



# Nothing to Hide:

## The Danger of One Wrong Provider

By Stephanie Crist

Like many of you, I've read articles and heard lectures on the importance of carefully choosing providers and selecting services for our children with autism. I've walked away from doctors, and even a school because of what I'd learned. I took charge of my children's care and actively led every team involved. Then, I learned how much damage one wrong provider could do.

### One Wrong Provider

"My children aren't broken, don't try to fix them!" In big, bold letters those words were the first thing our therapists saw when they took out the binder about my children. I explained to each therapist we emphasized growth and development, not "fixing" their autism. A year passed. Some therapists I adored. Others I distrusted. I took the program as a whole package. The system worked, so I didn't meddle with staffing decisions. Our household took to

the tidal flow of therapists. We learned to set our days by its rhythm.

A major shift in staffing brought a new psychologist in to lead my older boys' teams. From the beginning, we clashed. From her perspective, our children were very much broken. Our whole family was broken. "Instead of embracing your children, you should strive for normalcy," she said in a thousand different ways. Time and again we butted heads. Every time, on the surface, I won the argument. I was the parent and I was in charge. I felt safe staying in the program that provided line therapists who loved our children, whom our children loved.

Then, the visits from Child Protective Services started. I respect CPS's mandate, and I knew we neither abused nor neglected our children. So, when CPS started knocking, I opened the door and let them in. We had nothing to hide.

One visit turned into two, which turned into a dozen. The CPS worker picked at everything from the stains on the carpet to the food in our cupboards. Like the psychologist, she demanded we make our home as clinical as possible. My husband, the stay-at-home dad, grew more depressed after each visit. We were under attack, and didn't know why.

One day the police came to our door. Someone reported that our youngest son was running around with a butcher's knife. The call just wasted their time and ours – there was no danger. But things had gone too far. Nobody is supposed to inform parents who placed the call, but someone told us.

Looking back, I don't know how I didn't see it. The CPS worker used the same words and phrases the psychologist used. All those value judgments did

not start with CPS. They started with the psychologist – who had connections in the agency and even acted as an advisor for CPS. Once we knew, we fought back. Some well-placed people helped us. I knew I should pull my kids from the program. I threatened to do just that and the calls to CPS stopped.

But the damage was done. A charge of child neglect had been substantiated against my family. No trial, no lawyers; there was her word against ours, and hers was all that mattered. The day my appeal was due, I finally received the record the CPS worker had compiled. Misquotes and distortions littered every page. I showed portions of the document to interviewees. One response highlights their reactions: "I never said that! She can't do that!" Sadly, she could. I drew the appeal board's attention to these false statements, but the interviewees were never contacted for corrections. The substantiation was upheld without further

investigation. Unbeknownst to us, we had been tricked into signing a document that stated we were willing to accept services – an admission of guilt.

We did not lose our children. Two social workers came to train us in parenting – neither knew much about autism nor how to adjust traditional parenting techniques to children with autism. This new incursion lasted a few weeks, until my middle child, the one CPS spuriously labeled "severely autistic," ran screaming from the room the moment they came in. We didn't let them come back.

My family should never have been subjected to this unwarranted assault, but we made it through intact and have come away richer for the lessons we've learned. We're recovering; we're whole; we're together. Our children are surrounded by people who love, nurture, and accept them as they are – looking forward to all they can and will become. At the end of the day, that's all that matters.

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## Advice to Providers

- Listen actively.
- Check to make sure you truly understand what parents want and why.
- Parents are the experts on their children. Respect their knowledge.
- Combine parental and professional expertise to sculpt effective programs.
- Show appreciation for the accomplishments of the family.
- Establish a team environment whenever possible.
- Reassurance and recognition helps forge bonds that ease potential conflicts.
- Work with other practitioners involved in the child's care and education.
- Consult with an associate if conflicts arise.
- Avoid making value judgments.
- "Should" and "ought" are value-related words.
- Respect parents' values and priorities.

# Advice to Parents

A CPS worker, on the condition of anonymity, offers the following:

- Do not invite CPS workers into your home without a warrant.
- A child with special needs counts against the parents the moment the report is taken.
- Evidence collected during an investigation consists of observations and interviews, subject to whatever biases the CPS worker holds.
- In some states, little to no effort is made to corroborate these observations.
- Refusing entry to a CPS worker will limit the scope of an investigation and protect your family from intrusion.
- Other avenues of investigation may include speaking with your child's teachers and therapists.
- If the CPS worker feels there are exigent circumstances, they will speak with your child at school.
- Otherwise CPS must obtain written consent from a guardian.
- Do not sign any documents without legal counsel.
- When CPS workers cannot make their case in court, they trick parents into signing a "voluntary service agreement" – essentially an admission of guilt.
- By signing this you relinquish your right to trial.
- If you then do not cooperate, they can take you to court and win their case. Your child becomes a ward of the state even if the child stays in your home.
- Contact legal counsel early to determine what services they can provide at various stages of the investigation.
- Request as much information concerning the investigation as possible. Expect delays in receiving this information.
- Keep your own records of the investigation, on tape if possible.
- If CPS recommends counseling, pick your own provider. Recommended providers are often predisposed to support CPS' goals.
- If you have a meeting with CPS, invite as many witnesses as possible. Include friends, family, teachers, and other professionals.
- Being investigated does not make you a bad parent, nor does it mean you're guilty.

