Forward

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For permission to reprint contact:

Jacquie S. Mace

Normal, Illinois

309.824.4555

jmace463@gmail.com



www.autismmclean.org 309.661.9440 PO Box 422 Normal, IL 61761

The Little Book of Autism Resources

For permission to reprint contact:

Jacquie S. Mace Normal, Illinois 309.824.4555 mace.jacquie@comcast.net

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"While we try to teach our children all about life, our children teach us what life is all about." \sim Angela Schwindt



What Do I Do Now?

As a parent with a child diagnosed with Autistic Spectrum Disorder you will be looking for answers to a thousand questions. The original Train resource book was published in 2003, when finding information was much more difficult that it is today. With the growth of the internet, the amount of information available can actually be just as frustrating as not having enough information. With that in mind, we thought it was time to update and re-publish the book.

There are quite a few resources available in McLean County, the state, and nationally for people who live and work with individuals with autism. We are hopeful that this book will help you find the ones you need as you need them.

If your journey is just beginning, you may be overwhelmed with the number of questions you have and what is the right thing to do for your child. Take the time to explore each therapy and service. Talk to other parents about their experiences. We have a strong community of parents who have kids with autism and they are usually more than happy to share information and help whenever they can.

The book is intended to provide you with information to access many of the programs available. It is not meant to be a recommendation for any form of therapy. I have intentionally left out most of the alternative therapy options, as those are a very personal choice. The only intervention that I totally advocate for is early, intensive educational programming individualized to meet your child's needs. I strongly suggest that you learn all you can when it comes to the special education process, disability laws, and your districts placement options.

I have included a little of our family and a couple of other family's stories. I thought about how much it would have meant to me to have had the experience of another family as a reference when we first started and although our stories will be vastly different than yours I think it may help you to realize that this diagnosis is only the beginning for you and your child.

Kira's Story (Dees Family)

Before I start our Autism story, I want you to know everything will be OK. Yes, some things will be very hard, but it will all be OK. Take a deep breath, now another one (don't you feel a little better already?), and commit to doing everything in your power to be a detective when it comes to your child. Remember that all behavior is communication; we just have to figure out what our kids (ALL kids) are communicating to us with their behavior. You will hear a lot of stories, do a lot of research, and will find out about all sorts of other people on the Autism Spectrum. The most important piece of information you have is your gut and your knowledge of your child. Always remember that your child is not like every other person on the spectrum; some stories will resonate with you and others will not feel familiar at all. It's called a spectrum for a reason. There will be all sorts of experts (doctors, teachers, specialists, etc.) who know a whole lot about Autism. However, you will always be the best expert on your child. Be open to new learning, work with the team who is trying to help you, and do your darndest to listen to your child and discover who he/she is first and foremost.

At our well-baby checks, the pediatrician proclaimed, "Kira's perfect! "and it felt so good to hear those words! We heard those glorious word until, until she was 8 months old and had not started crawling (she didn't crawl until 10 months old). Then we started hearing, "She's fine; she's just on the low side of normal." When she wasn't walking independently at 15 months (she would walk a city block holding on to just a finger), the pediatrician said, "well, I will sign off on physical therapy if you want." So, we signed up for physical therapy and, when she still wasn't walking independently at 18 months, our insurance company indicated they would no longer pay for physical therapy. Coincidentally, Kira suddenly lost nearly all of her language at 18 months, stopped making eye-contact and started drooling. Just when Paul and I were asking ourselves, "now what?" Our physical therapist brought us a pamphlet for SPICE through MarcFirst and said, "I'm not

really sure what this place is, but they will test Kira for any and all delays and, if she qualifies, they will give you services at low/no cost." This is when I started to get very nervous. I had long since stopped reading my What to Expect books

because Kira was not hitting any of the milestones until much later dates than what was in that book. I called MarcFirst and asked them to test Kira for EVERYTHING they had tests for, because, suddenly, I thought, "Oh my gosh, I should have done this a long time ago!" and was panicked that I had already failed my sweet girl. The tests came back and showed global delays in speech, gross motor, fine motor, and developmental and so began our journey in earnest, just four months before Kira's sister, Haley, was born.

Our days and weeks were filled with therapy sessions and trying not to freak out. The therapists came to our house after Haley was born, and as she got older, she joined in the sessions whenever she was allowed. It was watching Haley develop that it truly hit me how different she and Kira were. Haley seemed to do everything so fast. When Kira was two and a half years old, our team of therapists all met at my house for what felt like an intervention. They told me they wanted me to take Kira to a developmental pediatrician and I immediately burst into tears. No one wants to be told to go see a developmental pediatrician, because that means there is really something wrong; developmental pediatricians are doctors who specialize in things going wrong with kids. The doctor in Champaign was the first time I heard the word Autism to describe my daughter. The therapists were stunned and they disagreed with the diagnosis, as did our pediatrician. "She can point to things in isolation! She is so affectionate! She has a definite sense of humor! I'm confident she is reading!" they said, and, because of those things, they also said she couldn't be on the spectrum. Autism scared Paul and I, so we chose to believe this group who had taught us so many ways to meaningfully engage with Kira and how she learns best instead of the developmental pediatrician, and started researching everything else it could be to determine what was going on with Kira. When she turned three, we made the hard decision to take Kira out of her church preschool program and enroll her in early childhood in Unit 5. It was hard because

I was so afraid of putting a label of any kind on Kira, that it would somehow limit her opportunities and people would have low expectations of her. It was hard because it was special education, and what I remembered about special education from my own schooling experience was that the students in special education had a classroom that was underneath the stage. When I was a kid and we had classmates that were identified as needing special education services, we never saw them again, except before and after school. No one talked about it and my peers were not very nice to this population of students. I wanted something different for Kira. I didn't know exactly what that was, but it wasn't THIS.

Early childhood education was simultaneously wonderful and hard at the same time. I felt like Kira was very well cared for in her program, but some of the behaviors of her classmates made me very nervous. Would Kira start quacking like one of her classmates? She already had a tendency for aggressive behavior when frustrated and there were students who had much more aggressive behaviors than she; would she pick up their behaviors? I wanted her to have typical peer role models and for her to "pick up" on their behaviors. Don't get me wrong, Kira had plenty of her own concerning behaviors; we knew how to deal with those, though, not the ones I saw of some of her classmates. "Different, not less," as Temple Grandin says, is how I felt about the array of behaviors in her classroom.

We had a series of events ranging from changing insurance companies to doctors retiring that had us running all over the place trying to find out what was going on with Kira. At one point, we were in St. Louis, the head of neurology told us "Stop shopping for a diagnosis." He used the R-word to describe our smart and beautiful daughter, telling us she would never have the mental capacity of more than an elementary student. He said this in front of Kira and Haley. We were devastated and couldn't even talk to each other until the car ride home when the girls fell asleep, exhausted. I was determined that Kira would prove that jerk wrong, no matter what.

When Kira was four years old, she started having quiet seizures. We didn't know that at the time, but she would stop walking and sit down and then be very angry. She fell down the stairs a couple of times and then, one night at bathtime, I watched her take two shoulder shrugs and melt under the water. I grabbed her out of the bathtub, got her dressed, and we all went to the emergency room. They told us they suspected she was having seizures and made a follow-up visit for us to see a pediatric neurologist. At that appointment, that doctor kept saying, "Well, in my other patients with PDD-NOS..." and "My other patients with Autism..." until I finally said, "why do you keep saying that? You act like she has Autism. The doctor said, calmly, "you don't know? It says so right here in her chart." That night, I went to the bookstore and stood in front of the Special Needs section and pulled out a book from a mother who put her son on a gluten-free/casein free diet and "cured" his autism. I wasn't sure about the diet, but the description of the boy in the book spoke to me; he very much resembled Kira. So, I bought the book and started researching the diet. Paul and I finally embraced the diagnosis and the next hurdle was whether or not to put it on her school records. By the way, Kira is still gluten free as she identifies that it helps her focus; the diet did not, however, "cure" her autism. Gluten absolutely does, however, negatively impact her behavior and, man, it's a whole heck of a lot easier to be gluten free in 2021 than it was in 2001.

One of the biggest blessings of our life has been being a part of the Autism Society of McLean County. It gave us a community. It gave us playdates where ISU students would play with our children and the parents could just sit and talk and not freak out if their kid was screaming, stimming, saying things that didn't seem to fit into the conversation (or any conversation), or feeling judged as a generally bad parent. It was a safe space to try out new activities with our kids (both Kira and Haley profited from these opportunities), and gave Kira the opportunity to be in sports which later translated to being in sports with all sorts of typical peers because of first being in those activities within the safety net of ASMC. The Autism Society gave us the opportunity to go to movies that were not totally dark, that kids could roam and self-

talk and be themselves so that later, Kira could go to movies and not do those things. Being part of ASMC made us brave to try out new things like Penguin Project (a theater experience where individuals with special needs are partnered with a typical peer to put on a play), which both our girls were part of from ages 9 and 11 until Haley went to college four years ago and this season will be Kira's last year before she "ages out." Kira is also part of a wonderful community of peers through Special Olympics and SOAR (Special Opportunities in Adult Recreation) through the City of Bloomington and she will be able to be part of that for the rest of her life! ASMC gave Kira the opportunity to go to camp, just like other kids. She still loves to go to Timber Pointe for a week of overnight camp at age 23. Oh, but that first weekend camp with ASMC was ROUGH on Haley and I. We cried all weekend long, worried about Kira who, as far as we know, did great.

We let any doctoral and graduate students studying autism and strategies come into our home and interview us, interview Kira, and try out their learning strategies on her as part of their research. We learned a ton from them. We learned about visual schedules we could use at home and in the car and we learned about social stories, which changed our lives. Kira could follow a story of what would happen throughout the day and she carried it with her everywhere she went for most of her years in school. Every now and then, when she is really frustrated and sad, she'll ask for a social story so she can read what is going to happen next and how she could respond.

Depending on the year, the teachers, and where Kira was developmentally, I had to fight for different things. Most times I advocated for full inclusion or as close as the school district would let us get to full inclusion, though, one year, I advocated for her spending more time in the self-contained classroom and volunteered to help that teacher bring the general education curriculum to Kira and her peers in that classroom. Most teachers and teams were at least willing to let me be part of the team and use my insights into Kira and thoughts from all my research to help problem-solve; Kira also had teachers

who told me what they thought I wanted to hear (like, "she's so sweet...") and those who weren't willing to be the detective to find out what she really learned and was capable of, and those who gave her inaccurate grades, both false As and false Fs. My unsolicited advice is to work with them; your child will benefit when you and the school use the same tools and language. Take every opportunity you have to partner with the people who are teaching and caring for your child, and when you feel like something is not right, advocate for your child. I ALWAYS had to fight Unit 5 transportation. From the time Kira was 3 years old in Early Childhood until we finally gave up and transported her ourselves for high school, she was picked up late, arrived at school late, and taken out of classes early to accommodate the bussing system, not what she and all of her peers with IEPs needed most - time in the classroom. Bussing was one of the most painful and unresolved fights I ever had. I don't want that to be your takeaway, though. Take away that there were so many wonderful teachers, paraprofessionals, and administrators who learned a lot from Kira and some of them have become friends of our family and/or are Kira's Facebook friends as an adult. Invest in your child's teachers and the teams working with him/her.

It has been quite an adventure, these past 24 years. There have been really great school experiences, and very awful ones. It's hard knowing that every single year in school you, as your child's best advocate, will have to teach a whole new team of people about your child and what autism looks like for her. Then you remember your best friend telling you, "Kira gets ONE shot at _____ grade; fight for what you believe is right for her!" It's hard to be 100% sure you are advocating for the correct things. I craved talking to parents of kids on the spectrum who were older than Kira. I wanted to know what the future could hold for her as it was all so terrifying to me. As a mom who has been in your shoes, I want to tell you to hold on tight, give yourself some grace, and, when someone offers to be your support, let them. Kira has done SO MANY things no one ever would have imagined she could do (attend sporting events and not lose her mind, learn foreign languages (yes, that's plural), take college classes, go to high school dances, have a

boyfriend she loves) and oh, the people who love Kira! They are too numerous to count, and some of them have been bit, hit, scratched, kicked, and all sorts of awful things that she did when she was younger that she has outgrown as an adult, and they STILL love her!

Let me know how I can help.

Kira's Favorite Joke

"Here's a joke...why don't people eat clowns?

.....Because they taste funny!"

It's the first joke she ever "got" and a turning point for her to understand teasing. She still doesn't like jokes she doesn't "get" or teasing, but she understands that some people love to tease/be teased even though she does NOT.

Nick's Story

I was asked to share Nick's story and at first, I thought, what would I say? Then I thought, hmmm... maybe. Nick is 26 years old and had you asked me 23 years ago if we'd be where we are today, I'd have said absolutely no way. When I look at Nick now and think back to the little boy — I think, there is no way this is the same child.

Nick came into the world perfectly normal and perfect in my eyes. He was beautiful and everything a parent prays for – 10 fingers, 10 toes, healthy heart, bright eyes – the whole package. He joined our family and made it complete. His big sister (all of 16 months older than him) seemed thrilled to have a baby doll that moved and made noise! Her fascination with him dropped off however when he learned to pull her hair and scratch her face – this was well before he was one.

At first, I didn't worry about him not sleeping through the night or not seeming to pay attention to us – he was happy for the most part and had the most infectious belly laugh! By the time he was two though, I found myself talking to other parents to find out if this or that was "normal". He wasn't talking – no words at all. He wasn't sleeping for very long – 3 to 5 hours max. He didn't seem interested in anything his family was doing – he seemed happy in his own bubble. And his anger was palpable when something didn't go "right" – and right could be so many things – I didn't understand what he wanted, his sister was within his grasp, his dad came home from work and altered the energy in the house. Any one of these would set him off as would a host of unknown triggers. Sometimes he lashed out for the reaction and would then laugh at someone being hurt. I don't think he put it together that way but that was the outward appearance.

At a wellness check, I asked his pediatrician if he thought Nick might be hard of hearing. He said it was possible, so we went to an audiologist and he tested within normal range. Ok. That was good. But what then. Our pediatrician, nice enough fellow (now I think rather incompetent) said not to worry, that children develop at different paces and that Nick would find his way. Wait and see. Yikes. So back to talking to other parents. One mom told me about a program called SPICE (part of

MarcFirst) and after putting him through several tests, they said they would provide therapy. Great! Surely, they would be able to get his development ball rolling. Deep breath. After several weeks of therapy, they asked me if I had considered taking him to a developmental pediatrician for a diagnosis. For a what? Why? He was fine – just behind. Right? Apparently not. They said there was a good doctor in Peoria and a good team of doctors in Champaign (my hometown). Familiar territory and nine doctors to evaluate him. Nine was better than one. Right?

So many doctors. So many tests. So many invasive tests. So much trauma to this little boy that would scream cry when he went to the doctor's office. Who scream cried when anyone messed with him. Who hit, kicked, bit, pinched whoever he could reach when he couldn't make them understand. Thankfully and finally, the testing was over. Nick, just barely two years old, was diagnosed with mild to moderate autism and mild retardation. They said he was at the developmental age of an 8-month-old. We were given many fliers and pamphlets to read and then sent on our way to navigate it, what felt like, all on our own. I felt beyond overwhelmed. I felt broken hearted that I had failed this beautiful little boy. I felt devastated and I was exhausted. And I had no idea where to go or what to do.

