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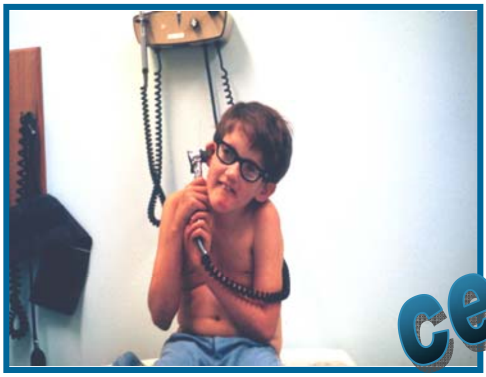

celebrate

Creating Partnerships between Physicians and Parents of Children with Disabilities

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Communicate,
Collaborate,
Celebrate:

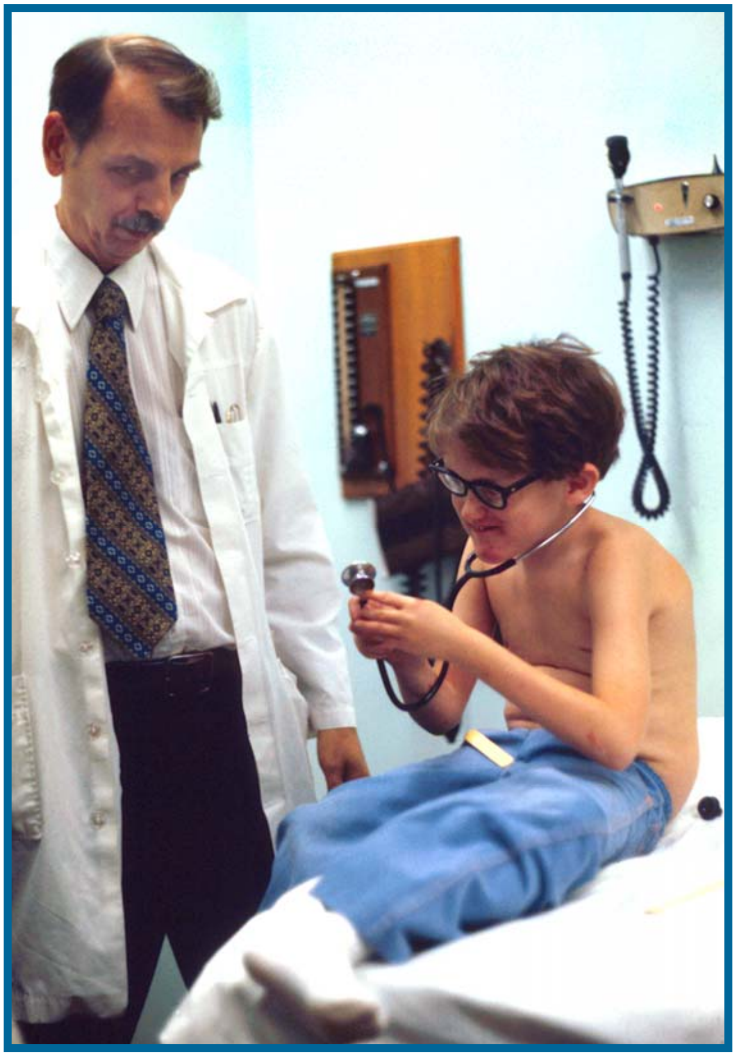
Creating Partnerships between Physicians and Parents of Children with Disabilities

Judy O. Berry, Ed.D.

Center for Learning and Leadership/UCEDD

Dedication

In memory of Doug Berry and in honor of Jim Coldwell, M.D.



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About the Author

Judy O. Berry, Ed.D., is a professor of psychology at the University of Tulsa specializing in developmental and family psychology. She is the author (with Michael Hardman) of *Lifespan Perspectives on the Family and Disability*. Her research centers on parental stress in dual-earner families and in families that include a child with disabilities or chronic illness. She developed (with Warren Jones) the *Parental Stress Scale*. She has received a number of advocacy awards for her work in the field of disabilities, including the Tarbel Achievement Award and the Medicine Wheel Award.

I navigate life using stories where I find them, and I hold tight to the ones that tell me new kinds of truth.

Kingsolver, 2002

The newborn baby boy was full-term, but had a low birth weight. No medical professional said that anything specific was wrong. No one offered a label. And yet the young mother worried. It was a small, rural town and the general practitioner and the mom were social friends. The doctor always was quick to reassure the mom that nothing was wrong with the baby and to dry her occasional tears. This dynamic remained throughout the first year, even though the baby's motor and language milestones were delayed and the mother's questions were more direct.

