



Mt. View Special Needs Resource Booklet ☀ 2013

Created by
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in collaboration with
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Special Needs Recreational Resources

Mount Olive Recreation: PEAK (Parents of Extraordinary Kids)

visit www.peakgroup.org for information on activities such as bowling, teen nights, therapeutic riding, T-ball, summer camp, etc.

Easter Seals New Jersey

visit www.nj.easterseals.com for information on camping (Camp Merry Heart) and other recreational and hotel/travel respite programs.

ARC of Morris County

visit www.arcmorris.org for information on recreational, respite and family support services

Camp Marcella

visit www.campmarcella.org for information on camping for visually impaired and multiply-challenged children and teens.

EPOCH (Educational Programs of Children Handicapped)

Madison Area YMCA-1 Ralph Stoddard Drive, Madison, NJ

call **973-822-9622** for information on afterschool recreational swimming and enrichment programs

MCARP

call **973-455-1288** for information on Morris County Adaptive Recreation Program for physically or otherwise handicapped persons

Saturdays in Motion-Somerset Hills YMCA-Basking Ridge, NJ

call 908-766-7898 for information on Recreational and social program for autistic children and families on Saturday afternoons

The Connection for Women and Families

call 908-273-4242 ext. 131 for information on adaptive aquatics (ages 4-adult), variety hour (10yrs +), Teen club (13-24), teen basketball, etc-co-sponsored with Special Olympics

Centenary College-Long Valley

call 908-832-7010 for information on Therapeutic Horseback Riding program.

Sun Ki Do Martial Arts-Hackettstown

call 908-850-4848 for information on special needs Karate programs

Cerebral Palsy of New Jersey

call 974-426-1522 for information on respite programs (Parent's Night Out, In Home Respite)

Special Needs Websites

http: www.diabetes.org	American Diabetes Association
http: www.cdfa.org	Chrohn's and Colitis Foundation of America
http: www.csaceliacs.org	American Celiac Society/Dietary Support Coalition
http: www.ndss.org	National Down's Syndrome Society
http: www.epilepsyfoundation.org	Epilepsy Foundation
http: www.sbma.org	Spina Bifida Association
http: www.ucp.org	United Cerebral Palsy
http: www.aafa.org	Asthma and Allergy Foundation of America
http: www.chionline.org	Children's Hospice International
http: www.wish.org	Make-A-Wish Foundation of America
http: www.curesearch.org	National Childhood Cancer Foundation
http: www.rarediseases.org	National Organization for Rare Disorders (NORD)

Special Needs Government Agencies

Morris County Special Child Health Services – 973-971-4155

609-777-7778 www.nj.gov/health/fhs/sch : County based system for children (birth-21) with complex medical or developmental delays or disabilities. Provides free evaluation, assessment and case management

Family Resource Network – 800-FRN-2345

www.familyresourcenetwork.org : Comprehensive, family focused service resource for families with children with disabilities- Affiliated with Autism Family Services of New Jersey, Caregivers of New Jersey, the Epilepsy Foundation of New Jersey, and the Family Support Center of New Jersey.

Family Support Center of New Jersey- 800-FSC-NJ10

www.fscnj.org : a clearinghouse of information about workshops, presentations, conferences and other training opportunities in New Jersey. Log onto www.thetrainingcalendar.org to view current workshops and trainings.

Children's System of Care (CSOC) – 877-652-7624

Determines eligibility for children with Developmental Disabilities and offers a wide range of services for children with health and developmental disability needs

Medicaid Community Care Waiver Unit Division of Developmental Disabilities – 609-987-2040

www.state.nj.us/humanservices/dmahs/childrens.html : Helps families access healthcare services when their income and assets make them ineligible for Medicaid Benefits

Catastrophic Illness in Children Relief Fund – 800-335-3863

www.state.nj.us/humanservices/catill/catill1.htm : Provides financial help for parents when their out-of-pocket Medical expenses exceed 10% of family income, plus 15% of any income over \$100,000

New Jersey County Boards of Social Service: Division of Family Development – 609-588-2000

www.state.nj.us/humanservices/dfd/dfdcwa39.html : Assists in meeting basic needs of low-income families through a variety of programs and services (i.e. childcare, food stamps, etc.)

