

High-Maintenance Parent or Parent Partner?

Working With a Parent's Concern

by Janet Gonzalez-Mena and Anne Stonehouse

Barbara is excited because for the first time since she has been the director at Happy Hollows Children's Center *, she

has the opportunity to include a child with Down syndrome. Drew, who is three, will start in two weeks. This is the first time they have had a child with these kinds of challenges, and when Barbara consults with the staff, some express reservations. She is pleased, though, that overall she gets a sufficiently positive response to feel confident.

The problem is that when Barbara brought up the

subject at a parent meeting, Candace, typically one of the most enthusiastic and supportive parents in the program, reacted negatively. She said little but Barbara picked up some feelings. Candace didn't make an issue of her

response; in fact probably few people noticed it, but Barbara did.

Now it is the next morning and Barbara isn't surprised to find Candace waiting outside the office when she arrives at work. Candace shifts her weight from one foot to the other while Barbara unlocks the door, takes off her coat, and invites her to sit down. Candace sits briefly, but then gets up and starts pacing the floor.

"Coffee?" asks Barbara. Candace rejects the offer, waits until Barbara settles down at her desk, and then blurts out, "You can't take that child!"

Barbara is tempted to quote the Americans with Disabilities Act, which states that the center can't turn away a child solely on the basis of a disability. After all, if this is going to be an argument, she has a strong legal leg to stand on. She quickly decides that an argument isn't her best approach, so instead she asks, "Why not?" There is no challenge in Barbara's tone or defensiveness in her manner. She leans forward to hear what Candace has to say.

"Well, because . . ." Candace sputters, not sure of what she will say next.

She had prepared good solid arguments before she got here, but now in her agitated state, they've become jumbled in her mind. "Because he will take too much staff time and the other children will be neglected for one thing . . ." Her voice trails off.

"Is there anything else you are worried about?" asks Barbara. "Tell me more about your concerns," she adds. Her goal at this point is to keep the conversation open rather than arguing with Candace or even trying to explain her fears away. She has had a lot of experience with people who are upset and knows that she needs to listen thoroughly and openly before she does much talking. She knows that if she doesn't listen and take Candace's concerns seriously, Candace may well go talk to other parents instead of her. That hasn't happened yet; she's convinced that Candace is talking to her first.

That's Candace's way. She also knows that this morning's conversation is crucial. If Candace feels that Barbara is brushing her off, minimizing her concerns, or manipulating her feelings, Barbara will soon be facing a wall of unhappy parents. Talk about high main-

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tenance — Barbara will be putting in enormous time and energy if she doesn't handle this meeting carefully right now. The parents are influenced by Candace, in part because she often will say what others are thinking but aren't saying. She is a key to the success or failure of this first attempt at inclusion of a child with disabilities. Candace, who has always been a constructive parent partner both in terms of her own child as well as contributing to the program through her leadership, could easily become an agent for dissent and tension. Barbara is taking early steps to prevent this shift from happening.

The fact that Barbara has created an atmosphere at the center where parents feel free to voice their opinions, express their concerns, and say what they don't like is a very important first step and offers some protection. Barbara reminds herself that it is much better to have this issue out in the open right away than for it to be unspoken and, therefore, not dealt with.

Although Candace may not be able to articulate her worries very well at this first meeting, they are common to many parents in programs moving into including children with differing abilities. "How will this affect my child and me?" is usually the question uppermost in the mind of most parents, no matter what new circumstance arises. This is one of the differences in perspective between most parents and professionals — and one that is somewhat inevitable. Professionals always have to think, "How will this affect each child and the group as a whole?" It makes sense that parents' first priority is their own child's well being.

Although we can encourage parents to think about other children and to broaden their horizons to take into consideration the whole group, it is unrealistic to expect them to be as concerned about everyone else as they are about their own child.