I quickly found out two things. First, the very new internet was chuck full of information – some good, some lousy and some scary. At the time when you searched "autism" there were something like 2 million hits. Seriously? 2 million? How was I going to read that much material when my 2- and 3-year-olds kept me very busy? Second, I learned from SPICE and other parents, that Nick was entitled to services from our local school district, Unit 5 of McLean County. We went through the steps necessary to enroll Nick and he started school at the age of 3. For his first year or two, I was often in the classroom to help buffer Nick's aggression towards other people – adults and children. He was what a friend (also a professional in the field) would come to call, "their 3-on-1 child". It routinely took 3 adults to contain my son, to keep him from hurting other children or staff. He was kicked out of summer school for hurting a fellow classmate when he was not yet 4 – this felt like my

breaking point. I knew he needed so much more than I was providing. He needed school – the structure at least.

I needed to learn more, to be a better advocate for Nick. I joined Autism McLean, I volunteered to be on a Unit 5 parent/professional Autism council, I attended any symposium I could find, I joined support groups. I learned to come out of my shell so to speak as I realized that my kids needed me to speak up for them. Speaking up and asking for help have always been hard for me. Top that off with not understanding a word of the teachers' secret language of acronyms I always felt behind when it came to my son's education. Over time, I developed close relationships with professionals in the field who would attend Nick's IEPs with me (strongly recommend having a support person with you during these – those extra ears, those extra minds are invaluable). They taught me the importance of routines, of social stories, of communication (and learning the various modes). They helped me help my son – I'm forever grateful.

Nick has been blessed with so many amazing teachers! There were a few that muddied the waters, but the vast majority worked hard to help Nick learn to communicate. They thought outside the box and worked hard to make Nick's experiences meaningful to him. He found speech (functional echolalia) around 5 years old – something he still uses today when needed. He wore headphones to filter out all the sounds that hurt him or confused him. He learned to use schedules and PECS and social stories – he even learned to create them himself when we got Boardmaker – a perfect example of self-advocacy – he knew what he needed and how to create it!

Every school year was a new test of his determination, his courage. He tried new things (although often times with a lot of complaining and behaviors) but his teachers stood by him, encouraged him, and believed in him. Over time, he figured out how to navigate the world, to make friends, to accomplish just about anything he wanted. He graduated from high school at 20 and went to community college where he earned a certificate in business technology. He got himself to campus, through the day and back home every day. It may have taken him longer than

typical, but he did it and is so excited at the prospect of finding a job and being a businessman!

Nick is also blessed to be a part of Autism McLean, SOAR, Miracle League and Best Buddies of ISU. Each of these organizations have been so important in Nick's growth – in his quest for independence. He has a girlfriend he wants to marry. He wants to live on his own. He wants to spend time with friends. His life is everything a parent hopes for when they bring that bundle home from the hospital. The struggles have been so many, but every step has had a purpose. Every step was and is an opportunity for growth. I often look back at his diagnosis and think – mild retardation – not this kid! He's smart as a whip! This young man is amazing!"

I think my point to all this is always assume that your child can. What they can do may be different than "the plan", but it will be ok. Seek out other parents to help you, know you aren't alone, and know that others are where you are or have been there and survived.

And I honestly believe that struggles make us stronger – You got this – but I'm here just in case.

Nicks club he started for social opportunities



Austin's Story

Autism...the word stuck in my head. My mind leapt forward to what that might mean for the future, and back to when at thirty-two weeks into our pregnancy with twins, we heard the words, "congestive heart failure". Somehow the news seemed to bring them both together. I left the doctor's office slightly dazed and more than a little scared.

Nearly three years before I heard the word "autism", we ran into problems causing our twin boys Michael and Austin, to be taken by emergency c-section. Michael was delivered first and was doing well considering he was so small, Austin was taken as quickly as possible after, but he didn't have a heartbeat. Resuscitation efforts were miraculously successful. Both boys spent several weeks at Riley's Children's Hospital and after a tremendous amount of care, they were pronounced healthy and we got to take them home.

In the first year and a half of their lives, both of the boys developed quite typically; eating, sleeping, walking, talking, and playing together. Then when they were about 18 months old we started noticing small changes in Austin. He slowly stopped responding to directions, or even acknowledging that someone was talking; began playing with toys in his "own" way; refused to eat things he'd always eaten; and was not talking anymore. We brought our concerns to the doctor many times, each time hearing "don't worry he'll talk when he's ready", or "don't compare him to his brother." Austin continued his slow regression and finally after more than a few visits to our local pediatrician we were able to get a referral and our first diagnosis; "developmental delays and atypical in the area of speech for autism."

About the same time we received the diagnosis we moved to Bloomington, Illinois. Wow, was that a good move. We immediately met with our local early intervention service providers, known as S.P.I.C.E. I cannot even begin to express what a wonderful, knowledgeable group of people they were. From the point of doing intake with our family to all of the services they provided, we felt that we had a tremendous

team of people working with us and for our son. But even as we worked and focused our attention on building Austin's skills, he continued to regress. After months of therapies, our team suggested we get another evaluation done by a developmental pediatrician. Taking their suggestion, we scheduled the appointment with one of the referred developmental pediatricians. I think they knew..... we didn't.

Within a few weeks we met with the Developmental Pediatrician (the wait wasn't near as long then) and within an hour of the meeting she gave us a new diagnosis of autism and mental retardation.

Autism...... What the hell do we do now? Sitting in the car before being able to start it, I held in my hand the one piece of information that the doctor gave us, a brochure for the Autism Society of America, and the advice to try and find a support group.

I felt that we had been on a journey for some time, but it had been without real direction until Austin's diagnosis. Although I felt a little relief that we had an actual diagnosis and direction, I also knew that we were playing in a new ballgame without the equipment we needed.

That little brochure was the beginning of our search. After getting home that night, I sat down at the computer and typed in the word "AUTISM", thus beginning our journey for Austin. We searched, we read, we studied, and we attended every conference that was within driving distance. The S.P.I.C.E. team seemed to be as eager as we were to find ways to reach him. They willingly tried new things, warned us against others, and fed us information about who we could contact within the community that might be of some help. From a seminar we attended, we learned about using pictures for communication and together with his speech pathologist Linda, we taught Austin that he had the power to communicate with us.

I had found a support group and met a few parents. With them I felt a connection and understanding whenever I talked about autism; it was just a feeling of "They Get It". I had also developed a passion for autism

and wanted to do more for Austin and the other families struggling with a diagnosis. There was a lot of concern about the amount of time we had lost looking for autism specific information and didn't want other families to lose that time. So I compiled the notes I kept and wrote the first TRAIN resource book and soon after with other parents and professionals in the community founded the Autism Society of McLean County (*Autism McLean).

Through networking in the community while working on the resource book I met some amazing people at Illinois State University, Dr. Stacey Bock and Dr. Karla Doepke. They had the same passion for teaching children with autism as I did, along with the skills and resources I needed. By combining various techniques and teaching methods, along with our own knowledge of how to get into Austin's world we were able to create a plan that has enabled Austin to make wonderful progress.

When Austin was diagnosed at 2 ½ years of age he had many challenging behaviors, (much of it I believe was due to frustration of not being able to communicate effectively). He could not tolerate going to public places. He could not tell us what he wanted or needed. He had a lot of sensory issues that we didn't understand. It was challenging and exhausting not knowing how to help him cope with everyday issues and anytime we faced a new situation with him. We spent hours sitting beside his bed to get him to stay in bed, it took nearly 2 years to teach him to stay in his room if he woke up. He was aggressive toward his twin brother, who for many years refused to fight back. He would lay and kick the walls and cry for hours.

We set up a classroom in the basement and developed a team to work with him. We practiced going to many public places, i.e., department stores, bowling, the theatre, and on train rides. We practiced self-help skills constantly; asking for help when he needs it, cooking his own breakfast, crossing the street independently. He was not always successful and of course did/does better in some areas than he does others. I believe for him to be successful as an adult, we will have to continually introduce various environments and situations so he can

build a tolerance and acceptance of them. With the support of so many exceptional people, Austin has made extraordinary progress. He is now learning to communicate much more effectively. He makes most of his wants and needs known verbally, including letting us know when he is sick and what hurts. At 25 years old, he has several friends and enjoys tons of activities in the community through SOAR and Autism McLean. He is able to relay information about past events (as far back as when he was 5 and couldn't communicate).

In 2018 we were making candles as a way to creatively pass time, there was some interest in purchasing them from a few friends so we started selling them locally. Soon after we started Smelly Elle Candles as a business for Austin. Austin, aka the Candle Boss is involved in all aspects of the business. He sets wicks with hot glue, measures wax and fragrance oil, pours the hot wax, helps label, package and deliver. His Dad, Step-Dad and Brother all help in various ways too. We have been blessed to find something he loves doing and can be successful at.

Our journey has been an amazing one, although not without difficulty, setbacks and frustrations. Austin's siblings; Michael, Christina, and Amanda all carry the burden of having a brother with autism and the fact that he has always required so much focus and attention. Michael has developed a sense of pride in autism and his brother and wrote a book about him and his brother when he was in the second grade (Winner; Young Authors, Colene Hoose, 2005). He has since graduated from the University of Illinois and teaches children with disabilities at Normal Community High School.

We have learned to accept that Austin's disability is a part of who Austin is (it's not like an attachment that you can get rid of). We've tried to utilize his fascinations to teach him and build on the things that he likes most. We do not lower our expectations for him. We treat him with the respect that he deserves and try to help him reach his full potential. Austin still faces many challenges in communication, social understanding, and the many other behaviors associated with autism, but the more his confidence increases and the better our understanding

becomes, the more he is able to do on his own. I'm not sure I agree with the mental retardation diagnosis, I truly feel that much of his limitations is from a processing disorder, he struggles to understand what you are asking or telling him – but when phrased a different way, he generally gets it.

We have met the most wonderful people since beginning this adventure and along the way created a much larger family. Our rewards may come slower than most peoples, but they mean so much more to us.

Understand that your child is unique and the challenges you face will vary from day to day. You will have to pick and choose what areas get priority and what will work for your whole family.

I have included bits and pieces of information that have fit into our puzzle. I hope a few of them will fit into yours. I wish you all the best on your journey and I will look for you on the path as ours continues.



All Big Things Start Small

On Your Journey

- Remember, this is the same beautiful child you had yesterday, before you were given a diagnosis.
- Yesterday you were a parent. Today you will start to become a researcher, a detective, and an educator. Most importantly you are still a parent.
- Seek out knowledge. Contact other parents, speech pathologists, developmental therapists and doctors. Ask questions, lots of them!
- Read at least one book by someone who has Autism, one book on how to help your child communicate, and one book that will make you laugh.
- Have your child evaluated for underlying medical conditions i.e.... seizures, allergies, hearing problems. Many times underlying conditions can be treated. If your child feels well their ability to concentrate and learn will be easier.
- There are no known cures for Autistic Spectrum Disorder. This is a lifelong disability. Be very cautious of any treatment or therapy that promises a cure or promotes its miracle cases. Our children are each unique individuals, one size does not fit all. You will find a tremendous amount of therapy options available. If you consider trying any of them, be sure to research them thoroughly. Find out what the long term effects can be for your child. Talk to at least two other parents that have went through the treatment with their child, and always ask questions.
- Find a doctor who will listen and research with you. This might be much harder than you think.
- Keep records. Start a file for doctor visits, therapies, research papers, school IEP's and contracts.
- Know your rights and the rights of your child.

- Take a break! You will be doing your child, your family and yourself a service. Look into respite services.
- You will need people to turn to for help, answers or just to talk.
 Build a support group of family, friends, other parents and educators. Work together as a team
- Believe! If you don't believe in yourself, you won't be able to make your child believe in you.
- Children with Autism can learn. Children with Autism can love.
- Find a way to help your child communicate. A speech pathologist can help you find different forms of communications. Remember even if your child is not verbal, if they can learn to express themselves through pictures or sign language they are communicating. Communication is power... Power builds confidence... with confidence you and your child can accomplish most anything.
- Don't assume your child is locked in a dark, miserable world. Assume instead that the world they're in is more like a circus (why leave when you're having a great time). Be animated and silly, try to make yourself the most interesting thing in your child's life. Catch their attention enough for them to want to take a peak.
- Don't take away the things they love. If it's spinning...spin with them, if it's dark quiet places they like... build them a tent and join them in it. Let them know that you love them for who they are, and build on it.
- Everything your child does is for a reason. Be a detective, watch for the causes and effect. Does your child scream when you run the vacuum? Maybe they have a sound sensitivity and the noise is painful. Do they throw themselves on the floor or push furniture over? They could be hypo-sensitive to touch. Keep notes.
- Cheer! For every accomplishment. It may seem like a small step for some, but it might be a giant leap for your child. Yea!

- Find what motivates your child and use it. Do they like balloons?
 *Get a helium tank, use them for requesting, counting or colors. If they love Barney, Learn the songs, sing and dance with them.
- Play hard, talk slow, be creative.
- Introduce your child to as many social situations that they and you can tolerate. Be prepared to leave, while you are both still comfortable so that it is a successful experience.
- React or Don't. Try to step back and look at what you react to or don't react to and how. Do you jump up, get animated, and yell when they suddenly decide to pour grape juice on the white carpet? Pretty good stimulus... (might want to try that again later). Do you sit quietly, reading or watching television when your child is calm? Maybe they'll want to get the juice again.
- Remember your spouse, your other children and your friends. Take time for them and for yourself.
- Try to include siblings in your endeavors. Explain to them what their brother or sister has, teach them to be peer models if you can. Look into Sib shop support groups, they are designed to help your child understand their emotions and share experiences with other children in the same situation.
- Tell your child what they have. Tell them that they are different than other children. Tell them that it's o.k.
- Remember that above all, you are your child's best resource.
 Nobody knows them better than you do.
- Create a positive behavior plan and stick with it
- Don't lower your expectations for your child, want for them the same things you want for all of your children; to grow up, be healthy, happy, and independent.

Autism Spectrum Disorder

National Institute of Mental Health (NIH)

What Is It?

Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior. Although autism can be diagnosed at any age, it is said to be a "developmental disorder" because symptoms generally appear in the first two years of life.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a guide created by the American Psychiatric Association used to diagnose mental disorders, people with ASD have:

- Difficulty with communication and interaction with other people
- Restricted interests and repetitive behaviors
- Symptoms that hurt the person's ability to function properly in school, work, and other areas of life

Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience. ASD occurs in all ethnic, racial, and economic groups. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and ability to function. The American Academy of Pediatrics recommends that all children be screened for autism. All caregivers should talk to their doctor about ASD screening or evaluation.

Signs and Symptoms of ASD

People with ASD have difficulty with social communication and interaction, restricted interests, and repetitive behaviors. The list below gives some examples of the types of behaviors that are seen in people diagnosed with ASD. Not all people with ASD will show all behaviors, but most will show several.

$Social\ communication\ /\ interaction\ behaviors\ may\ include:$

- Making little or inconsistent eye contact
- Tending not to look at or listen to people
- Rarely sharing enjoyment of objects or activities by pointing or showing things to others

- Failing to, or being slow to, respond to someone calling their name or to other verbal attempts to gain attention
- Having difficulties with the back and forth of conversation
- Often talking at length about a favorite subject without noticing that others are not interested or without giving others a chance to respond
- Having facial expressions, movements, and gestures that do not match what is being said
- Having an unusual tone of voice that may sound sing-song or flat and robot-like
- Having trouble understanding another person's point of view or being unable to predict or understand other people's actions

Restrictive / repetitive behaviors may include:

- Repeating certain behaviors or having unusual behaviors. For example, repeating words or phrases, a behavior called echolalia
- Having a lasting intense interest in certain topics, such as numbers, details, or facts
- Having overly focused interests, such as with moving objects or parts of objects
- Getting upset by slight changes in a routine
- Being more or less sensitive than other people to sensory input, such as light, noise, clothing, or temperature
- People with ASD may also experience sleep problems and irritability.

