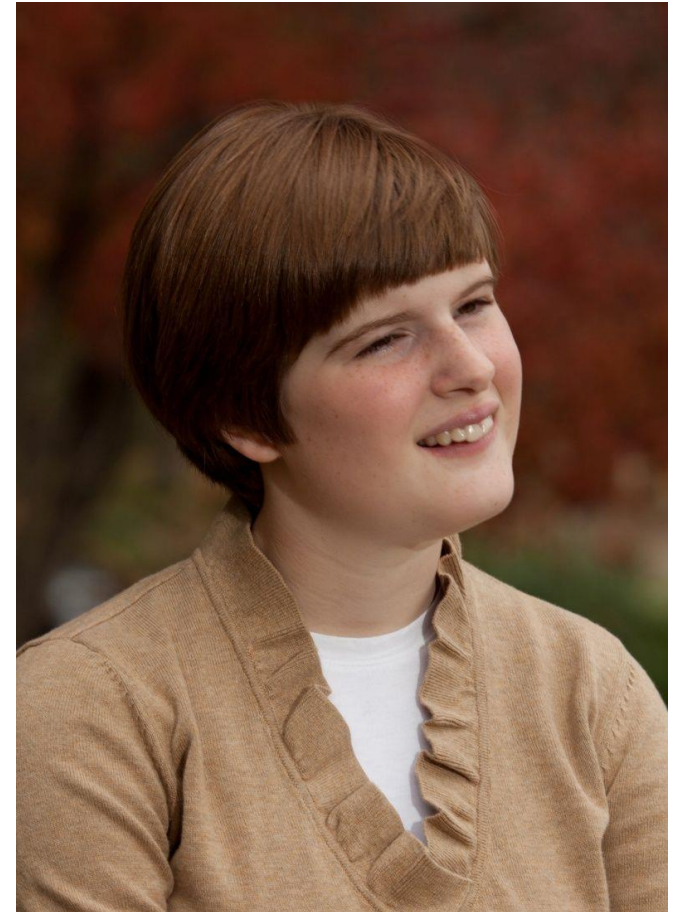
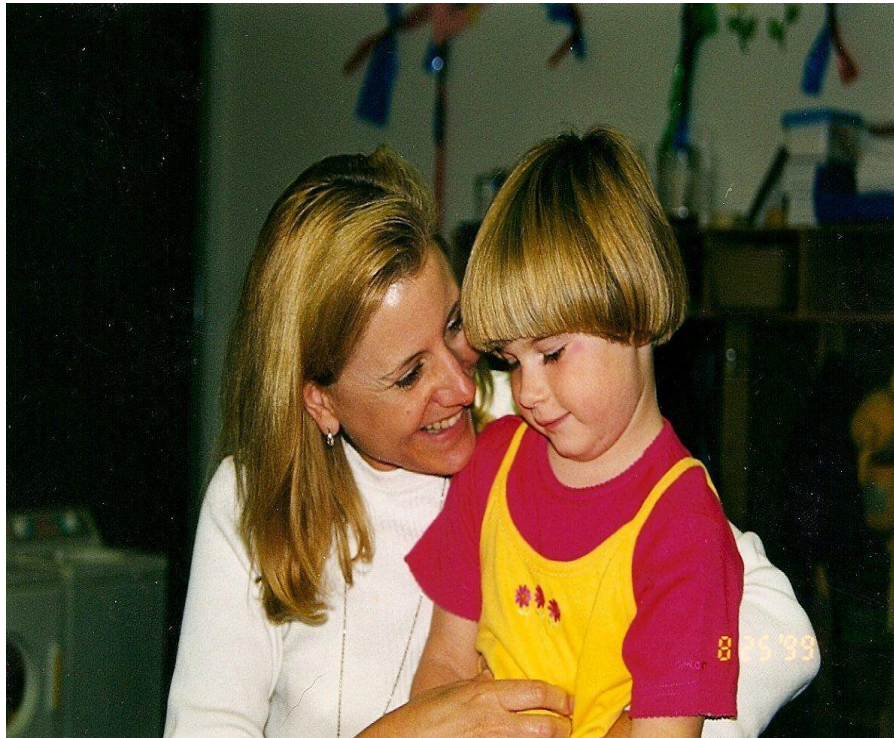


Taking Care of Business: Managing Your Child's Home and School Programs

Robin Jordan, RN, CPN
Mary Anne Hammond, BS

Kailey Grows Up



Boone Grows Up



My child has been diagnosed with an autism disorder...Now What?

- Role of the parent as “the CEO” of your child’s life.
- The sooner you begin to take charge of your child’s care, the better!
- You are now a **PROJECT MANAGER** on a **LIFE LONG PROJECT!**

You are responsible for:

- Gathering information
- Learning the rules of the game
- Planning and preparing
- Keeping written records
- Identifying problems
- Proposing solutions

First tasks after a diagnosis has been given

- Apply for services through a state developmental disability assistance agency
- Determine what special education and therapy services are needed. Take initial steps to secure those services.
- Begin to educate yourself about autism disorders and the available systems of support.

Working with state developmental disability organizations

- Kansas City Regional Office – “point of entry” into the state system for individuals with developmental disabilities. The regional office provides assessment and case management services. They also provide funding for direct services based on need and available resources. You must contact them, even if you are not in need of services at this time. The waiting list only gets longer as time goes on.
- CDDO: Community Developmental Disability Organization – the single point of entry for an individual or family to access services through the disability system in Kansas. Often, funding is not immediately available. The child’s name is placed on a waiting list. You cannot get your name on a waiting list unless you contact this.

