



Stresses on Families

(BBB Autism PDF article #18)

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Withdrawal and Over involvement

A pattern often seen in families with a disabled child is one parent who stays as remote from the situation as possible while another's involvement borders on obsession. The withdrawn parent may be just as concerned, but either doesn't have the coping skills or has delegated responsibility to the more-involved partner. Generally--but not always--fathers tend to withdraw, and mothers tend to jump in with both feet.

" My relationship with my husband is changed due to his (and most males', I'm finding) lack of whatever it takes to deal with this disability. "

--Holly, mother of three-year-old Max (diagnosed PDD-NOS and apraxia of speech)

This situation is not healthy for either parent, nor does it really benefit the child. Parents need to keep the lines of communication open, even when job responsibilities and schedule conflicts force one partner to be more directly involved in activities like in-home ABA training, attending school meetings, or talking with doctors.

Set up a time each week to talk about events and, perhaps more importantly, feelings and frustrations. Try to find ways to keep the parent who has a tendency to pull back actively involved. Perhaps that parent can take part in some rambunctious playtime while the other fixes dinner, or can take on a special weekend activity, such as Scouting, team sports, or a hobby. The trick is to actually schedule these activities and make sure that they happen. It's a rare pair of parents who are absolutely fifty-fifty in their involvement, but for the sake of their partnership, the most-involved parent needs to know that there will be regularly scheduled break times ahead.

Burnout and Respite

What happens when break time doesn't happen? Burnout. No matter how much you love your child, there will be a day when your batteries just quit. Single parents, and couples who have a very unbalanced system of sharing responsibility for their child with a PDD, are at high risk.

Anyone who's ever had a horrible job knows the symptoms of impending burnout. You start feeling hopeless, numb, resentful, and angry, all at the same time. You may get physically ill, suffering from an increase in headaches, stomachaches, bowel complaints, and fatigue. You start fantasizing about running away.

Sadly, some parents really do run away--away from their share of responsibilities, away from their marriage, even away from their child.

"His father simply saw him as flawed, and never became involved in searching for an answer or diagnosis. He abandoned me, Kevin, and his younger brother Jonah when the boys were seven



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and five, respectively. After I fought through the courts for support, he surfaced for occasional visits, but lives out of town. He never asks what is wrong with his son, and isn't careful with him when they are out in public. Jonah, who is thirteen now, "parents" his brother when the three of them are together."

--Cindy, mother of fifteen-year-old Jeffrey
(diagnosed verbal dyspraxia with "autistic-like" features)

Don't let this happen to you or your partner. It's okay to say that you're overwhelmed. Only then can you look for a way to remedy the situation. If you have trouble doing it on your own, a good family counselor can help you set up a schedule that gives you some time off to clear your head, take a class, or just enjoy a quiet cup of tea or a game of golf. Usually it doesn't take much to lift the burden of your day-in, day-out duties--but you do have to ask.

Like Jeffrey's father, some parents deal with feelings of guilt embarrassment, and shame with denial. These feelings are anything but easy to work out--particularly for men (or women) who have trouble articulating their emotions. A little understanding can go a long way.

Single parents, and couples who want their time off to be time together, should access respite-care services if they are available. Respite providers are trained to care for disabled youth and adults for the afternoon, overnight, or even during a family vacation.

"Dhylan is very hard to manage at times, and therefore we don't go out without him (kind of like the American Express card). We just applied for respite care and are hoping we get it. A break is so important."

--Sally, mother of four-year-old Dhylan (diagnosed PDD-NOS with autistic features)

Respite care may be available at no or low cost through community agencies, public or private. A county caseworker or local disability organization should be able to put you in touch with respite resources in your area.

As an alternative, perhaps you can set up an informal respite arrangement with one or more parents of children with disabilities in your area. For young children, playgroup co-ops can be a great idea, and they're one that many parents are already familiar with. The same concept can work with older kids and even adults cared for at home too, and can be extended to cover overnight care and occasionally longer visits.

If you have the financial resources, of course, you could hire someone with appropriate training to provide respite services in your home on occasion. If a nearby college has a special education degree program, students may be able to earn extra credit and gain valuable experience, as well as earning some money, by caring for your child.

