those students!

My daughter Kayla who is autistic graduated from a PUBLIC high school from Marion county this past school year, completing the Istep in the process. No waivers, no vouchers, and no excuses. She learned to be responsible for her work. She was supported by her teachers and the school system she attended. Her parents were involved. And she did the work. Without the last two no amount of assistance is going to matter whether the child is special needs or not. Government policies should reward and improve education and the systems that try to enhance learning instead of being used as an instrument for those individuals that use education to provide political points for career politicians and the institutions that provide for them financially.

Information/workshops designed for adult individuals with Asperger syndrome focusing on successful personal relationships would be a great tool for Aspies that would like to improve their social skills as an adult.

Schools should be allowed to have more freedom and flexibility in providing alternative methods of teaching to students who learn differently. Don't penalize schools who try but may have difficulty meeting state standards with autism who are placed in the general education classrooms.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

To Whom It May Concern,

I plead with you to develop a system that will support families trying to nurture and raise children with disabilities. In my case, I adopted children with disabilities. They were children from Porter County that others weren't interested in. None were babies. Little did I know that finding assistance to help them would be so difficult. I have worked full time since I was 16. I will continue to do so but at an age where my peers are retiring (not early mind you), I must constantly figure out ways to support those that I love. You see, my daughter with Dubowitz syndrome (much like Downs but extremely rare and diagnosed by facial characteristics and IQ is 27 and cannot receive services to help allow family to take care of her. My precious grandson has Autism and because of his behavioral issues my other daughter(also adopted) can't find child care for him and can't afford to feed or clothe him. I see those that "work" the system receiving benefits and abusing the system. I taught my children integrity. They might not be the brightest but they understand you don't lie and cheat to get something. We will stand by our beliefs. Please hear my plea. Help those of us who are willing to help ourselves given a hand up.

Sincerely,

Someone who cares deeply.

Ohio offers \$20,000/year to educate your child in a setting other than the public school setting or to pursue therapies outside the school setting. We need this in Indiana. We also desperately need teachers trained in autism. We need public service announcements educating the public about autism. The numbers are growing and these children are going to be in our communities for the long haul. We need to start teaching tolerance before these children hit the world.

The Waiver has been an incredible blessing for our family. Our child's first diagnosis was Autism and since then we have received many others such as seizure disorder and CP. The Waiver has made it possible for our son to access medical care that we could not have paid for even though we have GOOD private insurance coverage. The Waiver has made it possible for our son to work on much needed social skills in the community and receive PT,OT and Speech for many years previously. Thank you very, very much for continuing this program for Indiana families and giving us this opportunity to help you understand how vital this program is!

Thank you,

Lesa

We need more "wrap-around" services. This service delivery model would begin to support families from the time of diagnosis and help direct care and family support from a centralized location or "medical home."

Since our diagnosis in 2000, there has been a renewed interest and support for those on the autism spectrum. However, many services focus on early intervention (as they should!) BUT we now have a tsunami of kids coming of teen/adult age who are going to need services and support too. Pity the child with autism and a high IQ and good grades who cannot complete a college degree or hold down a job due to lack of social skills and ability to adapt when a problem arises or the "normal" social interaction changes. Thank you.

Having a child like our daughter has meant that even with the waiver, our ability to spend time with our other kids is compromised. We have made our special needs daughter the focus of our lives for over 20 years, and hope to get additional assistance to allow us to have a few normal family experiences without having to always worry about her needs first.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

It is very hard to find someone who knows American Sign Language that can do respite care and able to communicate with my son because he is Deaf and Autism. There is not many tutoring available for Deaf and Autism children who needs reading and writing tutor.

Thank you.

Fishers in Hamilton county

How are we able to be told no to a school four miles from our home that better fits his needs. When I tried to fight this decision I was told he could attend for three thousand dollars because that is what was given to our current school and they didn't have to give it back.

We need more services. Better testing to measure the ADS students, not ISTEP! We also need more life skills classes for these students to get a good job when they leave school. Not all of these students will make the core 40. Totally unrealistic.

One never knows when autism will disrupt one's day-to-day existence. Recently we had a police officer show up at our house. All was quiet within, so my heart sank as I wondered if he was there to give me bad news about some relative, news that they didn't want to share with us over the phone. As I asked the officer why he was there, my son with autism came to the front door and said, "I called him. I have been getting text messages from strangers on my cell phone, and I want it to stop. I also don't like getting texts from Walmart." We were lucky that the police officer was a kind soul, one who responded evenly and seriously to my son. The officer agreed that unwanted texts were annoying, but that my son should work with me on this if he received future texts from unknown sources. While this story is a bit humorous, my son's lack of understanding of how the world works is very sad.