At the end of that year, the family moved to a large, metropolitan city. There just a few days, the baby got diarrhea and his mom took him to the new pediatrician. As she filled out paperwork, which included developmental history, her heart sank because she knew the baby should be starting to walk and talk by now and he was not approaching either one. The doctor checked the baby carefully and brought in a colleague to see him as well. Then the doctor told the mom, "Before I discuss his diarrhea, I want to tell you that he is retarded." The mom asked, "What do you mean? What caused it? How bad is it?" The doctor replied, "You would-n’t understand.” The only good part of that office visit was a referral to a pediatric neurologist.

A few days later, this specialist examined and assessed the baby and interviewed the parents. It was clear to this doctor that these parents *could* understand, so he carefully explained everything he knew; admitted that there were some questions he could not answer such as the cause; suggested activities for the parents to do at home; and told them about an early intervention program that the baby could attend when he was a little older. He also set appointments to follow the baby on a regular basis.

These appointments led to a partnership. The mom tried the activities and invented more of her own. The baby made progress. The doctor was impressed with his progress and with the mom. In fact, he was so impressed that he asked her if she would meet with the mothers of some other young children he was seeing and share her ideas with them. She did, and this helped the other moms, but it also helped her because it provided supportive connections with others facing similar challenges. He then asked her to be on the program with him the next time he made a talk to professional colleagues and tell them about what she was doing for her child and for other children with developmental problems. This experience led her back to school to learn more about child development. Being acknowledged for her competence helped her become more so.

The literature strongly endorses the positive benefits of support networks for families of children with disabilities (Berry & Hardman, 1998; Worthington, 1992). Support has three components: information, emotional support and tangible help (Patterson & Geber, 1991). In the three stories just presented, the first physician offered only emotional support and the second only information (and quite limited, at that). The third offered all three, and furthermore he understood that this mother was bright, but lacked confidence in her ability to parent because this was her first child and her baby was presenting challenges that she did not understand and felt unprepared to meet. By responding to this specific need, he helped create a partnership that was mutually beneficial to physician and parent, but most of all, to the baby. This doctor and this mother were able to communicate, collaborate and celebrate success.

These stories are my stories. They give a snapshot of my first two years as the mother of a son with multiple disabilities and they reflect my point of view concerning the need for optimal communication between parents of children with disabilities and the physicians who provide services for these children and families. My parenting journey with my son, Doug, began with the stories I just related and ended in February 2003, when Doug died after a short illness. I continue to “parent his memory” and to tell our stories and listen to the stories of other families.

I also am a developmental psychologist who advocates an interdisciplinary approach that combines the skills of medical professionals with those of family members as well as other education and rehabilitation specialists. Finally, I am a realist who knows that optimal communication and collaboration is a worthy goal, but one not easily met. The purpose of this booklet is to provide information for physicians on forming and sustaining collaborative partnerships with parents of children with disabilities. The information is based on the literature, my own professional and personal experience, and knowledge gained through interviews with physicians and with parents of children with disabilities. It is intended to be a starting point for the very individual journeys that medical professionals and families will take together as they seek to communicate, collaborate and celebrate success. It is motivated as well by the reality that in the present and in the future, children with severe disabilities are likely to be raised at home and followed by physicians in their communities (Johnson & Kastner, 2005).

Communicate

When the boys first came home from the hospital, I was often housebound caring for two sick, fragile infants. I turned to the Internet for information and support.

Bissell, 2002.

Present medical information clearly and strive to be understood.

The relationship between physician and parent often begins with the stressful responsibility on the part of the physician of delivering bad news to the parents about developmental and health problems of their baby or young child. How to improve this task has been the focus of studies published in the medical and family literature, with core findings being that there is a need for specific training for physicians (Wolraich, Albanese, Reiter-Thayer, & Barratt, 1981) and that feedback from parents can be utilized to improve training (Leff & Walizer, 1992).

Wolraich (1982) also stressed the need for effective communication in the parent-physician relationship beyond this initial interaction. The major factors delineated as affecting communication were (1) the physician's knowledge of developmental problems, (2) the physician's attitude toward children with disabilities and (3) the communication skills of the physician. More recent work reflects a positive change in attitudes, some improvement in terms of knowledge of developmental problems and that effective communication is an ongoing challenge (Haslam & Miller, 1992; Dobos, Dworkin, & Bernstein, 1994; Sneed, May, & Stencel, 2000).

Being understood requires individualizing for families, but most families will benefit from written information, opportunities to ask additional questions through a follow-up phone call or at subsequent office visits, Web site recommendations and information about parent groups. Links to parent groups focused on the specific disability or to particular parents who are willing to share and network with the family are especially valuable.

