

## MEET BETH MACDONALD, PARENT AND CHAIR OF THE INTERAGENCY COORDINATING COUNCIL

In January of this year, Beth MacDonald became the chair of Delaware's Interagency Coordinating Council (ICC), a governor-appointed advisory council responsible for overseeing the development and implementation of federal and state legislation related to early intervention services. Since no one agency, organization, program, or discipline can be expected to meet the diverse needs of young children with special developmental needs and their families, the ICC serves as a mandatory base for interagency program planning. MacDonald, a parent of two children, one of whom has developmental disabilities, was asked to join the ICC in 1992. MacDonald feels that having parents participate on the ICC keeps everyone focused on the ICC's real purpose—to be responsive to the needs of children with developmental delays and their families. Although never having participated on any formal councils prior to being appointed to the ICC, MacDonald brings to the council years of experience, expertise, and sensitivity as a parent of a young child with disabilities.

MacDonald's daughter, Lizzie, was born in 1989 with dwarfism and additional medical complications. For the first 10 months of her life, Lizzie was a patient at DuPont Children's Hospital, where she was placed on a ventilator, had cervical spinal fusion surgery, and received a gastrointestinal feeding tube (g-tube). During this time, the MacDonald family lived with the minute-by-minute fear that each day would be Lizzie's last. The physicians and nurses informed the family that Lizzie would probably not live long enough to make it home—Lizzie did make it home! However, with 24-hour-a-day nursing care, physical therapists, speech therapists, and equipment company representatives coming in and out of her home, MacDonald says, "Running my house was like running a business."

But life took a turn for the better when, at age three, Lizzie began to be weaned from the ventilator. At age four, the tracheotomy and g-tube were removed. At age nine, Lizzie now attends public school in an exclusive setting, using



crutches to get around. She has an incredible sense of humor and determination, much like her mother.

Beth MacDonald recently returned from a conference sponsored by the National Early Childhood Technical Assistance System (NECTAS) for ICC chairs from across the nation. MacDonald says the conference really gave her a focus as the Delaware chair and a sense of pride about the genuine collaboration happening among the service providers and the parents of the Delaware ICC. "We are doing some pretty unique and important things that just aren't happening in other states," says MacDonald.

When first asked to join the ICC in 1992, MacDonald was concerned that there might be times that she would be unable to attend meetings. She suggested to the ICC that she and her husband be permitted to share the appointed seat. MacDonald's suggestion, approved by the ICC, has set a precedent for the membership of other parents. During the last two years, Delaware ICC has done "a really good job of bringing parents in to serve as chairs and co-chairs of ICC ad hoc committees," says MacDonald. "This helps us, as parents, to get our feet wet in interagency planning and build relationships with professionals and other parents on the ICC. As a parent, it's hard to say no when you know you have something to share."

MacDonald has witnessed tremendous positive growth within the state's early intervention system. Having once considered not renewing her ICC seat and feeling it was perhaps time for someone new to get involved, MacDonald is now very glad she decided to stay on. "I know there are times that parents get tired of being asked to serve on this or that board and times that they feel like they are just taking up space, but maybe, just maybe, they are being prepared for the next big step," suggests MacDonald.

Now, as ICC chair, MacDonald hopes to increase the participation of family members and their children in ICC activities. MacDonald feels that it's critical for families to get involved in the planning, development, and evaluation of the state's early intervention system. "I think the professionals on the ICC do have the best interests of children and families in mind," says MacDonald. "However, they have to also represent the interests of the respective agencies. Parents only have the interests of children and families in mind. That's what we bring to the ICC. We are the body who's not afraid to tell the ICC that perhaps we need to take another look."

For more information about the Delaware ICC, contact (302) 577-4643.

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