Dear Legislator,

There isn't any support for Autistic children in schools. I have to stay poor to keep my child on Hoosier Healthwise in order to provide him his medication and therapy. Now, Hoosier Healthwise has become such a hassle to get recertified. It is so frustrating as a parent. Jennifer Goodpaster

SS waiver has been a very important part of my son's recovery. Because of the FCAR, I have been able to take classes and learn to do the therapy that my son so desperately needs. Doing the therapy myself costs much less than paying someone else to do it, and I learn a new skill. Without this waiver, my son would be in an institution. However, the resources provided by the waiver allow him to live at home and experience about a 90% recovery from PDD. This not only has completely changed his life, but it has saved more money than I can estimate.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

To whom it may concern,

Everyday children are being diagnosed on the spectrum. However, funding has remained low and the needs of these children are being overlooked because of budget cuts in the schools. There needs to be a infusion of resources into the schools to help with the autism spectrum epidemic hitting this generations. Parents need schools and all teachers armed with the knowledge needed to aide and guide these children in becoming productive citizens. I, a mother of an Asperger's child, returned to college and obtained a degree in Special Education and Elementray Education to help me understand, work with, and help my son become all he can be independently, academically, socially, and ect... This education aided me during the IEP meetings, therapy meetings and all other meetings not mentioned in this letter. My concern are for the parents who are overwhelmed by the terms, standards, and professionals in the meetings. There needs to be more empathy and patiences shown to the parents and children in these meetings. Parents need to understand they have a voice in the child's education and rights to advocate for their children. I am lucking in the aspect that my son has Asperger's and not the more server and profound form of autism. These parents need moral and physical support. Empathy in the meetings, shown they are being listened to and not have there concerns and opinions over looked. Educators, professionals, staff, and all individuals included in the meetings need to show/ demonstrate patience and understanding while talking to the parents/ child. This will allow for school, teachers, parents, and the child to develop a plan that will work for everyone involved. Please remember that parents and the child have a voice.

In closing, schools need more funding to meet the needs of all students in the education system. Better education of teachers and staff to promote and increase inclusion when possible and patience during meetings with parents.

Thank you for taking the time to read this letter. I hope this information will help you understand the needs of the child, parents, and schools dealing with the autism spectrum daily.

Thank You,
Concerned mother
Thank you,
Concerned Mother

I strongly feel there should be a program to financially assist the parents of children with special needs. I am a single mother and my ex-husband randomly helps his children. My son is autistic and outside of school, receives multiple therapies. Because of his schedule alone (not including the care of my 3 year old daughter), I am unable to work. My son receives SSI, but it barely covers the services I have to pay out of pocket for- due to waiting lists to get into places covered by Medicaid. Please consider a program that covers the parents who are forced to stay home with their special needs child(ren). Imagine if you couldn't bring in any money to buy food, purchase the gas to get your child to his/her therapies and school, pay utilities and rent/mortgage....

Lisa
Hammond; Lake County

I am most worried about the teen/adult years. There are no hospitals to house these kids and I think this leads to public shootings and suicides. I pray we are able to help our son grow up and have control over his anger so that this never happens. but I worry what will happen to him as an adult or what he might do to others. I think many kids with autism and anger problems in the past would have been in mental institutions. The lack of mental institutions is a problem.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

Jamie was diagnosed when she was five at the recommendation she be tested by her kindergarten teacher. Eventhough we then had a label, there was no additional supports put into place aside from speech. Because she could function in a regular classroom we were told, and have been since, that the schools could not provide services unless her needs were interfering with her education. While she is an amazing reader with beautiful handwriting, she doesn't interact well with her peers. What good is her education if she never learns to interact with others? We have joined social groups at Purdue and kept her involved in extracurricular activities, but the truth is that so much of her time is spent at school not participating in social situations that we feel it is for naught. How can the schools ignore this need?

teachers need more training in dealing with autistic behaviours. there should be yearly mandatory training for all teachers.
indianapolis, indiana -marion county

This summer our first on support service waiver has been a much nicer one the. In the past. Because of time spent with support staff my daughter has had less physical flair ups as there is still some activity structure in her summer. I have had to run myself ragged before this year to keep a balance so she doesn't fight me trying to watch tv all day. She is actually going to aSan Sousec to vol with staff and able to feel good a out heloing others because of this. While here is also is working on life skills she will need later as well as social interaction which is a challenge.

My child is a wonderful employee. She always wants to work and is always on time. I am sure that some of her skills in relating to co-workers could be improved on, but keep on top of what is going on at work and get copies of work correspondence, schedules, emails, etc. More oppportunities for employment are needed but unfortunately a lot of the jobs that people like my daughter used to do, because of the employment situation, other people are now doing those jobs. A little compassion and understanding goes a long way when interacting with my daughter.

My husband and I live in New Albany, IN - Floyd County, and moved here from West Lafayette, IN - Tippecanoe County two years ago, as our son with Asperger's was entering his senior year of high school. One thing we learned was that there are bif differences in the amounts of services provided between these two counties. His high school here had a staff person who was an autism specialist in the building. Tippecanoe had a team that provided services to all county schools, and were located in a central office building. Seeing the autism specialist at school each day made a big difference for him. Another issue that he had at his prior school was being bullied, and sexually assaulted on the bus and in shop class. The bullies got a slap on the wrist, and the cameras were not functional on the bus the days it happened. People with limited social skills often will not report such abuse, but suffer in silence. I would like to see resources spent to educate the neuro-typical students about autism and encourage them to help and not hurt their fellow students who have it.

My son needs more social/emotional therapy but we can't afford it and insurrance won't cover anything related to his autism because "it's not curable".

I live in Indianapolis, Marion County

I am a Certified Nurses Aid, Home Health Aid. I have an 87yr old CNA,HHA that is the best staff I have ever had. The agency has sent me younger staff that brought their children and made a mess of my house. I have dealt with no staff at all most of the time. I have been my childs constant staff for 15yrs. I feel I am qualified to care for her. I just need finatual support. We can not go on vacations, shop for clothing or get her hair done. There is no television, internet or cell phones. We are living a very basic life. There is no gas to take a one tank trip. I do find free activities so she can do some things for fun. I hope someone can help. I want to keep her at home with me. I don't think she will do well in a house with others. I don't mean she will never go but as for now I don't see her adjusting to a house filled with people.