Although people with ASD experience many challenges, they may also have many strengths, including:

- Being able to learn things in detail and remember information for long periods of time
- Being strong visual and auditory learners
- Excelling in math, science, music, or art

Causes and Risk Factors

While scientists don't know the exact causes of ASD, research suggests that genes can act together with influences from the environment to affect development in ways that lead to ASD. Although scientists are still trying to understand why some people develop ASD and others don't, some risk factors include:

- Having a sibling with ASD
- Having older parents
- Having certain genetic conditions—people with conditions such as Down syndrome, fragile X syndrome, and Rett syndrome are more likely than others to have ASD
- Very low birth weight

Everyone is Unique

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. There are great differences among people with autism. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. The person may have difficulty initiating and/or maintaining a conversation, or keeping a conversation going.

People with autism process and respond to information in unique ways. Educators and other service providers must consider the unique pattern of learning strengths and difficulties in the individual with autism when assessing learning and behavior to ensure effective intervention. Individuals with autism can learn when information about their unique styles of receiving and expressing information is addressed and implemented in their programs. The abilities of an individual with autism may fluctuate from day to day due to difficulties in concentration, processing, or anxiety. The child may show evidence of learning one day, but not the next. Changes in external stimuli and anxiety can affect learning and coping strategies.

While no one can predict the future, it is known that some adults with autism live and work independently in the community (drive a car, earn a college degree, get married); some may be fairly independent in the community and only need some support for daily pressures;

while others depend on much support from family and professionals. While some adults with autism attend college, others can benefit from vocational training to provide them with the skills needed for obtaining jobs, in addition to social and recreational programs.

Many self-advocates are forming networks to share information, support each other, and speak for themselves in the public arena. More frequently, people with autism are attending and/or speaking at conferences and workshops on autism. Individuals with autism are providing valuable insight into the challenges of this disability by publishing articles and books and appearing in television specials about themselves and their disabilities.

"I am different, not less." ~ Temple Grandin

INTERVENTIONS

National Institute of Child Health and Human Development (NIH)

There is currently no one standard treatment for autism spectrum disorder (ASD).

Many people with ASD benefit from treatment, no matter how old they are when they are diagnosed. People of all ages, at all levels of ability, can often improve after well-designed interventions.

There are many ways to help minimize the symptoms and maximize the use of their abilities. People who have ASD have the best chance of using all of their abilities and skills if they receive appropriate therapies, interventions, strategies and instruction

The most effective therapies and interventions are often different for each person. However, most people with ASD respond best to highly structured and specialized programs. In some cases, treatment can greatly reduce symptoms and help people with autism with daily activities.

Because there can be overlap in symptoms between ASD and other disorders, such as attention deficit hyperactivity disorder (ADHD), it's important that treatment focus on a person's specific needs, rather than the diagnostic label.

Behavioral Management Therapy for Autism

Behavior management therapy tries to reinforce wanted behaviors and reduce unwanted behaviors. It also suggests what caregivers can do before, during, after, and between episodes of problem behaviors.

Behavioral therapy is often based on applied behavior analysis (ABA), a widely accepted approach that tracks a child's progress in improving his or her skills.

Different types of ABA commonly used to treat autism spectrum disorder (ASD) include:

Positive Behavioral and Support (PBS)

PBS aims to figure out why a child does a particular problem behavior. It works to change the environment, teach skills, and make other changes that make a correct behavior more positive for the child. This encourages the child to behave more appropriately.

Pivotal Response Training (PRT)

PRT takes place in the child's everyday environment. Its goal is to improve a few "pivotal" skills, such as motivation and taking initiative to communicate. These help the child to learn many other skills and deal with many situations.

Early Intensive Behavioral Intervention (EIBI)

EIBI provides individualized, behavioral instruction to very young children with ASD. It requires a large time commitment and provides one-on-one or small-group instruction.

Discrete Trial Teaching (DTT)/Training

DTT teaches skills in a controlled, step-by-step way. The teacher uses positive feedback to encourage the child to use new skills.

Early Intervention

Research shows that early diagnosis of and interventions for autism are more likely to have major long-term positive effects on symptoms and later skills. Autism spectrum disorder (ASD) can sometimes be diagnosed in children before they are 2 years of age.

Early intervention programs often include:

- Family training
- Speech therapy
- Physical therapy

Early interventions occur at or before preschool age. Early interventions not only give children the best start possible, but also the best chance to develop mental milestones and academic performance. The sooner a child gets help, the greater the chance for learning and progress.



Joint Attention Therapy for Autism

Research shows that many people with autism have difficulty with joint attention, which is the ability to share focus on an object or area with another person. Examples of joint attention skills include following someone else's gaze or pointed finger to look at something.

Joint attention is important to communication and language learning. Joint attention therapy focuses on improving specific skills related to shared attention.

Medication Treatment for Autism

Currently, there is no medication that can cure anyone on the autism spectrum disorder (ASD) or all of its symptoms. But some medications can help treat certain symptoms associated with ASD, especially certain behaviors.

Healthcare providers often use medications to deal with a specific behavior, such as to reduce self-injury or aggression. Minimizing a symptom allows the person with autism to focus on other things, including learning and communication. Research shows that medication is most effective when used in combination with behavioral therapies.

Nutritional Therapy

For a variety of reasons, children with autism spectrum disorder (ASD) may not get the nutrition they need for healthy growth and development. Some children with autism will only eat certain foods because of how the foods feel in their mouths. Other times, they might avoid eating foods because they associate them with stomach pain or discomfort. Some children are put on limited diets in hopes of reducing autism symptoms.

It is important that parents and caregivers work with a nutrition specialist—such as a registered dietitian—or health care provider to design a meal plan for a person with autism, especially if they want to try a limited diet. Such providers can help to make sure the child is still getting all the nutrients he or she needs to grow into a healthy adult, even while on the special diet, such as gluten-free or casein-free diets.

Parent-Mediated Therapy in Autism

In parent-mediated therapy, parents learn therapy techniques from professionals and provide specific therapies to their own child. This approach gives children with autism spectrum disorder (ASD) consistent reinforcement and training throughout the day and allows routine blending of practices in all environments throughout the day.

There are many types of therapies that parents can learn to do at home, including:

- Discrete Trial
- ABA
- Joint attention therapy
- Play Therapy
- Floor Time
- Social communication therapy
- Picture Exchange Communication (PECS)
- TEACCH
- Relationship Development Intervention RDI
- Sensory Integration

Studies suggest that parent-mediated therapies might be able to improve the child's communication skills and interactions with others.

Social Skills Training/Interventions

A lack of intuitive social ability is a hallmark of autism. Social skills training is aimed at addressing the challenges that result, and often plays a central role in treatment plans. (IAN Community Online)

Types of Social Skills interventions might include:

- Social Stories: are brief, personal stories written for children to help them understand social situations
- Comic Strip Conversations: involve "drawing" conversations to help the child learn the social rules that others learn more naturally
- Hidden Curriculum: These strategies involve directly teaching "unspoken" social rules

 Social Skills Groups: These groups offer an opportunity for individuals with ASDs to practice social skills with each other and/or typical peers on a regular basis

Speech-Language Therapy for Autism

Speech-language therapy can help people with autism spectrum disorder (ASD) improve their abilities to communicate and interact with others.

Verbal Skills: This type of therapy can help some people improve their spoken or verbal skills, such as:

- Correctly naming people and things
- Better explaining feelings and emotions
- Using words and sentences better
- Improving the rate and rhythm of speech

Non-Verbal Communication: Speech-language therapy can also teach nonverbal communication skills, such as:

- Using hand signals or sign language
- Using picture symbols to communicate (Picture Exchange Communication System)
- iPhones
- Calendars
- Communication Strips
- Visual Schedules

TEACCH (Treatment and Education of Autistic and related Communication-handicapped CHildren)

The TEACCH program focuses on persons with autism and the development of instruction and supports based on each individual's skills, interests, and needs. It emphasizes meaningfulness to apply learning across situations.

The TEACCH Approach to Autism Spectrum Disorders explains how:

- TEACCH targets critical areas in executive functioning, engagement, communication, and social skills.
- Strategies can be tailored to an individual's unique developmental and functional level.
- Parents become involved in all phases of intervention as collaborators, co-therapists, and advocates.

DIAGNOSTIC

The Autism Place (Illinois State University)

https://psychology.illinoisstate.edu/psc/autism

Phone 309.585.1117

2405 General Electric Road Suite A Bloomington, Illinois, 61704

- Grant Funded and therefore is free to families; they prioritize families for whom other options ae financially impossible
- No referral required
- Provides evaluations for children 2 and up

The Autism Clinic at Hope

2 locations in Illinois (Springfield, O'Fallon)

https://www.theautismclinic.org

Phone 217.525.8332

- In-network with all major insurance companies and Medicaid
- No Referral required
- Provides Evaluations for children ages 18 months-18 years

Waitlist is 1 year across shared locations

Carle Behavioral Health - Brent Sylvester, PhD

https://carle.org/find-a-doctor/2419

Phone: 309.556.7800 3024 E. Empire St. Bloomington, IL 61704

- Most insurance accepted, not in network with UHC, Private pay options exist.
- Referral through primary physical not required-can come from another provider who knows child well
- Provides evaluations for children ages 2 and up

Carle Clinic

https://carle.org/services/child-diagnostic-clinic

Phone: 217.383-3311 1802 S. Mattis Ave Urbana, IL 61801

- The Carle pediatric team provides a multidisciplinary evaluation
- Dr. Morton also sees patients in Bloomington/Normal on Friday's

Carle Pediatric Development and Behavioral Medicine

Prudence Hartwell, M.D., Erica D Wiebe, M.D., Charles Morton, M.D. https://carle.org/services/pediatric-developmental-and-behavioral-medicine

217.383.3100

1701 W Curtis Road, Champaign, IL 61822

- Accepts all insurance plans currently accepted by Carle
- Referral proves must be completed through the clinic

Center for Autism Spectrum Disorder (Southern Illinois University)

https://casd.siu.edu/a_screeners

Phone: 618.453.7130 625 Wham Drive Carbondale, Illinois 62901

- Grant funded, evaluations are completed at no cost to families
- No referral required
- Provides evaluations for children ages 2 and up
- Waitlist: 9-12 months for initial screening; 6 months for follow up evaluations

Easter Seals Central Illinois

https://ci.easterseals.com

Phone: 309.686.1177

507 East Armstrong Avenue

Peoria, Il 61603

- All major insurances accepted except Aetna
- Accepts Illinois Medicaid patients
- A referral is required for children aged 9 and younger

OSF Behavioral & Mental Health

https://www.osfhealthcare.org/services/specialties/mental-health

Phone: 309.664.3130 1701 E. College Ave. Bloomington, IL 61701

- Offers support to adults, teens and children seeking diagnosis, shortterm treatment or long-term management of mental and emotional health issues.
- Provides a variety of options to best fit your needs, from outpatient therapy to medication management

OSF HealthCare Adult Diagnostic Autism Clinic – Theresa Regan, Ph.D

https://www.osfhealthcare.org/services/specialties/mental-

health/programs-services/autism

Phone: 309.655.7378

515 BE Glen Oak Avenue,

Peoria, IL 61603

- Accepts all insurance
- A referral is required and must use the companies specific referral form
- Only diagnoses individuals aged 14 and up

It's okay to ask for support when you need it

Something Better Psychology - Aaron Poppy Psy.D

207 W Jefferson St Suite 402 Bloomington, IL 61701 309.520.2265

https://somethingbetterpsychology.clientsecure.me/

- Most major insurances and mental healthcare plans accepted
- No referral required
- Provides evaluations for children ages 3 and up

Waitlist: 10 months

Total Spectrum

https://totalspectrumcare.com/diagnosing-autism

Phone: 844.263.1613 1015 S Mercer Ave Bloomington, IL 61701

- Most major insurances accepted. Private pay options exist
- Provides evaluations for children ages 18 months 6 years

University of Illinois Psychological Service Center

https://psc.illinois.edu/autism-spectrum-assessment-services/

Phone: 217.333.0041

505 E. Green Street 3rd Floor Champaign, IL 61820

- Accepts Aetna, Health Alliance, BC/BS, Health Link and CPHP
- No referral needed.
- Screenings are free



EDUCATION, RESOURCES, & SERVICE PROVIDERS

Anchored Speech Therapy

https://www.anchoredspeechtherapy.com

Phone: 309.220.8641

- Providing convenient, efficient, evidence based speech, language, and feeding therapy to help individuals better communicate and connect with those around them
- Parent Coaching

Autism Professional Learning and Universal Supports (A+) project

https://autismplusil.org Phone: 309.438.7471

- creating a professional learning community for educators, related support personnel, and families supporting children and youth with ASD;
- promoting positive behavior growth and increasing the functional communication of children and youth with ASD across environments;
- increasing the access and inclusion of children and youth with ASD in schools and communities; and
- supporting the meaningful involvement of families in their children's education

Located at Illinois State University and Funded through The Illinois State Board of Education

> I know the price of Success: dedication, hard work, and an unremitting devotion to the things you want to see happen ~ Frank Lloyd Wright

Bloomington Housing Authority

www.bloomingtonha.com Phone: 309.829.2260 104 East Wood St

Bloomington, IL 61701

- Provides low income families decent, safe, sanitary housing
- Congregate Housing Services Program (CHSP) is a federally funded grant program that aims to prevent the premature institutionalization of persons with developmental disabilities.

Bloomington Pediatric Speech Therapy

https://www.bloomingtonpediatricspeech.com

Phone: 309.220.8641

- Speech Sound disorders
- Feeding Therapy
- AAC Device Use
- Assessments

Bridgeway

www.bway.org

Phone: 309.452.2797

420 Wylie Dr., Suite 464

Normal, IL 61761

- Community Support Services
- Mental Health Treatment and Recovery
- Employment Services for Persons with Disabilities

Chestnut Health Systems

www.chestnut.org Phone:309.827.6026

1003 Martin Luther King Jr Dr.

Bloomington, IL 61701

- comprehensive treatment for children and youth ages infant to 21.
- advocacy, case management, connections to community support, help in crisis situations
- Individual and Family Counseling
- Psychiatric Services

Childcare Resource and Referral Network

www.ccrrn.com

Phone: 309.828.1892

207 W Jefferson #301 Bloomington, IL 61701

- Childcare assistance program
- CCAP Health and Safety Training

District 87 Schools

www.district87.org Phone: 309.827.6031 300 E Monroe St.

