Parenting a Child with Special Needs

an interview with Meg Robinson

What is it like for the parents when their child has a disability?

When you have a child who has a disability, there's a lot that goes on. You go through the same stages you go through in any kind of very difficult situation. First, you have denial of the problem; every parent has denial in varying degrees. Then you want to hide it, make it a secret. No one should know that my child has a disability, that my child is going to be labeled. Then you have to try to deal with what the implications of the disability are for the child, for you as the parent of the child, for the school, and so on. And it's not like you go through all those adjustments and then wrap it up and put it on a shelf. The adjustment is an ongoing kind of thing — there are peaks and plateaus; you gradually reach some hurdles and you get over them.

I sound like I'm being very negative; I'm actually very positive. You gain a lot, too. It helps you become a more sensitive person, more aware of other people. I'm certainly more sensitive to anyone who has a disability as a result of having a child with that sort of problem. And the child develops subtly other strengths as a means of compensating for having the disability — and those can be very rewarding.

How can early childhood teachers help parents as they go through these adjustments?

Here is the issue for educators. A lot of times, up until the child is two or three, the parents may not know that there is a defined disability. (Sometimes, the parents may not know until the child is in kindergarten or even older.) The whole process of diagnosing what problems may be there is a very long, frustrating, and sometimes threatening process to go through. Often it's up to the teacher, particularly in the early years, to figure out what the strengths of the child are, what the weaknesses are, and if there are defined areas where the child needs help.

Part of the problem is the diagnostic side of this. A teacher is not a physician, and you don't want the teacher to be in the position of feeling that she's responsible for diagnosing the potential problems, whatever they may be. You don't want a teacher to look at every child as a diagnostic puzzle. In nursery school a lot of things can emerge, and the earlier it is diagnosed, the better. It's easier to get at that challenge when the child is five than when he is seven or eight.

The whole diagnostic process, then, is one that needs to be a kind of team effort. It should start, certainly, with the parents. However, if there is a strong element of denial, the teacher can play an important role in persuading the parents (if there is a problem) that the child needs to be tested or to receive physical therapy or whatever.

How can teachers most effectively communicate this kind of information?

It's real tough. It's always hard when you're a parent to listen to any kind of a problem connected with your child. The teacher is an authority figure for a parent and what she says carries a lot of weight. In listening to a teacher talk about a child, it's helpful to the parents if:

- It's done on a one-to-one sit down level in a non-threatening way.

- It takes place in person.

- The child is approached as an individual with many strengths. It's good for the parent to know what the teacher likes about the child. Things should be discussed in a constructive way.

- Words should be avoided that would be potentially threatening.

- Diplomacy is important. The teacher can be suggestive without coming down hard, without saying such and such is a problem. For example, teachers could say things like: "We see your child in just one of the many environments that he's in. These are just our observations. You, the parents, know him better than we do; we're just giving you some input. We do have the advantage of seeing 20 kids his age and stage every year, and you only have the opportunity of knowing him and a few other children his age. So we have that vantage point from which to share information with you." If the teacher approaches it from that standpoint, it's less threatening to the parent.

The other side of it is that the teacher has to level with the parent. If there is a problem, the parents need to know about it and do something to resolve it.

My child, David, has mild cerebral palsy. He wasn't walking at 18 or 19 months — but I was a late walker, so we didn't think one way or the other about it. I had a friend who said, "Look, David really should be checked out. He really looks like he might have a problem. Call . . . ." But there was a lot of denial there.

We took him to many doctors to figure out what the problem was. I had a terrible experience when I was sent to see an orthopedist who said to a resident, "Oh, this child obviously has mild cerebral palsy." I'd never heard the words cerebral palsy applied to my child! It was very difficult.

Then we thought, "We're not going to tell anybody because it will be a problem." But it was more that we were the ones who had the problem. We were the ones who were threatened, and it was that more than the fact that we were trying to protect David.

After David was diagnosed, a neighbor who was a priest suggested we call St. Columba's, because they have such a wonderful program which includes children with special needs.

How can teachers work with parents to provide the best experiences for children?

After the diagnosing, you get to the point of using an integrative approach. There are a lot of people who know the child in many different ways — teachers, parents, doctors, therapists. One of the tricks is to act as a catalyst to bring all these people together and to be the conduit of information that flows back and forth. All of these people have something to contribute and something to gain from listening to the others talking.

Even though St. Columba's has scheduled sessions with parents and teachers, I bring in the therapists. They talk about how David is doing and give each other suggestions: "Here's where David needs to be challenged" or "Don't push him in this area." And I send the doctor's reports to the school, so they are filled in and understand everything that's happening.

It's the parents' role to be the catalyst because parents are the only ones who know all the players. But if the parents don't pick up on it, the other way is for the teacher to try to play that role. The one big barrier the teacher has is if the parents are unwilling for whatever reason — they feel threatened, or they don't want to spend the time, or whatever — to pull all this information together. It's very difficult for teachers to go beyond a certain point. But they can encourage it to happen: "We know David is getting therapy. Could you send me any reports that the therapist has done, like some progress reports on how he's doing?"