The loop hole for insurance companies not to abide by the autism mandate in Indiana is disheartening. So many families left to pay out-of-pocket for therapies or have their child go without simply because of this. Hard working families are shelling out money for health insurance that is not benefiting the child/adult with autism.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

Good Afternoon,

I am a parent of a 10 year old child with ASD. We relocated to Indiana from Pennsylvania in December 2011, due to my husband's employment. I have found it extremely difficult to obtain services for my child in my local area. There are very long waits for appointments with physicians specializing in Autism, and also with local therapists for ongoing care. My family has been fortunate to recently have an appointment at Riley Children's Austim Clinic in Indianapolis. This is a 3 hour drive each way and is very expensive as it entails time lost at work, school, as well as added stress to my son enduring this long day. Prior to our move to Indiana, my son was seen every month for counseling and medication management. This will most likely need to continue in the future.

We do have a local center in our area called "The Logan Center" but many or most of their programs and therapists have 6-9 month waitlist. We have yet to have success in attending any of their programs due to waitlists. I have actively participated in their Parent Workshops, and have paid the attendance fee to do so. This is a small fee, but I am sure it is just one more added expense to families that struggle to meet the demands of caring for a child with a disability.

Thank you for allowing me to complete this Needs Assessment Survey. I am hopeful that we will see better services for our child and many others in our region very soon.

Granger, Indiana - St Joseph County, IN

There are very few services offered to families living in rural counties. I live in Dekalb county. We are fortunate to live close enough to Fort Wayne to be able to drive to receive some services, but the services available in our county and surround rural counties is very limited

I have been living with autism for 37 years, since my daughter's diagnosis. For 27 of those years, I've been helping other families find ways to help their children, as I have helped mine. I've always paid my taxes. Yet, now as I'm aging, my daughter has been denied the support she will need as my mind and body fade. She has many talents, but can only hope for placement in a boring, menial job by voc. rehab., as they have no experience locally with advanced placement. Here is a woman who speaks three languages, and all we can hope for is a placement as a bagger or stocker at a grocery store. She won't be able to continue to live in a rented home (by us) and enjoy her current personal freedom because an unqualified judge didn't listen at her hearing to the testimony from WORLD EXPERTS on autism who personally know her and have treated her that she needs daily support to continue living in her current environment. The judge said, "I heard the testimony, but she looks to good to be disabled." I feel her blessings of effort and near normal IQ have become curses... all of our combined hard work will result in her eventual incarceration in an institution. I will have no "graceful old age." Neither will she.

no

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

learning disabilities, and ADHD. We are in the process of neurological testing and barring a diagnosed medical problem, anticipate a diagnosis of Mildly Impaired by the end of summer. He, and others like him, seem to be the "forgotten children". We have a population of children who are not classified for Life Skills classes, but who are also not being supported to get a diploma. My son is one of these children. The school has no idea what is best for him. To their credit, the administration respects my knowledge of education (I'm a teacher) and of my son and takes most of my suggestions and implements them. The teachers have no idea how to help him or how to work with him. Let me clarify that he is not a behavior problem and takes school very seriously. My husband and I as well as our son, have always assumed he would graduate from high school. Now with the current diploma requirements we don't know if that is possible. My son has big dreams. We continue to nurture those dreams. It is a daily struggle to balance nurturing his dreams without him knowing why school is so hard for him. If I tell him he has a mild impairment, he will give up. If I don't he feels "dumb" because he doesn't understand physics in seventh grade. I pray every single day that my son won't turn to alcohol, drugs, or suicide once he realizes that what he envisions for his future may never happen. I have searched for hours to find a better educational solution. There isn't one. There are a couple of possibilities in Indiana, but they are private pay and cost more than I hope to pay for my older son to go to college. They are also over an hour away. So we just keep losing year after year with our son. It is left up to me to read things about how to help him communicate, how to help him be organized, how to come up with alternative outcomes for assignments, and to find ideas for many of his other needs. It is too bad that I have a job and apparently having another child was unrealistic, because meeting this son's needs is a full time job. NCLB is a great dream. It is a great goal. It isn't worth the many reams of paper it is written on when there is no support given for its implementation. Our whole junior high school has one special education assistant. She isn't trained and constantly confuses my son's responses that result from his disabilities as disrespect. He gets no behavior support, no occupational therapy, little to no assistive technology support, no organizational support, and no social skills support. What he gets is a glorified study hall disguised as a resource room. Until we as a state and as a nation make the needs of my son, and children like him, a priority, this will not change. Teachers want to teach every child, but if they don't know how to meet each child's needs, then they can't. If they don't have needed materials and support staff to meet those needs, then they can't. We are losing a vital part of our society by not meeting the needs of these children. These are students who can hold jobs and build careers. Some of them are brilliant beyond compare. You say we need to compete on a global scale-then don't sacrifice the intelligence of some of our brightest kids who just happen to be on the autism spectrum. Invest the time and money needed to help children like mine, the children who are brilliant but are not being reached, and all the ones in between so that they can

As a mother of 3 & 2 of them on the spectrum it is hard money wise to care for them. I do not receive foodstamps it tanf. I only ask for medicad for my children & every 10 mths I get a letter saying prove yourself. Insurance is so expensive I can't afford it or I would have it I choose to feed my children. Parents of disabled child have enough to worry about without having to prove things everytime we turn around support is what we need.

