

# EARLY CHILDHOOD BULLETIN

*News by and for Parents and Parent Members of State Interagency Coordinating Councils*

Prepared by the Federation for Children with Special Needs  
Parent Component Staff of NECTAS

Summer

2001

## Making a Difference by Involving Fathers

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What do fathers of children with disabilities want? How are they different than fathers of other kinds of children? What are the challenges of understanding the needs of fathers within the context of their families? How can early intervention programs understand the contributions that fathers make to their families? How can fathers be more involved in program and policy development? These questions are not easy ones to answer.

As we all continue to build strong inclusive communities, in which people with disabilities are active, respected citizens, we can't forget the changing roles and expectations of families and of fathers, in particular. Too often, the challenge of child rearing has ignored the contributions of fathers. By acknowledging the contributions that fathers can make to their families and to program and policy development, high quality early intervention programs are joining a small but powerful national effort to recognize the importance of integrating fathers more effectively into service delivery systems.

The stories captured in these pages were among those shared at an extraordinary session at a recent meeting of practitioners and family members from across the country. The stories are

striking for a number of reasons. They are intimate snapshots of each father's struggle to acknowledge his own strengths and needs and to adapt them to the challenging circumstances of family life. The fathers represent different regions of the country. One father, for instance, can see 200 miles in any direction from his hometown in Montana without seeing another community, while another is raising his family in the urban excitement of the Bronx in New York City. Apart from their regional diversity, the common themes, which link these stories, are powerful. Each of the fathers reflects on his identity as a man, a father, and a husband. Each has been challenged to reconcile the traditional expectations of fathers with less familiar roles as nurturer, advocate, and collaborator. Each of the fathers emphasizes the importance of changing his own personal attitudes toward himself, his spouse, and his children as a way of better understanding his responsibilities as a father.

What can early intervention programs do to better support fathers? A key first step is to provide safe places for their stories to be told and to listen to those stories for the lessons that they reveal.

## Andre Green

*Andre and his wife Lisa have three children: Andre (12), Tyla (7), and Marcus (4). Andre has been involved in the children with special needs movement since 1998, when Marcus was diagnosed with speech, cognitive, and occupational delays. At that time, he became a member of the New York State Parent Involvement Committee Early Intervention Coordinating Council. Andre plans to retire from the New York Police Department within a year, and is presently waiting to be appointed to the New York State Early Intervention Coordinating Council. "It is here," he says, "that I want my voice heard. Parents must be active at the policy-making level."*

"We realized something wasn't correct with Marcus at about three months--actually it was my wife. She's involved in special education.... I realized then that it was much harder for us to separate everything she'd been doing within her own career now that our child would have to have special education services. We went to our pediatrician a number of times, and it was very disturbing because he told us, 'Well, there's nothing wrong with your son. It just takes a little longer. Some children grow at different levels.' At this time he was eight months old. He didn't walk and didn't attempt to crawl. We waited another three or four months, and then we went back to see our pediatrician. At the time, our primary pediatrician wasn't there; there was another one. I told him the same thing that our primary had said about Marcus. He turned around and said, 'Listen, something is wrong, I don't know what it is. Let's find out.'

"He gave me a referral to a hospital. At the hospital ... I read the brochure and read it again. Everything that was in this brochure about early intervention--it discussed speech delays, developmental delays--I realized was talking about Marcus. It was difficult reading it, but it also made me realize that my son needed everything in the world for him.

"I'm a NYC police officer. I've been one for 19 years...I was always used to being in control. I'd get the bad guys--if someone was doing this or that, I would arrest him. Now, I was confronted with a problem that I could not arrest or control. I did not know. First of all, where were the bad guys? I had no idea. Confronted with this, I realized we had an interview with reality. I was suddenly dependent upon people I did not know, and, more importantly, I didn't know what they could do for us.

"Fortunately, I was lucky. We went to our EI designee and they did the first IFSP and provided

the services at home, and then there we had a special education teacher who was really good. I got lucky--she was opening a school. And it was opening up that following September (this was around February). She continued doing special education and ended up becoming our provider. And then Marcus went into the pre-school.

"The hardest thing I see is encountering people who I realize aren't particularly in my corner but I know I need them. And this issue isn't just for fathers. There are a lot of people involved in EI who can do things for us. The difficulties that we have--that just has to be. You just have to go in there and work with them.