The other approach teachers can take is to have parents get together and share some of these things. Maybe it's less threatening in a group than it is one to one. With any kind of problem, it's helpful to know that someone else has the same problem and to try to develop strategies together and learn from each other.

Last year, my husband, Jody, and I started a parenting group with parents from St. Columba's with children with identified special needs. We met once a month for six or seven sessions and covered a multitude of issues. Even though it was very beneficial for Jody and me personally and it worked out pretty well, we are not doing it this year. Once we went beyond a certain point, the issues became fragmented. The nature of the disability, the severity of the disability, how the child coped, how the parents coped all made the needs so diverse that we decided to take a different approach this year. This year there is a parenting group covering broader issues and within that context there may be a session that deals with parenting children with disabilities.

What things can an early childhood program do to bolster you as a parent?

At St. Columba's they have on their staff, as consultants, special education people who come in periodically to observe and to give feedback to the teachers. So there are other professionals teachers can turn to and people that teachers can draw into talking with parents. They're also available for parents. I found them to be very helpful, both from a technical standpoint and for psychological support.

St. Columba's looks at the child in a holistic way. They really hone in on the child's strengths and capabilities and potential. The child is encouraged to pursue avenues which will strengthen him as a person and allow him to grow. They transmit that to parents, and parents come away looking at their child a little bit differently.

We've grown a lot during the three years David has been at St. Columba's Nursery School. When he started the program I think we pampered him. I worked full time and we had a person full time taking care of him. She was wonderful and loving and, because of her great affection for David, she didn't push him quite as much as she could have. When we started St. Columba's, it was like night and day. They expected him to get his coat on, to take his coat off, to unsnap his pants when he went to the bathroom, and that sort of thing. And they said to us, very gently but very clearly, "Look, David can be doing more things than he's doing. He can take his coat on and off. We'll show you the way." They insisted on our challenging him more; and they did it by saying, "We know that David can do such and such and you should begin to insist that he do some of these things at home." That was very helpful.

When David was there the first year, I didn't really have the time to get quite as involved with things going on at the school. They never put pressure on me to do that. Now I think that maybe they should have encouraged me to spend more time in the school. But that's really not their role. I was being a good mother. The program has to accept the realities within each family. One mother may have more time to spend with her child than another. It's important for parents to know that teachers are not standing in judgment of them.

What do you think the program is like for your son?

There are two children with special needs in each class of 18 children. The structure is multifaceted — they don't stress just academics, just motor, or just psychological. The main objective is to make the child feel good about himself or herself and to bolster confidence and a sense of curiosity about themselves, other people, and their environment. They do it by being positive, by having an enthusiastic outlook. It's very contagious.

David, during the first year, was very shy. He wasn't sure of himself. Motorwise, he was very limited in what he would try to do. Over the three years, he's become much more outgoing, much more confident. He tries to do a lot more things, and they've encouraged him to try and not to worry if he fails. The trick is to try and if you fail, that's okay — you just get up and keep going. I think they've made him much more resilient in a lot of ways, personally, with others, motorwise; he's motivated to experiment.

They're very loving. It's one thing to challenge a child and try to encourage a child to try different things, but then you need to be there to have that net of support if the child needs to fall back or needs that reassurance. So you need both of those things. If you have only one or the other, it's not good. You need a balance.

The challenge for the teacher is to treat each child as an individual, to seek out differences and to be equitable. But if you treat everyone the same, you are not making use of each child's uniqueness. So you need to seek out and recognize the differences and to help the child feel comfortable with his own differences. The goal is to develop an appreciation for each child as an individual and then to help parents value their child as an individual.

Having a disabled child presents a lot of challenges. It really tests the strengths of the parents and the child and forces all to come to terms with being different and what that really means. The disability, which at first seems so significant, somewhat embarrassing, and difficult to acknowledge, slowly diminishes in importance as the individuality of the child emerges. David is witty, loving, bright, autonomous, and headstrong. I don't know to what extent his cerebral palsy has influenced his personality, but it is one of many facets of his life.

The disability will always be there. He once asked if he will always have cerebral palsy. I told him, "Yes, but it will improve through therapy and your own ability to deal with it." He cried about it, and I cried with him because it was a sad reality for us both. This was a year ago and I think that moment was a turning point. Openly acknowledging the disability has been helpful for all of us, and it must remain an open subject. However, everyone in the family feels that it is not the main focus or characteristic that defines David or that defines our role as his parents.

The issue of David's disability cannot be resolved at any one stage, because at each phase of development implications of the cerebral palsy will present themselves in different forms. However, my husband and I believe that it is our job to make him feel good about himself, to make him feel that he can accomplish almost anything he sets his mind to, and that we will be there if he needs us.

Meg Robinson (when this interview took place) was a free-lance consultant specializing in marketing, strategic planning, and microcomputers. She is the mother of four boys. Her son, David, who is now 11, has mild cerebral palsy. Joshua is 7, Micah is 5, and Noah is 1. Meg, a singer/songwriter performing under the name Potomac Red, is releasing a new recording for children 6 to 12 years of age.

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