Qualify process for waiver after you have been targeted needs improvement

GARY INDIANA.. PLEASE CHECK TO SEE HOW MANY CHILDREN HAVE BEEN DIAGNOSED WITH THE SPECTRUM.. THEN GO LOOK INTO MY SURROUNDING CITIES.. I BET THE NUMBERS WILL INCREASE.. HIGHLY!!

Already sent a letter to Pete Visclosky and got no reply.

Fort Wayne, Allen county. There are a lot more costs but without more thought and investigation I don't have the information at this time.

Because I had a daughter on the spectrum, she was not diagnosed until 5. No one up here ever saw a girl with ASD and was reluctant to diagnose. This was 13 yrs. ago, and I cannot emphasise the importance of early diagnosis and treatment. We also didn't have good insurance, so something like the ABA centers would have been cost prohibitive at \$110/ hr. Unless you live in the center of the state, it continues to be troublesome to find quality providers early that insurance does not deem EXPERIMENTAL and refuses to pay.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

We desperately need employers that will hire our disabled loved ones. Our loved ones need the opportunity to feel a sense of self-worth in the work force. Many are quite capable of holding a good job and there are many advantages available to an employer in hiring an individual with a disability. The area of Decatur, IN (Adams County) is extremely limited. There is no work here available for our loved ones. Sitting at home all day, every day is not good for anyone let alone a disadvantaged individual. Please help us.

Very frustrating to try to find services that are affordable. We do not have group employee health insurance but have a private health ins-policy that is VERY EXPENSIVE and we have huge \$11000 deductible. We pay everything out of pocket and trying to find services we can afford is very difficult. School programming is very limited for kids on the spectrum - there are the regular programs of sports and other extra curricular activities, but nothing that is geared towards kids with differences. We end up paying extra for EVERYTHING!! and the population of people with differences is growing. This should be considered when developing programs and budgets for government funding programming.

It is my experience that what is considered success at school is measured by very low standards, in my opinion. If my son makes it through the day, they call it a success. It doesn't matter if he paid attention, or learned anything, or interacted with others. If he can just get through the day, he is fine. I hear the word fine a lot when I ask for more help for him. He comes home from school so strung out from holding it together all day that we have a terrible time at home. But when I bring this to the attention of his teachers, they just tell me he was fine at school. He is not getting what he needs but I can't make them see it. On the other hand, Cornerstone Autism Center in Greenwood is meeting his needs and very well. After spending most of the summer there, he had a 6 minute conversation with his dad on the telephone this morning. His communication skills are fantastic and his attention is vastly improved. But since he can't attend there full-time (he does "fine" in school so he doesn't qualify) I worry that going back to his regular elementary will just cause a regression. I feel like I have no options.

Over the course of the last seven years since his diagnosis, my son has been on a roller coaster ride. There are good days/weeks/months, but in return there are bad days/weeks/months. We have been involved in therapy off and on, taken medication and come off of medication. With the changes in hormones, settings, schooling everything changes for him and our family and it affects him. We are a military family that lives apart from our sponsor (900 miles) because the court system mandates that I continue to reside in Indiana so that my son with autism and his younger brother can be close to their father that takes weekly visitation and biweekly weekend visitation when convenient for him. This inconsistent routine that does not provide support for autism coupled with a single parent support system with me at times can make it difficult for my son to keep his routine. Court support for my now four children and myself to move with my husband that supports routines would be beneficial for my son with autism.

Another finding that we are dealing with is the limited amount of therapy support in our area that is enrolled in Tricare (military insurance.) Because there is not a local military base does not mean that there are not military families. Legislators should encourage medical support by pushing for medical professionals to be enrolled in Tricare.

Lastly, to my benefit I am a special education teacher so I gather information, research, and evidenced based practices through working with students with autism. Not all parents have that benefit. Support groups should be more readily available for parents with children with autism.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

MY 11 YEAR OLD DAUGHTER WAS PUT THROUGH 3 SCHOOLS IN A PERIOD OF 6 MONTHS. NONE OF THE SCHOOL HAD THE RESOURCES TO SUPPORT HER ASD. NONE OF THE SCHOOLS COULD PROVIDE THE NAMES OF OTHER SCHOOLS THAT COULD HELP HER. THEY ALL SAY THEY HAVE RESOURCES TO SUPPORT HER, BUT THEY DO NOT. MY DAUGHTER WAS HANDCUFFED TO A WHEELCHAIR AND WHEELED OUT TO HER FATHER BECAUSE SHE DIDN'T WANT TO LEAVE THE CLASS ROOM AT THE END OF THE DAY. SHE BECAME DEFIANT BECAUSE SHE WAS STANDING UP FOR SOMETHING SHE FELT THE TEACHER MISCOMMUNICATED TO THE CLASS. SHE SHUT DOWN AND THE SCHOOL CALLED THE POLICE TO INTERVIEN. HOW IS THIS SUPPOSED TO HELP HER? SHE WAS TRAUMATIZED BY THE EXPERIENCE. I AM APPEALED AT THE EDUCATION MY DAUGHTER HAS HAD TO EXPERIENCE. WE FOUND A PRIVATE SCHOOL FOR CHILDREN WITH ASD, BUT IT IS EXTREMELY EXPENSIVE AND WE CANNOT AFFORD IT. I WANT THE SCHOOL TO SUPPORT MY DAUGHTERS INTELLECTUAL GIFT AND GROW IT. SHE GETS BORED IN CLASS. I WANT THEM TO TEACHER HER THE THINGS SHE IS INTERESTED IN. LET HER MOVE AT HER OWN PACE DO NOT HOLD HER BACK TO THE LEVEL OF THE OTHER STUDENTS.