Bloomington, IL 61701

- Sarah Raymond Early Childhood
- Special Education provided for children with disabilities ages 3-21
- Child Find Screening

Department of Human Services

Family Community Resource Center

www.dhs.state.il.us

Phone: 309.451.6000 (Bloomington)

501 W Washington St Bloomington, IL 61701

- Services and support for individuals with developmental disabilities are provided to help individuals with developmental disabilities achieve as much independence as possible to live in their home communities with family and friends. Skills and Vocational Training Services
- Residential Services
- Link Card, Temporary Assistance to needy families
- Medicaid, WIC

Department of Rehabilitation Services

www.dhs.state.il.us Phone: 309.662.1347 207 S. Prospect Road Bloomington, IL 61704

- State lead agency serving individuals with disabilities. ORS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education and independent living opportunities.
- Benefits Planning Program
- Home Based Services Program
- Vocational Rehabilitation Services

Door of Hope

https://www.doorofhopepediatric.com

Phone: 309.808.9806

- Provides speech and language evaluations and therapy to children aged 0-3 through the State of Illinois' Early Intervention program.
- Provides evaluations and therapy for children 4-10
- Prioritize family input and involvement, personalized home programming

Easter Seals of Central Illinois

www.easterseals.com/ci Phone: 309.663.8275 202 St Joseph Drive Bloomington, IL 61701

- ABA
- Speech, occupational, physical and developmental therapies
- Social skills group 4-7 years old
- Parent support and evaluation services
- New Diagnosis Orientation Training

EPIC

https://epicci.org

Phone: 309.271.7270

1913 W Townline Road

Peoria, IL 61615

- Serves Bloomington/Normal area also
- Behavioral Health
- Community Living, Respite Services
- Educational Services, Job Training

GBC/ABA

https://gbcautismservices.com

Phone: 312.882.1024 (Main # in Bolingbrook)

706 Oglesby Avenue #200

Normal, IL 61671

- ABA
- Social Skills
- School Consultation Services

[&]quot;Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible." ~Francis of Assisi

HALO Program – Heartland Community College

www.heartland.edu/halo Phone: 309.268.8255 SCB Room 1415 1500 W Raab Road

Normal, IL 61761

- College "certificate" classes geared toward individuals with disabilities
- Independent Living Skills
- Educational Development

Hammitt School

www.thebabyfold.org Phone: 309.452.1170 108 E. Willow St Normal, IL 61671

- Referrals made by public school districts within a 50mile radius
- Offers consultation services to the school districts to help in structuring academics, assessment of behavior and strategies to change behavior for children with autism.
- Elementary School, Jr. & Sr High School

Heartland Head Start

https://heartlandheadstart.org

Phone: 309.662.4880 206 Stillwell St Bloomington, IL 61701

- Provides comprehensive early childhood education, health, nutrition, and parent involvement services to low-income children and families
- Child must be 3 years old by September 1
- Must meet income eligibility

Homes of Hope

www.homesofhopeinc.org

Phone: 309.862.0607

705 E Lincoln Street, Suite 313

Normal, IL 61761

- Homes of Hope (HoH) is a nonprofit organization that has been serving individuals with intellectual disabilities in the Bloomington-Normal community for 25 years.
- They have 23 residents and six homes in McLean County in CILA (Community Integrated Living Arrangement)
- Offers 24 hour care provided by our compassionate, well-trained staff.
 We promote guided decision-making, self-advocacy and community involvement.

ISU Eckelmann-Taylor Speech and Hearing Clinic

https://isuspeechandhearing.com

Phone: 309.438.8641

Illinois State University

508 Dry Grove Street Campus Box 4720

Normal, IL 61790-4620

- Provides comprehensive, innovative speech-language services and hearing healthcare in Bloomington/Normal and surrounding communities.
- Speech Therapy
- Language and Cognitive Communication Disorder Therapy

Ivy Rehab

https://ivyrehab.com/physical-therapy-location/bloomington-kids

Phone: 309.948.6469

2103 N. Veterans Parkway Bloomington, IL 61704

- Pediatric Therapy
- Physical Therapy
- ABA
- Speech Therapy

Kumon Math and Reading Center

www.kumon.com/bloomington

Phone: 309.829.5053

Bloomington Commons 1701 E. Empire St. Ste 300 Bloomington, IL 61704

 Master math and reading, Establish study skills, Individualized lesson plans

Life Center for Independent Living

www.lifecil.org

Phone: 888.543.3245 (Toll free) 309.663.5433 (Local) 2201 Eastland Drive, Suite 1 Bloomington, IL 61704

- Promotes local, state and national advocacy
- Provides support services
- Raise community awareness about disability issues
- Educates disabled individuals about their rights and responsibilities

Lifelong Access

www.lifelongacess.org Phone: 309.451.8888 2000 Jacobssen Drive Normal, IL 61761

- The Supported Employment Program (SEP) helps people with developmental disabilities find and keep viable community jobs
- Friendsfirst: A drop-in program for adults
- Developmental Training (DT) program
- Pediatric Therapy Center, provides early intervention services for the families with children from birth through early childhood, who have developmental disabilities or delays or who are at risk for delay due to environmental or medical concerns. Services include but are not limited to ABA therapy, Physical Therapy, and Speech Therapy

McLean County Health Department

https://health.mcleancountyil.gov

Phone: 309.888.5450 200 W. Front St

Bloomington, IL 61701

- Mental Health First Aid Trainings
- Dental Medicaid / All Kids
- Immunizations

McLean County Local Interagency Council

www.cicfc.org/lic Phone: 309.888.5539

200 W Front St. Bloomington, IL 61701

- Degional intake according to shildren high to t

- Regional intake agency for children birth to three and their families to enter the Illinois Early Intervention System.
- Free developmental screenings
- Family Support
- Early intervention screenings

PATH

www.pathcrisis.org Phone: 309.828.1022

> 115 W Jefferson St Suite 103 Bloomington, IL 61701

• Suicide Prevention Hotline Call or text 988 for immediate support



The Place for Children with Autism

https://theplaceforchildrenwithautism.com

Phone: 224.436.0788

301 S Prospect Road Suite 2 Bloomington, IL 61704

- Individualized Autism Assessment
- Developing Communication Skills
- Developing Social Skills
- Potty Training
- Speech Therapy
- Parent and caregiver support

SOAR

www.bloomingtonparks.org/programs/soar

Phone: 309.434.2260

115 E Washington St. Bloomington, IL 61701

- Recreational opportunities
- Leisure Educational Opportunities
- Crafts and social opportunities

TCRC, Inc (Tazewell County Health Department)

https://tcrcorg.com Phone: 309.925.5511

> 21310 Illinois Route #9 Tremont, IL 61568

- Early Intervention
- Residential Services
- Vocational and Employment Services
- Job training and placement
- Day Programs

(TAP) The Autism Place at Illinois State University

www.psychology.ilstu.edu/PSC/AutismService.html

Phone: 309.585.1117

Karla Doepke, Ph.D., Affiliate Director

2405 GE Rd.

Bloomington, IL 61704

- Direct Clinical Services to children with autism spectrum disorders and their families.
- Community resources to parents and professionals
- Training for day care workers, first responders, social workers, physicians and other professionals throughout the community who may come in contact with individuals with autism
- Social Skills Groups

The Friends of TAP (FoTAP)

Phone: 309.452.9043

Website https://www.friendsoftap.com

 The Friends of TAP is a 501(c)(3) providing financial assistance to and increasing the awareness of The Autism Place (TAP) in Normal, IL.

Total Spectrum Center

www.totalspectrumcare.com/illinois/bloomington

Phone: 309.663.0488 1015 S Mercer Ave. Bloomington, IL 61701

- Contemporary applied behavior analysis (ABA) is at the core of everything we do.
- Speech Therapy
- Social Skills Groups
- School Readiness Program

Tri-County Special Education Association

http://www.tcsea.org Phone: 309.828.5231

> 105 E. Hamilton Road Bloomington, IL 61704

- Provides services to students enrolled in special education programs.
- Provides administrative, psychological, social work and supervisory services and serviced by the Regional Office of Education in Logan, McLean, Dewitt counties

Unit #5 School District

www.unit5.org

Phone: 309.557.4000 1809 W Hovey Road Normal, IL 61761

- Mclean County School District
- Sugarcreek Early Childhood & Brigham Early Learning Center
- Child Find Screening



University of Illinois Urbana-Champaign

https://dres.illinois.edu/apply/supports-for-students-with-autism

Phone: 217.333.1970 1207 S. Oak St. Champaign, IL 61820

- Disability Resources and Educational Services (DRES) has been providing accommodations and comprehensive support services to University of Illinois students with autism spectrum disorders for the past 20 years.
- Academic Coaching that focused on executive functioning
- Consultation with Housing
- We work with each student (and in many cases their family, college, and department) to set up accommodations and supports based on the students' strengths and weaknesses.
- Check in with their professors on a regular basis to see how things are going so we can be proactive about solving problems, and we serve as consultants with faculty, departments, and housing to provide recommendations for accommodations for unique classroom requirements or problem behaviors.
- Our graduation rate for students on the autism spectrum is 85%, which
 is consistent with the University of Illinois graduation rate. Most of
 these students are employed or go on to graduate school.

Western Avenue Community Center

https://westernavenuecc.org

Phone: 309.834.9252 600 N. Western Ave. Bloomington, IL 61701

- Western Avenue provides clients with services that include interpretation and translation in the Bloomington-Normal and central Illinois areas. The can help translate for Doctor visits, Hospital visits, Conferences, Court and more
- Western Avenue can also provide personal document and business document translations as needed

TRANSPORTATION

Connect Transit

www.connect-transit.com

Phone: 309.828.9833 TDD: 309.828.7511

351 Wylie Drive Normal, IL 61761

The ADA states that Connect Transit's regular bus service should be the primary means of public transportation for everyone, including people with disabilities. Under the ADA, Connect Mobility will serve as an alternate option for those persons who do not have the functional capability to ride Connect Transit's buses.

Connect Mobility

Connect Mobility provides a, shared ride, origin to destination service for persons who, because of disability, age, or injury are unable to use the fixed route buses

- Cost: ADA Eligible Riders / Regular Service area \$1.25 each way
- Personal Attendants of ADA Eligible Riders- Free
- To schedule a ride: 309.828.7511 (must have been approved through application process)

Links

<u>ADA Eligibility Application:</u> https://www.connect-transit.com/civicax/filebank/blobdload.aspx?BlobID=23471

Connect Mobility - Rider Guide: https://www.connect-transit.com/civicax/filebank/blobdload.aspx?BlobID=23844

Connect Mobility FAQS: https://www.connect-transit.com/riding/connectmobilityfaq.asp

DENTAL

Dental Lifeline Network

https://dentallifeline.org Phone: 303.534.5360

- Nationally provides access to dental care and education for people who cannot afford it, have a permanent disability, are 65 or older and/or who are medically fragile.
- Qualified applicants must be severe enough to prohibit or significantly limit gainful employment. In addition, they can neither afford dental care nor receive it through other programs. They must need extensive treatment, not just a cleaning and check-up.

DPD Smiles Pediatric Orthodontics

www.dpdsmiles.com Phone: 630.469.7696 722 S President St Wheaton, Illinois 60189

- Provides dental care for special needs
- Locations in Wheaton and St. Charles

Gibson Area Hospital Dental Health

www.gibsonhospital.org/locations/profile/dental-health

Phone: 217.784.2701 1120 N Melvin Gibson City, Illinois 60936

- Accepts Medicaid
- Full range of dental services



Humanitarian Foundation/Grottoes of North America

www.hfgrotto.org Phone: 614.933.0711 430 Beecher Road Gahanna, Ohio 43230

- A program that helps cover the cost of dental treatment and anesthesia costs, whether done in a hospital setting or dental office.
- The Dental Care for Children with Special Needs Program is designed for children under 18 with one or more of the following conditions: Cerebral Palsy, Muscular Dystrophy and related neuromuscular disorders, intellectual challenges for profound to 2 years overall delayed

Jerger Pediatric Dentistry

https://www.drbretpedo.com

Phone: 217.875.3080

2101 North Main Street Decatur, Illinois 62526

- Experience with special needs patients
- Full range of dental services

Just Kids Dentistry

https://www.justkidzdentistry.com/services/special-needs-dentistry Phone: 309.690.3368 (Peoria Office)

1320 W Northmoor Rd, Ste A Peoria, IL 61614

- special needs dentistry in Peoria and Washington, Illinois
- Individualized treatment plan

You don't have to brush your teeth – just the ones you want to keep.

McLean County Health Department Dental Clinic

https://health.mcleancountyil.gov/95/Dental-Clinic

Phone: 309.888.5479

200 W Front St Room 104 Bloomington, Illinois 61701

- Preventative and Restorative Dental Services
- Clients must meet financial requirements and be residents of McLean County, Illinois

Parkland Dental Hygiene Clinic

www.parkland.edu/Main/Academics/Departments/Health-Professions/Dental-Hygiene-Clinic

Phone: 217.351.2221

2400 West Bradley Avenue L148

Champaign, Illinois 61821

- Oral examination + X-Rays
- Nitrous and Oxygen Sedation
- Wide range of dental services

Pediatric Smiles of Bloomington

www.pediatricsmilesofbloomington.com

Phone: 309.663.7339 1112 Trinity Lane

Bloomington, Illinois 61704

 Serves infants, children and teens in Bloomington-Normal, IL and the surrounding cities of Lincoln, Clinton, and Pontiac, IL.

ORGANIZATIONS / SOCIAL GROUPS / RECREATION

LOCAL

Autism McLean

https://autismmclean.org Phone: 309.661.9440 Autism Mclean

PO Box 422 Normal. Illinois 6171

- Networking with other community organizations to be able to provide resources to families
- Connecting families, and individuals with each other
- Family outings and recreational opportunities
- Recreational and Educational Stipends
- Communication Boards in the community
- Sensory Bags to families and businesses to help individuals with sensory issues gain access to the community

Autism Friendly Community

https://autismmclean.org

- Autism Friendly Community (AFC) is Autism McLean's community
 outreach program— helping McLean County to be truly autism- friendly: one business, one organization, one person at a time! We
 partner with local businesses, organizations and individuals to expand
 awareness and inclusion.
- Six Aspirations to becoming an Autism Friendly Community
 - *Welcome Me *Learn with Me *A Place for Me
 - * Wellness for Me *Work with Me * Recreation for Me
- Visit our website to complete the survey and see what else you can do

Best Buddies

www.bestbuddies.org/illinois

Phone: 312.828.9313

Central Illinois Office of Best Buddies

7800 N Sommer St Peoria, IL 61615

- Illinois State University Chapter register online at the above web address
- Creates opportunities for one-to-one friendships, integrated employment, leadership development, and inclusive living for individuals with intellectual and developmental disabilities (IDD).

Central Illinois Courage - Special Hockey

www.facebook.com/profile.php?id=100095216676723&sk=about_details www.specialhockey.org/page/show/5887449-what-is-special-hockey Email: cishacourage@gmail.com

- Special needs hockey located at Bloomington Ice Center
- Special Hockey™ is our brand of an adaptive version of ice hockey for athletes with intellectual, developmental, and physical disabilities. Special Hockey™ provides a supportive environment for athletes of differing abilities with a focus on sportsmanship, teamwork, friendships and achieving goals on and off the ice. This focus leads to improved physical and mental health, and provides a community of families and peers, positively impacting the quality of life for the athlete and their family.

Eastview Christian Church Special Needs

https://eastview.church/specialneeds

Phone: 309.451.5000

1500 North Airport Road Normal, IL 61761

- Special Needs Care Group
- Buddy Program
- Sensory Room
- Adapted Curriculum
- Adult Special Needs Class

The HEAL Foundation (Heroes Embracing Autistic Lives)

www.jonsheroes.org/
JONS@gmail.com
309.663.6946
402 Lake Shore Circle
Bloomington, Illinois 61704

- Heroes Embracing Autistic Lives founded by Jon Miskulin (age 18)
 Bloomington, IL
- This is an opportunity for children with ASD to receive high quality physical education from teacher candidates enrolled in an Adapted Physical Education class at Illinois State University.