Summer day-camp programs, overnight camps, "parents' night out" programs, and other options are also available for giving yourself some much-needed time off. It's not a selfish thing to do at all; in fact, avoiding burnout is an essential part of being a good parent for a child with PDDs. The sanity you save may be your own!

Resentment

Resentment is an ever-present emotion in families affected by disabilities. Unfortunately, it usually festers away in private, only surfacing when an argument crosses the line of civility. It's hard not to feel resentment when this diagnosis



can take so much away your life: free time, undisturbed sleep, quiet mealtimes, the ability go places with your old friends and their "normal" children, community approval, financial security ... the list goes on.

"My husband has had to put off finishing school and finding a career in order to stay with my son during the day. He feels some resentment towards that, but now we have the common goal of our son to keep us warm."

--Shayna, mother of three-year-old Max (diagnosed multisystem developmental disorder)

Resentment is the result of feeling like you're not getting a fair shake, so it's important that any suffering that's being done for the child's sake is validated by other family members. No one should feel like a silent martyr (and with any luck, no one will act like one either).

Siblings may harbor more resentment toward their disabled sister or brother than they're willing to admit. We'll discuss this in the "Siblings" section later in this article.

Genetic Blame

Family problems are often compounded by the red herring of "genetic blame": whose crummy genes caused this PDD problem anyway? You would be surprised at how often this unspoken issue underlies arguments that only appear to be about disciplinary methods or parenting style. When it finally comes out into the open, watch out!

Parents and relatives all need to know that PDDs are neither rare nor exclusively found in your respective families. You could not have predicted that your child would have this diagnosis, not even if you had discussed every unusual relative in your respective family trees before procreating. Nor could a professional genetic counselor have been of much use.

It may also be useful to remind each other about what's good in your genetic heritage or your partner's. The same side that passed on the genes for PDDs probably also passed on many wonderful characteristics, which hopefully your child will also share.

Also, make an agreement with your partner early on that if your parents or other family members try to start a genetic blame conversation, you will nip it in the bud immediately.

Parental Neuropsychiatric Problems

There are real parenting issues that have to do with genetic heritage. PDDs are, at least in part, inherited disorders. It is not uncommon for one or both parents to have neurological difficulties of their own, and these may make it even harder to raise a child with a PDD.

It's been said by some professionals that a few of Bruno Bettelheim's "cold and distant" mothers of autistic children may have actually been suffering from mild forms of autism themselves. Certainly, parents of children with PDDs have a slightly higher incidence of depression and other mental disorders, as well as a higher incidence of health problems in general, perhaps related to an underlying immune-system dysfunction. Some of this may be genetically based, although some may derive from being in a difficult situation.

It's best to be open about these problems with your medical provider. Medical care and counseling for your own neuropsychiatric problems can help you feel better, and that alone will make you a better parent. You will be more available to your child, more patient, and less easily stressed.



Unfortunately, it isn't always to your advantage to let state or school authorities know if you are experiencing mental or physical problems. There are many people in social services and education who have negative attitudes about parents with psychiatric or neurological diagnoses. They may not take you seriously when you discuss your child's needs, and in some cases you may even be danger of losing your children.

Siblings

When a child is in crisis, the everyday problems of her brothers and sisters seem to recede into the background. Reactions differ. Siblings may become superachievers to get their share of the attention--or they may seek negative pursuits, for the same reason.

Resentment is also a natural reaction when another child in the family takes more attention and more financial resources than you do.

"Our child's siblings are wonderful with him, however, they do sometimes feel that he gets away with more. But so far we have been able to talk this out with them."

--Julie, mother of four-year-old Sean (diagnosed PDD-NOS)

Problems faced by the siblings of disabled children are beginning to get more attention. Books are available that discuss typical reactions. One of the best is *Views from Our Shoes: Growing up with a Brother or Sister with Special Needs* (Meyer, Woodbine House, 1997). It's an excellent guide to sibling issues, and it's written from the children's point of view.

Chat groups and workshops can also help. You may be able to get your other children involved in SibShops, which are part of a Seattle-based sibling-support project. SibShops and similar workshops give siblings a chance to meet other kids their age who share their situation. With a little help from adult facilitators, these workshops can help siblings talk about their feelings and fears. Friendships are frequently a nice side effect.