Why is it important to learn how to effectively work with your school district's special education program?

- They are a valuable resource for your child and family and it is within this structure that your child will be accessing most of their educational endeavors. It will be in your best interest to develop and maintain respectful relationships with school personnel.
- So that you can understand what can/should be offered/available to your child.
- You are going to have a long relationship with them – it is much easier to have a positive relationship than a adversarial one.

Working with school districts/ special education programs.

- Educate yourself about the special education process and special education laws.
- Know what information/records you need to keep.
- Take an active part in being a member of the IEP (Individual Education Plan) team.

Rules of the game with school:

1. Be prepared. (ex: review IEP goals, behavior support plan)
2. Be on time for meetings – sometimes many schedules have been rearranged in order to be present.
3. Shake hands. Introduce yourself to each one there.
4. Protect the parent-school relationship by keeping emotions under control and using them as a source of positive energy. To be an effective advocate you must be able to control your emotions.
5. Present concerns in writing: If it was not written down, it was not said. If it was not written down, it did not happen.

Preparing for IEP meetings

- Prepare ahead of time – review provided IEP that has been sent home.
- Identify concerns and list problems on paper.
- Make requests and propose solutions to problems
- Practice in advance making requests. This helps decrease anxiety.
- State your concerns clearly and concisely.
- Be open to options suggested by school personnel.

Rules of a successful IEP meeting

1. Know what you want (ex. 30 minutes of speech therapy)
2. Do not blame or criticize
3. Protect the parent-school relationship
4. Seek win-win solutions to problems
5. Understand the school's position
 - a. what are their perceptions?
 - b. what are their interests?
 - c. what are their concerns?
6. Take notes. It may be helpful to have someone attend the meeting with you that does that in addition to you. The school district will absolutely have someone doing the same.

My child's program notebook

- Personal
- Medical
- Education
- Glossary
- Correspondence

What education records do I need to keep?

- Keep a large file box that temporarily holds everything your child brings home from school.
- Current and previous IEPs.
- Representative examples of your child's school work.
- Any correspondence from school.

The value of keeping a communication log:

- Why is it important? It is YOUR voice to the people you are entrusting your child
- It can alert staff to things that may make a difference for them, like a medication change, or a rough night of sleep.
- It also serves as a reminder for you of what has occurred in the near past.

Tips for communicating effectively with the people involved in your child's care

- Email is a valuable means of communication. It is a big help to have a paper trail to serve as both reminder and proof that the communication took place. Be sure and print out or file the communication in appropriate folder for easy retrieval if necessary.
- Be well-prepared each time you talk with one of these professionals. Jot notes before you talk and send a reminder email regarding what was discussed and assigned, if applicable.
- Really *plan*, and if necessary, rehearse what you are going to say.
- If you are in a meeting (IEP meeting, for instance) and are finding your anger/frustration mount, it is FINE to excuse yourself for a few minutes, gather your emotions, and then return to the meeting.



Managing Your Child's Medical Needs:

- Time can be a factor for your child – try and schedule appointments at the beginning of the day or first appointment after lunch to minimize waiting times in the clinic setting.
- Communicate with Clinic Staff about your child's needs (example: sensitivity to crowded waiting rooms, may grab for items that could be dangerous, sensitivity to sudden movements, automated blood pressure cuff etc.)
- Don't assume the staff has a good understanding of Autism disorders.
- Do not discontinue or change doses of medications without first consulting with your Doctor. Some medications require tapering even to discontinue them and it can be harmful to suddenly do so.

What medical records do I need to keep in my child's notebook?

- Immunization record
- List of all current and previous medications (the Dr. is the medication expert, you are the medication manager – you must communicate)
- List of all diagnoses and surgeries
- List of all physicians and facilities that have given care to your child
- Copies of past neurodevelopmental evaluations

When you wish things were going better:

- Document. Note on your calendar if it is a behavior issue. Sometimes we can see a pattern if we keep track. It is impossible to remember.
- Ask for help: teacher, therapist, Doctor, friends, spouse, significant other. People do not know that you need help if you do not ask. And then, accept the help that is offered.
- One day at a time, one hour at a time, sometimes, one minute at a time. That is just the way it is!

Possible members of a support network

- Grandparents, aunts, uncles, cousins, siblings
- Family Friends
- Case workers
- Ministers and church family members
- Neighbors
- Support Group (ASH, Autism Alliance, Autism Works)

Special Education Advocacy Organizations

- **Missouri: MPACT** can help you learn about special education services, the Individual Education Process (IEP) and disability laws. MPACT offers many training sessions for parents. <http://ptimpact.org>
- **Families Together:** An organization that helps parents gain support and information concerning specific disabilities, special education, financial resources and understanding their rights.

Helpful Resources

- Kansas City Regional Office
Phone: (816) 889-3400
Toll Free: 800-454-2331
 - Albany Regional Office
Phone: (660) 726-5246
Toll Free: (800) 560-8774
- Kansas Community Developmental Disability Organizations, <http://www.srs.ks.gov/services/Pages/DevelopmentalDisabilityServices.aspx>
- MPACT, www.ptimpact.org
- Autism Society of the Heartland, www.asaheartland.org
- Autism Speaks, www.autismspeaks.org
- Autism Asperger Publishing Company, <http://asperger.net/>
- www.allaboutautism.org