Elicit the family's most salient need.

Professionals provide information to families based on what they feel families need to know to care for the health of the child, and that is as it should be. But, communication theory (i.e., Cragan & Shields, 1998) informs us that communication may break down due to different agendas, different priorities and false assumptions. For example, families may fail to listen and comprehend advice about administering medicine if they are seeking advice about toilet training. Taking time to find out and respond to parents' priorities first can set the stage for communication in which there is optimal listening to and understanding of the professionals' priorities.

Inquire about daily family life.

Asking questions about the daily family routine may elicit information valuable for predicting and improving medical compliance. Sleep disorders, feeding problems and difficulty with teaching independence in hygiene all are common for these families. Offering suggestions or printed materials that make care-giving easier will lessen the daily stress and build a supportive relationship and a realistic collaboration.

Discuss and plan for future concerns (yours and theirs).

Each day is challenging for these families and each medical crisis quite enough in and of itself. But, a view to the future is both wise and warranted. Start by eliciting concerns from the family. These will likely include availability of programs and services in the future, but also may address such basic care-giving challenges as how to manage a child with mobility problems as age and size increase. Your concerns may be similar or may address areas that the family has not anticipated. A discussion of these issues can lead to mutual research into programs and services and allow the family time to assess available family resources such as time, energy and money.

Discuss information that parents bring.

A wise pediatrician I interviewed told me that there was no way he could be an expert on every rare medical condition. He said a child might present with problems that he had encountered rarely or never, and yet the parents might have acquired enormous expertise in that particular disability. He stated that in addition to learning from the medical literature, he could learn from the parents. He also commented on the explosion of information, particularly from the Internet, and the physician’s role in helping parents separate what is accurate and useful from that which is not.

Establish a means of ongoing communication that works for both of you.

These families are likely to need more than well-child medical check-ups and appointments for illness. Finding a way that works for you and for them is essential, whether it is reaching you directly by telephone or e-mail or designating a nurse, assistant or social worker as the contact person. Short communications can alleviate anxiety and prevent mistakes and should not be underestimated as families assume more and more responsibility for medical care at home (Guberman, et al., 2005).

Collaborate

Imagine the synergism if we believe both the patient and the provider are powerful systems that join to interact.

Saba & Fink, 1985

Involve the family in the assessment and treatment process.

Family involvement is, of course, a component of care for all children. However, for children with severe disabilities, there are important differences that can make a difference. A salient issue for these families is their history of medical care, not just the facts of the care, but the emotional toll it has taken on the family. The paradox is that parents and children may come to medical care settings with increased anxiety due to the number and type of procedures they have experienced in the past, and yet the parents can be the key to helping the child approach and sustain the procedure calmly.

Important considerations include decisions about parent presence during the procedure. A review of 28 studies comparing parent presence or lack of parent presence during medical procedures revealed mixed results for child distress, no difference for parent anxiety or satisfaction and no evidence of increased technical problems or increased staff anxiety. After looking at these findings as a whole, these authors recommended parental presence and informational preparation of parents (Piira, Sugiura, Champion, Donnelly, & Cole, 2004). These recommendations seem particularly salient for procedures with children with severe disabilities. Time should be spent preparing the parent about what to expect. In addition, time should be spent learning from the parent how best to explain to the child what is happening and how to help the child relax. These parents have had to learn the tricks of preparing their children for procedures and medications and for keeping them calm during the process. If the child needs to be anesthetized or to receive medication for anxiety, parents should be included in this choice.

Incorporate medical care into family rituals and routines.

The first step is to learn about the family's daily routine and to ask questions to determine the most stressful family times and activities and the most relaxed and fun times and activities. It also is important to learn what therapy programs the child participates in and if there are home programs connected to the therapy. Then you can collaborate to incorporate medical care. An overloaded care system will break, so it may be necessary to cut back on home therapy if medical care routines are to be added. Also, administering medicine or medical treatment is likely to be stressful to both child and parent, so developing a schedule that avoids predictable stress points is of value as is collaboration to devise activities to follow the treatment. Concluding a stressful treatment session with a time of cuddling, story reading or play can be rewarding for both child and parent.

Understanding the needs of siblings is vital as well (Damiani, 1999). Parents have to meet the needs of all their children and may need help in organizing and prioritizing to do this. Siblings, however, can be an asset by providing distraction and entertainment during treatment procedures and by providing developmental modeling of self-help skills such as eating, toileting and brushing teeth. Physicians who see the child with disabilities and the siblings as patients are in a unique position to help parents balance the needs of all their children.