In the case of the arrival of a child with differing abilities, the question of how that child's participation will affect other children brings lots of questions. Here are the issues on Candace's mind:

- What kind of extra care will Drew need? Will his care take away from the care of and attention to my child?
- What about the educational aspects of the program? If Drew can't keep up, will the program change so things are no longer as interesting or challenging for my child?
- Even if his condition isn't contagious, isn't he likely to have health problems that are?
- How about behavior? Children imitate each other's behavior. Won't my child learn things from Drew and start acting immature?

Maybe Candace won't ask all these questions right away; but they are bound to come up eventually, not just from her but from the other parents as well.

Barbara is grateful that Candace is being honest and tells her so. She also tells her that her concerns are legitimate and will have to be addressed satisfactorily if the experience is to be positive for everyone. Barbara thinks to herself that it might be good to collect some information about Down syndrome to share with parents and staff. She also considers inviting the director of a neighboring center to come and talk to parents and staff about the challenges and rewards of having a child with a disability or a particular set of disabilities.

Before she says anything though, she realizes that the best thing would be for people to meet Drew and his family, and hopefully set aside any stereotypes they may have about children with

Down syndrome. She wants them to have information, but not start out with a biased mindset about what Drew will be like. Drew is, of course, a unique individual, and who knows what assumptions Candace and others who have reservations are operating from? She knows that she wants to eventually address each and every concern that Candace and everyone else may have, but that can't be done at one sitting.

Another thing that Barbara knows from experience is that many people, including parents in her center, have had little firsthand experience with individuals with disabilities. This means that often there is a kind of avoidance and resistance that comes from discomfort and fear of the unknown. Barbara's experience before has been that usually they become comfortable when they quit focusing on the disability and can finally see the person.

Candace asks if Drew will be visiting the center with his mother before he officially starts. That question gives Barbara an idea.

"Yes, he'll be here for an hour next Tuesday morning. Any chance you could be here at that time and meet his mother? You're so good at making new parents feel comfortable . . ."

"Well, I'd have to rearrange my schedule, but yes, I think that would work."

"Great! I'd like you to meet them — Drew and his mother, Sarah. I'd also like to ask her, while you're there, about how she wants staff and parents to answer any questions children may have about Drew."

The meeting ends with Candace feeling that her concerns have been heard if not answered. Barbara's calm, confident manner has helped her feel a bit better. Barbara knows that Candace

isn't reassured completely, but at least she is open to taking some next steps.

Barbara's experience tells her that there will still be hitches and things to work through, no matter how careful the planning beforehand, but that's almost always the case when a new family begins coming to the center. She's completely convinced that having Drew enrolled is the right thing to do.

She knows that Drew will benefit from being with his typically developing peers. She figures that eventually Candace and the other parents will come to see how everyone benefits, including the children as they learn acceptance and appreciation of differences. Drew will teach them all that plus they will learn from him how every single person, child, or adult has something to contribute.

Barbara also knows that changes and new circumstances just have to be lived before people can truly accept them.

In other words, explanations and information are not a substitute for first-hand experience. Barbara knows that no matter how well she handles the concerns, it will take time for the parents to feel comfortable.

It is normal and natural for parents to feel uncertain in this situation. The fact that Candace talks about her discomfort doesn't make her a "high maintenance" parent; in fact, just the opposite. It's the parents who have concerns but don't voice them that are likely to behave in ways that will eventually put them in the "high maintenance" category. By opening up to Candace, listening to her worries, and including her as a parent partner, the director is likely to gain her support and help to bring the other parents on board.

Barbara accepts the fact that it will take a while to bring all the parents along with her in this new venture. She wishes that everyone were as enthusiastic as she is, but she appreciates the

hesitancy some parents are bound to feel, even though it wasn't expressed at the meeting. She's not discouraged though, because she knows she can deal with the reluctance. As the meeting with Candace ends, Barbara feels confident. She looks forward to what's ahead, especially to the way that Drew's and Sarah's participation will enrich everyone's experience.

Partnership between professionals and parents requires mutual trust and respect for the views of the other. Working in partnership with parents means taking all their concerns seriously, welcoming them, and being committed to working through these concerns to provide the very best experience possible for each and every child.

**Editor's Note: People and places depicted in this article are fictitious.*