



Fall 2011

NEW DIRECTIONS



Early Childhood Direction Center

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ECDC is a regional clearinghouse that provides free information, referral, technical assistance and support to families, professionals, and community agencies concerned with children birth to five with suspected or diagnosed delays or disabilities.

We provide ongoing community training programs for both parents and professionals.

ECDC is funded by the New York State Education Department, hosted by Women and Children's Hospital and provided in-kind support from People Inc.

If you would like to be included on our list serve to receive the latest federal, state and local updates, please send an email to ecdc@kaleidahealth.org and indicate whether you are a parent or a professional.

PREPARING FOR A HOSPITAL STAY

By: Kathy Ralabate Doody, M.S. Ed

I am beginning to feel like an area expert on emergency treatment facilities. As a mom and preschool teacher, working with kids with autism and special needs, I have visited many area emergency rooms with my own children and my students. I have quickly learned some tricks to make hospital visits as stress-free as possible.

Obviously, preparing for a scheduled hospital stay is a bit easier than a surprise visit. Here are some ideas to keep in mind:

- ✓ Alert hospital staff to any special needs your child may have. Often they will make exceptions to rules if it will make the hospital experience easier for the patient.
- ✓ Pack comfortable clothes for your child. Although some hospital stays will require the use of a gown, your child may feel more comfortable with something familiar from home, even if it is a pair of socks. In my experience, physicians and nurses are very agreeable to any ideas which will make the child more comfortable.
- ✓ Bring along sights, smells, and textures from home. Hospitals are full of strange smells, loud noises, unfamiliar blankets, etc. A pair of headphones connected to an iPod with favorite music may be helpful. Stuffed animals or pillow pets may provide the child with comfort and reassurance from home.
- ✓ Pack the child's own toiletries, as children with autism may be highly-routinized and prefer their own things. Hospital items such as lotions, toothpaste and shampoo, may have a different taste, texture or smell and may make a child nauseous, agitated or anxious.
- ✓ A portable DVD player or laptop from home can allow your child to watch favorite DVDs or to play computer games. Children can have high energy levels, but following medical orders while resting quietly in bed can speed the recovery process.
- ✓ Work closely with the dietary staff to discuss any special diets, preferences or dislikes your child may have. The dietary staff will welcome your input; it is important to create healthy and nutritious meals that your child will *actually* eat. Seek permission before bringing in foods from home and make sure they are labeled with your child's name and room number, along with a date to preserve freshness.

Be as prepared as possible for unexpected hospital visits:

- ✓ Keep non-perishable favorite foods or juice boxes in your car, along with a change of clothes for your child, including socks, underwear and pajamas.
- ✓ Pack a small bag with travel-sized, preferred toothpaste, shampoo and soap.
- ✓ After your child receives new toys, movies or games for a birthday or special occasion, rotate out some old favorites. Throw them in a box in the trunk of your car as opposed to a storage bin in the basement.

Hospital stays, even brief ones, can cause anxiety and stress for all of us. Take the time now to pack an emergency travel bag – fingers crossed that you will never have to use it!

What is Patient and Family Centered Care?

“Patient and Family Centered Care (PFCC) is a collaboration that puts patients and families first, not just when it’s convenient, but all of the time. It empowers families, and gives them a voice in decisions that affect patient care, and family experience.

The ultimate goal of PFCC is to create partnerships among health care providers, patients and families that will lead to the best outcomes, and enhance the quality and safety of health care.” *

Patient and Family Centered Care acknowledges that families are the center of patient’s lives. Families, patients and staff are working together as a team to provide the very best care for your loved one. Families provide the support and encouragement that patients need.

Information sharing is an overriding issue. Health care practitioners practice this principle by creating an atmosphere where information is shared openly and candidly among patients, families and providers. And information goes in two directions; providers share information with patients and families about their illness and treatments options; and patients and families share their perspectives and ask questions. When such an exchange occurs, patients, families and providers all learn from each other and make the best decisions concerning care plans and treatment.

Supporting patient and family participation, means welcoming and encouraging patient and family participation in care, and care planning. They are not labeled as “visitors” and the hours they spend at the patient’s bedside are not limited. Patients and family members are encouraged to participate in rounds and other decision-making processes. Staff prepares and supports patients and families to participate in care at a level they choose.

Patient and Family Centered Care Programs at Women and Children’s Hospital of Buffalo

The Family Advisory Council (FAC): The Family Advisory Council has worked with Hospital leaders since 2005 at a strategic planning level. Members of the Family Advisory Council include parents of children who are, or have been served by Women and Children’s Hospital.



Council members work on projects that promote our united goal for Patient and Family Centered Care to be integrated throughout the hospital. They provide a family perspective to committees, training initiatives, and hospital programs.

Family Faculty: Members of the FAC also participate in staff orientations, providing new nurses and residents and other staff, with a patient and family perspective through panel groups and a home visiting program. The video **“The Constant: Parents as Partners in the Delivery of Care”** was developed and produced by FAC members, parents and staff, and is used in nursing orientations; and it can be viewed on the WCHOB website (www.wchob.org) under “Patient and Family – Family Advisory Council”.

Patient and Family Centered Care news in the **Bambino** newsletter: WCHOB has a quarterly newsletter, The Bambino, which features a Patient and Family Centered Care page, to keep you up to date on happenings in the hospital. This is online, or you can obtain a copy at the hospital.

NICU (Newborn Intensive Care Unit) Parent Advisory Council: for families that currently or have had children in the NICU. Council members work on objectives pertinent to NICU needs and services.

NICU Parent Services: Overnight rooms for families as they prepare for discharge or unexpected admissions (include bathrooms with showers), pumping rooms, lactation consultant, family services coordinators (two NICU designated social workers), and discharge planners are all part of the Patient and Family Centered Care team. Parents also choose whether they would like to be present for necessary non-surgical procedures on their infants.

Family Centered Care Coordinator: available for staff and families to use as a resource for education, linkages for service needs and as an on-site resource for matters related to patient and family centered care, quality and safety.

For further information or assistance about Patient and Family Centered Care and the Family Advisory Council/NICU Advisory Council, please contact Ann Maghran, Family Centered Care Coordinator, at 716-878-1839, or at AMaghran@Kaleidahealth.org.

*Cincinnati Children’s Hospital

Websites to investigate:

Check out ECDC’s new Resources Page:

<http://www.wchob.org/ECDC/resources.asp>