Assess and incorporate supports.

The primary goal here is to identify the players and include them in the collaboration. Who, besides the parent who brings the child into the office (most likely the mother), is involved in care-giving? If it is a two-parent family, identify times when it is optimal to have both parents present, such as when delivering stressful information. Also, find out who typically provides child care and parental support. Those providing care and support such as babysitters, grandparents, aunts, siblings or friends can be included in appointments to better understand the child's needs and to assist parents. Often by the time a child has been examined or treated, the child is upset and needs to be comforted by a parent. It is difficult to comfort a child and listen to and understand medical instructions at the same time. Encouraging parents to bring a significant person with them provides a comforter and a listener or two listeners, and in these situations two sets of ears always are better than one. Grandparents often play important roles in the daily lives of children with disabilities (Katz & Kessel, 2002) and need to be involved both for optimum care of the child and to minimize conflict between grandparents and parents.

Get to know the child at his or her most capable level.

This can be a challenge. Physicians will most frequently see these children when they are ill and anxious. Well-child check-ups often are incorporated into sick-child check-ups because the child is in the office so often. Even if the child is well, associations with previous visits may increase anxiety and behavior problems. Observing motor skills, language and cognitive abilities may be impossible, or at least compromised. A creative approach is necessary to overcome this problem and may include some or all of the following: take advantage of natural opportunities to see the child in the community, such as at church, at a restaurant in a store (this may be easier for rural physicians); plan a visit to the child's school or therapy session; ask parents to bring photographs and/or short videos to describe the child's capabilities and accomplishments. The last suggestion is particularly important if your first interaction is with a very sick child.

Refer and follow up on referrals.

Thanks to passage of federal legislation, children with severe disabilities are eligible for a broad array of services from the time of birth or diagnosis, including education, speech, occupational and physical therapy, and psychological services (see Hardman, Drew, & Egan, 2004 for a discussion of rights and services). States vary in how the services are provided and how referrals are made, so the first task is to be informed about the process of making referrals. For infants and young children, a referral for early intervention services leads to a team assessment to determine what specific services are needed. After the assessment an Individualized Family Service Plan (IFSP) is developed. For older children, services are provided through school special education programs. An Individualized Education Program (IEP) that includes therapy and other services is developed for each student. The right to and receipt of needed services has been of inestimable value for these children and families.

The availability of services is meaningless if families are not informed about the services and given information about how to access them and about the potential developmental impact of the programs. Physicians frequently are the first contact persons for families and hold the key to attaining the comprehensive array of services the child and family will need. As physicians make referrals for additional medical and therapeutic services, attention to selecting professionals with a track record of working well with children with disabilities and their families can make this process much smoother. Furthermore, getting feedback from families about the referral services is vital for having a comprehensive plan of treatment for the child and to assist in future referrals for other families.

Parents also may need referrals for counseling or other services aimed at reducing stress and facilitating family coping. This need has been identified by parents as very important and infrequently met (O’Sullivan, Mahoney, & Robinson, 1992). In addition, enhanced discussion of psychosocial concerns has been shown in research studies to be linked to more effective communication between physicians and parents (Nobile & Drotar, 2003).

Become familiar with *Healthy People 2010* and Medical Home Initiatives

A goal of *Healthy People 2010* is to “reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles, to zero by 2010 for persons aged 21 years and under” (Johnson & Kastner, 2005, p. 507). The Medical Home Initiative is a means for meeting this goal and other goals related to collaborative care. According to the Medical Home Web page (http://www.medicalhomeinfo.org/), “In a medical home, a pediatric clinician works in partnership with the family/ patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support and other public and private community services that are important to the overall health of the child/ youth and family.” Additional information, including programs within each state and an E-newsletter can be found on the American Academy of Pediatrics Web site at http://www.aap.org.

Celebrate

Nathan has many strengths and surprises many people (including me!) with what he does and what he knows.

Berry, 2003.

Inquire about the child's successes and acknowledge parents for their role.

Find those strengths and celebrate them! Sadly, this happens infrequently. The focus (in both the medical setting and in society in general) is so often on what is needed and what is wrong that what is right gets left out. Praise parents for successfully following a complicated medical regime or for successfully navigating the referral maze. Let them know that you understand how challenging this can be. The best praise, however, is for developmental progress. Whether noting this directly in the child or receiving information from the parents, it is an occasion to pause and be pleased before continuing on to the hard work ahead.

Remember, record and share what works.