New Jersey Familycare - 800-701-0710 www.njfamilycare.org : Provides health insurance for children (birth -19) for low to middle income families

Statewide Parent Advocacy Network (SPAN) -800-654-SPAN
www.spannj.org : Provides information, support and advocacy assistance, and parent support

New Jersey Resources: A comprehensive Directory - 800-258-3036
www.state.nj.us/humanservices/dds : free directory of services that help people with disabilities in New Jersey

National Resources: Exceptional Parent Annual Resource Guide –
800-EPARENT www.eparent.com : A free directory of resources on
specific conditions and services

The ARC of New Jersey - 877-272-0277 www.arcnj.org : Association
which provides services and assists families of children with all
disabilities

New Jersey Family Health Line for Community Based Dental Clinics
800-328-3838 : Call for information on Community Dental clinics
available for discounted and/or free dental services

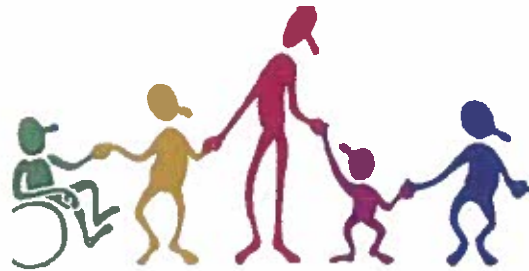
Mount Olive Township Board of Health - 973-691-0900 x353

Call to find out more about free well child clinic, immunizations, and
complete physical exams for eligible residents of Mt. Olive Twp.

-National Relief Hotlines-
Financial Assistance for Families

Child Support Enforcement Hotline.....	877-696-6775
Childcare Subsidy Hotline.....	800-424-2246
Mortgage Payment Assistance.....	800-750-8956
Debt Relief Hotline.....	800-453-1738
Student Loan Relief Hotline.....	866-836-9168
Tax Relief Hotline.....	877-283-8580
Free Bankruptcy Advice.....	800-379-0985
Discount Prescriptions.....	800-291-1206

Helpful Articles
for
Exceptional Parents
of
Extraordinary Children



ABCs and Learning Difficulties

Preparing your special needs child for school.

Loretta Clift

Starting school, whether in September or January, is a major milestone in a child's life. But for a parent of a special needs child, it is more than a new beginning, new friendships and the gateway to great academic and social growth. Beginning school for a special needs child signals the start of a whole new community of professionals entering the family's life.

Starting school can also mean many challenges for parents of special needs children as the parents strive to ensure their children receive proper attention, are accepted by their peers and learn and perform well. One of the best ways to overcome these challenges is through good preparation.

By anticipating and planning for a child's needs, parents can have solutions in place to meet those needs before they become problematic. Like many schools dedicated to children with special needs, the nonprofit organization I oversee works with parents and their kids every day to overcome the challenges of starting school and thriving in the community. The nonprofit, which is known as The Arc, teaches children with developmental disabilities, and many of our staff members are also parents of special needs children. The following stories of some staffers and parents at The Arc reveal strategies to prepare children for a successful school year.

One common challenge families face is planning for a child to manage the events of the school day. For children with communication difficulties, the school bus is one of the first hurdles. Will kids have a way to communicate with others on the bus? Will they be able to make friends? Or, will they be teased or rejected by other children?

The concern is shared by parents of children with physical disabilities, as their children's differences are readily apparent. Fortunately, certain tactics can help make riding on the school bus a positive experience. Consider having a child ride with a neighborhood friend, befriend the driver and practice traveling up and down steps.

Adhering to school routines is another concern for families of children with special needs. If a child has language delays, it impacts the way he makes his needs known—from asking to go to the bathroom and requesting a snack, to telling the school nurse he's sick. Susan Pytel, a physical therapist at The Arc, has a 5-year-old son, Matthew, with articulation delays. Matthew needs extra time to express his thoughts and ideas. Pytel's son recently developed a stammer and is easily frustrated when he is not given the opportunity to complete his thoughts. This usually happens when people first meet him.

Pytel has made it a practice to give teachers detailed information, including strategies her family uses at home, to help her son communicate. Teachers have implemented these ideas, and Pytel's son has become more independent and gained acceptance among his classmates.

For children who have attention and behavior challenges related to sensory needs, parents may find that establishing routines at home can facilitate a successful start to the school day. Paul Stengle, The Arc's executive director, is the father of a child with multiple learning disabilities. Stengle began implementing a sensory brushing program every morning before leaving for school. He finds that this enables his son, Harrison, to participate more fully in classroom and school routines, such as activities that require Harrison to sit among other young children.

It is also important to make teachers aware of children's strengths and weaknesses when they start school. Diana Polec, data technician at The Arc, started this process early for her high school-age son, Jimmy, who has physical disabilities. Polec visited prospective classes with her son and his teachers about two weeks before school started. The mother and son then practiced common school routines with teachers, such as going to class and ways her son would be participating in class. This preparation gave Polec and the teachers time to develop techniques that the boy would use to successfully navigate the school day, including how to manage his locker and be on time for auxiliary classes. The adults paid careful attention to any signs of stress Polec's son expressed, modifying their strategies to reduce it. This approach has helped Polec's son succeed in public school with typically developing teenagers.

Many children put pressure on themselves to perform. When a child has learning differences, this tendency can affect the child's self-esteem and feelings about school.

Kavitha Patel, a social worker at The Arc, has a son named Vijay who has a language delay. Vijay judges himself harshly, and once he fails at a task he needs considerable reassurance to try again. To be motivated by his teachers, Vijay needs to trust their faith in his abilities. Patel has discussed this with her son's teachers. She has had her son in both specialized and inclusive settings, and facilitated communication between his past and current schools to share information about what helps her son learn. As a result, the learning process goes more smoothly for Vijay.

