

PARENTS SPEAK OUT

Parents Perspectives on the Benefits of Parent to Parent Support

Voices from Parents Sharing Experiences

Participants on our Beach Center Early Childhood Family Support Community of Practice shared their thoughts about the supports they had received from other parents. Here are some examples of comments about the benefits they experienced.

Making a Sustainable Difference in Quality of Life

Beach Center on Disability



A Sense of Belonging and Common Bonds

“I am also passionate about parent-to-parent support, partly because it was so hard for me to find. I live in a small town in Nevada, where there are no other young children with disabilities similar to my son's (quad CP, visual impairment, seizures, sensory issues etc). I was asking all our early intervention therapists for support groups to meet other parents, but there weren't any that fit our family and because of HIPAA the providers couldn't give out any other family's names. I finally wrote a letter giving Early Intervention the right to give my contact info out to anyone who had a kid with CP and wanted to get together. I finally got the name of a family in Reno (an hour away.) We are now good friends and that family's mom has helped my in starting a parent networking group for families of kids with physical disabilities. It is still a small group but we have families driving many miles to come to our meetings. The meetings are the highlight of my month and it is so nice to talk to other parents who have been there, exchange local resource information, share ideas, and problem solve with them. We had a new family join us last month and the mom was so grateful to be able to meet other people who understand her experiences and she got to meet our kids and see that her child isn't so different after all.”

“I remember begging our Neonatologist to tell us the name of a family that had a child with the same genetic disorder as our son had while he was in the Neonatal ICU. They finally called another mom who called me. It gave me great comfort to know that children can live with the disorder and that there was hope. She taught us many things regarding the ins and outs of the disease. Now I have the opportunity to do the same for others, then see them come back a few months or years later and give back to those coming behind them. It's amazing to see a young family go from being very frightened, to empowered in a fairly short period of time, then on to helping others. Other parents have supported me with my other children's needs. I save time in learning more about their disabilities by listening to parents that are ahead of me. These relationships are invaluable!”

Action Steps

- *Write a letter giving early intervention professionals permission to give out your contact information.*
- *Share resources, ideas, problems, and solutions.*
- *Save time by listening to those who went before you.*

An Opportunity to Learn from other Parents

“For a parent to "understand" that their child will have a permanent disability is inexplicable at this age, so parents ease into it by doing all that they possibly can through therapies, etc. If they didn't pursue this, then they would feel incredibly guilty when the time came for the diagnosis and they felt they did not do all they could to prevent the diagnosis. So, it's a real catch 22. Therefore, families need to be introduced to inclusion immediately by families who have been successful (through a Parent to Parent match) yet allowed to make their own realizations about their child's condition when they are ready. If families can talk to other families who have found inclusive services and settings which build skills, then they'd be more inclined to seek those services and settings for their own child.”

“Later when we moved to PA, it was another mom who introduced me to the philosophy of inclusion. I remember saying “Oh, no – that’s for higher functioning kids, not for someone like my daughter with all her behavioral and cognitive challenges.” She invited me to accompany her to a TASH conference and I began to learn that my daughter deserved a place in the mainstream and would thrive if I believed in her and worked to find her that place. When we moved to RI I sought out all the families I could to find out what and where the resources were in this new state. (They most often knew a lot more than the educators or medical people I turned to about what was available). I always seem to be able to find parents who are a few steps ahead of me on the path to help guide the way.”

“I have learned so much from other parents, I would suggest that parents join parent-to-parent and avail themselves of any trainings that are offered by their programs. Trainings are a good way to meet other parents. Then be open, open to seeing things through someone else’s eyes--I had difficulties with the concepts of natural environments early on, but allowed myself to listen to what the parent leading a training was saying and went on to do more research and learned that how I was experiencing early intervention bore no relationship to what Best Practice defines as natural environments.”

“Reading all of your responses reminds me of the scores of parents who have entered into my life because I was searching for answers, better resources, etc. I too agree that finding parents whose children are a couple of years older than mine has provided valuable resources, suggestions, and hope. I think one of the barriers to making connections with other parents is that our society does not value interdependency. The message most of us learned overtly or covertly is “pull yourself up by our own boot straps.” When I am really struggling and know that I need to reach out to other parents, I try to recall a quote by Jon Kabat Zinn. He says, “There is no giver, there is no gift, there is no receiver, it is just the universe rearranging itself.””

Action Steps

- Pursue every option for your own well-being as well as your child’s.
- Look for other parents or parent groups as soon as possible.
- Find organizations and go to their conferences to meet other parents and learn.
- Find parents whose children are slightly older than your own.
- Be open to seeing things from someone else’s perspective.
- Value interdependence with other families.
- Consider helping to create a Parent to Parent program if there isn’t one in your area.

General Benefits

“When my daughter was an infant (24 years ago), I began to have concerns about her development, but docs were taking a “wait and see” approach. I happened to be in a play group with other moms for my older daughter who was a toddler. One of these moms had an older son with CP. She took me aside one day and said “I don’t care if you never speak to me again and I don’t care what the Docs are saying, your baby does not have normal muscle tone. I know the difference.” She gave me the name of the best EI program in Cleveland where we lived at the time and invited me to join the parent support group that she ran. I feel so blessed that right from the start I learned the value of information and support from other families.”

“Eighteen years ago, my daughter was born 3 months premature. She was 2 lbs. 9 oz. and you could see right through her skin. I was so scared of hurting her, and wasn’t sure we would ever bond because of my fears. Another mom had just given birth to a preemie 3 weeks prior, and seeing that I was having difficult time bonding, began giving me support. She told me how she had already gone through the same feelings I was experiencing, and then showed me how to hold my daughter and actually enjoy her. It was amazing! It worked! Eighteen years later, I still remember that remarkable woman who changed my outlook on life by sharing her own life experiences with me.”

Action Steps

- *Share information about programs and procedures.*
- *Don’t be afraid to offer comfort and advice to parents who are experiencing something you have been through. It makes a difference!*

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