Lifelong Friends

www.lifelongaccess.org Phone: 309.454.8888 2000 Jacobssen Drive Normal, IL 61761

- Gives people the opportunity to learn new skills, share talents and foster independence.
- Activities include gardening, music, arts and crafts, lessons related to overall well-being

The Miracle League of Central Illinois

https://miracleleagueci.com Phone: 309.454.9661

- Provides physically and mentally challenged children a safe and spirited program in which they can play on a baseball field just like other kids.
- Miracle League baseball offers a unique and memorable opportunity these children would not otherwise have.



The Penguin Project of McLean County

www.penguinprojectmclean.org penguinprojectmclean@gmail.com

- Once a year, a magical and touching celebration of the human spirit unfolds at U-High's Stroud Auditorium in Normal, Illinois. A group of young people in a program called The Penguin Project® McLean County take to the stage to perform a modified version of a wellknown Broadway musical.
- The roles are filled by children and young adults with developmental disabilities and are joined on stage by their "peer mentors," a group of young people the same age without disabilities, who have volunteered to work with them side-by-side and guide them through 4 months of rehearsals and to the final production.

Seedling Theatre

www.ilvoicestheatre.org info@ilvoicestheatre.org

- Providing a creative stage for the young at heart, of all abilities and challenges, to embrace and let shine our true selves through the magic of theatre
- winter/spring workshops and our newest addition, Seedling Encore, encompassing our older special needs population 18 years and older in performing live theatre.
- Seedling Theatre has had quite a successful run since 2009 bringing
 McLean County's special needs population together with their ablebodied peers to enjoy the fun and challenge of performing live theatre



SOAR (Special Opportunities Available in Recreation)

www.bloomingtonparks.org/home-parksrec

Phone: 309.434.2260 115 E. Washington Bloomington, IL 61701

 The ultimate goal of S.O.A.R. is to provide therapeutic recreation services for individuals with disabilities who are unable to successfully participate in general recreation programs. With these specialized services, participants will benefit through skill development, leisure education and socialization..

Special Olympics Illinois

www.soill.org/

Phone: 309.888.2551 605 E Willow St Normal, IL 61761

- Special Olympics Young Athletes program is an innovative sports play program for children ages 2-7 with intellectual disabilities and their peers, designed to introduce them into the world of sports Sporting Competitions
- Athletes are the focus of our organization and the reason we are here.
 Our traditional sports program serves athletes from ages 8 onward
- Ages 8-over 80



STATE

Autism Support of Central Illinois

http://autismcil.org Phone: 217.585.1421

5220 S. 6th Street Road, Suite 23008

Springfield, IL 62703

 ASCI is a 501 ©(3) nonprofit organization, founded in 2002 for the purpose of improving the lives of those affected by autism in central Illinois

ARC of Illinois

www.thearcofil.org Phone: 815.464.1832 7550 183rd St

Tinley Park, IL 60477

- Assistive Technology Fund up to \$500

 Consumer Stipend (Financial Assistance for Training)
- Provides services to people with developmental disabilities and their families.
- Assists with transportation, child care, lifespan options and training opportunities.

The Autism Collective (Easter Seals)

https://theautismcollective.org

Phone: 844.910.9770

507 East Armstrong Avenue Peoria, IL 61603-3201

- Connects families with support services in your area.
- Assists with navigating complexities of health insurance.

Alone we can do so little; together we can do so much

Central Illinois Autism Association

https://autismpeoria.com Phone: 309.686.1177 x 2241 507 East Armstrong Avenue

Peoria, IL 61603

- Provide grants to local schools, therapists, families, and individuals that help support those with autism.
- Provide autism-friendly community events where children, adults, and families can thrive.
- Promote the acceptance and inclusion of the autism community in Central Illinois

CU ABLE

https://www.cuable.org

Facebook: https://www.facebook.com/groups/CUAble Champaign, IL 61803

- Provides resources to the Champaign Urbana area
- This passionate 501(c)3 organization works to create a safe and accepting support network for families with children with disabilities

Family Resource Center on Disabilities

https://dscc.uic.edu/dscc_resource/family-resource-center-on-disabilities-frcd

Phone: 800.322.3722

Home Federal Building 11 East Adams St. Suite 1002 Chicago, IL 60603

- The FRCD serves the following eight Illinois counties: Cook, DuPage, Grundy, Kane, Kendall, Lake, McHenry and Will
- Assists in finding specialized medical care
- Resources and information
- Assists in preparing for transition
- Care coordination program

Giant Steps

www.mygiantsteps.org Phone: 630.864.3800 2500 Cabot Drive Lisle, IL 60532

- Innovative educational and therapeutic program for individuals living with autism.
- Non-therapeutic day school for children with autism spectrum disorders.
- Day School
- Adult Day Care
- Equine Center

Illinois Center for Autism

https://illinoiscenterforautism.org

Phone: 618.398.7500 548 S Ruby Lane Fairview Heights, IL 62208

- A not-for-profit community based mental health treatment and educational agency dedicated to serving people with autism.
 Referrals are made through local school districts, hospitals, doctors and DHS.
- Advocacy and choice to promote lifelong independence
- Positive approach to maladaptive behavior
- ICA is approved by the Illinois State Board of Education

Illinois Lifespan

www.illinoislifespan.org Phone: 800.588.7002

20901 South La Grange Road

Frankfort, IL 60423

- A division of the ARC of Illinois
- Website provides searchable state-wide resources

PUNS -Central Illinois Service Access

(ISC = Independent Service Coordination)

https://ccrpc.org/ 217.732.4731 101 Madigan D Lincoln, IL 62656

- Bloomington-Normal families contact this agency to sign up for PUNS (Prioritization of Unmet Needs and Services)
- PUNS is a statewide database that records information about individuals who have developmental disabilities and are potentially in need of services.
- The State of Illinois uses the data to select individuals for services as funding becomes available.
- The ISC (Independent Service Coordination) Agent will work with the individual and their family to identify the need for services, explain services, and identify the urgency of need.
- PUNS funding will be essential as your child ages, needs services after the age of 22, needs housing.
- PUNS selections are based upon funding availability or if it's determined that you need help right away regardless of age or income.

The Autism Project of Illinois

https://tap-illinois.org

Phone: 217.953.0894 x 30476

Hope Pavilion

5220 S. 6th Street Ste. 2300B

Springfield, IL 62703

- Service network that is a collaboration of 4 universities and 11 organizations that operate 20 centers across Illinois
- Offers services unique to each individual in each specific community.
- Continually develops systems and initiatives and a network of resources for autism across the state

NATIONAL

Autism Research Institute

www.autism.org

Phone: 833.281.7165

4182 Adams Avenue

San Diego, California, 92116

- Support the health and well-being of people affected by autism through innovative, impactful research and education.
- Pioneers research, outreach, and cooperative efforts with other organizations worldwide. ARI advocates for the rights of people with ASD, and operates without funding from special-interest groups.

Autism Society of America

https://www.autism-society.org

Phone: 800.328.8476

6100 Executive Blvd Suite 305 Rockville, Maryland 20852

- Autism Resource Database
- Advocacy
- Training and Educational Opportunities

Autism Speaks

www.autismspeaks.org

Phone: 888.288,4762

1060 State Road, 2nd Floor

Princeton, NJ 08540

- Printable Toolkits for home, family, school
- Financial Planning Toolkits
- Autism information and links to other organizations



CAMPS

Camp Big Sky

https://campbigsky.org Phone: 309.258.6002

17185 E McCord Road Farview, IL 61432

 Provides education, training and skills development to children and adults with disabilities through participation in accessible via outdoor activities.

Camp New Hope

https://campnewhopeillinois.org

Phone: 217.895.2341

1364 County Road 100 East

Neoga, IL 62447

- Year-round recreational opportunities for individuals 8 years old and above with developmental and physical disabilities on the Lakes of Mattoon in central Illinois.
- Week long overnight camps
- Respite Program
- Holiday Programs

Special Camps

www.specialcamps.org

Phone: 630.690.0944

26 W 684 Lindsey Avenue

Winfield, IL 61090

- Provides opportunities for children and adults with intellectual disabilities to experience new activities, form friendships, increase independence and self-esteem in 5 day/overnight summer camps.
- Weekes are separated by 8-23 and over 24yrs.
- Stipends available

Timber Pointe Outdoor Center

www.timberpointeoutdoorcenter.com

Phone: 309.365.8021 20 Timber Pointe Ln.

Hudson, IL 61748

 Weekend Camps, Family Retreats, Day Camps, Summer Overnight Camps

 Campers participate in traditional camp activities such as zip lining, fishing, boating, arts & crafts, target sports, music, horseback riding and more



GENERAL AUTISM WEBSITES

Autism Grown Up

https://www.autismgrownup.com

- Lifespan Toolbox
- Free Resources
- Life Course Library
- A multitude of great resources

Autism McLean

www.autismmclean.org

- Local activities for families
- Resources for therapies and support
- Stipends

Autism Research Institute

www.autism.org

- ARI is devoted to conducting research and to disseminating the results of research on the triggers of autism and on the methods of diagnosing and treating autism. Research based information for parents and professionals.
- Six decades sustaining independent autism research & education.

Autism Society of America

www.autismsociety.org

- Since 1965, the Autism Society of America, and our affiliate network, connects people to the resources they need through education, advocacy, resources, and community programming.
- Resources on friends, puberty, siblings, sleep, and more

In the end we retain from our studies only that which we practically apply.

~ Johann Wolfgang Von Goethe

Autism Speaks

www.autismspeaks.org

- Resources to many prominent autism sites
- Education Campaign Materials
- Online Merchandise Store
- Printable Toolkits for home, family and school

Autism Today

www.autismtoday.com

- Resources for families and professionals
- Scholarships
- Mentor programs
- Exceptional Resources offers an ever expanding, wide variety of easy-to-use, cost effective tools, tips and tricks for the autism and neurodiversity spectrum which is backed up by leading and professional expertise in the field.

Ohio Center for Autism and Low Incidence (OCALI)

https://ocali.org

- Autism Certification Program
- Grab and Go resources
- Teaching diverse learners tips and strategies
- Lifespan transition framework and tools

Organization for Autism Research

https://researchautism.org

- OAR was founded in December 2001 by seven individuals whose lives and families had been directly impacted by autism.
- There are many organizations dedicated to autism. What distinguishes OAR is our singular focus on applied research and the quality and practical value of our resource materials.
- Resources for families, siblings, and professionals

Spark of Autism

https://sparkforautism.org

- World's largest autism research study which is part of the Simons Foundation Autism Research Initiative (SFARI)
- The Diversity, Equity, and Inclusion (DEI) Advisory Board guides SPARK's efforts to increase representation of communities of color in autism research.
- Many resources and videos

University of Illinois Chicago

https://cfl.uic.edu/overview/rcadd

- Many online resources including; social stories, printable visuals, tip sheets, and back to school tools
- Regular virtual workshops



DISABILITIES IN EDUCATION GUIDANCE

Individualized Education Program (IEP)

The IEP annual review meeting, required by Federal statutes, is convened at least once a school year to plan educational services that are tailored to the individual needs of each child with a disability. Any member of the Team may request an IEP meeting. The annual review is held to review the child's progress on goals and objectives over the past school year, to develop new goals for the following year, and determine placement. The child's Team is composed of parents, teachers, administrators, therapists, and any other invited parties. Team members bring to the table, knowledge of not only their field, but of the child's strengths and weaknesses. It is important that all members speak openly, yet respectfully, while discussing the child's disability, and educational plans.

Make Every Attempt To Maintain A Pleasant Relationship With The Team

- Show respect for each other.
- Be patient as the Team learns about your child.
- Model the behavior you want from the other IEP Team members

Preparation, Preparation, Preparation

The IEP may be an overwhelming and emotional experience for the parent. Be prepared, and plan ahead. One aspect of being prepared for the annual review is to have a continuing channel of communication throughout the school year with Team members.

- About one month prior to the annual review, make a written request to Team members to obtain proposed goals and objectives. If you. the parent have proposed goals, you should provide them to the appropriate Team members for consideration. Set up an appointment to discuss the proposed goals, at least one week in advance of the IEP.
- The IEP can be a very intimidating experience. Many parents ask a friend or support person to attend the meeting. The support person is present to take notes, enabling the parent to actively listen and contribute to the Team's educational planning for the next school year.

Focus On The Child's Needs, Not The District's Nor The Parents

The Individuals with Disabilities Education Act IDEA. is designed for children with special needs to have access to a Free and Appropriate Public Education FAPE. in their Least Restrictive Environment LRE.

- The Team will evaluate your child. Together, the Team develops a strategy.
- Design specific, measurable, and realistic yearly IEP goals.
- Although parents want the best for their child; school districts do not have to provide "the best", schools are obligated to provide an appropriate education for your child to make progress. Learn to find what is "appropriate" for your child and work to achieve that.

Have A Dilemma? Or Confused

- When differences occur, try to work as a team to find creative solutions to meet the educational needs of your child.
- Encourage problem solving prior to the IEP with the Team.
- Have more than one approach to offer.
- Be prepared to back your suggestions with documentation/research on why and how it would work for your child
- If you have a disagreement, try to not make it personal. Everyone is entitled to their view and position. You just have to learn to sell yours as the most appropriate choice.

Build Your Paper Trail.

- Be calm if you are concerned about how a situation is developing.
- Prepare to produce reports to illustrate, if for example, goals are not being attempted.
- Always have a written record of all reports, documents, as well as, documenting dates and times of informal meetings and telephone calls.
- Provide written solutions for the Team on how situations are handled at home for your child.

Trade Shoes for a Day

- Think seriously about the Teacher and District's view.
- Volunteer occasionally in your child's class or school.
- Invite Team members to visit your child's home life.
- Offer suggestions instead of demands.
- Provide research to the Team regarding your child's special needs.

Listen, Even If You Don't Want To

- Open your ears, heart, and head.
- Try to not over react, keep listening.
- Stay focused and calmly state your position.

Good Faith

- Generally, trust your child's Team to act in good faith.
- If they need education, supply it.
- If you need educated about something, ask for it.

Illinois State Board of Education information for parents of special needs

https://www.isbe.net/Pages/Special-Education-Parents-of-Students-with-Disabilities.aspx

The above was taken with permission- in part and consolidated from "Play Hearts, Not Poker", By: Jennifer Bollero, Esq.
Full version of this article can be found at: www.wrightslaw.com

Least Restrictive Environment (LRE)

In implementing IDEA's LRE provisions, the general education classroom in the school the student would attend if not disabled, is the first placement option considered for each student with a disability, before a more restrictive placement is considered.

If the IEP of a student with a disability can be implemented satisfactorily with the provision of supplementary aids and services in the general education classroom in the school the student would attend if not disabled, that placement is the LRE placement for the student.

However, if the student's IEP cannot be implemented satisfactorily in that environment, with the provision of supplementary aids and services in the general education classroom in the school the student would attend if not disabled, it is not the LRE placement for that student.

Placement decisions are to be determined by the services the child needs. Cost or administrative convenience, are not the force that determines the placement of the child. It is the duty of the Team to determine the most appropriate placement, considering the opportunities and appropriateness of being educated with similar-aged non-disabled peers.

