

“Cases that are less complex medically often become extremely complicated due to other non-medical concerns such as language barriers and poverty. PACC has been vital in that it has led the families through the process of caring for a child with special health care needs not only medically but also socially.”

—Martha Eliot Health Center Physician



SECTION 4

Key Components of Family-Centered Care

Role of Parent Consultant

Parents who have experience raising a CSHCN can provide special support and empathy to families in your program. Providers should identify a parent in their practice whose child's medical condition is stable, and who seeks an opportunity to help other families and has sufficient time and energy to reach out. Although it is not necessary for the parent to have specific education or training in the social work disciplines, it is important to provide the parent with the tools and backup necessary to fulfill their role (see Supporting Your Parent Consultant.) Your parent consultant should receive a stipend (e.g., \$150 per month) and reimbursement for any expenses.

Supporting Your Parent Consultant

Resources and technical assistance are available from:

Parents Helping Parents, www.php.com
NPSPIS: National Parent to Parent Support and
Information Services
PO Box 907
Blue Ridge, GA 30513
800-651-1151; 706-632-8822
www.nppsis.org
e-mail: judd103w@wonder.em.cdc.gov

Supervision

The lead physician should meet with the parent consultant initially and then periodically, not only to reinforce the importance of this role, but also to

monitor and adjust the specific guidelines for the parent consultant's interactions with the practice and the families. The care coordinator should arrange to talk by phone or meet weekly with the parent consultant and use this time to see that she or he is up-to-date on any specific resource needs or assistance required by families in the practice. The care coordinator and parent consultant together can decide who will be responsible for following through on specific needs. These exchanges can also address other general planning ideas such as arranging a spring picnic for families.

Parent consultants can fill the following roles:

1. Advisor to providers and the practice in general

- Family experiences and perspectives can inform many aspects of the practice, from the actual physical layout/accessibility of the office to the way staff interact with the families—on the telephone and during visits

2. Personal and direct support to families

- The volunteers can provide both enormous direct emotional support and practical advice to other parents, especially at the time of diagnosis. They need not be professional counselors, but should be trained in effective communication.
- Support can include: periodic telephone calls, connecting in person at events, and e-mails. Some parents prefer phone calls, others would rather attend an event.

3. Organizer and coordinator of family events

- Families have a great need for information about resources and for social connections with others in similar circumstances. A wide range of events will meet many needs from 1) social, “coffee hours”; to 2) informational meetings, e.g., financial planning for CSHCN; adapting toys, handling stress; and 3) family events such as music/art sessions, and holiday parties.

Tips on Organizing Family Events and Outreach

- Be sure to remind families early and often about upcoming events – telephone reminders work best
- Minimize barriers to attendance by arranging for free parking and/or transportation and volunteers who can help with care for the children
- Consider pooling resources with other practices if your office is small or serves a more rural area; it can be hard to find parent volunteers in these settings
- Ask for donations of goods and services; many speakers or organizations are responsive to events related to CSHCN

4. Information disseminator

- Distributing a newsletter three times a year is a great way to stay in touch with the families in your program. If that is not feasible, even brief, periodic memos can be helpful. Setting up bulletin boards in the waiting room to post important news is another option. Useful items to include by any of these methods are:
 - Information on upcoming workshops and programs
 - Resource tips such as summer camp guidance, where to find used durable medical equipment and specialized clothing
 - Updates about important legislation affecting children

Office Staff Training

Your office staff members make the first and sometimes most lasting impression on your patients and their families. Training and sensitizing them to the particular issues confronting families with CSHCN can make an enormous difference in their overall experience as a member of your practice. A single, one-hour session with some follow-up can effect useful changes. Excerpts from PACC’s “Tip Sheet” and “Disability Etiquette” illuminate this work.

Staff Training Agenda

- A parent “consultant” – a parent known to the practice who has a CSHCN – is the best facilitator. A practice nurse or whomever is managing your care coordination should organize the meeting.
- Physician presence at all or part of the meeting sends a strong, positive signal to staff about your commitment to this patient population
- Holding the session during lunch or a regularly scheduled staff meeting minimizes office disruptions
- Strive to give staff a chance to learn more about what special challenges families face such as:
 - constant stress and exhaustion; difficulties associated with travelling with a child who uses medical equipment; dealing with “the public”
- Focus on special circumstances that may arise at the office (e.g., big enough exam room to accommodate wheelchair) and how to handle them
- Remind staff that simple courtesies such as making eye contact with children, smiling and addressing them directly, has a profound affect on families’ office experience

Follow-Up

Recapping the work done in the meeting is essential to creating lasting change. Visual reminders often work best.