Parents of children with chronic medical conditions might face the greatest challenges. Shelly Ortiz is a special education teacher at The Arc and a mother of two children with special needs. Her daughter, Mikayla, has a seizure disorder, and has been unresponsive to medication. Ortiz copes with many of the previously mentioned challenges as well as the task of educating new teachers, nurses, special class personnel and other support staff to recognize signs of her daughter's seizures.

Ortiz has been successful. She credits her daughter's school for its ongoing efforts to teach the signs of seizures to everyone, including the students, the administrators and the lunchroom staff.

Parents can also meet hardship regarding their child's Individualized Education Program (IEP). Stengle has had considerable experience with the IEP process. He recommends keeping communication lines open with teachers, particularly if there are issues with the child's IEP at the start of the school year. Being able to advocate and compromise are crucial components in obtaining the appropriate resources for a child's school success.

All of these parents were able to help their children commence school successfully thanks to two common factors. They discovered their children's unique strengths and resilience, and school personnel were willing to adapt and listen.

When schools disappoint, it's vital to communicate and resolve each situation as it arises. And when things work well, trust your abilities as a parent to let go and relish the outcome in making the transition to school a positive experience for your child with special needs.

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Tagged as: [Disabilities](#), [Education](#), [Learning](#), [School Resource](#)



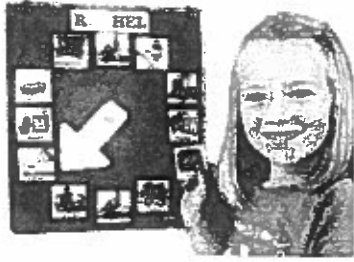
About the author: [Loretta Clift](#) [View all articles by Loretta Clift »](#)

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A Space of Their Own

Organizing the home for children with special needs.

Susan Varsames, M.Ed.



Setting up spaces in the house for safety and efficiency is simple, and the results produce immense benefits. For children with special needs, homes should have a visual flow, be free of extraneous distractions and clutter, and offer clear choices. You will find the environment dictates functional behavior when spaces are deliberately planned at home.

Suggestions for the Kitchen

- Eating areas should have a table that is the appropriate height for children to sit with their feet on the ground. A small table with accompanying chairs are perfect for kids to enjoy snacks and quick meals. For family meals at the main kitchen table, offer a bench to go under children's feet, allowing bodies to feel organized and offering good posture for eating, chatting and socializing.
- Food preparation areas should have a stool for children to climb up on for helping with meal preparation. Perhaps invite kids to spin and tear the lettuce, place it in a bowl and toss in some small tomatoes. Consider encouraging children to put a handful of breadsticks in a basket to carry to the table. Offering kitchen helpers opportunities creates a sense of family participation and personal value. It's also a great chance to model language, reinforce family values like teamwork and provide practice for increased attention with caregivers.
- For pre-verbal children, affixing pictures of food choices on the refrigerator is a great way to link language to requesting preferred food choices. Velcro or magnets are excellent for this. Children won't needlessly become frustrated or rummage to find what they want. Instead, kids can be taught to hand the pictures to you to indicate something like, "I want this please." Use that golden moment to state, "Oh, you are telling me (pause) 'Mommy, I want applesauce.'" Then wait for some paired vocalization from your child before delivering the food. Even if it's just an approximation, keep practicing to shape the sound to eventually sound more like the accurate word.
- Establishing kitchen-related chores is a great way to teach household responsibility. If children have the ability to match similar item, glue it to a grocery list or copy the label onto the list so the item can be found in the supermarket on your next shopping trip.

Suggestions for the Play Area

- Keep toys in bins with lids in a closed closet. Rotate toys that are thematically related and only display a minimal amount at one time. You might have wooden blocks with cars and trucks available at a certain time. Maybe a toy garage could be taken out to go with that. Model the function of the toys and the sounds you can make with them, as well as the nouns, verbs and adjectives that correspond with them. After a week or two, put away the toys that are out and take out another set such as the pretend cooking utensils and food. Repeat the modeling. You will find that your children's play is more focused when the language is consistent, the clutter is removed and the theme is reinforced throughout the house. This prevents children from getting tired of seeing the same toy. In addition, as kids develop, new and more mature themes arise when you revisit toys that have been in the closet for a while.
- Again for pre-verbal children, provide pictures of the toys. You can cut out photos from the box or print them from Google Images, for example. This way kids can make choices and express them by handing you the pictures of what they desire. Use such moments to model the language you hope to soon hear.

Suggestions for the Rest of the House

- Follow the same format as above. Clear the space, organize materials into bins, provide pictures as visual models and model the behavior you wish to see in each space. Even pictures of clothing on drawers can assist children with things such as getting dressed and putting away their folded laundry as they match what's in the pile to the visuals on the drawers.
- Color code as needed. Perhaps all kitchen toys are in red bins while all vehicles are in blue and so forth. Visual learners connect to this and can find and use toys more efficiently when there's order in the house.
- Remember that in every room, safety comes first. Use cabinet locks, child-proof drawer latches and take other safety measures to avoid dangerous situations. They can be removed once your child demonstrates safe behavior.

