

Leadership Notes



2005 ICC Parent Leadership Institute

Our sixth annual Parent Leadership Institute will take place May 11-15, 2005 in San Francisco, CA. We have a number of states that are interested in participating. The Institute's mission is to meet the learning needs of participants and to support the work that groups of leaders will do once they leave the Institute and return home. The three-and-a-half day Institute will include parent storytelling, interactive activities and intensive state-team planning, during which teams will develop a focused plan for implementing a parent leadership-related activity in their respective states six to nine months after the Institute. We will be offering these states project support as needed.



Team Leader Conference Call

The project also hosted a conference call with the State Team Leaders who participated in the May 2004 Parent Leadership Institute in Orlando, FL. Leaders from Vermont, Florida & Indiana shared some of the accomplishments their teams have made since the meeting. Here are a few of their comments:

- The **Indiana** team reports that things are going well. A central location was chosen for their recent ICC meeting, where the former Part C Coordinator and several providers attended as guests. The parent team facilitated the meeting and it was an open discussion. The team is committed to promoting more gatherings
- The **Florida** ICC hosts an annual event called "Family Café" for family members with disabilities. The ICC also met at the end of July. The group is in the middle of changing its by-laws and went from four standing committees to three. The state has parent consultants in 16 service areas. Roles are being revised to help families connect to hospitals, ARCs, and pediatricians.
- **Vermont** had its ICC retreat in November 2004. The team members presented their action plans and their newsletter. Parent outreach is being done by the ICC participants. The state team is also outreaching to the Abenaki community, where there is an increase in minority involvement. The team's main focus right now is getting their "grieving booklet" completed and putting it up on the website. James Austin, a Vermont team member, started a dad's group. Two fathers showed up at the first meeting; now there are six dads, and that number is expected to increase. One dad met with the Chief of the Abenaki community. The meeting place for the dads group is different each month so that the driving is shared by members. A moms group was also started ("Moms night out"); it is a social group, not a support group.

Resources

www.carseat.org features automobile restraints for children with special needs. This website has a description for each product listed, as well as a list of manufacturers and distributors.



Trips, Inc. (www.tripsinc.com) is rooted in special education rather than the travel industry. Trips, Inc. tailors trips to accommodate a broad range of developmental disabilities and personal needs. There is one chaperone for every three to four travelers. They offer support to the needs of individuals by matching the travelers by age, mobility, social skills and capabilities. Female chaperones are paired with female travelers to help them with personal needs. There are also additional chaperones, personal attendants and nursing care to address other needs. Individuals needing one-on-one care may bring their own support person. For more information please call (800) 686-1013.

You Will Dream New Dreams, by Dr. Stanley Klein and Kim Schieve. This book consists of inspiring essays written by parents of special children for new parents of children with disabilities. Contact your local bookstore, library or the publishing company at Kensington Books, 850 3rd Avenue, New York, NY.



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Resources for Dads:

The National Fatherhood Initiative (www.fatherhood.org), has an online bookstore, support, “dad email,” information on events, conferences, exhibits, and speaking engagements. Contact: National Fatherhood Initiative, 101 Lake Forest Boulevard Suite 360, Gaithersburg, Maryland 20877. Phone: (301) 948-0599. Fax: (301) 948-4325.

Books:

- *Fathers of Children with Special Needs*, by James May.
- *Uncommon Fathers: Reflections on Raising a Child with a Disability*, by Donald J. Meyer.
- *Breaking Autism's Barriers: A Father's Story*, by Bill Davis.

Fathers Network (www.fathersnetwork.org) includes a statewide and national database of fathers, articles by dads, upcoming conferences, events, and workshops. You can read articles about advocating for your child, Men and the Health Care System, and much more. A section for providers offers articles on working with diverse families, a Bibliography of Cultural Competence, Equal Partners, and other relevant topics. Contact: Chris Morris, Program Director, Washington State Fathers Network, Kindering Center, 16120 N.E. Eighth St, Bellevue, WA 98008. Phone: (425) 747-4004 ext. 4286. Fax: (425) 747-1069

National Center for Fathering (www.fathers.com). The Urban Father/Child project offers articles, programs and training programs. The email address for training programs is gwillimas@fathers.com. Contact: The National Center for Fathering, PO Box 413888, Kansas, City, MO 64141. Phone: (800) 593-DADS. Fax: (913) 384-4665. For general info, send email to: dads@fathers.com

Upcoming Event:

“Annual Conference on Disability Issues: National ADA Symposium and Expo,” May 17-19, 2005, Kansas City (Overland Park Convention Center). For schedule and registration, go to www.adaproject.org

If you would like to share stories, an article, or any ideas you may have, please call or email Marilyn Gutierrez-Wilson (800.493.2338 x 151; marilyng@fcsn.org).

Check out our website for more details: www.iccparent.org