"I would just hope, in closing, to tell people that as a father this is the hardest thing I've ever done. I'm from the straight, jock portfolio: I played football, I did the whole nine yards. With my children, I've been "The Dad." But when my son was diagnosed, the concrete was destroyed. There's a side of me now that, in a way, is very thankful for the disability because this is the part of me that has made me a better person. I've had to take the lead in a lot of situations and really express myself. I'm not an emotional person, but I *have* to be. And I have to temper that emotion with intelligence and understanding. So I would say that people--particularly men--who are involved need to get a lot more involved. And the women out there--there's no measure for the work that you're doing. But the men who aren't involved but can be--if you can somehow move them to do something, only because there's too much work that *you're* doing already....

"I think there are a lot of men out there like myself. I tell people, I don't wear a red cape, I don't have blue boots, I'm not Superman, I'm not a Super Dad. I'm nothing like that. I'm just a man who loves his son, and whatever I can do for him I'll do."

## Fred Brown

*Fred and his family reside in a rural community in Montana. He and his wife have a daughter with special needs.*

"My daughter is 21 months old. How do you spell getting a father involved with their children? R-E-S-P-I-T-E. If you don't have it, you have to get it! If the parents--and my wife is sitting right here--if the parents can't be partners and gain a relationship with each other, the father can't just come home (I also work in law enforcement) from something stressful and go into something stressful and then be expected to keep it together. I mean, I was a little bit goofy *before!* You have to pull it together with your spouse. A lot of times, the service provider and even the spouse don't understand that the husband needs that time with her to build their relationship. Once that gets squared away, and you have that time with her, you understand her better and can help her better at home.

"I worked on the railroads for seventeen years, and five years ago I switched the whole philosophy of my life. There's a book out there called *The Margin*. It dramatically affected my life and how I'd continue to live it. I retired from the railroads, so that was a plus for me. And I moved into a simpler kind of living, which has been very positive. My definition of success now is not what it used to be when I was what I call a 'corporate weenie.' Now, I am a father first. I do other things so I can continue to be a father and husband at home. In a strange way, we've become isolationists without moving to Alaska! But we find right now in our life that this is what's good.

"All our solutions are not all of everybody else's solutions. Everybody has a different perspective on how to go about raising their children and what to do that's best for their children. But one of the foundations you have to have as a father is to make sure you're in tune with your wife...Again, R-E-S-P-I-T-E: If it's not there, something gets lost.

"One more point I'd like to make that a lot of people don't understand: Men as a whole are goal-oriented. From the perspective of a father involved with his children, I notice my wife is

more process-oriented. And process is good. Men see it as a way to get something, while women are living the process life; they enjoy the process. Men still do the process--I'm not saying it's wrong. We're just looking at something besides the process--we want a goal. With Lauren, whether it's to get her to start walking, if the pediatrician tells me, 'I think she can walk at such-and-such an age,' cut it down three months, cut it down six months--give me something I can work with with my wife, my family, my child to produce that goal.

"If men don't have something out there to look for, we can go through the process to get there, but we have to know where we're *getting*. Even on the boards I participate on--they're really heavy with people involved with government and probably the majority of them are female--the process frustrates me something terrible. What are we processing? What is it out there that we're going after? If you can just help guys like me to know what we're going after, everything else will be kind of clear. I don't get as frustrated as long as I know where I'm going.

"I guess that's pretty much who I am, where I come from, and what I do."

### Book Recommendation

***Fathers of Children with Special Needs: New Horizons***  
(Revised Version), by James May, M.A., M.Ed.

*"The first national publication entirely focused on fathers of children with chronic illness or disability."*

#### **Information regarding:**

Research ♦ New paradigms for professionals ♦ Strategies for effective service delivery ♦ Developing support programs for fathers ♦ New visions for family-centered care ♦ Resources for parents and professionals.

## Walter Black

Walter Black has been a stay-at-home dad for the past 4 years. When his second son was born premature at 26 weeks and only one pound four ounces the doctors would not even offer a 50/50 chance the child would survive. Leaving a management position in the hotel industry, Walter took on the responsibility of caring for his son. He has been active in Dad-to-Dad, an organization dedicated to connecting fathers, who are the primary caretakers of their children, with one another.