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Tagged as: [Disabilities](#), [Organization](#), [Safety](#)



About the author: Susan Varsames, M.Ed. [View all articles by Susan Varsames, M.Ed. »](#)

Susan Varsames, M.Ed., has been teaching and consulting in special education for more than three decades. She is the owner/founder of the Holistic Learning Center, LLC, in New York, where families can access both traditional services and alternative practices for both children and adults.

Make a Plan

Insight for special needs families to gear up for a fulfilling summer.

[Dr. Scott Barkin](#)

Summer options abound for all families. Fundamentally, the key to enjoying the summer rests in the planning. Consider what your needs and goals are, know your options—from camps and educational programs to vacations—have a budget and identify resources for information.

In planning for the summer, first consider the desired goals or priorities for the months ahead. Among the potential goals of a summer break are enjoying family togetherness and amusement, socializing, providing a respite for a primary caregiver, embracing adventure, fostering independence, granting rest and relaxation, offering a cultural experience or change in climate or locale, and maintaining skills acquired during the school year—whether clinical or academic. Constraints also need to be considered. Potential limitations include money, distance, accommodations and accessibility, transportation, availability of information and fear or anxiety. Here's some guidance in navigating a few of the most popular summer options to ensure you meet your family's needs and address any limitations that might arise.

Summer Camps

There are a significant amount of summer programs for children with special needs. And the number seems to grow each camp season. The opportunities include day and sleepaway camps, local and international camps, short-term camps that span a few days and longer term camps that run six weeks or more.

Decide if you and your child are interested in an integrated opportunity or a camp that defines itself as serving a specific special needs population. Camps for children with special needs generally offer a traditional camp experience along with clinical therapy, academics or programs to enhance daily living skills. Sometimes such camps address all of these areas. Participation in a fully funded day camp with a focus on recreation and socialization grants a respite to the family of a child with a disability that may not otherwise be able to accommodate the child's school vacation with such comprehensive attention.

Summer School

Another option is summer school or a summer education program. In many states, including New York and New Jersey, children who receive support services through the public school system are often welcome to attend a summer school program. The programs are intended to preserve and advance skills acquired during the school year. Programs have the added value of being familiar to your child if your son or daughter has been attending the school or has previously attended the affiliated program.

Family Vacations

When considering a family vacation, examine the environments your trip includes, such as car rides, commercial travel like a train or airplane, a resort or hotel, restaurants, and urban and rural destinations. Then consider the following elements: accessibility and

necessary accommodations, crowds, delays, lines, intrinsic stimuli associated with environments—sights, sounds, smells—and available medical attention. Evaluate all of your travel options, including mode of transportation, size of travel hub (regional airport versus national) and peak times of travel.

Though plane travel may seem to be the fastest mode of transportation, you may need to deal with delays during the departure or arrival, a relatively confined area and a limited availability of emergency care. Road travel may offer greater flexibility, should plans need to be modified.

Knowing what accommodations are essential to your travel plans should contribute to a successful trip. Make phone calls to confirm that all the appropriate accommodations are available for you on the schedule you are following. Many popular family resort destinations have wonderful accommodations for families with special needs. However, the availability can be limited. If temperature or weather is an issue, look for destinations with stable conditions that are not at the extremes. Determine where quieter areas can be found early on. If your child has limited food preferences, cater to them. Pre-determine a supervision schedule and share the responsibilities if you can.

If you don't have a spouse who can pitch in, is there a friend, therapist or respite worker who might be able to accompany you? Think about the crucial objects, routines and possibly clothes that make a difference to your child, and do your best to incorporate them. Consider what strategies can be employed if long waits arise, like having DVD players, MP3 players, favorite toys and snacks on hand. Compile a "to-go packet" of information so that if a last-minute opportunity becomes available, you are prepared with a list of questions and items to pack for the journey. Identify the location, contact information and directions for seeking emergency care. Take along a first aid kit, a camera to document the trip and a journal to note successes.

Include your child in the planning process in any way possible. What are your child's wishes and fears? Also consider whether the trip is for just one child's benefit or the entire family. Compromising and remaining flexible are the next essentials following planning. Be creative and utilize your knowledge and experience. Upon initial presentation, a trip to the museum may not appeal to everyone in the family. But, the content of the museum may appeal to one member, a visit to the gift shop might appeal to another, a change in environment might appeal to another person, a different mode of transportation or just time alone might appeal to another family member.

Resources

With all of this in mind, it can be a challenge to make a decision about what to do this summer. A variety of resources should be contemplated, including experience, which is always an important factor. See if any of the professionals, such as teachers, physicians, therapists and daycare providers familiar with your family, have suggestions.