You can find an international directory of sibling support groups, including SibShops, at http://www.chmc.org/departmt/sibsupp/sibshopdirectory_map.htm This site also has links to a variety of online and offline resources for siblings.

The behaviors of people with PDD-NOS or atypical PDD can be difficult for siblings to deal with. If your child has behaviors that are aggressive or assaultive, dealing with these is the first order of business. It's not fair for your other children to be at risk for actual harm. If you need this kind of help, call a behavioral professional immediately.

You may need to take special steps to safeguard the personal property of your other children, and to ensure that they have a quiet place to get away from your disabled child's tantrums, loud noises, or intrusive behaviors. Some of the solutions are not things that most parents would normally want to do. Possibilities include putting a keyed lock on a child's door, situating children's bedrooms as far apart in your home as possible, and providing niceties like a telephone, television, computer, or stereo in the child's room (or in a lockable family room) to permit their uninterrupted use. You'll have to set rules for the use of these devices that prevents the sibling from withdrawing into couch-potato land, of course.

It goes without saying that a fair share of your time is far more important than possessions, space, or even privacy. It's essential to make some special time for your other children. Some parents have a meal out, go to a movie, or enjoy an activity with their other children each week, and swear by the results. Ensure that your other children can find time to talk with you about school, friends, ideas, and concerns, without interruptions from your child with a PDD. You may need to be flexible about bedtimes one night each week, allowing another child to stay up just a bit later than usual to enjoy some one-on-one time with you. Another way to carve out time is to wake one child up a bit early once a week for a cup of cocoa and some quiet talk.



Your extended family may be able to help by taking up some of the slack. Grandparents, aunts and uncles, or older cousins may be available to take on some minor duties, such as transporting another child to soccer practice twice a week. Some grandparents may be willing to fund enrichment activities or excursions together.

Many parents have special friends or neighbors who might be willing to get more involved, if you ask--this system can work out very well if you can recruit the parents of a sibling's friends. Family friends, and other trusted adults in the community, can act as mentors and advisors, and help your other children pursue personal interests.

Most siblings do have worries and questions about PDDs, and they may be afraid to talk to you about their fears. Children are exquisitely sensitive to family stress, and they don't want to burden you with more. It's essential for their well being that these issues be put on the table, though. Common fears include wondering if their sibling is going to die from his illness, worries about possibly dangerous medication, feeling different from other children who don't have a disabled sibling, being teased because of their sibling's odd behaviors, and fear that their parents are unconcerned with their needs because of the other child's demands.

Quality information is the key. There are some films available that can help you start the conversation. What's Eating Gilbert Grape?, starring Johnny Depp and Leonardo DiCaprio, is a particularly good one, as is the Dustin Hoffman-Tom Cruise film Rain Man, although both portray individuals with more severe forms of autism. Short videos for siblings may be available through disability advocacy organizations as well.

Children's books on autism, of which there are quite a few, may be more frightening than reassuring to siblings of children with PDD-NOS or atypical PDD. They may fear that their brother or sister will become "worse," like the child in the story, or they may not identify their sibling with the more severely autistic child at all. Teens may find books by high-functioning autistic writers like Donna Williams or Temple Grandin interesting and informative.

Adolescent and adult siblings may resent the very real impact on their future of having a brother or sister with a disability. As Joe's quote in the section "Financial problems," later in this article, illustrates, siblings may lose out on a lot, including opportunities for higher education, participation in community sports leagues, music and dance lessons, having a car, or (as explored to tragic-comic effect in Rain Man) receiving an inheritance.

They may also fear that as their parents age, they will be expected to take on increasing responsibilities for their sibling--and this is not an unreasonable worry. You may indeed need to pass on guardianship at some point. This is something that should be discussed and understood as early as possible.

As siblings approach the teen years, where family conflicts can get especially difficult, parents will need to ensure that each child has activities that give him a chance to shine on his own. School activities, religious youth groups, and volunteer organizations can be good choices if money is tight due to medical bills.

Quite a few parents interviewed for this book report that their children have become fierce advocates for their brother or sister with a PDD. Some have even chosen careers in medicine, teaching, or psychology due to the influence of their sibling's struggles.