Extended School Year (ESY)

During the annual review the team will make a determination of the need for Extended School Year Services. ESY is in essence, a continuation or extension of the prior year's IEP. ESY services may consist of all academics with related services, i.e., speech. Should the team deem ESY appropriate, services should be delivered in the same placement option as was done in the regular school year. IEP Teams should consider the following factors in making ESY decisions:

- Regression and recoupment in the Fall
- Degree of progress toward IEP goals
- Emerging skills/breakthrough opportunities
- Interfering behavior
- Nature and/or severity of disability
- Availability of alternative resources
- Areas of curriculum that need continuous attention
- Vocational needs

The difficulty lies not so much in developing new ideas as in escaping from old ones

7 Areas for Consideration

In the development of the Individualized Education Program (IEP) for a student on the autism spectrum (which includes autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Rett Syndrome, as defined in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV, 2000)), the IEP team shall consider all of the following factors:

- 1. The verbal and nonverbal communication needs of the child.
- 2. The need to develop social interaction skills and proficiencies.
- 3. The needs resulting from the child's unusual responses to sensory experiences.
- 4. The needs resulting from resistance to environmental change or change in daily routines.
- 5. The needs resulting from engagement in repetitive activities and stereotyped movements.
- The need for any positive behavioral interventions, strategies, and supports to address any behavioral difficulties resulting from autism spectrum disorder.
- Other needs resulting from the child's disability that impact progress in the general curriculum, including social and emotional development.

This Act of the 95th General Assembly does not create any new entitlement to a service, program, or benefit, but must not affect any entitlement to a service, program, or benefit created by any other law.

These changes to the Illinois special education regulations were finalized and published on June 29, 2007. A full copy of these regulations can be found at: https://www.isbe.net/Documents/ASD_guidance_08-1.pdf

EDUCATION, TRAINING & ADVOCACY

Illinois

Autism Training and Technical Assistance (ATTA)

https://autismcollegeandcareer.com

Phone: 309.438.5122 Campus Box 5911B Normal, IL 61790

 Creates resources and provides professional development that assists individuals with autism spectrum disorder in their transition from secondary to post-secondary education or employment.

Breaking Autism

www.breakingautism.com Phone: 224.552.0265 Chicago Based

- Online Special Education Rights & Resources
- How to track progress on IEP Goals
- Education, Media, & Speaking Engagements
- Legal Assistance and Advocacy

Center for Best Practices in Early Childhood (Western IL University)

www.wiu.edu/coehs/thecenter

Phone: 309.298.1634 x 252

Horrabin Hall 32 1 University Circle Macomb, IL 61455

- Promotes family-centered, research-based practices designed to improve educational opportunities for all young children.
- StarNet (link below) offers professional development to support educators and families

Equip for Equality

www.equipforequality.org

Phone: 800.537.2632 (toll free)

312.341.0022

20 North Michigan Avenue #300

Chicago, IL 60602

- Promotes self-advocacy
- Advocates through public policy and legislative activities to give people greater choices in their lives and ensure their independence and inclusion in all aspects of community living
- Serves as the federally mandated Protection & Advocacy System for the state of Illinois

Family Matters

www.fmptic.org

Phone: 866.436.7842

1901 S. 4th St., Ste. 209 Effingham, IL 62401

- Parent Training and Information Center
- Builds upon families' strengths, empower parents and professionals to achieve the strongest possible outcomes for students with disabilities
- Offers parent and professional trainings
- Resources online

Illinois Assistive Technology Program

https://iltech.org

Phone: 217.522.7985 701 N Walnut St

Springfield, IL 62702

- Assists people of all ages with disabilities and health conditions greater access to assistive technology (AT) devices and services.
- Offers numerous assistive technology programs and services to learn about and try AT devices.

Illinois Early Childhood Clearinghouse

https://eiclearinghouse.org

Phone: 877.275.3227

Illinois Early Childhood Clearinghouse University of Illinois Champaign Urbana Children's Research Center Room 20 51 Gerty Drive

Champaign, IL 61820-7469

- Identifies and collects research-based and best-practice early intervention information to share with families
- Provides a collection of services for families of children from birth to age 3

Starnet-Regions I and III

https://starnet.org/home Phone: 309.298.1634

Western Illinois University

Horrabin Hall 32 Macomb, IL 61455

- Provides a variety of opportunities for personal and professional growth for those who touch the lives of young children, ages birth through eight, with an emphasis on children with special needs
- Supports family-centered, researched and effective practices in early childhood education and care.

Illinois State Board of Education

www.isbe.net

Phone: 866.262.6663 100 N. 1st St. Springfield, IL 62277

- ISBE Parents Rights Guide IEP Guide
- Dispute Resolution
- Listings for Residential placements start at the local level

EDUCATIONAL WEB SITES

Access Living

www.accessliving.org

- A center of service and advocacy for people with disabilities, run by people with disabilities.
- Update to date information for educational and disability laws in Illinois

Center for Parent and Information Resources

https://www.parentcenterhub.org/

- All the materials found on the CPIR Hub have been created and archived for Parent Centers around the country to help them provide support and services to the families they serve
- Hub" of information and products created for the network of Parent
 Centers across the country serving families of children with disabilities.
- Monthly e-news
- Spanish translation

OCALI - Ohio Center for Autism and Low Incidence

www.ocali.org/autism-center

- Resources and interventions to support students with autism
- Introductions to autism
- Find breaking news and the latest in autism research

Teachers Pay Teachers

https://www.teacherspayteachers.com

- Subscription based resources for anyone to use
- Teachers Pay Teachers is the go-to platform created by teachers, for teachers to access the community, content, and tools they need to teach at their best.
- A marketplace for teachers to exchange instructional materials and access easy-to-use digital tools.

U.S. Department of Education's Individuals with Disabilities Education Act (IDEA)

https://sites.ed.gov/idea

- (IDEA) website, which brings together IDEA information and resources
- Whether you are a student, parent, educator, service provider, you are here because you care about children with disabilities and their families and want to find information and explore resources on infants, toddlers, children, and youth with disabilities.

Wrights Law

www.wrightslaw.com

- Accurate, up-to-date information about special education law and advocacy for children with disabilities.
- Online advocate library
- Online law library
- The Special Ed Advocate Newsletter

[&]quot;The true character of a society is revealed in how it treats its children"
~Nelson Mandala

FINANCIAL INFORMATION & ASSISTANCE

ABLE Accounts

https://www.ablenow.com

Phone: 844-669-2253

- Contribute up to \$15,000 each year.
- Tax advantages
- Save while maintaining eligibility for public benefits such as Medicaid and Supplemental Security Income (SSI).
- Pay for a variety of expenses related to maintaining health, independence and quality of life.

The All Kids Program

Healthcare and Family Services (HFS)

www2.illinois.gov/hfs/MedicalPrograms/AllKids/Pages/default.aspx

Phone: 866.255.5437

McLean County Health 200 West Front Street Suite 400 Bloomington, IL 61701

The All Kids program offers many Illinois children comprehensive
healthcare that includes doctors visits, hospital stays, prescription
drugs, vision care, dental care and medical devices like eyeglasses and
asthma inhalers. Some families pay monthly premiums for the
coverage, but rates for middle-income families are significantly lower
than they are on the private market.

Autism Care Today

https://www.act-today.org/apply-for-grant/

- Autism Care Today's goal is to introduce and help facilitate early and on-going treatment by providing the necessary resources (including referrals, funding and guidance) to individuals with autism and their families throughout the United States.
- Grants typically range from \$100 to \$5,000

Autism Hero Project

https://www.autismheroproject.org/

 Grants to sponsor medical insurance for individuals with autism to cover the cost of ABA therapy.

Autism McLean

https://autismmclean.org

Phone: 309.661.9440 Autism Mclean

2404 E Empire St

Bloomington, IL 61704

- Recreational and Educational Stipends
- iPad Grants
- Post-Secondary Scholarships

The Arc of Illinois

www.thearcofil.org/

Phone: 815.464.1832 7500 183rd St

Tinley Park, IL 60477

• The Arc of Illinois, through a grant from the Illinois Council on Developmental Disabilities, administers the Financial Assistance and Training and distributes consumer stipend funds to enable people with developmental disabilities and their family members to attend conferences of their choice that are directly related to developmental disability issues.



Healthwell Foundation

https://www.healthwellfoundation.org

The HealthWell Foundation is a leading independent non-profit dedicated to improving access to health care for America's underinsured. When health insurance is not enough, we fill the gap by assisting with copays, premiums, deductibles and out-of-pocket expenses. In 2021, we awarded more than \$818 million in grants through our Disease Funds, and since 2004 we have helped more than 727,000 patients afford essential treatments and medications. HealthWell is recognized as one of America's most efficient charities — 100 percent of every dollar donated goes directly to patient grants and services. We provide financial assistance to help with:

- Prescription copays
- Health insurance premiums, deductibles and coinsurance
- Pediatric treatment costs
- Travel costs
- Behavioral health services

Illinois Department of Human Resources

www.dhs.state.il.us/page.aspx

Phone: 800.843.6154

Local offices located throughout the state of Illinois

- SNAP
- Medical Assistance
- Cash Assistance

IL Department of Rehabilitation Services

www.dhs.state.il.us

Phone: 309.662.1347

207 S. Prospect Road

Bloomington, IL 61704

- May be able to provide a personal support worker in the home.
- Vocational Rehabilitation Services

Maggie Welby Foundation

https://www.maggiewelby.org/scholarships-grants

- The Maggie Welby Foundation offers scholarships for children grades
 Kindergarten through twelfth grade. The scholarships are awarded
 annually to children who demonstrate a financial need, and complete
 the Maggie Welby Foundation Scholarship Application
- awards scholarships twice per year. Applications are accepted in the months of October and March and awarded in the months of December and May
- Please note this is for <u>scholarships</u> for school and <u>not grants</u> for therapies and medical bills

Medicaid

www.medicaid.gov

Phone: 309.451.6000 (Local)

DHS Family Community Resource Center

501 W Washington St Bloomington, IL 61701

Income / disability / age based medical assistance program

• May cover services for behavioral therapy for children with autism

PUNS -Central Illinois Service Access

(ISC = Independent Service Coordination)

https://www.cisagroup.org/

Phone: 217.732.4731 101 Madigan Dr. Lincoln, IL 62656

- Bloomington-Normal families contact this agency to sign up for PUNS (Prioritization of Unmet Needs and Services)
- PUNS is a database that registers individuals who want or need
 Developmental Disability Waiver services (i.e. Community Integrated
 Living Arrangements, Home Based Supports, Child Group Homes)
 funded by the Illinois Department of Human Services/Division of
 Developmental Disabilities

Social Security Administration

www.ssa.gov

Phone: 800.772.1213 (National Number)

877.405.4640 328 Susan Dr # 100 Normal, IL 61761

- SSDI Social Security Disability Insurance, children can qualify for this if one of their parents already receives SSDI or is deceased
- SSI Social Security Income, you may qualify if you are over 18 and have a lifelong disability or if under 18 and your family meets income quidelines
- Must schedule an appointment in advance

Special Angels Foundation

https://specialangelsfoundation.org

- MISSION is to provide grant support in obtaining therapies, equipment and resources to families raising children with special needs
- Special Angels Foundation prioritizes support for therapy within the applicants' network which ensures that individuals receive accessible and affordable care. There are a few exceptions to this rule which will be evaluated on a case-by-case basis.



FUTURE PLANNING

Future planning is one very important and often complicated issue that parents confront when they have a son or daughter with any type of disability: How to plan their estate to best provide for their child's future security. Parents may ask themselves:

- " What will our son or daughter do when we are no longer here to provide help when it's needed?"
- "Where and how will our child live?"
- "Will he or she have enough money to sustain a decent quality of life?"

These are complex questions and difficult ones to answer. When a child has a disability, you are going to have concerns about their future.

As parents, you may have a tentative plan in the back of your minds that one day, in the near or distant future, you will write a will that leaves your son or daughter with a disability sufficient resources to make his or her life secure. Many of you may have already written such a will. Yet there are many things to know and consider when planning your estate.

Finding the people who have experience in future planning is very important. The understand and can explain third party trusts, SSDI asset limits, ABLE accounts, Guardianship and more

Remember that future planning also means writing up a plan about and for your child/adult – it can include things like calming strategies, likes, dislikes, preferred foods and schedules. All of the things that you do naturally can be written down to help others make life the best it can be for your loved one.

Brian Rubin - Benjamin A. Rubin, Esq., LLM

www.rubinlaw.com Phone: 847.279.0090

> 1110 W Lake Cook Road Suite 165 Buffalo Grove, IL 60089-1997

- Legal and future planning for our fellow Illinois families of individuals with special needs, including intellectual disabilities, developmental disabilities, physical disabilities, and/or mental illness
- Brian and Benjamin Rubin are available to speak to groups and organizations

Clancy & Associates

www.clancyassociates.com 773-929-9000 901 Warrenville Road, Suite 201 Lisle, Illinois 60532

- Special needs planning and trusts
- Transition Planning
- IEP / Education
- Guardianship

Costigan & Wollrab: Robert W. Porter

https://www.cwlawoffice.com/

Phone: 309.838.4310 308 E. Washington St

Bloomington, Illinois 61701

- Special needs planning and trusts
- Guardianship
- Power of Attorney

Haning Law Office

https://haninglawoffice.com

Phone: 309-808.2227

2416 E. Washington, Suite C-4 Bloomington, Illinois 61704

Power of Attorney, Guardianships, estate planning

Julia Davis Law Firm

www.juliadavislaw.com

Phone: 309.661.1104

409 S. Prospect, Suite F Bloomington, IL 61704

• Estate Planning, Special Needs Trust, Guardianship

Special Needs Alliance

www.specialneedsalliance.org

- National Alliance of Attorneys for Special Needs Planning
- Search by state

WEBSITES

The ARC

https://thearc.org/financial-planning-resources/

- A financial plan can help determine how a person with IDD will pay for the things they want and need in the future.
- Download free financial planning resources

Autism Speaks

https://www.autismspeaks.org/tool-kit/financial-planning-tool-kit

Download a free financial planning toolkit

Kids Health

https://kidshealth.org/en/parents/needs-planning.html

- 10 steps to planning your child's financial future. Some are simple, some are challenging; some cost nothing and some require paying legal fees.
- Get started on some of these now, so you'll have peace of mind down the road

Books

INFORMATIONAL

30 Days of Autism Casey Chaffey

All Cats Have Asperger Syndrome Kathy Hoopman

Aspergirls: Empowering Females with Asperger's Syndrome Rudy Simone

The Autism Job Club

Michael Bernick and Richard Holden

Autism Spectrum Disorder: The Complete Guide to Understanding Autism Chantal Sicile-Kira

The Autistic Brain: Helping Different Kinds of Minds Succeed Temple Grandin and Richard Panek

The Child with Autism at Home and in the Community: Over 600 Must Have Tips for Making Home Life and Outings Easier for Everyone Kathy Labosh and LaNita Miller

Dad's and Autism: How to Stay in the Game Emerson B Donnell III

Do-Watch-Listen-Say: Social and Communication Intervention for Autism Spectrum Disorder
Kathleen Quill

Facing Autism: Giving Parents Reasons for Hope and Guidance for Help Lynn Hamilton

High Functioning Autism and Difficult Moments: Practical Solutions for Meltdowns

Brenda Smith Myles

In a Different Key: The Story of Autism John Donvan and Carin Zucker

Knowing Why: Adult Diagnosed People on Life and Autism Autism Self Advocacy Network and Elizabeth Bartmess

Let me Hear Your Voice: A Family's Triumph Over Autism Catherine Maurice

Life Animated: A Story of Sidekicks, Heroes and Autism Ron Suskind

Navigating College: A Handbook for Self Advocacy Written for Autistic Students by Autistic Adults

Autism Self Advocacy Network and Melody Latimer

No More Meltdowns: Positive Strategies for Dealing with and Preventing Out of Control Behavior

Jed Baker

Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders

Eric Schopler

Positive Parenting for Autism: Powerful Strategies to Help Your Child Overcome Challenges and Thrive