There are also terrific online resources for identifying camps with special needs programs. For guidance, log onto www.mysummercamps.com, www.verypecialcamps.com, www.kidscamps.com, www.campresource.com and www.parentguidenews.com. Some travel-related resources for families with members who have special needs include www.tsa.gov/travelers/airtravel/specialneeds/, www.globalaccessnews.com, www.nichcy.org and www.icdri.org.

Posted in: [Special Needs](#)

Tagged as: [ADD](#), [Anxiety](#), [Camp](#), [Camp Resource](#), [Choosing A Camp](#), [Day Camp](#), [Disability](#), [Family Vacation](#), [Fear](#), [Program](#), [Routine](#), [Sleepaway](#), [Sleepaway Camps](#), [Social](#), [Summer Camp](#), [Summer Programs](#), [Support](#), [Travel](#)

ADHD and the AM Routine

Making mornings go smoothly for kids with attention problems.

John F. Taylor, Ph.D.

When it's time to get your child up in the morning, could you use a little help? Children with ADHD tend to have problems rousing themselves to become fully awake from sleep. As they first wake up, they also tend to be irritable, argumentative and oppositional. A third common issue is that children with ADHD tend to be absent-minded, disorganized, indecisive and forgetful in the morning. In other words, they may be like scatterbrained grizzly bears upon first arising.

Launching the day can tax the patience of any parent, as well as the patience of siblings and the child who has ADHD. Here are tips for getting your child with ADHD out of the bedroom, ready for school and equipped to begin the day on a positive note.

The Night Before

Hogging the bathroom creates a lot of conflict. And as children with ADHD are generally overly aware of skin sensations, they often relish the gentle stimulation of a shower or bath and take a long time in the bathroom in the morning if given the opportunity. To quell any conflict, and save some hot water, arrange that long shower or bath in the evening as part of the bedtime routine. The experience will calm your child, making bedtime go smoother and granting a more restful night's sleep.

Provide a protein-rich bedtime snack about 30 minutes prior to bedtime. Tryptophan, the protein that occurs in abundance in milk, turkey and chicken, is a natural sleep inducer for anyone, including those with ADHD. But just about any protein-rich snack is likely to be helpful. Oatmeal, Oat O's, whole-wheat cereals, Cream of Wheat, an egg, some meat or fish, milk (not chocolate), cheese, pumpkin seeds and sunflower seeds are examples of wholesome snacks that often work as a practical and relatively efficient get-to-sleep aid for most children with ADHD.

Protein can be a two-edged sword, however. Be mindful not to feed your child any protein that he or she might be allergic to. There is about a 75 percent likelihood that ADHD symptoms will worsen when a child with ADHD experiences any food allergy.

And instead of expecting your child to make a lot of decisions upon first arising, set out clothes for school the night before. Also agree on school lunch items, breakfast food choices and other decisions that can be made the evening prior to school. Lastly, place your child's notebooks, textbooks and other school items on a chair near or blocking the front door. This way your child won't forget them.

In the Morning

Sometimes children with ADHD have difficulty coming out of sleep into wakefulness. Try an extra loud alarm by placing an alarm clock on a metal pie pan with dimes in it in a metal cookie tin turned on its side. You can even purchase alarm clocks with extra big bells on them. Or try one of the special vibrators that can be pre-set to start vibrating in the morning as a wake-up device.

One of the most efficient ways to help children with ADHD become fully awake is to take advantage of the sensitive awareness of their skin. Gently wipe a cool and damp washcloth over your child's brow and cheeks while whispering a greeting such as: "Good morning, Sweetie, time to get up. I love you!" Don't try water in the face as a surprise. Likewise, no squirt guns, please. Rather, agree upon an arrangement ahead of time. Your child must want and expect the water as an aid to waking up. Have your child show you the desired water temperature with a practice wipe before going to bed.

Sit down with your child and arrange the correct sequence of morning preparations you want to employ. Put them on a friendly chart that can be placed in a location convenient for your child to refer to, such as inside the bathroom or your child's desk drawer. For a young child who has ADHD, make a fun chart with pictured reminders about brushing teeth, putting pajamas in the hamper, combing hair, gathering school books and doing other launch-of-day routines. Or invite your child to make a tape recording in which your child reminds himself what to do when. No more being nagged at by mom or dad!

I often teach physicians a method of adjusting early morning medication to allow everything to go smoothly. The technique is to give the child 2.5 milligrams of short-acting (not timed-release) stimulant medication 30 minutes before the alarm is to ring, then have the child lay back down and rest until the alarm rings. This small amount of medication should supplement, not replace, the amount already prescribed as the morning dosage. But the method should be employed only with your physician's guidance and approval.

Once the child comes downstairs, eating breakfast together is great— except when a war ensues rather than peaceful meal. Carefully decide who sits where at breakfast, as well as who eats when.