Other parents noted that siblings have been therapeutically important, particularly when it comes to helping their child with a PDD learn language and social skills. Children can insist on interaction in ways that adults can't seem to get away with. Basically, they know how to make it fun--and we should always let them know how much we appreciate their efforts.

Lack of Family Support

If it takes a village to raise a child, some extended families of autistic-spectrum children don't see themselves as part of that village.



"As far as the extended family, most of them act like Doug doesn't even exist. That's mainly on Doug's father side of the family. On my side, Doug is just kind of "there," nobody really does much with him. I don't have much help or support from them."

--Debbie, mother of eleven-year-old Doug
(diagnosed PDD, fragile X syndrome, and sensory integration disorder)

You ought to be able to turn to your own parents and other relatives for support and encouragement, but it isn't always possible. Many families of people with PDDs find that their child is passed over for family activities, such as invitations to grandmother's house for Christmas or trips to the mall with siblings. Some family members even neglect to send birthday cards.

Sometimes the problem is simply a deep-seated prejudice against disabled people, and you can't do much about that. Often it's related to a lack of adequate information about the child.

"It has been a source of tension in the family because, with my son at least, diagnosis is not clear-cut. He is not classically autistic and is, in fact, very affectionate and related to his family, both immediate and extended. There are those in the family who think nothing is wrong and say we are stigmatizing him by seeking help. There are others who think he is just poorly disciplined and out of control."

--Jennifer, mother of three-year-old Joseph
(diagnosed atypical PDD)

It might make you feel uncomfortable to do so, but you can share evaluations from your child's school or doctor with the family member(s) who seem to question the disability's existence. Some parents have even brought a grandparent along for a psychiatrist or doctor visit, with hopes that hearing the diagnosis from an expert in a white coat will help it be accepted at last. You might want to discuss this possibility with one of your most accessible professionals, perhaps asking that they deliver some suggestions for helping your child along with information about the disability.

Community Isolation

All it takes is one embarrassing episode in the checkout line or at the public park to make the average parent want to crawl under a rock. Every time the worst happens, the impulse to withdraw from public life is amplified.

"We cannot do anything with him, except go for car rides (this calms him), walk with him (he needs the motion), and bring him to the playground. He prevents people from talking to each other with his noise and disruptions. He is not communicative, he is hyperactive, and he makes weird noises. We cannot even bring him out to eat. We try to shop in the early morning when the stores are empty."

--Joe, father of seven-year-old Kyle (diagnosed PDD with autistic features)



One of the most difficult areas for family members of people with PDD-NOS or atypical PDD is dealing with rude or clueless remarks from strangers. Children with PDDs are rarely beneficiaries of the sympathy factor. There's no wheelchair or leg brace to signal, "This is a disabled child," so onlookers may assume that they're witnessing willful misbehavior. Some are quite vocal about letting parents know it, which can do a number on your self-esteem.

Some people carry cards explaining the problem that they can give to busybodies. Others have a canned speech for these situations, such as "My daughter has a neurological problem that can cause [insert the unusual behavior of the moment here]. I'm sure you understand."

You may be tempted to add, "In other words, she's disabled. What's your excuse?" although it's probably not a good idea. You may also be tempted to avoid the problem altogether by disappearing from public view. But isolation is a breeding ground for depression, and it does a child with social deficits no favors, either. But what about parents?

It's sadly true that the friends you had before your child's problems became evident may fall away. You'll have to be the judge of whether the cause is fear, prejudice, dislike of your child, or simply the fact that you have less free time to spend with friends than you used to. Disability support groups are frequently a source for new, and potentially rewarding, friendships. On the other hand, you may struggle mightily to hold onto friendships that have no relationship to PDDs, just to avoid having your child's disability permeate every aspect of your life.

As for being included in community activities, such as attending civic events or religious services, you will probably have to turn educator to make a place for your family. Some religious bodies do have formal programs for including people with disabilities in services and religious life. Check at the national, regional, or diocese level to find out what's available. Religious life is one area that many parents interviewed for this book cited as an island of acceptance in the larger community.

Other interest groups, from car clubs to the Grange to volunteer organizations, may also be able to find room for you, either with your entire family or as an individual participant. Be direct: ask how your child (or your hectic schedule) can be accommodated.