Parents have to fight for every right. There doesn't seem to be much help available. We feel we are on our own. If it weren't for support groups to encourage one another, I don't know how we'd survive!

would be nice to hear back from agencies regarding waiting list that my son's on. Very hard finding information and getting things done especially since he is older.

I found it very difficult to get a diagnosis for my son. We turned to the school first, and were let down. We heard things like "Well, he makes eye contact!" and was told by the autism consultant "Autistic kids don't play sports!" If I had not gone out and sought more help (encouraged by his wonderful teacher!), my son's struggles would be worse than they already are. It was very obvious to many that dealt with my son on a daily basis that something was going on. The school was of no help at all really. They went as far as to diagnose him with a Pragmatic Speech Impairment. I was furious when I researched this, as this is something common with children on the spectrum. I was even told to wait until he was in high school and have him retested! Like that would be of any help for the awfulness of middle school. Even after acknowledging the difficulties he was having, the only help that was offered was 20 minutes of speech therapy a week. This was of no help with helping him deal with his peers socially, or in helping him in language arts, or even health class! He cannot read between the lines, cannot tell you what a character is thinking, he cannot tell you steps in building a friendship! Yet, he was expected to do so, on his own, as "he is a 6th grader!" He was offered very little help on some things, and none on others. There were no suggestions on IEP plans, nor even any reports for the entire year of therapy. Now, having went out and found a doctor, and waiting for the appointment, then going through another (but better) evaluation, we still have to present this new diagnosis to the school and hope they decide to acknowledge it. I think the school should be held more accountable when turning someone away with no diagnosis, and making them seek it out on their own. It was obvious to our dr. at the first meeting that my son was on the spectrum, she did a lot of evaluating to find out where on the spectrum he was. If I had listened to the school, my son would be getting no help, even at home. Luckily, we had the support of his teacher, who knew the school was wrong, and pushed us to get help, and even helped us find a support group, which has been the most help of all!

Casey,
Elkhart, IN

Receiving direct services in the Concord Schools has always been a fight. Getting training for the administration and staff is a battle. Getting trained professionals to deliver the direct services is a battle. Getting a Paraprofessional that is trained in Asperger's is a battle. Then they wonder why these kids struggle so much. Without your knowledge they pull the supports that have been put in place for your child to help them succeed, then they continue to struggle. They fail to follow the IEP. They don't realize the importance of these items or they don't have the funds.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

It would be great if no insurance agency were exempt from covering autism. If they would cover it would could find better doctors for our children, they seem to forget that children are Indiana's most valuable resource!

It is frustrating to know that the state will not provide funds for Medicaid Waivers and has such a long waiting list for these kids. I am luckily able to support myself and both children on the spectrum at this time. I make too much money for any kind of support. However, a child should never be denied coverage of key services that are proven successful. The state insurance program covers these therapies yet my insurance company does not. Being a self insured company keeps them from having to provide. These kind of loop holes should not be allowed for companies. I have sought a separate insurance policy for this child to pay for ABA, ST and OT. Without this policy, I would not be able to provide these services which have significantly improved his ability to communicate and socialize. He makes progress weekly proving their effectiveness. I am not sure how the Health care law just upheld by SCOTUS will affect us, but I am hopeful that it will close the loopholes and eliminate the ridiculously long waiting list for waivers. Deny me my insurance, but how can a modern society EVER, EVER deny a child services in good conscience. Legislature, I pray for you to think on these simple terms from a legal standpoint and I pray for you to think on these terms from an ethical and moral view. Innocent children should be covered for any proven treatment, all the time every time. Thank you. Kelly, Lincoln's mom

the self funded exclusion for ABA is not fair. it enables the largest companies to not cover therapy that is scientifically proven to help these kids.

If we do not make it a requirement for school staff to receive training in all special needs areas; ASD, ADHD, Downs Syndrome, etc. we are doing a great disservice to the children and the staff. My son's ASD anxiety led to many disruptions to his class and because the teacher and paras did not understand that their scolding him while he was upset made the behavioral response worse, things got out of hand several times. It also led to my son's confidence level decreasing significantly. If I can't trust the people I leave him with everyday to support him and help him learn and grow with ASD, he will never thrive on his own. Education for our educators is a must. We live in St Joseph county in South Bend.

The school system is very poor and things change so frequently that these children do not get the solid and secure foundation they need at school in order to thrive to achieve their best capabilities. Things (such as routines, dependable staffing, autism team support) my son needs at school is always a fight and struggle which puts added stress and concern on me, my husband and our 3 other children. It seems no matter how hard we try as an involved family, the school system continues to disappoint the special education services of Clay County. The teachers and the therapists do work hard and are very open to working with the children and their families but the administration part is very frustrating and unempathetic to the needs of the families in this area. The waiver helps tremendously with medical and incontinence supplies. The waiver does help with respite greatly but we have had to turn to family members for respite because there are no other people that are able to handle our child with autism. The waiting time for the DD or the autism waiver has been over 12 years and counting for us which is a bit frustrating as well.