Another way to help get a child with ADHD through morning preparations stress-free is to have a visual time reminder that provides constant feedback as to how much time is left prior to your child's having to leave. Auditory reminders such as buzzers and bell timers are not as effective and tend to interrupt and irritate rather than teach time management. I have created an optimum device (the Time Timer, available from numerous outlets including my site www.add-plus.com), which has a red disc that slowly disappears as time passes. You can even arrange a "beat the clock" contest with a special long hug awaiting your child if all of the preparations are accomplished prior to the disc's complete disappearance.

Why are Mornings Difficult?

Why do kids and teens with ADHD have so much irritability and mental disorganization upon first arising? There are several reasons.

1. **Lowered Brain Nutrients.** The ten or so hours between dinner the preceding evening and the moment of arising the next morning deplete needed brain nutrients.
2. **Too Many Decisions.** Children with ADHD can be thrust into making too many decisions first thing in the morning, such as what to wear and what to take to school.
3. **Time Pressure.** The child with ADHD, along with the rest of the family, may be rushing around, gathering needed materials and competing for bathroom time and breakfast food.
4. **Insufficient Sleep.** Children with ADHD require about ten hours of sleep but usually get far less. They are apt to have sleep abnormalities and disturbances during the night that further rob them of the REM sleep needed to refresh brain functioning.
5. **Allergens.** Research reveals that about three out of four children and teens with ADHD show increased irritability and mental disorganization when exposed to allergens, including what may occur in a bedroom if certain anti-allergenic measures are not taken.

Posted in: [Special Needs](#)

Tagged as: [ADHD](#)



Autism Spectrum Disorders

Adjusting to the reality of a diagnosis.

Nancy D. Wiseman

With approximately one in 150 children being diagnosed with autism (67 children are diagnosed every day), autism is more common than pediatric cancer, juvenile diabetes and Down syndrome combined. And yet, no parents can predict how they will react to the news that their child has autism. The diagnosis may come as a devastating blow or, if parents have been searching long and hard for answers, it may come as somewhat of a relief.

No doubt parents will experience a wide range of emotions, from anger and guilt to overwhelming grief and hopelessness. Every family needs a great deal of support. The most important thing to remember is that the diagnosis is no one's fault, and there is hope.

The journey faced by a parent of a child with autism is one of the most challenging and life altering experiences anyone could ever imagine. It's not a journey a parent can take alone. It requires a network of extended family members, friends, neighbors, doctors, therapists, educators and total strangers to reach out and help.

The earlier the intervention begins, the better the outcome. The first few years in a child's life are critical. Current treatment approaches offer real hope and improvement, and even the possibility of recovery as autism is treatable. This treatment should take a comprehensive integrative approach, consisting of appropriate clinical, educational and biomedical treatments.

The Top Ten Essential Actions for Parents

What follows is a quick summary of the most crucial steps parents of a child with autism should take during the first year following a diagnosis to facilitate a successful journey.

1. **Understand and accept the diagnosis.** You will need to arrive at a deep understanding of the complexities of the disorder and how it may be affecting your child specifically. It is more than a matter of reading about autism spectrum disorders. Actually accepting the diagnosis means moving from the denial stage to acknowledging that "yes, my child has autism. But I can do something about it." For some parents, acceptance comes quickly. For others, it takes weeks, months or years.
2. **Document everything, and become informed and well-connected.** Being methodical and organized is key to maintaining your sanity during this journey. Also keep the contact information for your network of support organized and accessible.
3. **Establish your A team.** You must assemble a top-notch team of medical, therapeutic and educational specialists to ensure you have the breadth and depth of expertise you need in managing your child's autism diagnosis. There is no way you can do everything on your own. You should draw on the expertise of your network of specialists to form the most accurate assessment of your child and to identify the treatments that will best meet his or her needs. Members of the team will change over time, but the team will remain essential to your success.
4. **Take the driver's seat; oversee the business of recovery.** You are the team leader and ultimate decision maker. While you will be relying on specialists, you need to question everything to be sure the steps taken make sense for your child. Do not automatically assume anyone is an all-knowing expert. During this process, you might become more of an expert than some professionals because of the fact that you know your child better than anyone. Use this knowledge to manage your team and your child's recovery program.
5. **Recognize your child's likes, dislikes, strengths and challenges.** Get a complete developmental profile of your child from a skilled developmental specialist. This is critical if you and everyone else on the team are to understand the depths of your child's strengths and challenges. Generally this profile comes from a developmental pediatrician or a pediatric psychiatrist or psychologist.
6. **Put the proper supports in place.** This will be a very long and often exhausting journey. You will be of infinitely greater value to your children and family if you are not falling apart. To maintain your health and sanity, ask for assistance from a support system of family members, friends, community members and professionals. There are many parents in the same situation who can be a great resource and part of that support system. It truly does take a village to raise and nurture a child with autism.
7. **Know and exercise your legal rights.** Federal laws— chiefly the American Disabilities Act (ADA)— and affiliated state laws govern the supports and treatments you can get. If you don't know and exercise your legal rights, you probably won't get what

you need, such as reimbursement, proper services and adequate schooling. The more legal knowledge you have, the further you will get.