In the US, the Americans with Disabilities Act (ADA) was passed specifically to ensure that people with disabilities have equal access to community life and facilities. If your child's condition is causing discrimination against your entire family, the ADA covers you, too. The European Community charter and some European countries have similar regulations--and legality aside, full inclusion is certainly the ideal that people everywhere should aspire to. Don't be afraid to assert the natural right that you, your child, and your family have to participate in everyday life whenever possible.

Financial Problems

PDDs can be a financial drain, and that's a family strain. Parents do cite money woes as a major source of family stress.

"We've spent about \$11,000 out-of-pocket in four years! We had to recently use our home-equity line of credit to pay for this, and haven't been able to save money for our older son's college (we have four kids, ages seventeen through seven). We rarely can afford nice vacations, music lessons for the other children, etc. I drive a car with 200,000 miles on it because we cannot afford a replacement."

--Joe, father of Kyle

As this father's words indicate, money problems are about more than a low bank account balance. Other family members may miss out on important opportunities or do without some material things. Unless the situation is thoroughly and



regularly discussed with them, they may not understand why the person with PDDs needs are costing so much, and why they are a family priority.

Social services programs are both a source of assistance and a source of financial difficulty for many families. Job choices and saving money for future needs may be jeopardized by these programs' earning and property rules. Parents who want to take advantage of these services and still meet their responsibilities to their other children (not to mention to themselves) may need specialized financial planning

Family Therapy

Finding professional help for family problems isn't always easy when a person with a PDD is part of the equation, because few family therapists know much about neurological disorders. The wrong therapist can cause irreparable harm by once again blaming the parents for the disorder, looking around for nonexistent sexual abuse, or inflaming feelings of guilt or resentment in one partner.

"The last thing we needed was for the therapist to goad us into a fight during the session. We are dealing with an incredible amount of stress. At the end of the hour, he got to leave. We got to go home steaming, our problems still unresolved. When we hadn't gotten around to talking about making any positive changes after three sessions, we decided to call it quits."

Parents interviewed for this book cited many negative experiences with traditional models of family therapy, particularly when sessions were conducted by inexperienced or "old-school" personnel. Parents of autistic-spectrum adults interviewed for this book had particularly heinous tales to tell from the "bad old days." But in the hands of a competent, experienced professional, family therapy can be a positive growth experience for people dealing with PDDs.

"My main sources of strength are the autism news list on the Net and the other parents at therapy."
--Dorthy, mother of five-year-old Jesse (diagnosed PDD-NOS with autistic tendencies)

According to parents who have tried family therapy, there are two models that seem to get the best results: "whole family" approaches that may include working separately with parents, siblings, and the patient, then bringing everyone together on a regular basis to hash out interpersonal issues; and group therapy sessions that involve several parents. The latter can provide families who are new to the diagnosis with a built-in support system, and participants in well-run groups report a growing sense of confidence as they, too, are able to pass knowledge on to others.

The focus of either approach should be less on "fixing" dysfunctional family systems than on empowering family members with new coping skills and providing a safe place to work out conflicts. Some therapeutic groups for parents operate more parenting classes, with speakers invited in to discuss various topics of concern to the group.

Separation and Divorce



Marriages suffer when a child is disabled. The legal aspects are beyond the scope of this book, but it is important that parents of child with PDD-NOS or atypical PDD who do choose to end their relationship take the child's special needs into account.

Issues may include:

- Custody arrangements that allow both parents access to the child and respite. These arrangements may constrain the parents from living too distant from each other, which can be a difficult situation.
- Financial settlements that take into account the added expenditures needed to care for a disabled child, possibly including extended alimony for a stay-at-home parent.
- Financial arrangements to ensure that both parents will be responsible for the child's needs after the age of eighteen (most divorce decrees only cover support until the age of legal majority).
- Written agreements about which parent will pay for medical bills, tuition, therapy, and other expenses related to the disability, and to ensure that health insurance coverage is maintained.
- Special agreements may be needed if the divorce is due to abuse, neglect, or substance abuse by one parent, in order to protect the child.

There's very little good that can be said about families splitting up, unless it's for reasons of safety. Parents should simply do their best to ensure that each partner's relationship with the child(ren) is maintained. Professional help, either in the form of social-worker aid or family counseling, is strongly advised.