Walter was appointed to the Georgia State Interagency Coordinating Council in February of 1998 and elected to chair that council in December of the same year. At the 1998 Georgia parent conference and every year after, Walter has spoken with other fathers about the joys and challenges of having a child with special needs. Elected to chair the Council of ICC Chairs in 1999 and now invited to take part in the planning process for the NECTAS conference, Walter suggested a session to focus on the fathers point of view. The suggestion was warmly received.

Walter shares his home with his wife, Sabra, two sons, Carter 10 and Garrison 6, along with 2 dogs, "KiKi" and "Travis", and "Doodle" the cat.

"I was away in Galveston, Texas doing an installation for a hotel. My wife was 26-weeks pregnant with our second child. Whether it was divine intervention or a spiritual connection with my wife or just blind luck, I got up early one morning and called to check on her. I did not get an answer on the phone. Fortunately we had neighbors whom we know well and I called one of them and asked if they would go over and check to see if her car was in the driveway because it was too early for her to go to work. Well, it turned out that she hadn't. I got a call about a half-hour later telling me, 'You've got to come home now.'

"...Our second son was born at a pound and four ounces, and my life has not been the same since. It was a dramatic change in my perception of what a father gives. For my older son, I was 'The Dad.' I was *that* dad: Go to work, come home, throw the ball, play, stuff like that. With our new son, it changed completely. I found that I had to be much more than life had prepared me for. We see that a lot in fathers, particularly the ones here.

"One of the things that I find is that fathers need an opportunity to grieve, not for the child they have, but for the one they *don't* have. We go into the planning of our family with certain expectations, and for fathers it can be very difficult when those expectations are not met. This does not mean I love the son I have any less; it's just that things did not go as expected.

"I've had the opportunity in Georgia to speak with fathers about the challenges that they have, and some of the things that they tell me are that if the father is the working parent and

the mother is the one interacting with the service provider that they have a difficult time getting the information...So it is vitally important that that father is involved right from the very start so that he is also an expert on his child, that he doesn't rely on information from his wife--he relies on info from the therapist, and he has opportunities to ask questions.

"Unfortunately, we also see fathers who, when the diagnosis comes in, they turn and leave. We've seen it happen. And so we must nurture the relationship between the husband and the wife, so that we maintain the support for that child."

Participants from many states attended the session on Fathers at the national conference. When asked to offer advice on better involving fathers, states responded with these ideas:

1. Use the media. Publish articles by fathers and about fathers in program newsletters. Encourage community newspapers to publish pieces on fathering and its importance to family life.
2. Sponsor structured meetings for fathers. Use skilled facilitators, familiar with the needs of fathers.
3. Schedule meetings about ongoing progress of a child at times when fathers can participate.
4. Avoid assumptions about what fathers will and will not do. Don't be afraid to ASK for participation and then find ways to support it.
5. Be careful that public relations materials do not inadvertently exclude fathers.
6. Sponsor workshops on ways families can juggle responsibilities.
7. Recognize the uniqueness of each family.
8. Network with other programs and individuals attempting to define new ways to support fathers.

## Dan Dinnell

*Dan has been the State Family Resource Coordinator for Early Intervention Services of the Nevada Department of Human Resources since 1996, when this position for statewide parent representation was first created. He previously worked for USAir and is a member of the National Guard. He and his wife Cheryl are the parents of 3 boys; the oldest son was diagnosed with Attention Deficit Disorder (ADD); the middle son has "middle child syndrome"; and the youngest son, Eric, was born with a very rare genetic disorder (DeBary syndrome), and has multiple disabilities. As parent/family representative he guides policy and program development, supporting interagency community-based approaches, and most important of all helping to find ways to increase parent/consumer knowledge and involvement in early intervention services in the State of Nevada. He has served as a Nevada Hearing Officer for the Department of Education, on several National focus groups, and is a 1999 graduate of Nevada's Partners in Policymaking.*

"On Thanksgiving morning, 1989, Eric was born into our family. They had him in ICU for about two weeks. He was about three pounds, six ounces...We did a split shift at that time, so I was at work for four hours, then I'd come home for four hours to give my wife a break so she could go off to the NICU, then I'd take off to work, and then go back to the NICU myself that night. So we were able to rotate our duties at the NICU and be there pretty much all the time, with minor breaks in-between. Toward the end of the two-week period, the doctors did an operation on Eric's eye--took a cyst off--and then said, 'There's nothing more we can do for you, take him home.'

