

## **Parent Voices on the Frontlines of First Steps**

*By Emily McKinley, Health Information Specialist*

First Steps, Indiana's early intervention program, relies heavily on family voices and parent perspective to drive initiatives, provide feedback, oversee policy and procedures, and to ensure that care is always family-centered. To do this, First Steps has developed two types of committees, one at the state level and the other at the regional "cluster" level.

The Interagency Coordinating Council on Infants and Toddlers (ICC) is a statewide council that addresses issues, concerns, and trends that may affect First Steps policies, implementation and impact. This council of First Steps stakeholders, providers, professionals, and parents of children who used the First Steps system meets on a quarterly basis to review policy changes, actions proposed, and the system in general. The council was formed in 1987, and since that time, the parent perspective has been an integral part of the committee.

At present, there are three parents of children with special health care needs who serve the ICC solely to provide the family voice. According to Robyn Nelson, one of the parent representatives, all three parents have had different experiences with First Steps, and the services provided to their children were vastly different in scope, intensity and frequency. Nelson stated, "The Parent perspective is vital. If a member of the committee is not an end-user of the services, they are not always aware of what will happen down the line. The parents will say, 'here's what might be a better way to look at it.'" Nelson further commented that the parent voice is essential to painting an accurate picture of the system.

Council members serving the ICC meet quarterly to discuss the overarching issues and concerns currently facing First Steps. Additionally, members are expected to serve on subcommittees to provide input and explore current issues. Presently, the ICC has three active subcommittees; those are Best Practices, Quality and Oversight, and Family and Parent Partnerships. There is a parent representative on each of the three subcommittees.

Parent council members are appointed by the governor to a three-year term after completing a screening process, which is intended to ensure that no conflicts of interest exist. An additional service requirement is that the prospective parent representative has a child who used the First Steps system and is no older than twelve years of age. Parents interested in serving on the ICC should contact the Council Chair, Susie Lightle, at [susan.lightle@fssa.in.gov](mailto:susan.lightle@fssa.in.gov). For parents who are interested in contributing to the ICC but are unable or unwilling to make the commitment of joining the council, Nelson recommended providing feedback to the committee during public comment and hearing periods as well as when other issues arise. She said, “The parent voice on the ICC is an important voice. I sit there to provide the parent voice. The unfortunate thing is, I can provide *my* voice—one. It is so important that I share others’ (voices), so I can be more than one.” She said committee members are especially interested in learning about ideas and strategies to improve the services and family experience with First Steps.

Overall, Nelson has enjoyed her experience on the ICC, and coined it, “eye-opening.” She noted, “First Steps is not a small operation—it’s a multimillion dollar system. It is fascinating to see how it happens, and how we can use the dwindling resources to affect as many children as possible. To see the passion that people have for children and to ensure the program is able to do the most it can—it’s fascinating.”

In addition to the statewide council, First Steps also looks to the guidance and support of regional “cluster” councils called Local Planning and Coordinating Councils (LPCCs). These regional groups are charged with “identifying issues in the delivery of services and to design and implement strategies to effectively address those issues.” Issues that may be tackled by the respective LPCCs may include ensuring access to and knowledge of community resources and providers and improving the coordination and communication within the system, among others. Each LPCC may be comprised of subcommittees, task forces, county councils, and other smaller groups that are designed to tackle specific issues for the respective cluster.

Like the ICC, many LPCCs meet quarterly with subcommittees meeting more frequently as needed. The schedules and issues tackled by the LPCCs vary depending on the region's needs.

Also like the ICC, the LPCCs require that parents interested in serving have a child who used the system and who is twelve years or younger. Those interested in serving should contact their local System Point of Entry (SPOE) office, or, cluster, to express interest to the LPCC Coordinator. The coordinator can then provide parents with specific information about serving their cluster.

According to Melinda Dupler-Singer, the Mid-North cluster LPCC chair and one of the parent representatives, the make-up of the councils is as diverse as the area. Typically, local professionals and providers sit on the LPCC alongside parents. She noted that in addition to the parents who are serving solely in their role as parent representatives, many of the council members serving in a different capacity are also parents of children and youth with special health care needs.

Dupler-Singer noted, "It is very important to have the parent perspective. It is very easy for providers and others to see from their perspective and forget the angle of the parents. Therefore, it is very important to have that parent voice." She encouraged parents who are interested in sharing their voice but unable to join the committee to provide feedback to the council by presenting at a meeting. Dupler-Singer called the opportunity to serve a "learning experience" and encouraged those interested in serving to pursue a position on their regional LPCC. She said, "It's a great way to give back to the program." She also noted that parents who are interested in serving on a council but are concerned about the financial implications of attending the meetings should apply to the Family Involvement Fund for reimbursements.

For more information about the ICC or to contact a council member, please visit: <http://www.in.gov/fssa/ddrs/2823.htm>.

To learn more about your cluster LPCC, please contact the cluster office. Contact information is available here:  
<http://www.in.gov/fssa/ddrs/3383.htm>.

For more information about the Family Involvement Fund for LPCC representatives, please contact Cathy Beard at [beardc@indiana.edu](mailto:beardc@indiana.edu).

If you are interested in serving on these or other councils serving children and youth with special health care needs, Family Voices Indiana may be able to assist you. The family to family health information center's Family Leadership Development Fund is designed to reduce the financial burden on families wishing to participate in formal meetings, task forces, committees, and other work groups that are intended to solicit public/consumer input and perspective concerning disability-related public policy, programs and services. For more information contact: [info@fvindiana.org](mailto:info@fvindiana.org) or your local Health Information Specialist.

For more information about other opportunities for financial support to participate on these and similar councils, please inquire directly with the organization that you will be serving for financial aid and scholarship opportunities; investigate local scholarship opportunities offered by civic organizations; or visit the Indiana Governor's Council for People with Disabilities, Consumer Investment Fund at <http://www.in.gov/gpcpd/2328.htm>.