Single Parents

Couple problems are plenty of trouble, but it's trouble that those going it alone sometimes wish they had. No matter how ineffectual one half of a couple is, your partner is still an adult sounding board and a shoulder to cry on.

Single parents also face increased financial pressure, and have terrible time getting meetings with school districts, doctors, and other helpers to fit into their schedule. Voicemail, pagers, email, and fax machines can be the single parent's best friends. You may also try to fit several appointments (school, psychiatrist, and pediatrician, for example) into one day off work. If your child has a low tolerance level, however, the results may not be great.

Some therapists do offer evening and weekend hours, and school districts can often be convinced to hold early-morning meetings. You may need to work with an advocate who can represent you at meetings. A friend, relative, sitter, or professional hired specifically for the purpose may be able to take your child to medical appointments.

And don't forget to take some time out for you--if you can find it! There's nothing like a child with a PDD to stop any semblance of a post-breakup love life. The time commitment alone may take you away from the dating world for years, and explaining what your home life is like could turn off a potential mate.

"Theron's behavior problems keep me from finding a partner to share my life with, as his father left six years ago. His two younger brothers have many of the same problems, though not the same diagnoses, so my attention is divided fairly equally amongst them, none for me!"

--Ann, mother of eight-year-old Theron (diagnosed PDD-NOS, psychotic disorder, borderline intellectual functioning)

Single parents have more reason than any others to seek allies in their extended family or community. Respite care and quality after-school care are absolute necessities. Foster grandparents programs, Big Brothers, Scouting, religious institutions, and parent groups can all be part of your web of support.



Multigenerational Living

If you're part of the "sandwich generation"--caring for children and aging parents at once--your family also faces extra stress.

Older relatives in the home can be a wonderful addition to your life, but if they have many medical needs of their own or can't handle the behaviors of your child with a PDD, the situation will eventually explode.

An extra pair of hands is a must in these situations. In the US, Canada, Britain, Australia, and most parts of Europe, home health aides are available for frail or disabled elderly people, even when they are cared for by their children. Private social-service agencies and religious institutions may also be able to provide assistance.

Housekeeping help may give you more time for the important stuff, if you can afford it. Again, volunteer help or public assistance may be available in this area. Contact your government department for services to the elderly for more information, and be sure to explain that you have the extra burden of caring for a disabled child.

As with siblings, you may need to take special care to ensure that older relatives are safe from aggressive or assaultive behaviors, and that they can secure their possessions and peace of mind. Locks, latches, intercoms, and soundproofing can help in some situations.

Noncustodial Parents

In some countries, and in some US states, parents are told that they must give up legal custody of their child to the state if he needs publicly funded residential services. Disability advocacy organizations can help you sort through various options.

Giving up custody need not mean having no input. However, some programs are so unused to parental involvement that they aren't sure how to include family members in the lives of their institutionalized clients. Set up a meeting to discuss the ways you can help your child, activities you want to continue to share and, if applicable, issues related to financial management and personal safety.

Although full independence is every parent's goal, some adults with PDDs do continue to need help and oversight long after the age of 18 or 21--and retaining a close relationship with one's parents is valuable in and of itself. Custody issues can get in the way here, however. Once your child has reached the age of majority, you don't have the right to determine her medical care or to control any other aspect of her personal life. You may find yourself shut out of important decisions about housing, food, medical care, education, and vocational choices. If your child is able to handle these choices alone, that's great, even if you don't always agree with her decisions. For many families, the problems occur when the adult child's friends, therapists, or professionals with various programs start calling the plays. You may not be sure that your adult child is in agreement with these decisions, and sometimes these individuals will deliberately try to prevent you from having access to the decision-making process. Your input can help ensure your child's safety and keep his personal needs met. You may need to take legal steps to make sure that you stay in the picture.

Divorce can also prevent parents from retaining full custody. Both parents' level of personal and financial involvement should be written into the divorce settlement. If the settlement is unsatisfactory, or you are being prevented from involvement in your child's life, you will need legal help to assert your custodial rights.