My son has very poor social skills which makes it hard for him to keep a job. He is very intelligent, but is having difficulty find a job that meshes with his interests. He cannot get medicaid and our private insurance will not cover him due to his age. He and I would both like him to become independent, but he has tried working with the agencies that work with Vocational Rehab with no success. They don't seem to realize that people with autism have trouble with relationships with others and frequently changed people working with him. he needs an agency that has a stable support staff for people with autism. He also needs social skills training for adults. There needs to be more resources for adults with autism.

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

The schools have got to mandate behavioral psychology for ALL educators. They also need to mandate less money on sports, facilities, and more on education, particularly education ALL . My son just had a HS PE . A teacher went up to a group of students he was in because they were slow to finish filling out some paperwork. He said "What's taking so long here, are you guys special needs?" When my son called him out the teacher said he was just kidding. This mindset is pervasive in the schools. I wrote the principal and my special services director. The email I received back was an attempt to get a name or Id the teacher. My son didnt know the man. I told the principal who emailed me that I wasnt interested in an apology, I was interested in his staff getting further training so this doesnt happen another child in the future! I have received no response back.

This is my blog--no names
www.thisisourautism.blogspot.com

To Whom It May Concern,

I am an educated, working parent of a 7 year old son on the Autism Spectrum. He is a great kid, and we are doing our best to give him an amazing life and support him in the best way to reach his potential. We face many barriers everyday. Simple errands and activities of daily living that occur in other families without a second thought take careful planning for us.

I do not believe my family deserves "extras" for my son, but I would like a level playing field. Everyday is more difficult for my son than a nuero-typical child. He is slowly learning how to process his environment and what society expects of him, but he needs time, patience and support.

He does not mimic or learn the same way as other children, but he can learn! He needs different delivery of information and a clear explanation of what is expected of him. Unfortunately, in today's world "free and appropriate" education has budgetary constraints just like everything else, and it seems these most vulnerable of our population are among the first to experience cut backs. Educating our youth with disabilities will be a savings in the long run. Providing this section of the population with skills to be productive members of society will make them taxpayers as opposed to burdens of the state. This is an investment, not an expense. One our country, our state, can not afford to miss out on.

Sincerely,

Amy

Bloomington, Monroe County

Please feel free to include a letter highlighting your personal experiences. Do not include your last name in the letter. You may include your city and county. These letters may be shared with state legislators.

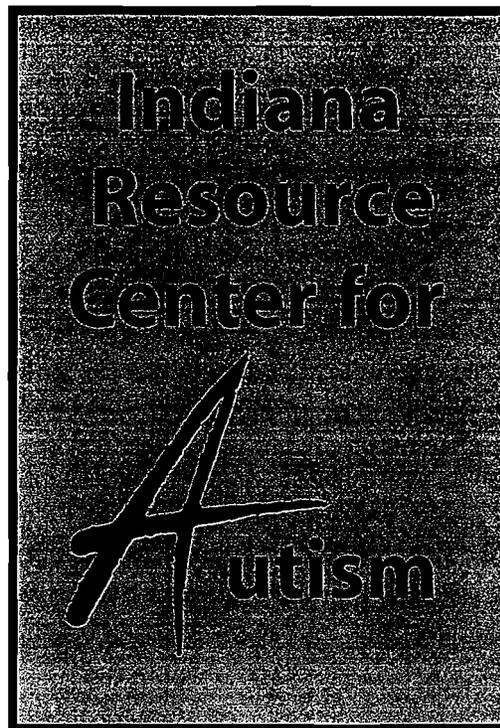
Our son is included in a regular classroom. In it he does not do well. He has a TA, although she is good with my son she has no ASD training whatsoever. When they are unable to deal with my son I am called and have to go to the school to collect him. I cannot explain the humiliation you feel when this is done. And both the beginning and end of school it is done regularly. At the beginning of the past school yr the school asked so many different professionals to come and observe my son. However no reports were handed down to me. We managed to increase his school day but the last month we had to scale it back due to his aggressive behavior. At the beginning of the school yr it was suggested to me that my son would be better off in another school, however no information was given. Also it felt as though the principal did not want my child there, saying he was not a "Typical Autistic child", due to his aggressive behavior. We do not have any behavioralists in our county. The closest we know of is Rileys where there is a 6month wait but we are unable to get these services as he already has a diagnosis. It has been very difficult to find and obtain the few services we do have and receive very little through the school so have managed to get some through our medical. The psychologists and psychiatrists here are very limited and just wanted to use puppets or write prescriptions rather than talking with my son. We live in the Vigo county area, in Terre Haute. Due to our income we do not qualify for any services other than the little given by the school. Seven though we earn a decent living we still struggle with the almost \$4 500 in medical costs each year.

At this time yes I feel there is much need for help in locating jobs and homes for the support needed and care. The current employment is not good, and I wish it could be better for so many, I feel fortunate my son has a job, knowing he could do more but thankful he does have employment.

I wish Children's Special Health Care covered children with autism.

Laura
Noblesville, IN
Hamilton County

My son began to regress in 4th grade in his public school, Hagerstown Elementary, as they were not willing to adapt to his needs and he was being bullied. I moved him to a small private school, Richmond Friends School, and have seen tremendous improvement with regards to not only academics but also socially. Many of the therapies that work with my son are not traditional and therefore insurance does not cover anything. I spend a minimum of \$1000 a month between school tuition, supplements, and alternative treatments such as therapeutic horseback riding. As a single parent, it is extremely difficult to find not only a balance financially but also with regards to time to make sure he gets what he needs.