Victoria Boone

Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew About Growing Up, Acceptance and Identity
Autistic Women and Non-binary Network, Emily Paige Ballou

Teaching Children with Autism to Mind-Read: A Practical Guide for Teacher and Parents

Patricia Howlin and Simon Baron-Cohen

Ten Things Every Child with Autism Wish You Knew Ellen Notbohm, Stephanie Cozart

Thinking Person Guide to Autism: Everything you need to know from Autistics, Parents and Professionals

Shannon Des Roches Rosa

Turn Autism Around: An Action Guide for Parents of Young Children with Early Signs of Autism

Mary Lynch Barbera and Temple Grandin

Uniquely Autism: A Different Way of Seeing Autism Barry M Prizant

We Walk: Life with Severe Autism Amy S F Lutz

AUTOBIOGRAPHIES

Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant \
Daniel Tammet

Emergence: Labeled Autistic Temple Grandin

Look Me in the Eye
John Elder Robinson

Mozart and the Whale: An Asperger's Love Story Jerry Newport

Nobody Nowhere: The Extraordinary Autobiography of an Autistic Donna Williams

Population One: Autism, Adversity and the Will to Succeed Tyler McNamer and Tyler Tichelaar

Pretending to be Normal: Living with Asperger's Syndrome Liane Willy Holliday The Reason I Jump: The Inner Voice of a Thirteen Year Old with Autism Naoki Higashida

Somebody Somewhere: Breaking Free from the World of Autism Donna Williams

Soon with Come the Light: A View from Inside the Autism Puzzle Thomas A McKean and R Wayne Gilpin

Thinking in Pictures: My Life Explained Temple Grandin

Welcome to the Autistic Community

Lar Berry and the Autistic Self Advocacy Network

SIBLINGS, PEERS AND AUTISTIC CHILREN

The Abilities in Me: Autism Gemma Keir and Adam Walker-Parker

Able the Autistic Turtle Margi Marino-Majors

All by Stripes: A Story for Autistic Children Shaina Rudolph

Alone Bird: A Story About Autism
Amelia Peace and Georgina Vaughn

Anything But Typical Nora Raleigh Baskin

Autism the Invisible Cord: A Siblings Diary Barbara Cain

A Boy Called Bat / Bat and the Waiting Game / Bat and the End of Everything Elana K Arnold and Charles Santoso

Can You See Me? Libby Scott

Do You Want to Play?: Making Friends with an Autistic Kid Daniel Share-Strom, Naghmeh Afshinah, et al.

Everybody is Different: A Book for Young People with have Brothers or Sisters with Autism

Fionna Bleach and AAPC Publishing

A Friend Called Henry: The Remarkable True Story of an Autistic Boy and the Dog that Unlocked his World

Nuala Gardner

I See Things Differently: A First Look at Autism
Pat Thomas

lan's Walk Laurie Lears and Karent Ritz

The Ice Cream Sundae Guide to Autism: An Interactive Kid's Book to Understanding Autism

Debby Elly, Tori Houghton, et al.

My Brother is Different: A Parents Guide to Help Children Cope with an Autistic Sibling

Barbara Morvay

My Brother Charlie Holly Robinson Peete

My Brother Samuel is Special Becky Edwards and David Armitage

Russell is Extra Special: A Book About Autism Charles A Amenta III

Siblings: The Autism Spectrum Through Our Eyes Jane Johnson Uniquely Wired: A Story About Autism and It's Gifts Julia Cook and Anita DuFalla

What About Me?: A Book By and For an Autistic Sibling Brennan Farmer and Mandy Farmer

SENSORY

Answers to Questions Teachers Ask About Sensory Integration: Forms, Checklists and Practical Tools for Teachers and Parents
Christian Kressmann, Mirja Pischel, et al

Asperger's Syndrome and Sensory Issues: Practical Issues for Making Sense of the World

Brenda Smith Myles Ph.D., Cook Catherine Prescott, et al

The Out of Sync Child: Recognizing and Coping with Sensory Processing Disorder

Carol Kranowitz and Lucy Jane Miller

Sensory Challenges and Answers Temple Grandin Ph.D.

The Sensory-Sensitive Child: Practical Solutions for Out of Bounds Behavior Agnes Pias

When Things Get Too Loud: A Story About Sensory Overload Anne Alcott

SOCIAL

Autism Asperger's: Solving the Relationship Puzzle—A New Developmental Program That Opens the Door to Lifelong Social and Emotional Growth Anne Alcott

Asperkids (Secret Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger's Syndrome Jennifer Cook-O'Toole

The Hidden Curriculum and Other Everyday Challenges for Elementary Age Children with High Functioning Autism

By Hayley Morgan Myles and Annellise Kolar

Nerdy, Shy and Socially Inappropriate: A User Guide to Asperger Life By Cynthia Kim

The New Social Story Book By Carol Gray

Peer Play and the Autism Spectrum
By Pamela J Wolfberg

Relationship Development Intervention with Children, Adolescents and Adults By Steven E Gutstein and Rachelle K Sheely

The Social Skills Picture Book: Teaching Play, Emotion and Communication to Children with Autism

By Jed Baker, Ph.D.

Social Skills Training: For Children and Adolescents with Asperger Syndrome and High Functioning Autism

By Susan Williams-White

Social Skills Training: For Children and Adolescents with Asperger's Syndrome and Social Communication Problems

By Jed Baker

The Survival Guide for Kids with Autism Spectrum By Elizabeth Verdick



AUTISM PUBLISHING HOUSES

Future Horizons Publishing

www.fhautism.com Phone: 800.489.0727

> 2201 N Collins St #250 Arlington, Texas 76011

• Specializes in autism publications, magazines, books, etc.

Guilford Press

www.guilford.com

Phone: 800.365.7006 Ext 1 370 Seventh Street #1200

New York City, New York 10001-1020

 Publishes materials on various topics, including autism for teachers, professors, students, families etc.

Jessica Kingsley Publishers

https://us.jkp.com Phone: 215.922.1161

123 S Broad Street #2750

Philadelphia, Pennsylvania 19109

Publishes materials on various topics, including autism

APPS: Android and iOS platforms

Every year developers and app creators release new autism apps. The apps are intended to support the autism community, focusing on social, communication, emotional, language, and organizational needs of children with autism.

Finding the right quality apps can help a child with autism in several ways. They can assist in developing skills, communication, social interaction, independence, and can be used as motivation to learn.

There are several apps to help track behavior and to create schedules. Both of these can help you regulate difficult areas. Finding a means for your child to communicate and visual schedules will help your child make sense of the world around him/her – once that happens your child will be readier to learn.

Augie AAC

 augie, now available on the Apple App Store, is an easy-to-use voice output augmented communication app for the iPad and iPad 2. augie serves anyone in need of a portable AAC solution that is specifically designed for functional communication. augie users recommend it for people of all ages in need of customized functional communication support.

Avaz

well-recommended AAC app that emphasizes language development.
 Focuses on helping children enhance their communication skills. It is particularly appreciated for its intuitive design and robust learning tools, and it's available for free

ChoiceBoard Creator

 ChoiceBoard Creator is the perfect app for creating customizable choice boards for the unique needs of individuals with communication challenges. It reinforces correct choice by expanding the selected image as well as playing customized auditory rewards.

Choiceworks

• The Choiceworks app is an essential learning tool for helping children complete daily routines (morning, day, & night), understand & control their feelings and improve their waiting skills (taking turns and not interrupting). Based on the multi-award winning Choiceworks Visual Support System, this app is designed for caregivers to provide clear and consistent support to foster a child's independence, positive behavior, and emotional regulation at home and in the community.

Endless Reader

 One of the first steps in learning to read is recognizing sight words, which are some of the most used words in children's books. Endless Reader begins here, teaching children the words to develop reading skills. The app and first package of words are free! The app uses colorful monsters and fun sounds to keep users entertained and engaged.

Conversation Therapy

 A valuable resource that offers comprehensive training in conversation skills. With perfect user ratings, it serves as an excellent tool for enhancing communication abilities, making interactions easier for nonverbal children.

Dexteria VMI

 Dexteria is a set of therapeutic hand exercises that improve fine motor skills and handwriting readiness in children and adults

First Then Visual Schedule HD

 This simple but powerful tool engages kids to independently follow a schedule.

Goally's AAC Talker:

 This app serves as an Augmentative and Alternative Communication (AAC) device, allowing users to create messages using visual supports and personalized images.

Grace 4 Picture Exchange for Non-Verbal People

 A simple picture exchange system developed By and For non-verbal people allowing the user to communicate their needs by building sentences from relevant images. It can be customized by the individual using their picture and photo vocabulary with the user taking and saving pictures independently to the app.

Habitica

- Gamifies habit formation, offering a fun way to foster life skills and emotional stability.
- Skill building and emotional support

Happi Papi Apps

Happi Reads is a game for beginning reading/sight word practice.
 Match a word with one of three pictures. Earn fruit you can "eat."
 Healthy and fun! Happi Spells is a mini-crossword puzzle game where you drag tiles to complete the puzzles. Vivid, original artwork and hours and hours of content.

Leeloo

 Promotes language skills and helps children articulate their thoughts through an engaging interface

Let's Be Social

This app targets areas that can be very challenging for students with social difficulties. There are 25 lessons that help students work on problem solving, forming friendships, recognizing emotions, and predicting outcomes.

Model Me Going Places™

 Model Me Going Places™ is a great visual teaching tool for helping your child learn to navigate challenging locations in the community.
 Each location contains a photo slide show of children modeling appropriate behavior. 6 locations: Hairdresser, Mall, Doctor, Playground, Grocery Store, and Restaurant.

Mood Meter-building your emotional intelligence

People on the autism spectrum may not only have difficulty
understanding how other people emote. They may have difficulty
understanding their own emotions, too. Mood Meter is specifically
designed to help people get in touch with their emotions. You use it to
gauge your feelings each day or at regular intervals throughout the
day. Look back and identify any patterns and grow your emotional
vocabulary.

MoodPanda

 A mood tracking app that encourages children to monitor their emotions, fostering awareness and regulation.

Otsimo | Special Education AAC

 The Otsimo app uses techniques designed around applied behavior analysis (ABA) and alternative and augmentative communication (AAC) to help children reach speech development milestones as well as achieve desired lifestyle skills, behaviors, and much more. It has over 50 games that can be personalized to a child's specific needs, and it provides progress reports along the way that show how far they've come since using the app.

Pictello

 Create and share visual social stories and schedules with this app for iOS. Adding your own pictures, videos and recordings to stories you create makes it easier to share information while building literacy skills, as well as confidence in storytelling.

Proloquo2Go: AAC In Your Pocket

- \$249.99
- Proloquo2Go is a new product from AssistiveWare that provides a full-featured communication solution for people who have difficulty speaking. It brings natural sounding text-to-speech voices, up-to-date symbols, powerful automatic conjugations, a default vocabulary of over 7000 items, full expandability and extreme ease of use to the iPhone and iPod touch.

Reading Machine

Once children learn basic phonics, the best activity for reading skills is reading. Now kids can spend more time reading books—on their own or with you—without getting stuck on any words. When they come to a word they don't know, they type it in the Reading Machine. The Reading Machine doesn't just tell them the word: first it shows them how the letters and sounds go together, so they can try figuring it out themselves.

Social Story Creator & Library by Touch Autism:

 This app allows you to create personalized social stories, which are short narratives that teach social skills, behaviors, and coping mechanisms in a way children with ASD can easily understand

Starfall ABCs

Starfall ABCs is an app created to help children learn the alphabet. It's
a great tool for some children with autism. It allows them to progress
at their own pace, learning to recognize letters and the sounds
associated with them. The app uses bright colors and games to keep
children engaged and entertained.

Tell Me About It!

 Tell Me About It! teaches the label, category, function, and features of more than 235 language targets over 6 levels of incremental difficulty. The presentation of each target conforms to an Applied Behavior Analysis program with reinforcement provided by a token economy system. This App is ideal for both parents and educators who are working on teaching children language through ABA/VB teaching methods.

Time Timer Apps

 Ideal for visual people with Autism, these Apps help the whole family, classroom and workplace improve time management skills. Time Timers can automatically repeat, display time in 4 bright colors, run multiple timers at once, and even teach children how to read a clock!

Toca Boca

Toca Boca is a play studio that makes digital toys for kids. We think
playing and having fun is the best way to learn about the world. They
make digital toys and games that help stimulate the imagination, and
that you can play together with kids.

Visual Daily Schedule

• Using the iPad or iPhone app, a caregiver can make a visual schedule for the user. There are included icons or icons/photos can be uploaded to the app to make custom icons. The schedule can then be sent to the users Apple Watch and will alert them when he/she needs to change tasks or start a new task.

Touch and Learn-Emotions

What does a sad face look like? For people with autism, the answer to
this and similar questions isn't always so simple. This app helps teach
these facial cues to autistic children. It uses more than 100 photos to
show expressions and body language that we encounter every day.
You can customize the app so the images and emotions are
appropriate for your child.



The most important thing in communication is hearing what isn't said.

~ Peter Drucker

SAFETY

Local Registries

City of Bloomington Premise Alert Program

https://police.bloomingtonil.gov/services/premise-alert-program
Bloomington Police Department
305 S East Street
Bloomington, Illinois 61701

Bloomington Fire Headquarters 310 N. Lee St. Bloomington, IL 61701

- The Illinois Premise Alert Program (Public Act 96-0788) provides for Public Safety Agencies in the State of Illinois to allow people with special needs to provide information to Police, Fire and EMS personnel to be kept in a database. The information can then be provided to responders dealing with situations involving Special Needs Individuals.
- Premise Alert Program application can be printed online
- Drop off can be made to the Bloomington Police Department or Bloomington Fire Department at the above addresses.

McLean County Functional Needs Registry

https://health.mclean countyil.gov/1691/McLean-County-Functional-

Needs-Registry

Phone: 309.888.5450

McLean County EMA 104 W. Front St. Bloomington, IL 61701

• The McLean County Functional Needs Registry is a program set up to help individuals with special needs during an emergency situation. The program is a voluntary registration by county residents with functional needs to help local emergency responders during an emergency with planning and preparedness, so they know in advance who needs extra assistance

Town of Normal/McLean County Early Notification Program

www.normal.org/288/Early-Notification-Program

Phone: 309.454.9535

Normal Police Department 100 E Phoenix Avenue Normal, IL 61761

- The McLean County Early Notification Program is specifically
 designed to provide responding law enforcement officers with
 information to assist them in responding to calls involving
 individuals with special needs. If responding officers are made
 aware of these special needs prior to arrival, they may be better
 equipped to understand and appropriately respond to calls involving
 these residents.
- McLean County residents wishing to register may do so by completing the registration form and agreement, which may be picked up at their local Police Department. Completed forms must then be submitted to the local Police Department. Police agencies receiving mailed applications will contact the applicant to verify the information provided.



Safety Information, Trackers, I.D.'s & More

Alerta Patch

www.alertafamily.com Phone: 833.443.5799

- Wearable Patch with alarm and receiver
- Tracking system with chime

Alexa

www.amazon.com

Not necessarily designed as a safety device, but has a lot of features that can be helpful in the home.

- Ring Doorbell let's you see who is at the door and speak to them helpful if your child might open the door for anyone.
- Alexa show utilizes alexa with a monitor can be put in various rooms to monitor childs where-a-bouts
- Alexa can be used to talk room to room, great for simple check-ins in larger homes.