Medical care is a frequent sticking point. If parents disagree about the right medical approach (for example, if one is totally opposed to using medications and the other is not, or if one prefers a traditional approach while the other is into alternative therapies), they may need to use the services of a counselor or arbitrator to work things out. Alternatively, parents may be able to agree on a practitioner or program, and simply agree that both will abide by recommendations of this third party.



Worst of all is the situation of having your children forcibly taken from you. This has happened to parents of children with neurological disorders when uninformed social workers thought the child's behavior resulted from abuse, especially when the disorder had not been diagnosed before the action took place. Parental neuropsychiatric problems are often a complicating factor in such cases. Of course, families of people with PDDs are not immune to abuse, neglect, or parental substance-abuse problems, either.

If you feel that you are at risk of losing custody of your child to state or to an ex-spouse, do not delay in seeking legal (and medical) support. Disability advocacy organizations may be able to provide you with advice and, in some cases, legal assistance.

Adoption and Foster Care

Although hard numbers are not available due to confidentiality laws, it's well known that childhood disability is a major factor in adoption and foster care placements by natural parents. Some simply don't have the knowledge or resources to take care of a child with a potentially lifelong disability. Tragically, these children are among the hardest to place. Parents who step up for this duty deserve a medal and may need special support.

"Stevie was originally diagnosed as deaf, which is why I got him, as I sign. He was three and a half years old when first diagnosed with autism. I'm in the process of adopting him. His deprivation was so severe we aren't sure just how much is the autism and how much is the deprivation.

Unfortunately, Early Intervention wasn't an option in his case. All diagnosis, progress, services, schooling, etc., started 21 months ago, when he came to live with me.

Finding community resources has been the biggest thorn in my side. We are hooked up with a regional center that tends to pass the buck to the foster agency or school district until the adoption is final. Our FFA [foster family agency] has not been helpful in any way. No backup, no help finding babysitting services, it all falls on me. I'm not complaining, honest, I wouldn't trade my life now with Stevie for anything!

As I am raising Stevie as a single mother, I can tell you that I have depleted most of my savings and live hand-to-mouth many months. Even though I receive a monthly stipend for him, it hardly covers the cost of shoes! It's a great struggle, but I have great faith and trust in a Higher Power ... if I didn't, I couldn't survive."

--Roni, foster parent, and soon to be adoptive mother, of five-year-old Stevie (diagnosed atypical autism)

Some foster-care and adoption agencies that work with special-needs children have more to offer than Roni's. Private agencies for the disabled could help those that do not, but communication between the public and private sectors is



apparently difficult. Parent support groups and disability advocacy groups can sometimes provide a bridge between the two.

Some parents of children with PDDs may have to place their children in a therapeutic foster home, either temporarily or permanently. This type of foster-care arrangement is set up to provide specially trained round-the-clock caregivers for medically fragile or disabled children who cannot be cared for at home. Typical reasons for placement may include assaultive or aggressive behavior that endangers parents or siblings; a parent's disability, incarceration, or death; or difficult medical issues, such as tube feeding.

With temporary foster-care placements, the goal is usually to wait out or find a solution for the situation that led to placement. Natural parents must stay as involved as possible--it's very important to attend all meetings and therapy sessions when your child is in foster care, even if the placement was voluntary. Lack of participation can lead to the termination of parental rights in some cases.

Natural parents also need to maintain oversight of the child's medical, educational, and personal needs during the foster-care placement. Foster-care arrangements vary in quality, ranging from homes you wish you had grown up in to the worst of abusive environments. Most therapeutic foster parents are quite good, however.

If the foster placement is in another city, you may need to secure assistance to make regular visits, or send an advocate to make visits for you. Regular communication by mail, email, and/or telephone with your child should be assured when distance is an issue.

It's sad that in the US, foster-care placement is sometimes chosen as a way to ensure the delivery of essential services to children. Foster parents merit a stipend to pay for the cost of the child's care, and the child receives publicly funded healthcare and mental health services. In a better world, natural parents could receive the special training provided to therapeutic foster parents, as well as the subsidies and services they need to care for their difficult children. In all of the nations of Europe, and in many other parts of the world, parents of disabled children are guaranteed financial assistance, healthcare for their child, and other services.

A notice to our readers...

The founders and contributors of BBB Autism Support Network are not physicians; we are parents contributing in a totally voluntary capacity.

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