

What is the Role of Parents in FCESS in NH?



**THOUGHTS AFTER ATTENDING THE IDEA
LEADERSHIP CONFERENCE 2013**



Reasons for this Talk



- **A requirement of accepting a scholarship from EIFA (Early Intervention Family Alliance)**
- **Inspired by other parents at the IDEA Leadership Conference**
- **Desire to become more active in my involvement in NH's ICC**

Parent Leadership Examples



- The Parent Leadership Project in Massachusetts (www.eiplp.org) supports parent involvement at many levels of EI.
- A parent, Kurt Kondrich, that was a policeman before his daughter, Chloe, was born with DS. After getting a Master's Degree in EI, he is now a full time Outreach Director and Advocate in Pennsylvania. (www.chloesmessage.blogspot.com)
- In NY state, parents are directly involved with teacher education, where they act as faculty in courses designed to teach parent teacher collaboration. (www.advocacycenter.com/news/2012/10/23/teacher-candidates-collaborating-with-parents)



National ICC Meeting for Chairs

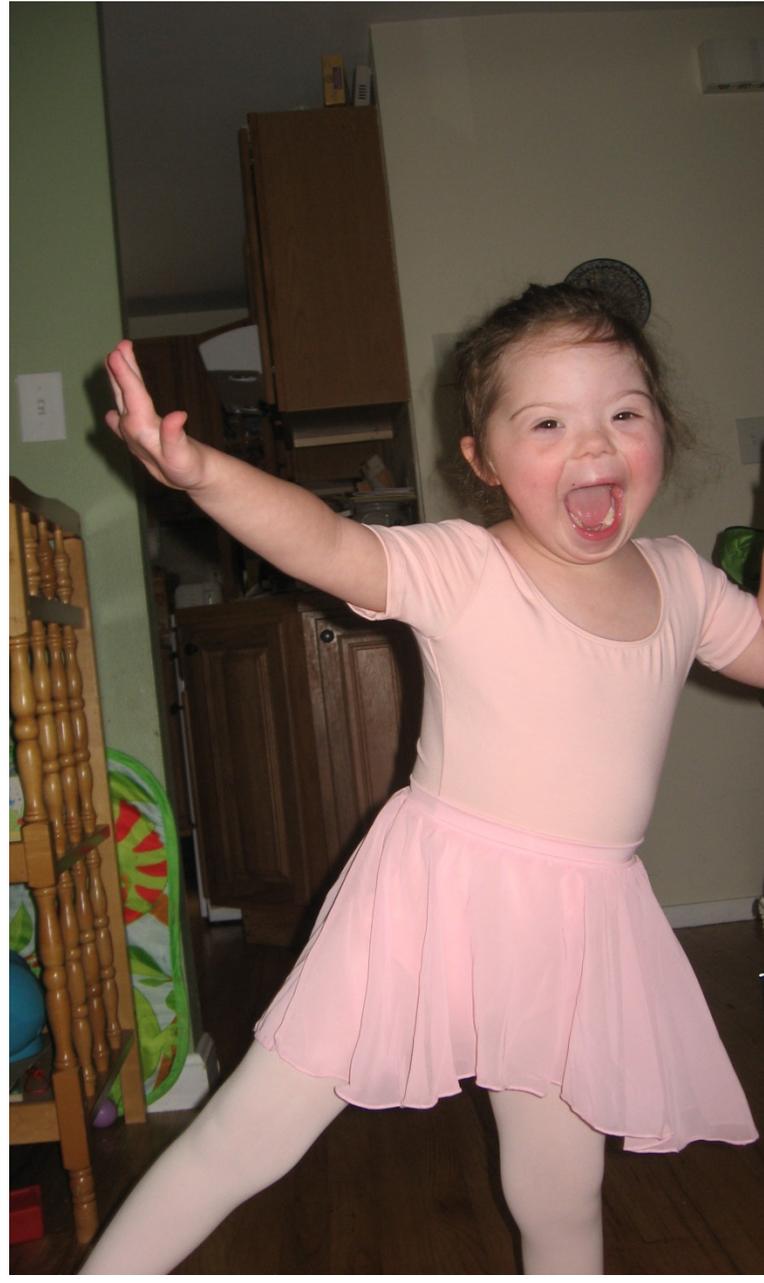


- Overall theme heard, “not as much parent involvement as in past”, “not as many parent leaders”
- Morning session was broken into small groups that focused on different topics, each participant could choose their topic of interest
- Most popular: Mentorship and training to promote parent leadership
- A lot of newer parent members of our SICCC wanting the basics of where do we start, how do we become leaders, how can we be more effective, how can we get our states to support us,...

TA & D Network



- Previously known as the NING site
- SICCC has a closed group on the site
- Quarterly webinars with SICCC's and state advisory panels
- <http://tadnet.ning.com/group/siccchairsmembersandstaff>



A Few Ideas



- **Wanted to set a few simple, achievable goals for myself**
- **Wanted to promote more parent involvement in their child's FCESS, in advocating for their child, in getting involved at the local/ state/ national level**
- **Want to educate parents and families from a parent perspective**

BDS Website Link



- Add a tab under “For Families” on BDS website that lists opportunities for parents/families to get more involved
- Passive way to promote involvement
- <http://www.dhhs.nh.gov/dcbcs/bds/families.htm>



FAQ Guide



- Create a frequently asked questions guide for parents/families that covers *questions you should ask*
- Would include questions not already covered in the FCESS Family Guide
- I never knew what to ask when I was involved in FCESS; I think of things now that we are out of it!

Sample Questions



- Why should my child receive FCESS? What happens if I choose not to use FCESS?
- Is my local area agency the only source for FCESS?
- What is my role as the parent/family? What are some ways I can help my child between sessions?
- What should I expect from FCESS? How do we know it is working?
- What if I do not want services provided in my home?

Sample Questions



- What if I do not feel comfortable with the therapies being used with my child? What if I do not get along well with the therapist(s)?
- What are additional resources that may be beneficial for my family and my child now?
- If I give permission to access my health insurance/Medicaid, will it affect my benefits?
- How does FCESS fit into the big picture? What is the point? Why is this so important for my child and my family in the long run?



Roadmap



- **Create a visual roadmap of available services and supports in NH**
- **A single page/poster view of available services at a glance similar to a mall directory or theme park map; paper or magnetic view for the fridge, web link format**
- **A prototype already started by Family Voices**



Who I am



- **Sharon Davis Laliberte**
- **Veterinarian, Wife, Mother of Madeleine (age 4) and David (age 1)**
- **Madeleine was born with Down syndrome**
- **Entered FCESS when she was 3 months old; didn't know we could have benefited from supports earlier**
- **Parent member of NH's ICC since 2011**





Questions
or
comments?



Thank You!!!