8. **Obtain key evaluations and reports to get the services you need, and keep them up-to-date.** To get the intervention your child requires, your greatest tool is comprehensive, detailed reports from top specialists in the field. These reports should clearly spell out the diagnosis and specifics about the educational program, therapies and support services that best meet your child's needs.
9. **Learn which treatments and programs are most appropriate for your child.** Many different treatment and educational options are available. To allow you to intelligently select what is most appropriate for your child, you and your team must have a thorough understanding of your child and the various treatments.
10. **Advocate!** When it comes to obtaining treatment and educational services, you are always going to be your child's best advocate. Assert yourself and ask questions— no one can speak up the way you can. It is critical to learn how to advocate and do it well.

Posted in: [Special Needs](#)

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Nancy D. Wiseman is the parent of a 13-year-old child with autism, and founder and president of First Signs, a national nonprofit organization with the mission to educate parents and professionals about the early signs of autism and related disorders. She has appeared in interviews with USA Today, NBC's Today Show, Larry King Live and Parents magazine, and she is the author of *Could It Be Autism? A Parent's Guide to the First Signs and Next Steps* (Broadway Books) and *The First Year: Autism Spectrum Disorders. An Essential Guide for the Newly Diagnosed Child* (Da Capo Press). Wiseman is the 2006 recipient of the American Academy of Pediatrics' Daie Richmond/Justin Coleman Award for her outstanding achievement in the field of child development.

Special Needs Trusts FAQ's

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What are special needs trusts?

A trust is created when property (real estate, finances, tangible items) is managed by a person for another person's benefit. The person managing the property is called the "trustee". The person whose benefit it is for is called the "beneficiary". The trust lasts as long as it is needed. This usually means the trust will go on until the beneficiary's death or until the funds are expunged.

Special needs trusts are made specifically for the benefit of disabled or mentally ill beneficiaries. These beneficiaries lack the mental capacity to manage their own finances. The trust is created with the specific needs, lifestyle, and future of the beneficiary in mind. Often times these special needs trusts are used to ensure that the beneficiaries don't lose government benefits they are receiving. The trustees of special needs trusts can be family members or, if an appropriate and trustworthy family member is unavailable, a third party will be appointed by the court. Choosing the right trustee must be done very carefully, especially for special needs trusts that are used for the benefit of a younger person.

What are the benefits of special needs trusts?

Often times, people with disabilities qualify for government assistance such as Supplemental Security Income (SSI), Medicaid, vocational rehabilitation, and subsidized housing. Many people make the mistake of leaving assets to their disabled loved ones through a will. This is problematic because acquiring assets, such as a lump sum of money, can disqualify your loved one for these types of government assistance programs. By setting up a special needs trust, instead of solely using a will, you can avoid these issues. Because the trustee has total control over the management of the funds, and the beneficiary does not, government program administrators, like the ones from SSI and Medicaid, ignore the trust assets when considering eligibility.

Special needs trusts can also be used to set up inheritance funds or proceeds from a settlement on behalf of the disabled person. This way, if your loved one is the plaintiff in a successful lawsuit or inherits assets, those funds will go into the

trust and will not disqualify him or her from receiving those government benefits. On the flip side, if the beneficiary is ever sued, the funds in his or her special needs trust cannot be touched--they are not subject to any judgment.

What if we are not concerned with government benefits?

The beauty of special needs trusts is that they address the specific needs of the disabled person, whereas, other types of trusts do not. Even if a family is not interested in government benefits, they should still consider a special needs trust to address those specific needs. Furthermore, you never know what the future holds. There is no sense in sacrificing government services that could be beneficial for your disabled loved one in the future.

How can the beneficiary access the special needs trust?

Having the trustee directly give your loved one money could disqualify him or her for government benefits. Instead, the trustee can use the trust assets to purchase necessities for your loved one. The trustee can buy services and products, like personal care attendants, vacations, home furnishings, medical and dental expenses, education, vehicles, physical therapy, and even recreation.

Should I consider a pooled trust?

Pooled trusts are a type of special needs trust that are managed by nonprofit organizations. These nonprofit organizations pool the money from multiple families and invest it. Each beneficiary still has his or her own separate account and his or her own trustee, chosen by the nonprofit organization. These appointed trustees even purchase things for the beneficiary, just like a trustee appointed by the family or the court would. If you are having a hard time coming up with someone who would be a good fit as a trustee, a pooled trust may be something to consider. Check your local nonprofit organizations to see what is available in your area.

How should special needs trusts be worded?

- Most importantly, a special needs trust must state that the trust is intended to provide "supplemental and extra care" beyond that which the government provides.
- State that it is not intended as a basic support trust.
- Do not include a "Crummey Clause," an estate tax provision.
- Reference the Social Security Operations Manual and this specific parts in the manual that authorize the creation of the special needs trust.
- Include the required language regarding payback to Medicaid.
- Explain the exception to the Omnibus Budget and Reconciliation Act.
- Include a copy of the relevant provisions from the United States Code.