"So we brought Eric home, and my wife got in touch with the early intervention service program (at that time there was no connection that the hospital made for us; we did it on our own).

"Eric had to struggle quite a bit. He had hip operations when he was about a year old. He had hearing aids for awhile, and then they did a test and determined that he could hear, so we threw the hearing aids out. The hip operations were allowing him to get around and actually forced him to have upper body strength, which he did not have.

"My wife is the reason I'm here today, basically. To a certain extent, the only time I was allowed 'in' when the therapists were over was if I "forced" my way in. It was them and her. That was fine for me as a father; I didn't mind. I had my job to take care of me. But it occurred to me that I needed to be more involved. And then one day, my wife said, 'I'm doing a parent panel at the University, and it's real important to have parents tell the students, who will eventually become social workers or special educators, about our son.' I didn't have experience with a situation like that in which I would be talking about my son, which at that time was very emotionally draining. You go through a never-ending grieving process because you had a vision, a

vision of your child doing things growing up that are 'typical.' Then the world suddenly becomes different.

"A few years later, we'd just gotten Eric into regular kindergarten. The school district didn't want anything to do with that originally. They wanted to send him off to a separate school where he'd get good, structured one-on-one, quality help. My wife said, No. And that sort of caught them off guard. They allowed us to put our son into a regular education kindergarten room with the assistance of an aide. And my wife delved into it full force. We got him into kindergarten. He's doing great--he's doing wonderful. He loves the kids there, they love him.

"Anyway, my wife has been everything that I could ask for in giving me guidance. When I came back to Nevada after resigning from the airline, this new position came up working for the state. They wanted a parent to represent Early Intervention statewide and be able to provide input for policy and procedures as well as increase family involvement. I thought it was totally out of my realm of experience. But my wife said, 'No--you're a dad, you've been involved in IFSPs, and you've been involved in it from day one.' Plus, the fact that I was a guy applying for the position--a minority, so to speak--I ended up being selected to become the state-wide parent rep for Part C, and I've had a lot to do lately with policy and procedure development in the state, Child Find and family involvement activities. I really have to say that my experience tells me that in most cases the best person to bring the father into the room is going to be the mother. Now, there are single parents, too, and that's a different scenario--there are going to be different solutions there. But some of the best solutions for getting the father in the room, is through the mother."



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**On-line Resources for Fathers...**

**The Fathers Network.** This network provides positive support for fathers, families and providers. Here you will find invaluable and insightful information on the joys and challenges of raising a child with special needs.  
<http://www.fathersnetwork.org>

**FathersOnline.com.** A place where fathers can gather on the Internet to share their unique knowledge to assist and empower other fathers in their ongoing effort to be meaningful contributors in the lives of their children.  
<http://www.fathersonline.com>

**The Fatherhood Project.** A national research and education project that examines the future of fatherhood and developing ways to support men's involvement in child rearing.  
<http://www.fatherhoodproject.org>

**Father to Father.** This national organization encourages local communities in their efforts to bring fathers together for mutual support and resource sharing, and to develop pro-active approaches to fathers in the community and workplace.  
<http://www.fathertofather.org>

**National Center for Fathering.** The mission of the Center is to inspire and equip men to be better fathers. The Center conducts research on fathers and fathering, and develops practical resources to prepare dads for nearly every fathering situation.  
<http://www.fathers.com>

**Slowlane.com.** The online resource, reference and network for Stay At Home Dads and their families. The site provides dads with a searchable collection of articles and media clips written by, for, and about primary caregiving fathers.  
<http://www.slowlane.com>

**The National Fatherhood Initiative.** The Initiative was founded to stimulate a society-wide movement to confront the growing problem of father absence, and to increase the number of children growing up with involved, committed, and responsible fathers in their lives.  
<http://www.fatherhood.org>

**Fathering Magazine.** A comprehensive, on-line magazine for men with families.  
<http://www.fatheringmag.com>

**The Single & Custodial Father's Network, Inc.** An international organization dedicated to helping fathers meet the challenge of being parents. SCFN provides informational and supportive services to fathers and their families, and supports fatherhood through research, publications and interactive communications.  
<http://www.scfn.org>

**The National Center on Fathers and Families.** A policy research center dedicated to research and practice that expands the knowledge base on father involvement and family development, and that informs policy designed to improve the well-being of children.  
<http://www.ncoff.gse.upenn.edu>