- Given this chance to brainstorm together, staff often display their ability to devise approaches and solutions to various situations that may cause discomfort or difficulty for families
- Consolidate these solutions and write them in a way that can be shared with current and incoming staff
- Simple suggestions for adaptations to office procedures include:
 - Posting the names of the families in your program near the telephones so staff can recognize and greet them by name; this is both appreciated by families and helpful for handling the call appropriately
- Physician support is critical to integrate modifications in day to day practice

These meetings can enhance the comfort level for staff in working with families with CSHCN and facilitate positive interactions on the telephone and in person.

Tips for Families to Identify Local Support Resources

- Identify any regional or local associations related to a particular special health care need (e.g., United Cerebral Palsy). The local library should have appropriate listings of organizations.
- Ask school nurses, guidance counselors, and the special education department about any groups serving families with CSHCN
- Call the town recreation department for any programs available to CSHCN; they may include sports activities as well as general recreational programs
- Contact the education department of any local colleges or universities (or any other relevant department such as physical therapy). Most institutions have social service/community organizations that may sponsor appropriate groups for children or provide volunteer support to families.
- Contact Exceptional Parent magazine at < www.eparent.com > to link with your state's Parent Training and Information Center and Parent to Parent program for names of people who can help in your own area

Community Support— Places Families Can Inquire for Home Modification Help

Contact fraternal organizations such as the Knights of Columbus, Kiwanis, Rotary Club, the Elks and Shriners.

- Often they provide wheelchair ramps, purchase other types of equipment, and facilitate access to transportation services. The non-profit organization Habitat for Humanity does home modifications/remodelling.
- Local lumber and hardware stores may contribute materials or labor for installing ramps or other home modifications

In-Office Conferences

Another way to enhance communication between parents and professionals is through in-office conferences. Attendees should include the pediatrician, pediatric nurse practitioner and parent/guardian(s). Not every practice may be able to set aside time accordingly but components of these meetings can be valuable for everyone. Below is a tested format and some outcomes:

- The PNP encourages parents to think ahead about what they wanted to mention and accomplish in the meeting
- Pediatrician meets with parent and PNP for 30-40 minutes to discuss particular parent concerns, and to review reports from the child's subspecialists and any relevant testing schedules
- PNP meets with the parent alone afterward for 45-60 minutes to review and update the IHP and to focus on goal setting for the child and family if the latter is not completed in the prior meeting
- The relatively unhurried nature of the encounter allows the physician to gain insight into the difficulties involved in caring for a CSHCN and to obtain important health information that otherwise might be missed
- The three way dialogue among parent, physician, and PNP is a very effective and efficient way to solve a host of different problems – an opportunity that doesn't present in typical office visits
- The parents are very pleased to have the extra time with the physician, and the forum helps the PNP to further a bond and connection to the family

Meeting the Needs of Culturally Diverse Populations

- Provide for interpreter services at office and home visits
- Have bi/multilingual providers available
- Understand cultural values and biases, acquire knowledge of cultural beliefs and practices
- Coordinate transportation and patient appointments
- Initiate telephone calls to durable medical equipment and home health companies; arrange physician/specialist appointments
- Assist with early intervention and special education referrals and with school transitions
- Advocate for families at special education evaluation team meetings at schools
- Incorporate extended family supports, when applicable, in patient teaching
- Inform families of available community resources



Disability Etiquette: Some Do's and Don'ts — from the Parent's Perspective:

Tips to Make the Office Visit Better for Everyone

The following suggestions have been compiled from parents of children with special health care needs across the country:

- ✓ DO respond positively to our children in your initial interaction. Tell us they are cute, sweet, cool, that they are wearing a neat hat. Let us know that you value them even if you can't cure them.
- ✓ DO ask questions of our children, even if the child can't speak. Show your recognition and respect. Don't worry; his parent will find a way to facilitate the communication.
- ✓ DO look at our children when you are talking to them. Please make every effort to establish a personal connection.
- ✓ DO get down to our child's level. For example, if our child is in a wheelchair, kneeling or sitting down will help make him feel more comfortable.
- ✓ DO realize that parents sometimes are very tired of telling their story over and over. Even though you may have your own personal medical interest, don't ask if you don't need to know. Be understanding if the parent shows frustration at telling his child's "story" yet again.
- ✓ DO notice and be attentive to brothers and sisters. They have grown up in a situation where their sibling has, by necessity, received lots of extra attention. They don't understand why they shouldn't be just as entitled to a sticker or balloon.
- ✓ DO be aware that our grief and sadness may recur at any time and often does at transitional times — beginning pre-school or high school, the day of the senior prom, an anniversary of another loss. It's never resolved entirely.
- ✓ DON'T ask questions or raise issues that could be painful for us (and our child) in front of our child. If you need to understand more about the birth history, for example, find a way to talk separately with the parent. You should never assume our child doesn't understand or doesn't have feelings.
- ✓ DON'T refer to our children by their diagnosis (e.g., "MR kid", "Downs kid"); it's a good habit to develop no matter with whom you are talking.
- ✓ DON'T judge parents; we are doing the best we can under often difficult circumstances. If we are impatient or rude, it may be that we are under particular stress.
- ✓ DON'T be surprised if we need instructions, procedures or explanations repeated several times, especially if the information is complicated, upsetting or unexpected. We are often thinking about a million other things and we are trying to synthesize what you have to tell us at the same time.

TIPS FOR OFFICE STAFF — AS DEVELOPED BY YOU!

The following tips were developed by Longwood Office Staff to help them better serve the needs of PACC families.



On the phone...

- ✓ Become familiar with the names of the PACC patients by keeping a list posted near your work area. When booking an appointment, note on the schedule that this is a PACC patient.
- ✓ PACC patients may have urgent medical needs but may not identify themselves on the phone as a PACC family. By recognizing them yourselves by name, you will be able to help them get what they need as quickly as possible.

◆ Also, your acknowledgment of a PACC family on the phone or in person with a friendly “Hi, Mrs. Ainsworth,” will be very much appreciated by these families, many of whom are in touch with the practice much more frequently than the average family.

◆ By recognizing a family’s name, you can avoid situations like putting them “on hold” when there could likely be an urgent need or asking a question that may not apply (e.g., “Is this a sick visit or a well visit?”).



Upon arrival...

- ✓ Be aware that the PACC family is coming in. Be prepared to acknowledge them when they sign in. A low-key but welcoming acknowledgment is very meaningful to families.
- ✓ When a PACC patient is coming in and will do best in a particular examining room (e.g. because of size of equipment with the child), remind the nurses so they can save that room.
- ✓ When the family signs in, write PACC next to their name.
- ✓ For some families, the waiting room experience is particularly difficult:
 - ◆ Their child may have immune problems and should not be exposed to other sick children;
 - ◆ The amount of equipment they bring with them is large and awkward; they don’t know where to head;
 - ◆ There is nowhere to sit in the waiting room;
 - ◆ They are uncomfortable with the stares and looks they may get in the waiting room from others unfamiliar with their child’s medical situation.

There are a number of ways in which you might help the family:

- ✓ If they are “struggling” with equipment or just maneuvering into the office, offer them assistance by asking, “How can I help you?” (Some families may prefer not to be helped, so by asking directly you are letting them decide what help they want.)
- ✓ Help find them a spot in the waiting room.
- ✓ Offer to have them go into a room immediately.
- ✓ If a doctor is running behind schedule, give the family the option of leaving (e.g. for a cup of coffee) and returning at a certain time. Many PACC families carry cell phones and you might ask if they are reachable that way.



In the examining room...

- ✓ Before getting started with any clinical procedures with the child, (e.g. weighing) ask the parent, “Before we get started, is there anything I should know about your child or what works best for him/her when he’s here at the office?”
 - ◆ Another way to inquire about a procedure is, “How do we usually weigh Julie?” (Note: The parent may even want to speak with you out of earshot of her child.)
 - ◆ Given the age/awareness of the child, it may be inappropriate for them to hear any discussions about current concerns.
- ✓ If you have any questions or concerns about what you are observing/learning from an exam, think carefully about whether to share this concern or to comment openly with the parent present. Again, these kinds of comments can be very painful for a parent.
- ✓ Some PACC families may be visiting the office because of some urgent need. You may want to consider delaying some of the routine aspects of the examination until after the parents’ anxiety has been attended to by the physician.
- ✓ In cases where a child is examined frequently and/or repeatedly, you may want to consider letting the physician decide whether it is necessary to undress the child or proceed with routine steps, such as weighing. This can spare the parent what in itself can be a challenging situation.
- ✓ Before assuming that a parent wants to receive a sheet of developmental milestones, give the parent the option of getting this information. For some parents, this sheet only serves as a painful reminder that their child is not developing typically.