Do I need a lawyer to set up special needs trusts?

Anyone can create a special needs trust, as long as the required language is included. There are plenty of good do-it-yourself books you can buy that will walk you through how to properly create a special needs trust. However, there may be times when your circumstances are a bit more complicated. For instance, if you are setting up a trust with money the beneficiary received from a settlement. In these types of cases, consulting an attorney is a good idea, because complicated and state-specific rules then apply. The best thing to do is to let a lawyer take care of your special needs trust for you. There are so many different requirements and details that experienced probate attorneys will be able to hash out for you.

The Blossoming of Peace

Parenting a child with Down syndrome.

Kathryn Lynard Soper



The bluish-white glow from the laptop screen was the only light. It was late on an autumn evening, and I was alone in my hospital room. Twenty-eight weeks pregnant—and scared. I had been put on strict bed rest a few days earlier when my preterm labor had finally stopped, leaving me dilated to four centimeters.

On the laptop screen was a chart showing the most common complications resulting from premature birth and their likelihood of occurrence based on gestational age. Respiratory failure. Cerebral hemorrhage. Severe intestinal infection. I couldn't help imagining how awful it would be to face any one of these complications. What kind of a life would any of these issues cause this child? What kind of a life would it be for me?

I looked at the last item listed on the chart of complications: mortality. Facing the possibility of my baby's death was terrifying. But, as I sat in the dark hospital room with tormenting fears in my head and a time bomb in my uterus, facing the bleak possibilities surrounding his life felt just as menacing, or even more so.

What happened next is difficult to describe. A deep sense of calm overcame my heart. The dark, dense cloud of fear shrunk and dissolved. My mind was still imagining all the challenges my baby might face, and all the trials I might have to endure. However, the hardships stopped mattering as much. I felt awareness growing deep inside of me—awareness of something good, something real, something stronger than dread and pain. I felt the beauty of life itself. As it sprouted within me and burst into bloom, I was filled with profound peace. Life is a gift, I suddenly understood. A good gift.

Two weeks later my contractions started again, and after a difficult labor and delivery, Thomas was born. Before I could see him, he was whisked into the NICU. My husband and I waited soberly for the Apgar scores. We sighed with relief when we heard the good news—a one-minute score of eight, a five-minute score of nine. We looked at each other, hardly believing our good luck.

Then two doctors entered the room with solemn faces and sobering words, "We think your son has Down syndrome."

Though it seemed like months, it was only a few weeks before I sat in front of the computer monitor again. E-mails were streaming in from friends and family members in response to the birth announcement we had mailed out the week before. To their credit, our loved ones were full of cheer and encouragement regarding Thomas's arrival. But I felt resentful and even angry about their easy words of goodwill. Why?

It was because I had too much to process and adjust to. I wasn't ready to hear about how great my life would be, especially not from people who didn't know anything about it themselves. Thomas was stuck in a NICU isolette with tubes and wires poking into every extremity. I was stuck in a new reality that I could not yet understand or appreciate. I felt so alone.

Then, a few days later, I received an e-mail from Ellen, a dear friend from high school. She has an adult brother, David, who has Down syndrome. In part, Ellen wrote: "I have no doubts that you will love and appreciate Thomas as he grows and develops on his own timetable. I had the opportunity to have David at my house for most of the summer and fell in love with him all over again. (Crying now!) You are beginning on a journey with countless rewards and blessings. Thomas will touch so many lives and educate so many around him. What a wonderful gift you have been given." A gift.

I remembered the wisdom and calmness that graced me that night in the hospital room. Exhausted and bewildered, I tried unsuccessfully to again reach that same wondrous, restful place within myself. Yet, I believed my friend. I trusted her assurances that all would be well. She knew; she had lived it. And her words planted seeds of hope that someday, somehow, I would regain my sense of peace.

The winter months following Thomas's birth and diagnosis were long and dark, in more ways than one. Thomas was home, but he needed oxygen supplementation and a feeding tube. I had to seclude him from public places. All the usual stress of recovering from childbirth and adjusting to life with a new baby was compounded by the complex medical situation and the frightening unknown of what the future would hold for our family.

But, as the light and warmth of springtime crept back into my days, my crisis began to abate. Thomas's health stabilized. My daily routine with him felt increasingly like the work of parenting a typical infant. Life didn't seem nearly as daunting. And, surprisingly, neither did Down syndrome. Though there were still challenges, such as juggling visits with specialists and therapists, Thomas was becoming more and more incredible to me. As my friend's letter had predicted, his arrival in our family was bearing many positive changes. Thomas's sheer presence was the greatest blessing. Over time the influence of his gentle spirit brought me that longed-for assurance that life is a gift—specifically, my son's life is a gift.

With summertime, the last wisps of darkness that had clouded my thoughts and feelings slipped quietly away. Soon peace unfolded into full bloom.

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