Angel Sense Products

www.angelsense.com Phone: 888.999.2023

- Non-removal wearable products (requires parent key)
- School Bus Tracking
- GPS Tracking w/ Monthly service fees

Apple Air Tag

www.apple.com

- A way to keep track of your stuff. Attach one to your keys, slip
 another in your backpack. And just like that, they're on your radar in
 the Find My app, where you can also track down your Apple devices
 and keep up with friends and family.
- No monthly fee

The Autism Program of Illinois (Emergency Response Kit)

https://tap-illinois.org/safety Phone: 217.953.0894 x 30476

- Emergency kit includes emergency response window cling
- Personal emergency information worksheet
- A "what hurts" story board

Autism and Risk Management

https://autismriskmanagement.com/

- Trainings by Dennis Debbaudt
- Presentations and training for law enforcement
- Links to other resources

Autism Speaks - Safety Kit

https://www.autismspeaks.org/tool-kit/autism-safety-kit

- Safety & Wandering Prevention Checklist
- Family Wandering Emergency Plan
- Autism Elopement Alert Form
- Neighbor Alert Letter Provide this letter to trusted neighbors to inform them of your child's tendency to wander.
- School Alert/IEP Letter A sample letter to your school about your child's tendency to wander.
- Teaching Safety FAQ Tips and strategies
- Wandering Tips for First Responders

It is hard to fail, but it is worse never to have tried to succeed.

Big Red Safety Box

https://nationalautismassociation.org/big-red-safety-box/

Phone: 877.622.2884

National Autism Association

310 Maple Avenue #E1

Barrington, Rhode Island 02806

- Box contains educational information and tools
- Wireless door alarms
- Visual Prompts
- Road ID Bracelet or Shoe tag

CPR 4 EMI

https://cpr4emi.godaddysites.com Facebook/CPR 4 Emi

- First Responder training on how to work with individuals with autism
- Family & Friends CPR Course
- Heartsaver CPR & First Aid Course student receives completion card
- Basic Life Support (BLS) Course, Heartsaver First Aid Course

ICE Medical ID

https://theiceid.com

- Personalized medical ID bracelet
- he ICE ID simply communicates vital health + family contact information to first-responders in case of emergency / injury.
- The ICE ID communicates for you when you cannot speak for yourself.

iPhone

www.apple.com

- Use Friends & Family tracking to see where your child is
- Use Life 360 app to track your child
- Use ICE to enter emergency contact information, along with medical information

Safety First Products

www.safety1st.com Phone: 800.544.1108

- Locks and latches
- Gates
- Monitors

State of Illinois Disability ID Card

 $www.ilsos.gov/publications/pdf_publications/dsd_x164.pdf$

Phone: 800.252.8980

- You can obtain the card from the Illinois Secretary of State. Although the State charges a fee for certain types of ID cards, there is no fee for the Disabled Person Identification Card.
- The completed form requires a doctors signature to confirm the stated disability.

Tot Locks

https://protectenfant.com

 The TotLock® Magnetic Locking System is the original magnetic lock that could be used to lock cabinet doors and drawers in any room, including the kitchen, the most dangerous room in any home. Secure cupboards and doors and help keep little ones safe from accidents. A magnetic "key" placed on the cabinet door releases the latch. When the magnet is removed, the latch springs back into the locked position.

Other Items to consider

Most can be found at your local hardware store

- Child video and./or audio monitors
- Door locks
- Window locks
- Door chimes
- Magnetic cabinet door latches
- Safety/support animals

MISCELLANEOUS

Autism Friendly Businesses in McLean County

This is not an all-inclusive list and will hopefully grow daily. The following businesses at the very least have Sensory Bags available for individuals with autism. The sensory bags help individuals who get too overwhelmed to go into stores, restaurants or other places people typically enjoy.

Altitude Trampoline Park

Bloomington Christian Fellowship Church

Bloomington Public Library

Carle-BroMenn Medical Center – Emergency Room

Central Illinois Regional Airport

Children's Discovery Museum

Chuck e Cheese

Eastview Christian Church

Faith Lutheran

Illinois State University

Lifelong Access

McLean County Sheriff's Department Cars

McLean County History Museum

Miller Park Zoo

Nexus Church

Normal Public Library

OSF Pediatrics

OSF Behavioral Health on Forte Jesse

SOAR Special Opportunities Available in Recreation

Timber Pointe Outdoor Center

Twin City Lanes

Unitarian University Church

Vale Church

If you are a business or know of a business who would like a sensory bag, please have them contact Autism McLean at 309.661.9440 or info@autismmclean.org

We would love to have more businesses join our Autism Friendly Community



Grief and Loss: Helping Children with Autism Cope

Dealing with the death of a loved one can be hard for anyone, but for children with autism it can be especially difficult to comprehend. As a parent it's a difficult topic during a difficult time. Below are a few resources for helping you help your child.

Death and Grieving: Tips from Pathfinders for Autism

https://pathfindersforautism.org/articles/home/parent-tips-death-and-grieving

How to Talk to Your Child with Special Needs about Death

https://www.friendshipcircle.org/blog/2013/08/20/how-to-talk-to-your-child-with-special-needs-about-death

Supporting Individuals on the Autism Spectrum Coping with Grief and Loss through Death or Divorce

https://www.iidc.indiana.edu/irca/articles/supporting-individuals-on-the-autism-spectrum-coping-with-grief-and-loss

Guardianship at age 18

School

- If your child has an IEP, they are entitled to attend school until the end of school the year they turn 22. You, however, are not automatically the decision maker after age 18. Either you need to get guardianship, or have your child sign a form provided by the school.
- If your child is unable to sign, the school team can make a determination that you can continue to make decisions on their behalf

Medical / Financial

- After the age of 18 your child is considered an adult and thus can make their own decisions. If you feel that your child is not capable of making decisions you can apply for guardianship.
- In Illinois there are many types/level of guardianship. You should consult a lawyer to help you through this process
- Power of Attorney If your child is capable of making sound decisions, but still needs your help you might consider drafting Power of Attorney papers. There are two types of Power of Attorney (POA) – One for Medical, and one for Financial. Power of Attorney forms need to be signed and dated to be valid.

Hidden Disability Sunflower Program

Central Illinois Regional Airport

Central Illinois Regional Airport (CIRA) is excited to make air travel, and the airport more accessible to everyone. Many travelers have disabilities that are not immediately visible but still create challenges in their daily lives. Airport staff is trained to recognize the individual wearing the lanyard may need extra help, time or assistance.

CIRA is among the many U.S Airports to join the Hidden Disabilities Sunflower Program. The Sunflower Program allows a person to self—identify as someone with a hidden disability who may require additional assistance. This will allow passengers who require a little require extra assistance with travel through CIRA easier. The Sunflower Lanyard helps creates a simple way to signal airport staff that a passenger has a disability without revealing the nature of the disability.

Simply, airlines can provide the lanyard to any passenger who asks for one. There is no prerequisite for them and passengers should still arrange assistance with their airlines if a disability service is needed. Hidden disabilities can include autism, anxiety disorders, epilepsy, learning disabilities, post-traumatic stress disorder (PTSD), and many other impairments or chronic illnesses.

Illinois State Regulated Insurance Coverage

- The Illinois Insurance Bill was passed in 2008.
- Services covered are diagnosis, psychiatric care, psychological care, habilitative or rehabilitative care and therapeutic care. ABA is provided for individuals under the age of 21 with a cap of \$36,000 per year.

Selective Services Registration

www.sss.gov/register

- Virtually all men must register with Selective Service
- If your son gets a call from a recruiter, simply tell them he has a disability/autism.

Service Dogs

According to service dog organization Paws for a Cause, these dogs help to "improve social interactions and relationships, expand verbal and nonverbal communication, teach life skills, increase interest in activities and decrease stress within the family." These tasks include:

- Helping their person get ready for school in the morning;
- Picking up dropped objects
- Alerting passers-by to an emergency situation
- Simply act as a calming presence in their person's life.

Whatever their particular assignment may be, autism assistance dogs provide incredible help and companionship. They have been known to help with sensory issues, social skills, seizures, and wandering

Service Dog Organizations

Autism Assistance Dog www.autismassistancedog.com

Autism Service Dogs of America

www.autismservicedogsofamerica.org

Medical Mutts Service Dogs Inc

https://medicalmutts.org/our-service-dogs/autism-service-dogs/

Paws for Ability

https://4pawsforability.org/autism-assistance-dog

Paws with a Cause

www.pawswithacause.org

Unfortunately, a service dog can cost upwards of \$20,000, the cost is almost never covered by health insurance.

There are a variety of groups that provide funding for people to afford service animals, like Petco Foundation.

Ultimately, many people who don't have the money needed of a service animal look to community and fundraising like GoFundMe to help cover the cost.

Six Flags Amusement Parks Special Passes

www.sixflags.com/greatadventure/plan-your-visit/accessibility

- Six Flags has been designated as a Certified Autism Center (CAC) from the International Board of Credentialing and Continuing Education Standards
- Six Flags' Attraction Access Program is designed to accommodate guests with various disabilities or certain impairments so they may participate in the enjoyment of the parks. Each Six Flags has been evaluated for the necessary criteria for an individual to ride safely.
- Guests with cognitive disorders, disabilities or mobility impairments
 who request helpful accommodations must obtain the IBCCES
 Individual Accessibility Card (IAC) by registering at
 www.accessibilitycard.org. Once a guest has filled out the online
 application and uploaded necessary documentation, they will be able
 to access their digital Accessibility Card. Guests will present the IBCCES
 Accessibility Card and Information Sheet to the to the Ride Information
 Center to receive the necessary accommodations.



Autism: Past Present & in the Movies

Historical Figures thought to have Autism/Asperger's

Hans Christian Anderson - Writer

Jane Austen - Writer

Ludwig Von Beethoven - Composer

Marie Currie - Polish-French Physicist

Charles Darwin - Naturalist and Geologist

Emily Dickenson - Poet

Leonardo Di Vinci - Inventor, artist, writer, scientist

Thomas Edison - American Inventor

Albert Einstein - German-American scientist

Bobby Fischer - American chess player

Henry Ford - Founder of Ford Motor Company

Ben Franklin - One of America's Founding Father's

Sir Alfred Hitchcock - British Movie Director

Thomas Jefferson - Third President of the United States

James Joyce - Irish writer

Michelangelo - Italian Sculptor, Poet, Artist and architect

Franz Kafka -Bohemian writer

Stanley Kubrick - Movie director and chess master

Wolfgang Amadeus Mozart - Composer

Sir Isaac Newton -Scientist

Friedrich Nietzsche - German Philosopher

George Orwell - English Novelist and essayist

Nikola Tesla - Serbian-American inventor and researcher

Alan Turning - British Mathematician

Mark Twain - Writer

Vincent Van Gogh - Artist

Andy Warhol - Painter

William Butler Yeats - Irish Poet

People with Autism in the 21st Century

Dan Akroyd - Actor, Comedian and Screenwriter

Julian Assange - Founder of Wikileaks

Roseanne Barr - Actress and Comedian

Sean Barron - Author

Susan Boyle - Professional singer discovered on "Britian's Got Talent"

David Byrne - Scottish American singer-songwriter

Tim Burton - Film Director / Producer

Eminem – Rapper / song writer

David Campion - Snowboarder

Bram Cohen - Inventor of BitTorrent

Jim Eisenreich - Retired MLB Player who also has Tourette's syndrome

Bill Gates - Microsoft Founder

Temple Grandin - Designer of humane food handling systems

Darryl Hannah - American Actress best known for her role in "Splash"

Steve Jobs - Founder of Apple

Sir Anthony Hopkins - Academy Award winning actor, diagnosed as an adult

Kodi Lee - Blind ASD pianist/winner of America's Got Talent

Courtney Love - American signer and actress

Clay Marzo - Competitive Surfer and author

Wentworth Miller - British and American actor

Elon Musk -South African Entrepreneur

Carl Sagan - Scientist

Matt Savage - Musician

Stephen Shore - Author and Professor

Jim Sinclair - Autism Activist

Dr Vernon Smith - Nobel Prize winning economist

SIA – Pop singer

Satoshi Tajiri - Inventor of Pokemon

lan Terry - Reality TV star

Greta Thunberg - Swedish climate activist

Cody Ware - Racecar Driver

Wentworth Miller - Actor

Liane Holliday-Willey - Author

Tallulah Willis – Daughter of actor Bruce Willis

Autism & Autism-Like characters in movies and TV

The Accountant – Ben Aflec

Adam - Adam Raki

After Thomas - Andrew Byrne

Amelie - Amelie Poulain

Atypical (TV) – Keir Gilchrist

The A Word (TV) - Max Vento

Backstreet Dreams - Tony Fields

The Big Bang Theory (TV) - Dr. Sheldon Cooper

The Big Bang Theory (TV) - Dr. Amy Farrah-Fowler

BioShock - Brigid Tenenbaum

Bob's Burgers - Tina Belcher

Bones (TV) - Dr. Temperance Brennan

Boston Legal (TV) - Jerry Espenson

A Boy Called Po - Christopher Gorham

The Boy Who Could Fly - Eric Gibb

The Bridge (TV) - Detective Sonya Cross

A Brilliant Young Mind - Asa Butterfield

Chicago Med (TV) - Dr. Isidore Latham

Community - Abed Nadir

Cube - David Hewlett

The Curious Incident of the Dog in the Night Time(Play) -Christopher Boone

Drive - The Driver

Extremely Loud & Incredibly Close - Oskar Schell

Fly Away - Beth Broderick

Forrest Gump - Forrest Gump

Fringe - Astrid Farnsworth

The Girl With the Dragon Tattoo - Lisbeth Salander

The Good Doctor (TV) - Freddie Highmore

The Horse Boy - Rupert Isaacson

The IT Crowd - Maurice Moss

I Am Sam - Sean Penn

Jack of Red Hearts - Taylor Richardson

Keep the Change - Brandon Polansky

Lars and the Real Girl - Lars

Life, Animated - Owen Suskind

Little Man Tate - Adam Hann-Byrd

Mary and Max - Mary and Max

Mercury Rising - Miko Hughes

The Middle - Brick Heck

Miracle Run - Mary-Louise Parker

Mozart and the Whale - Donald Morton and Isabel Sorenson

NCIS (TV) - Abby

The Other Sister - Juliette Lewis

Parenthood (TV) - Max Braverman

Please Stand By – Dakota Fanning

P.S. I Love You - Daniel Connolly

Rain Man - Raymond "Ray" Babbitt

The Reason I Jump - Naoki Higashida

Salmon Fishing on the Yemen - Dr. Alfred Jones

Sesame Street (TV) - Julia

Silence (Also known as Crazy Jack and The Boy) (1974) - Will Geer

Snow Cake - Sigourney Weaver

To Kill a Mockingbird - Boo Radley

Temple Grandin - Clair Danes

What's Eating Gilbert Grape? - Leonardo DiCaprio



The difference between life and the movies is that a script has to make sense, and life doesn't.

~ Joseph L. Mankiewicz

Information Gathering

There will be many times that you are searching for information. Sometimes the amount of information you gather and who you've talked to can be daunting. Below are a few starter pages to help with your note taking.

If you have knowledge, let others light their candles in it. ~Margaret Fuller

Name of Organization:
Who did I talk to?
Phone Number:
Address:
Information:
Cost:
Suggested I talk to:
Notes:
Name of Organization:
Who did I talk to?
Phone Number:
Address:
Information:
Cost:
Suggested I talk to:
Notes:
Name of Organization:
Who did I talk to?
Phone Number:
Address:
Information:
Cost:
Suggested I talk to:
Notes: