










BBB AUTISM SUPPORT NETWORK

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Tips for Daily Family Life With an ASD Child

(BBB Autism printable article #20)

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There are a lot of things about raising a child with PDD-NOS or atypical PDD that teachers, therapists, and doctors don't know much about. The way you live will change, like it or not.

The good news is that the behaviors that cause these changes usually don't last forever: the child who this week broke wineglasses just to hear them smash will probably not be tossing them two years from now. But if you want to avoid rushing from disaster to disaster, you must have a proactive parenting style.

Avoid conflict, redirect behavior, and always be on the lookout for an alternative solution to behavior problems.

Here's some advice culled from many parents on handling typical trouble spots:

Haircuts

If you can figure out what it is about haircuts that drives your child wild, then remove that particular trigger. You may then be able to get the job done at a regular barbershop or salon, with modifications. Common problems and solutions include:

Sensitivity to barbershop or salon odors.

If this is the case, look for an old-fashioned barbershop that eschews smelly shampoos, or buy a home haircutting kit. Unscented products are often available, but you may have to buy them yourself and bring them in, or request them in advance.

Sensitivity to the sound of buzzing clippers or snapping scissors.

Some people can tolerate one but not the other. There are also old-fashioned hand razors for cutting hair, but it's hard to find a barber who can wield one with precision. Call around! You might also try earplugs, or a Walkman playing a favorite tape over headphones. Your barber will happily work around headphones if it keeps the child in the chair. You might also choose to accept a longer hairstyle, if grooming is not a problem.

Sensory sensitivity in general.



Try brushing the head and hair frequently with a medium-soft hairbrush. This may desensitize the area in time. You may be able to have your child sit in your lap during a haircut; a tight hug may calm him down. Again, home haircuts may be your best bet. Make sure you or your professional uses a neck strip and a cape to keep hair off the skin and clothes, and clean up with a soft brush and/or a blow dryer set on cool. Parents whose children are of African descent may have a particularly hard time with sensory issues when it comes to hair care. Braided styles are the most convenient when it comes to grooming, but take a long time to achieve and involve a lot of pulling. Straightening chemicals and pressing are no picnic either. Short, natural styles may be the easiest to manage.

Extreme hyperactivity

One false move in the barber's chair can result in inadvertent punk rock 'dos. Many parents swear by cutting hair while the child is fast asleep. Scissors work best for this operation. Keep a brush and comb handy, and work slowly. You may want to use a plastic bowl on the head to get an even length or, for longer styles, hair tape (available at beauty supply stores and many drugstores or chemists).

Toenail and fingernail clipping/cleaning

It may be an exaggerated fear of being cut, a desire to not lose a part of oneself, or the metallic clicking of the clippers, but many children with PDDs hate this grooming task. It's best if kids learn to do it for themselves as early as possible, although those with fine-motor problems may find it difficult.

Curved toenail clippers are larger and easier to operate smaller fingernail clippers, and can do both jobs passably. This is another job that parents can do while a child is asleep.

Bathing

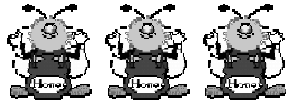
This is a problem area with teenagers more often than it is with young children, according to parents. You may have to institute a schedule, or even allow gym-class showers to suffice during the school year.

Even for older kids, tub toys, soap "paints," bubble bath, or other items may allow you to get them in and out of a warm tub once a week.

Contrary to popular belief, it's not necessary to bathe children daily unless there are special medical or sanitary reasons to do so. Use a washcloth to zap any particularly grungy areas daily, and schedule an unavoidable bath time for one or more days each week. A flexible shower hose can be very useful for washing the hair of children who are afraid of the big shower.

Some kids who won't go near a bathtub will go swimming, which usually comes with the added bonus of a mandatory shower. In a pinch, you can see if they'll run through a lawn sprinkler in a pair of shorts. The novelty of pools and sprinklers sometimes trumps fear of getting wet.

Clothing



What do you do with a child who strips off his clothes at every opportunity? First, you try to find out why. The most common reason is sensory sensitivity, so first talk to an occupational therapist about instituting a program of sensory integration therapy.

In the meantime, see what you can do to make staying clothed more comfortable. Verbal children may be able to explain what they don't like about wearing clothes. Common problems include chafing waistbands, itchy fabrics, "new clothes" smells, and annoying tags. Kids who can't stand regular waistbands can often handle elastic-waist pants and shorts, especially those made with soft fabrics, such as sweatpants. Others can wear only overalls or coveralls with ease--and these have the added bonus of being harder to remove.






For children who wear diapers, the diaper itself may be the problem. Check for and treat any actual diaper rash (incidentally, diaper rash can be caused by a yeast infection on the skin, which may indicate a larger problem with yeast overgrowth. Experiment with different types of cloth diapers, various brands of disposables, and larger diapers if tightness around the waist and legs is an issue.

Over the diaper or training pants, sweatpants, overalls (especially the ones with snaps along the inseam), coveralls, jumpsuits work well. Some parents actually stitch down the overall straps each morning, or replace easy-open fasteners with something more complex. It's possible to open overalls and coveralls for larger children along the inseam and add unobtrusive snaps or Velcro for easy toileting without complete clothes removal.

Some children who tend to remove all their clothing in the bathroom are simply taking extreme steps to prevent getting their clothes dirty. Careful work on toileting technique and rewards for good performance can help. Some may also want to have wet wipes available to improve their after-toilet cleanup, and thereby avoid dirtying their clothes. Wipes can be purchased in small, discreet containers that fit well in a purse or backpack.

Catalogs that carry special clothing for children with disabilities.

Many items in these catalogs are especially good for older children who have toileting problems, or for children with orthopedic impairments in addition to PDD-NOS or atypical PDD.

-  Shirts and dresses that button up the back are also hard to remove.
-  Many people with sensory problems prefer soft fabrics, such as cotton jersey or terrycloth, over stiff fabrics like denim. If this is the case with your child, go shopping with that in mind. It can help to wash new clothing a few times before wearing it, to remove that stiff feeling as well as any unfamiliar smells.
-  And speaking of smells, if an aversion to clothing crops up suddenly, make sure you haven't just changed your detergent or fabric softener. There may be a smell or allergy issue going on.
-  Remove tags from inside of garments as needed.
-  One solution that will save you money and hassles is purchasing used clothes instead of new ones. These presoftened garments may already feel "just right." Again, they may need to be washed a few times to take away any bothersome scents.



Decorating for autism

The homes of most young children with autistic-spectrum disorders have a certain uniformity. After a few incidents of shattered heirlooms and leaning towers of furniture, accessible areas tend to get a makeover in the direction of a simple, stripped-down look. Baby gates, locked doors, childproofing devices, and the like abound.





When shopping for new furniture, pay extra attention to sturdy, easy-to-clean pieces. You may want to use sticky-back Velcro or foam to secure a few knick-knacks, but it's best to relegate the family china and precious ornaments to an inaccessible room or a locked (and hard to overturn or shake) china cabinet.

Bunk beds and other furnishings that invite acrobatics may not be a good idea for your child. Then again, they might, if your child tends to be unresponsive to her environment, but gets excited about climbing up to an upper bunk or bouncing on a springy mattress.

Likewise, shelves that could be used as steps up to precipitous locations should be removed or very securely anchored.

Even though he couldn't walk yet, Ian kept using our dining room chairs to climb up onto the table. Several times he made his way up there in seconds, knocking items onto the floor and risking a fall of several feet. We solved the problem by chaining the dining room chairs to the wall, one in each corner. It made visitors scratch their heads when they saw us do it, but to use the chairs at the table, we just unhooked them.

Some children seem to have a compulsion to move furniture around, often using it to build ramps up to places they shouldn't be. Solutions include:

-  Removing wheels or plastic sliders from furniture legs
-  Choosing very heavy furnishings
-  Weighting or blocking the movement of furniture with heavy concrete blocks hidden beneath stuffed couches and chairs
-  Literally attaching furniture to walls or floor with hook-and-eye fasteners or other hardware

For the early years at least, it's good if you can learn to appreciate thrift-store chic. You'll feel a lot worse if your child picks holes in a \$1,000 couch than if he damages a \$75 sofa from a garage sale. Slipcovers are a good idea for protecting nice fabrics.











If you want to have one or more nice rooms, either lock them or be prepared to stand guard at all times. Experienced parents can attest that the latter option is not worth it--you definitely have better things to do with your days than worrying about stains on your Persian rugs. There will probably be a time when you can enjoy some of the finer things again, but now may not be that time.

Childproofing dangerous items

Most parents of crawling babies and toddlers take pains to remove hazards from their reach. You may need to continue and even expand this program with a child who has PDD. Funding may be available through government developmental-delay or mental health departments or private agencies to help cover the expense of these modifications.



Items that can pose dangers include:

-  Exposed electrical outlets. A variety of plugs and covers are available for these.
-  Exposed electrical wiring and extension cords. Obviously, any exposed wires should be walled off somehow. Extension cords can either be eliminated by adding additional wall outlets or stapled to the wall. Rubber channels are available for making them inaccessible; these can usually be found at office supply stores.
-  Electric fans. Box fans are less dangerous, but little fingers may still fit in. Experiment with fan placement. You might consider using ceiling fans, swamp coolers, or air conditioning instead in hot weather.
-  Stove burners. Burner covers can eliminate the attraction of fire or glowing coils, but can also cause burns if touched when hot. Some parents remove the knobs from their stove, place a barrier in front of the stove, add a disconnect valve for the gas behind the stove or unplug it when not in use, or add locking doors to the kitchen.
-  Matches, lighters, and combustibles. Lock these up, and watch out for guests who carelessly leave lighters or matches on tables.
-  Household cleaning supplies, paints, solvents, and other chemicals. A securely locked cabinet is a must if your child tastes and smells everything. Some young autistic children have incurred serious brain damage by repeatedly sniffing gasoline, glue, or other solvents. Of course, these items are sometimes abused as drugs by adolescents and teens.
-  Medications, including herbal remedies and vitamins. Most people are unaware that aspirin and Tylenol top the list of medication overdose causes--in other words, keep everything that's medicine out of reach. Securely locked bathroom cabinets can work, but storing medications in the bathroom is actually not that great an idea due to the moisture level. You might install a similar cabinet in another room or use a simple lock-box. Small cash boxes work well and are available at office supply stores for a reasonable price. For convenience's sake, you may wish to keep one week's medications, supplements, and vitamins counted out in a plastic pillbox, then keep the pillbox in your purse or another more secure location. Be especially wary about leaving chewable medications and vitamins within reach.
-  Houseplants. A few are out-and-out poisonous, but heavy pots coupled with tantalizing fronds and tendrils can lead to hurt heads and major messes. Use ceiling hooks to hang trailing plants well out of the way, or try using sticky-back Velcro or foam to secure pots to a flat surface.
-  Cigarettes. You would think they'd taste too horrible to eat, but some kids will do it. Tobacco can be quite dangerous when eaten. Keep cigarettes, cigars, chewing tobacco, and full ashtrays under wraps.
-  Alcohol. It's dangerous to mix even a little with many of the medications used for PDDs, and it has plenty of inherent dangers of its own. If you like to keep a selection of liquor, wine, or beer at home, you might consider a locked liquor cabinet, or keeping a separate refrigerator in a locked garage or basement.



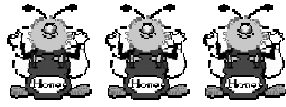
- 🐱 Cat litter boxes. Cat feces carry disease and should not be handled by pregnant women or anyone with immune-system problems. The covered boxes may or may not be less attractive to marauding children. Protect the room where the cat box is with a baby gate, or add a cat door to a locked door.
- 🚪 Stairs and stair banisters. Baby gates or locked doors at the top and/or bottom of stairs may be enough. If the stairs need to be available to your child, make sure that any slats and banisters are too closely spaced for heads or bodies to slip through. If they aren't, you could add more slats or change the banister's style or position. Another solution is blocking access with a net, piece of fabric, or sheet of wood. Commercial stair nets are available that tie securely to open banisters and slats in a stairwell.
- 🔫 Guns and other weapons. These do not belong in the homes of children with neurological disorders, particularly teenagers. The combination of a high potential for depression and easy access to lethal force is very dangerous, and younger children with PDDs may be at risk simply due to their impulsivity. As some recent, tragic cases have shown, storing guns in a locked box under the parents' bed or in a gun cabinet does not guarantee safety around determined teens. If you enjoy shooting sports or hunting, see if you can store your guns at a shooting range or hunt club.
- 🔪 Knives. Sharp knives are common household tools, of course, but they also pose dangers. A drawer latch may be sufficient for keeping kitchen knives out of reach, or you may need to install a keyed lock on the knife drawer. Watch out for knives and other sharp kitchen tools that may be left in the sink, on countertops, or in the dishwasher.
- 🍷 Glass, including glass items and windows. Some children seem to enjoy the sound of broken glass. This may necessitate using window treatments that can be locked down or even boarding up some windows. Cutting a piece of foam to fit within the interior window well is an inexpensive solution that has worked for some parents. Replacing the glass in picture frames with unbreakable plastic may save accidents.
- 🪟 Window-blind cords. These present a danger of hanging if the child puts her head inside the loop. Simply cut through the loop. For persistent offenders, you may want to cut the cords very short as well.

Take a walk through your house with your child's size and interests in mind. If you can notice and remove potential problems before your child sees them, you've done well.

Safety precautions


Some autistic-spectrum children seem to have a Houdini-like ability to escape their rooms, homes, and yards. This would be an amazing talent if it didn't cause families so much fear and heartache. In the film *What's Eating Gilbert Grape?*, an autistic boy runs away repeatedly to climb a nearby electrical tower, with near-tragic results. The recent thriller *Mercury Rising* presented another autistic character with no fear of heights, trains, or traffic.


Incidents of harm to autistic individuals are depressingly common. At least two autistic children in the US have died in drowning accidents after escaping from their homes in recent years. A third spent several harrowing days alone in the Florida Everglades before being rescued--an experience that the nonverbal child's pictures indicated may have included an encounter with an alligator.





The parents of all three of these children had spent considerable time and expense to secure their homes--all it took was a second for the child to slip out of view. If escapes are a problem for your family, please consider using the services of a professional security consultant. You may be able to get help from government developmental-delay or mental health agencies or from private agencies, to find and even pay for these services. Most of us would not normally wish to turn our homes into fortresses, but in some cases it's the most caring thing a parent can do. It could very well save a life.


Security options that parents have tried, with varying degrees of success, include:


 Installing key locks or doorknobs with twist-locks facing outward on bedroom doors can keep a child securely in his room at night. Obviously, toileting could be a problem with this solution. An intercom or buzzer to summon parents can solve this problem (as could a chamber pot, for those willing to try it).


 Latch-style locks, hook-and-eye hardware, or chain-locks installed at the top of interior doors can limit access to certain rooms, or keep a child in one room. Of course, these can be foiled easily when a child gets taller, becomes strong enough to force the door, or figures out how to stand on a chair.

 Double- or triple-bolt security doors can slow down a would-be escapee, and some types can be unlocked only from the inside with a key. While expensive, they are tremendously jimmy-proof. Keep the keys well hidden, of course--on your person, if need be. Fire regulations may require that an exterior-lock key be secured in a firebox or stored at the nearest fire station in case of emergency.


 Windows can be nailed or latched shut.

 Bars can also be placed on windows, as many homeowners in urban areas already do. Like key locks, these can be a fire hazard. A security consultant, or perhaps your local fire department, may be able to come up with ideas. Some types of bars have interior latches.

 Alarms are available that will warn you if a nocturnal roamer is approaching a door or window. Other types only sound when the door or window is actually opened. Depending on your child's speed, the latter may not give you enough response time.

 Obviously, fences and gates are a good idea for backyards. Some types are less easily scaled than others. Although it might seem cruel, in extreme cases a child's safety could be secured by using electric fencing (usually this involves a single "live" wire at the top of a tall fence). Electric fencing kits are available at some hardware stores or at farm-supply stores.

 Key locks are more secure than latches for gates.

 Electronic locks of various types are another option, including remote control and keypad varieties. These can be used for garage doors, gates, or exterior doors.






In some cities, the local police department is sensitive to the needs and special problems of the disabled. Officers may be available to provide information about keeping your child or adult patient safe and secure, whether he lives in your home, in an institution or group home, or independently in the community.



Some also have special classes to teach self-defense skills to disabled adults.

Some police departments also keep a registry of disabled people whose behavior could be a hazard to their own safety or whose behavior could be misinterpreted as threatening. If your child is an escape artist, has behaviors that could look like drunkenness or drug use to an uninformed observer, uses threatening words or gestures when afraid, or is extremely trusting of strangers, avail yourself of this service if possible.

People with PDDs can have a bracelet or necklace made with their home phone number, an emergency medical contact number, or the phone number of a service that can inform the caller about their diagnosis. Legends you might want to have engraved on this item include:

-  Nonverbal
-  Speech-impaired
-  Multiple medications
-  Medications include ... (list)
-  Epilepsy (or other medical condition)

Members of the general public, and even some safety officials, may not know the word "autistic." They are even more unlikely to know what pervasive developmental disorder or PDD means.

If this article has conjured up visions of a nightmarish life with your child, please remember that most people with PDDs do not experience severe problems in the home that cannot be helped with therapeutic, medical, or educational interventions. However, as experienced parents can tell you, once one problem behavior is extinguished it invariably seems to be replaced by a new one.

Parents always need to keep on their toes, and it can be exhausting. Take time occasionally to look at the positive side of life with PDDs. There is humor, joy, and sweetness to be found and appreciated along with the challenges.

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