

Welcome to Our Fall 2003/Winter 2004 Edition of Leadership Notes!

Our 5th ICC Parent Leadership Institute

Our 5th annual Institute will take place this year from May 13 to May 15 in Orlando, Florida. Six states will participate: Florida, Idaho, Indiana, Kansas, Rhode Island, and Vermont. 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 3.5-day Institute will include parent storytelling, interactive activities and intensive state-team planning; 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.

Topic Calls

We held two topic calls for ICC parents, one on July 30, 2003 and the other on December 17, 2003. Twenty-one people participated on the July call, while six joined the December call. The notes from the calls are posted on our website. The second call was a follow-up to the early-bird parent discussion groups held at the November 2003 OSEP meeting in Washington, DC. Most notably, parents during these discussions expressed strong interest in the idea of forming an Association of ICC Parents which could hold meetings and determine an agenda for itself.

Our next topic call will be held in early April. Please send us your ideas for call topics. (One suggestion focuses on successful strategies for involving parents from underserved populations in ICC activities.) We will also have a Spanish topic call in the near future.

Updates from the May 2003 Institute Participants

Tennessee: *"The State ICC approved the three main goals of our action plan developed at the 2003 Institute. Committees were formed to begin ideas for implementation. The ICC also approved a retreat to further expand the vision and include input from the local districts. The retreat is being held April 13 and 14, 2004 and will be led by Jo Shackelford of NECTAC. Some ideas from the original vision of our action plan would be costly, (e.g., having extra parents on the ICC, traveling to different parts of the state for meetings), so we have discussed the use of video conferencing to improve feedback from different areas of the state and to involve more stakeholders. More details will follow after the ICC retreat."*

North Carolina: *"We have had four meetings and narrowed the focus a bit more... The local ICC hosts the meetings and receives support to pay for it. The action plans will be revised. There will be 18 local lead agencies by next year. They will primarily do assessments and service coordination. They are responsible for large areas (five to six counties). There are four local areas. Parents comprise 20% of the Regional Council in the LICC in each county. The present idea is to work with pilot programs and look at diversity and recruitment issues. For those pilot programs we will try to put together a plan for the council and the LICC. The pilots may do focus groups and gather family information. We also hope to expand the team. Our Part C Coordinator felt good about the plan, yet we have to be realistic about what the costs will be. Perhaps Kathleen Osta can be a resource."*

Georgia: Their state ICC meeting was on July 24, 2003. They have meetings all over the state (which requires nine to ten hours of traveling for some). The entire ICC has a reception the night before the meeting at which individuals bring up issues. They have been doing a lot of information gathering. They will compare what people have gathered and re-tool what will be done for the Hispanic population. (There are many Hispanics in the rural areas.) There are clear assignments for the summer.

Iowa: *"The first parent presentation to a parent group (Parents as Presenters) was planned for September 5th and 6th. The By-laws committee members are working on the by-laws. There will be a reception the night before the SICC meeting. Usually there are meetings in the same place. The Executive committee has given its full support to the parent sub-committee."*

Resources

Babies Can't Wait

A program for babies with special needs Birth to 3. Describes children's developmental stages. If your baby has developmental disabilities it is possible that he/she may need services. For more information, contact Babies Can't Wait, (800) 247-6538 or 245-6565; in Georgia, (800) 229-2038. Address: 2700-C-N. Oak Street, Valdosta, GA 31602.

Early Childhood Transitions in North Carolina: A Parent's Guide to the Infant-Toddler and Preschool Programs. A guide for parents or guardians with children under Part B. The booklet includes such topic areas as: 5 steps for accessing special education services from your local education agency; helpful hints for a smoother transition; a "Transition Checklist"; information about "My Child's Chart"; a community resources list; organization of a "Parent Notebook"; common abbreviations and acronyms; and a glossary of terms. It also includes a comparison of the NC Infant-Toddler program with the Preschool Program. For a copy of this booklet, please contact: The Transition Committee, 319 Chapanoke Road, Raleigh, NC 27603. (919) 662-4543

Early Access for Children and Families/IOWA SCRIPT. This is an Early Intervention program in Iowa for children Birth to 3 with health conditions that affect growth and development; or who have delays in their ability to play, think, talk and move. To find the Regional Early ACCESS Program nearest to you, call (800) 779-2001.

A Baby First. This pamphlet is used by parent support volunteers at the National Association for Down Syndrome working with new parents. It is filled with color pictures of kids with Down syndrome and reinforces the idea that "our babies are babies first." For more information about the pamphlet, or about the National Association for Down syndrome, visit www.nads.org or contact NADS at PO Box 4542, Oak Brook, Illinois 60522-4542. (630) 325-9112

Involving Families as Leaders in Early Education and Intervention Programs-Parent Leadership

Development Project. An Early Intervention program for infants and toddlers with disabilities. The program offers resources for children and families on policy, planning, evaluation, management, governance, training, family support, community organization and education. For more information contact: Parent Leadership Development Project, FPG Child Development Institute, UNC Chapel Hill, CB #8185, Chapel Hill, NC 27599-8185. (919) 966-0067; (919) 843-4133. www.fpg.unc.edu

If you would like us to include any of your own ideas or resources in our next newsletter, please don't hesitate to contact Marilyn Gutierrez-Wilson at (800) 493-2338 x151 or via email at marilyng@fcsn.org.

And don't forget to check out our website for more details: www.iccparent.org