Indiana Resource Center for Autism Annual Report for 2011-2012

Cathy Pratt, Ph.D., Director, BCBA-D

Indiana Institute on Disability
and Community at Indiana University

David Mank, Ph.D., Director



INDIANA UNIVERSITY

INDIANA INSTITUTE ON
DISABILITY AND COMMUNITY

**Indiana Resource Center for Autism
Annual Report 2011-2012
Submitted by: Dr. Cathy Pratt, BCBA-D
Director, Indiana Resource Center for Autism**

“The Indiana Resource Center for Autism staff conduct outreach training and consultations, engage in research, and develop and disseminate information on behalf of individuals across the autism spectrum, including autism, Asperger’s syndrome, and other pervasive developmental disorders. Our efforts are focused on providing communities, organizations, agencies, and families with the knowledge and skills to support children and adults in typical early intervention, school, community, work and home settings.”

Below is a summary of some of the activities of the Indiana Resource Center for Autism located at Indiana University’s Indiana Institute on Disability and Community in the areas of professional development, university coursework and supervision, information development and dissemination, research, grant writing, and community service.

Professional Development

During the past 18 years, Indiana Resource Center for Autism (IRCA) staff have trained 346 teams (over 2400 family members and professionals) from local special education planning districts across Indiana to address the diverse learning needs of students across the autism spectrum. To support these teams at the local level, IRCA supports 140 autism leaders that are located in almost every school district in Indiana. Support is provided via regional and state meetings, and a collaborative listserv.

IRCA staff members provide training and ongoing consultations across Indiana. During the 2011-2012 year, 19,244 individuals and family members received some level of training through center.

For the past four years, IRCA has been involved in a federal project to implement evidence-based practices in schools. The first two years of the Professional Development in Autism (PDA) Project, IRCA staff were in three districts. The next year, IRCA staff were in 7 schools and last year in 12 schools. This coming year, 25 schools have requested to work with center staff.

University Coursework and Supervision

This year, IRCA provided graduate credit course options to participants enrolled in Autism Summer Institutes and Autism Team Training. Individual staff members provided course lectures. Dr. Cathy Pratt supported six students in their work towards graduate credit and supervised six students as they pursue becoming Board Certified Behavior Analysts. Seventeen social work and school psychology students were also supported through IRCA. Finally, 25 students on the spectrum are part of a self-directed club supported through IRCA.

Information Development and Dissemination

Information is disseminated to families and professionals through the IRCA Reporter E-Newsletter, listservs, Facebook, the IRCA website, and through training events. The E-Newsletter is distributed to nearly 7,000 subscribers consisting of families and professionals in Indiana and available worldwide. Newsletters are distributed an average of twice a month. IRCA maintains four listservs, including a network of speech-language/hearing specialists, autism leaders, parent group leaders and those involved in our PDA Project. These listservs reach 850 professionals and family members. Each person on the listserv is expected to disseminate information they receive. The IRCA website (www.iidc.indiana.edu) has approximately 250,000 hits per year and is ever evolving in providing information. The IRCA Facebook page is another host for information dissemination with 2132 followers and a total annual reach of about 500,000. In addition, IRCA staff respond to approximately 26,000 emails annually and numerous phone calls daily. And finally, IRCA develops and disseminates information worldwide. Approximately, 200,000 brochures and articles are disseminated via trainings events, or via participation in various regional events. Below is a list of articles and books written during 2011-2012.

BOOKS

- Davies, C., & Dubie, M. (2012). *Intimate relationships and sexual health: A curriculum for teaching adolescents/adults with high functioning autism spectrum disorders and other social challenges*. Shawnee Mission, KS: Autism Asperger Publishing Company.
- Moreno, S. J., Wheeler, M., & Parkinson, K. (2011). *The partner's guide to Asperger syndrome*. Philadelphia, PA: Jessica Kingsley Publishers.

TECHNICAL REPORTS AND NON-REFEREED PUBLICATIONS

- Wheeler, M. (2012). *Summer 2012 camps & programs*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelId=3423>
- Wheeler, M. (2012). *Indiana's home and community-based waivers*. Retrieved from <http://www.iidc.indiana.edu/?pagelId=555>

NEWSLETTERS

- Bellini, S. (2012). Changing systems and changing lives through research. *The IRCA Reporter E-Newsletter 16(11)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelId=3435>
- Davies, C. (2012). Increasing independence in adults with autism spectrum disorders: Using a "to do" list. *The IRCA Reporter E-Newsletter 16(20)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelId=3502>
- Davies, C., & Hume, K. (2012). Structured teaching articles - collection. *The IRCA Reporter E-Newsletter 16(18)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelId=394>
- Davis, K. J. (2011). Life after high school...so now what? *The IRCA Reporter E-Newsletter 16(7)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelId=3483>