Inquiring about developmental progress, day-to-day management skills and improvement in family coping will lead to information that will be of use to other families. It is a way to find out if referrals have been successful and why the family thinks that certain services have been helpful. It also is a time to learn about new services or activities that the family may have discovered, such as swimming lessons or therapeutic horseback riding. Little tricks, like how to give a distasteful medicine, also can be noted and shared. Parents will appreciate knowing that you think they have shown creativity and good adaptive skills and will be flattered to know that you consider what they have learned important enough to share with others.

Honestly praise the child.

Again, this does not happen often enough. Praise developmental progress, of course, but noting a child’s cute haircut, pretty dress or winning smile will be appreciated more than you can imagine.

A Note About Time

Every physician that I interviewed had this to say about working with children with severe disabilities and their families, “It takes more time.” They went on to advise that accepting this and scheduling appropriately saves time and eases frustration for everyone in the long run.

REAP what you sow

What Do Parents Want? Of course what parents want and need most is optimal medical care for their children. Beyond that base, however, these points emerge from the literature and they are supported by anecdotal evidence from parents themselves. To summarize, parents want referrals, empathy, accessibility and praise.

Referrals: When I first started the project that led to this booklet, I talked about it with a good friend who has a daughter with severe disabilities. I told her about my feelings when Doug first was diagnosed. What I wanted most from his doctors was reassurance that I was doing the right thing. She responded, “Not me. This was my fourth baby. I knew how to take care of her. What I wanted was referrals for therapy.” Most parents do want these referrals and most children need them. The literature suggests that getting and staying up to speed in this area is challenging, but a necessity (Dobos, et al., 1994; Sneed, et al., 2000).

Empathy: When Doug was a teenager, he had hip surgery with complications and spent several months in a body cast. Changing the cast was a frightening and upsetting event for him and stressful for me. I found out that seeing him so upset also was stressful for his orthopedic surgeon. The second time the cast was changed, this physician came to Doug's hospital room himself to collect Doug for the procedure and to reassure me. He told me as we proceeded down the hall that he had given Doug a little Valium to calm him. I suggested that next time I would like some, too. He replied that next time he thought he would take some himself. He cared. He understood.

My stress and anxiety response were not unusual. The literature indicates that mothers of children with disabilities are more likely to report anxiety and depression (Breslau, Staruch, & Mortimer, 1982; Goldberg, Morris, Simmons, Fowler, & Leninson, 1990) and that mothers who are depressed and anxious are more likely to consult their children's physicians (Chamberlin, 2003).

Accessibility: "We e-mail," said the young mother of a baby with disabilities and a rare medical condition. "That way I can let him know my concerns right away and share changes, both good and not so good." Finding and agreeing on the best way to communicate is strongly advocated by parents and by the literature (O'Sullivan, 1992).

Praise: A father made this comment about his son, Jay, who has disabilities and his daughters, Amy and Kate, who are experiencing typical development. "The joys Amy and Kate bring are both great and small, and they occur daily. The joys Jay brings likewise are great and small, but they occur infrequently (Turnbull & Turnbull,1985, p. 120). This is a reminder that less frequent joys call for extra celebration. Receiving positive feedback on the child's progress and the parents' ability to enhance and support this progress is empowering to parents and helps them believe in their competence (de Geeter, Poppes, & Vlaskamp, 2002; Dempsey, 1999; Driskill, 1996).

Everyone, particularly the child, will **REAP** the benefits of a strong partnership between the physicians who care for children with severe disabilities and their parents.

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Take-Away Message

Communicate

- Present medical information clearly and strive to be understood.
- Elicit the family's most salient need.
- Inquire about daily family life.
- Discuss and plan for future concerns (yours and theirs).
- Discuss information that parents bring.
- Establish a means of ongoing communication that works for you.

Collaborate

- Involve the family in the assessment and treatment process.
- Incorporate medical care into family rituals and routines.
- Assess and incorporate supports.
- Get to know the child at his or her most capable level.
- Refer and follow up on referrals.
- Become familiar with *Healthy People 2010* and Medical Home Initiatives.

Celebrate

- Inquire about the child's successes and acknowledge parents for their role.
- Remember, record and share what works.
- Honestly praise the child.

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Communicate, Collaborate, Celebrate

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Notes

Notes

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Please tell us what you think about *Communicate, Collaborate, Celebrate: Creating Partnerships between Physicians and Parents of Children with Disabilities.* Complete the sections below and send back to: Vyonda G. Martin, Center for Learning and Leadership, P O Box 26901, ROB 342, Oklahoma City, OK 73190-0001 or fax to (405)271-1459. You may e-mail comments to vyonda-martin@ouhsc.edu.

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