## Finding the Right Provider

As a family, you must decide what matters most concerning your service providers. Professional experience may be your top priority. Or, perhaps bedside manner is more important. Make a list of what you need and what you want. Do you tend to run late? If so, what will happen? Are the therapists booked so tight they won't be able to work around your schedule? Will you be able to talk with your provider if a concern arises between appointments? Will this practitioner recommend other services that may benefit your child? If it's important to you, don't hesitate to put it on the list. The goal is to obtain quality care for your children while enduring little unnecessary stress. Knowing what you need, what you want, and what you'd like to avoid simplifies the decision-making process.

I also advise you to anticipate your breaking point. What will it take for you to leave a service provider? It's often easier to stay and look for an alternative, than to leave without another provider lined up. Easier isn't necessarily better. One wrong provider can do a lot of damage, as our story demonstrates.

After you've determined what you're looking for, you then have to seek out your options. Start looking at the providers your insurance recommends. When the approved practitioner is not a good fit, don't settle for what doesn't work. Insurance companies and scarcity of qualified services seem to limit our choices. Presenting a legitimate alternative often opens these closed doors. Networking is your best chance for finding viable candidates. After a frustrating experience with one doctor, my son's occupational therapist recommended a physician with more experience, a better bedside manner, and treatment alternatives. Getting my insurance to cover this doctor was as simple as asking – we weren't the first to make the switch.

The Internet can help in your search for candidates. There are valuable testimonials online, along with links to hard-to-find providers. A prospective provider's website can offer clues about the services provided and the care your family is likely to receive. The Autism Source (<http://www.autismsource.org>) is an excellent resource. This database and similar resources only offer limited coverage, however. Do not assume that a service is not available because it is not listed. Once again, networking is the key to discovering service alternatives. Therapists, teachers, and program administrators often have connections to local providers.

A willingness to do some traveling may be necessary. A hospital of specialized clinics is only forty-five minutes from our house. We started there, but one terrible experience sent us looking for alternatives. We choose a similar hospital two hours from our home, where our children, our family, and our right to choose are respected and encouraged. The right providers are well worth the extra travel time, even when gas prices spike.

Provider teams pose unique challenges. Intensive in-home therapy programs, schools, and specialist teams are examples of provider teams: several people packaged in a single program to provide services to your child. Personality or philosophical conflicts between individuals can derail the efforts of the team. For some of these programs – especially schools – it's an

## Resources

- Legislation guiding child protection agencies varies from state to state. Terminology may vary.
- Search the Internet with the words: Child Protective Services [Your State].
- The top hit for Wisconsin is <http://dcf.wisconsin.gov/children/CPS/index.HTM>.
- States provide access to documents and publications relevant to their policies.
- Annette M. Hall administers the site Kidjacked (<http://kidjacked.com/>), which offers parents a wealth of information about CPS, including legal resources, case law, family rights news and actual family court cases.
- A pro bono legal assistance organization may be able to assist you. Or contact disability rights organizations in your area for information.
- Family resource centers in your community may provide further information.
- Center workers may be former CPS workers, so you may run into prejudice when contacting these organizations.

all-or-nothing choice. You can't pick and choose individual providers, but you may be able to forgo specific services. Sometimes real alternatives are available within the same program. Present your concerns to the person in authority. Be honest, but diplomatic. Use I-statements, such as, "I feel this person isn't the right fit for my family." Keep seeking solutions to the problem. Brainstorming is a useful way to develop creative, workable alternatives.

## Your Family, Your Choice

Choosing your provider isn't about right or wrong, it's about a mutually comfortable fit. As parents, as families, we all have different priorities. No concern is too trivial if it affects your family's well-being. Keep in mind that service providers are just as human as the rest of us. A perfect fit may not be available, but a good fit should be. Keep looking, keep asking questions, and know that your children and your family are worth the effort. Not all poor fits will end in a confrontation with CPS, but the system is not perfect. Knowing the risks is an important step in making effective decisions. With a little effort and some acceptable compromises, you can find the right providers for your family. 📌

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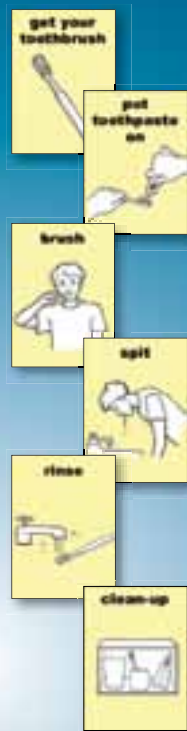
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## 20 Reasons to Use Visual Strategies



1. to solve behavior problems
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4. to share information
5. to establish attention
6. to communicate rules
7. to organize the space & materials in the environment
8. to help students handle change
9. to give choices
10. to support transitions
11. to speed up slow thinking
12. to communicate emotions
13. to clarify verbal information
14. to aid memory
15. to teach new skills
16. to stay on task
17. to manage time
18. to promote independence
19. to teach routines
20. to ignore distractions