- Davis, K. J. (2011). For general education teachers: Helpful questions to ask about students with ASD. *The IRCA Reporter E-Newsletter 16(6)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3280>
- Dubie, M. (2011). Teaching a young woman to shave. *The IRCA Reporter E-Newsletter 16(2)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3455>
- Dubie, M. (2011). Hats off to Asperger autism group of Goshen: Meeting parents' needs. *The IRCA Reporter E-Newsletter 16(10)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3492>
- Grandin, T., & Pratt, C. (2012). An inside view of autism. *The IRCA Reporter E-Newsletter 16(12)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=595>
- Hume, K. (2012). Structured teaching strategies: A series. *The IRCA Reporter E-Newsletter 16(16)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3520>
- Lofland, K. (2012). PICO - a decision-making tool for selecting apps. *The IRCA Reporter E-Newsletter 16(17)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3549>
- Pratt, C. (2012). Autism awareness month: Facts and tips for working with students on the autism spectrum. *The IRCA Reporter E-Newsletter 16(14)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=359>
- Pratt, C. (2012). Increasing incidence of autism spectrum disorders continues in Indiana. *The IRCA Reporter E-newsletter 16(13)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=361>
- Pratt, C. (2011). Applied behavior analysis: A focus on outcomes. *The IRCA Reporter E-Newsletter 16(1)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3446>
- Pratt, C. (2011). Applied behavior analysis: The role of task analysis and chaining. *The IRCA Reporter E-Newsletter 16(4)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3458>
- Pratt, C. (2011). Clarifying the services of the Indiana Resource Center for Autism: What we do and what we don't do. *The IRCA Reporter E-Newsletter 16(8)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=285>
- Pratt, C. (2011). What to do if you suspect your son/daughter might have an autism spectrum disorder. *The IRCA Reporter E-Newsletter 16(3)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3457>
- Schroeder, W., & Pratt, C. (2011). Literacy resources for children on the autism spectrum. *The IRCA Reporter E-Newsletter 16(5)*. Retrieved from <http://www.iidc.indiana.edu/index.php?pagelD=3467>

Research

Indiana Resource Center for Autism staff were involved in eleven research studies from August 2011 through July 2012. Seven studies have been completed, two have an anticipated completion date of July 2013, and two of the studies are ongoing. Below are the titles of the research studies:

- Social Skill Interventions for Youth with Autism Spectrum Disorders: A Meta-Analysis of Interventions Implemented in Clinical Settings
- IRCA Family Needs Assessment Survey

- Program Evaluation: Assessing the Learning and Practice Outcomes of the Autism Team Training
- Using Video Self-Modeling to Increase Compliance in Children with Conduct Disorders
- Increasing Social Engagement in Young Children with Autism Spectrum Disorders using Video Self-modeling and Peer Training
- An Examination of Attentional Deficits in Youth on the Autism Spectrum
- The Feasibility and Acceptability of an Evidence Based Practices for Youth on the Autism Spectrum:
- Qualitative Study: Change Process in Schools
- Social Skill Outcomes of the Social Skills Research Center
- Examination of National and Regional Identification Rates of Students with Autism Spectrum Disorders
- A Comparison of Social Stories and Generic Social Narratives for Increasing Social Responses in Youth with Autism Spectrum Disorders

Grants

During the 2011-2012, three grants were written and funded.

- Wheeler, M. and Pratt, C. (2011). Parent Group Meetings. Autism Advocates of Indiana. \$3000. Funded.
- Wheeler, M. and Pratt, C. (2011). Eustacia Cutler Event. Answers for Autism Indiana. \$3200. Funded.
- Pratt, C. and Viehweg, S. (2011). Act Early Grant. Centers for Disease Control. 15,000. Funded. Working in conjunction with the Indiana State Department of Health.

University and Community Service

Staff at Indiana Resource Center for Autism participated in 19 university-related, state and national committees during the 2011-2012 year.

University-Related Committees:

- Students on the Spectrum Club, Staff Advisor – Marci Wheeler

National Committees:

- Association of University Centers on Disabilities, Autism Special Interest Group, Coordinator – Cathy Pratt
- Autism Society of America, Chapter Leadership Committee, Member – Cathy Pratt
- Autism Society of America, Panel of Professional Advisors, Member – Cathy Pratt
- Autism Society of America, Professional Development Committee, Member – Cathy Pratt
- College Internship Program Board, Member – Cathy Pratt
- Inclusive Education Task Force, Member – Cathy Pratt
- National Professional Development Center on Autism Spectrum Disorders, Member – Cathy Pratt

- Network of Autism Training and Technical Assistance Programs, Co-Chair – Cathy Pratt
- TASH, Membership Committee, Member – Cathy Pratt
- Temple Grandin/Eustacia Cutler Autism Fund, Member – Cathy Pratt

State Committees:

- Act Early Committee, Co-Chair – Cathy Pratt
- Answers for Autism, Autism Information Store Chairperson – Marci Wheeler
- Answers for Autism, Board Member – Marci Wheeler
- Autism Society of Indiana, Advisory Board, Member – Cathy Pratt
- Illinois Autism Training and Technical Assistance Project, Advisory Board Member – Cathy Pratt
- Indiana Interagency Autism Coordinating Committee, Advisory Member – Cathy Pratt
- Indiana Speech Language and Hearing Association, Scholarship Committee, Member – Kristie Lofland
- Maap Services Incorporated, Board President – Cathy Pratt

As the number of individuals diagnosed with an autism spectrum disorder continues to increase, meeting the growing needs of those involved with individuals across the autism spectrum presents a tremendous challenge. Twenty years ago, the incidence of autism was 1 in 5,000. Today, Indiana's Child Count Data the incidence is 1 in 83. Areas of continued need include: early identification, registry that reflects children on the autism spectrum, individuals who are dually diagnosed with ASD and mental health issues, bullying, the use of seclusion and restraint, and adult options.