

Building Bridges to Parent and Family Engagement in the N.C. EHDI Program

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Introduction

Research has shown that the most successful models of parent-to-parent support are programs that are parent-led and parent-driven. (NCHAM EHDI eBook Chapter 19, pg. 3)

Recognizing the importance of parental engagement to successful outcomes for children with special health care needs, the Children and Youth Branch of the NCDPH, fostered a top-down, bottom-up initiative for greater parent involvement in all aspects of all of its programs and units.

The EHDI program was the first program to take on the challenge of developing a model inclusive of parents at every level of its operation. The EHDI program has been strengthened by the assets the Parent Consultant has added to the EHDI Team as illustrated in the list below:

- Intimate personal experience
- Commitment and vesting in the process
- Passion for helping others
- Access to a network of parents and families who have gone through similar experience
- Know what families need and want
- Credibility and empathy for other families
- Speak frankly from experience
- Experience in navigating services

Purpose

To create a family engagement model, consistent with the goal of the agency to have top-down and bottom-up family engagement in all of its programs, to empower parents and strengthen the EHDI program.

Objectives

1. Hire a parent consultant
2. Include the family perspective in EHDI program planning, implementation, and quality improvement activities (inclusive of: strategic planning, policy development and program evaluation).
3. Increase family support, family engagement and parent leadership opportunities across the state and in local communities.
4. Document a viable and sustainable model of parental engagement.

Method

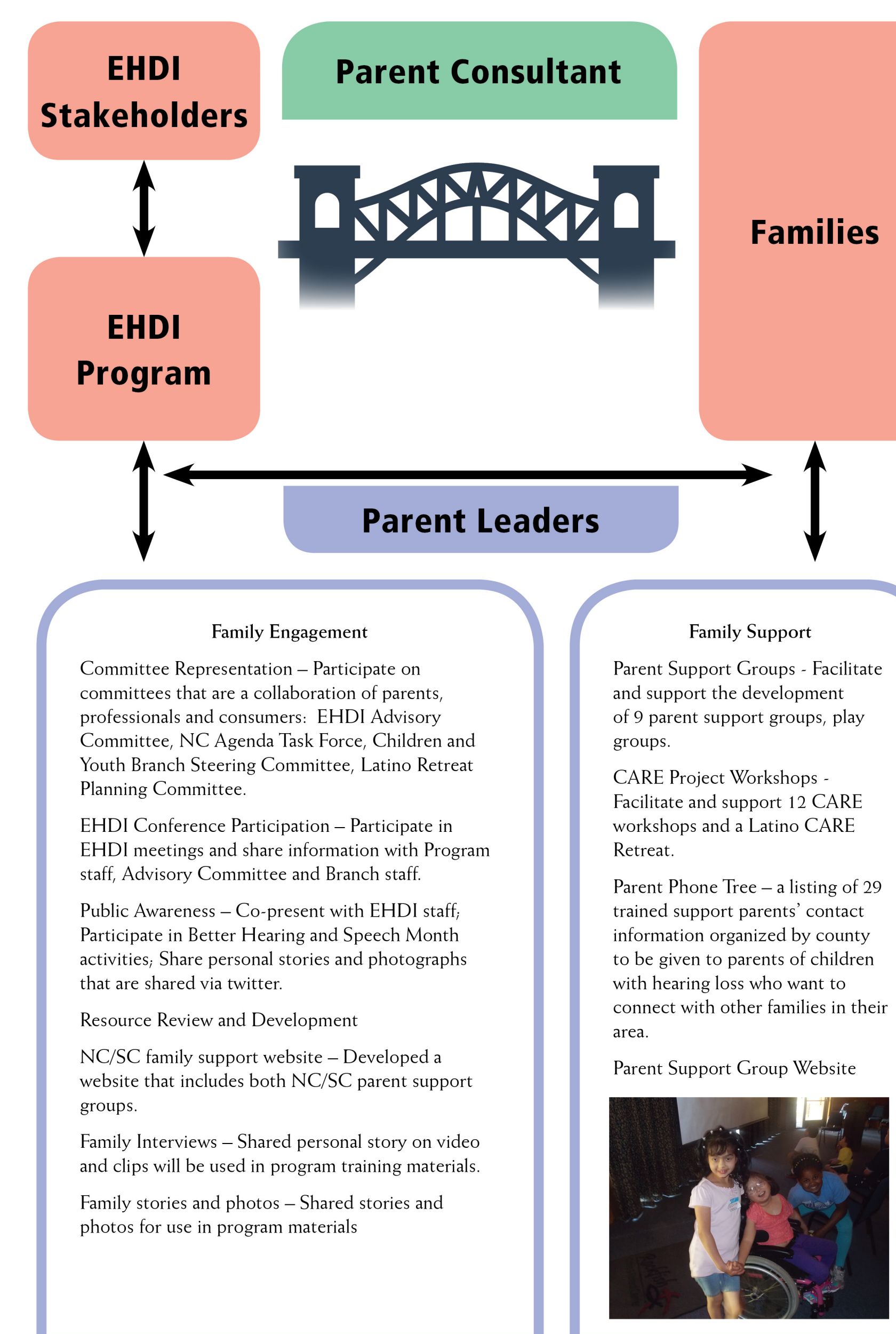
How to identify and engage an EHDI Parent Consultant/Leader

1. Secure upper-level management approval, commitment and support.
2. Secure internal stakeholders (other programs and units) and external stakeholders (Advisory Board, EI networks, local health department) support and commitment.
3. Go to places where parent leaders are: parent support groups, EHDI Advisory Committee meetings; talk to Early Intervention Providers, Audiologists, Speech Therapy Providers; and host CARE workshops.
4. Look for parent leaders who demonstrate the following characteristics: positive attitudes, passion and confidence, as well as commitment to the "cause" (improving the lives of children with hearing loss); parents who are proactive and knowledgeable about children and hearing loss, have previous advisory board experience, good interpersonal skills and follow through, and are active in local community endeavors.
5. Approach parents that exude energy and passion and ask them if they want to become more engaged in improving the lives of children diagnosed with hearing loss.
6. Connect parents' personal stories and experiences with relevant and ongoing EHDI activities.
7. Include parent leaders in all EHDI team activities and provide shared opportunities with guidance (adhering to program planning and policy guidelines).
8. Provide training/technical assistance and learning opportunities on an on-going basis for professional development.
9. Provide financial support for parents to participate in EHDI team activities (meetings, trainings, surveys) to show their time and expertise is valued.
10. Showcase outcomes for upper level management and stakeholders.
11. Provide parent leaders with opportunities to showcase their parent engagement experiences at local, state, and national conferences in collaboration with EHDI program staff.
12. Provide parent leaders with opportunities to mentor other parents to expand the cadre of parent leaders within local communities.

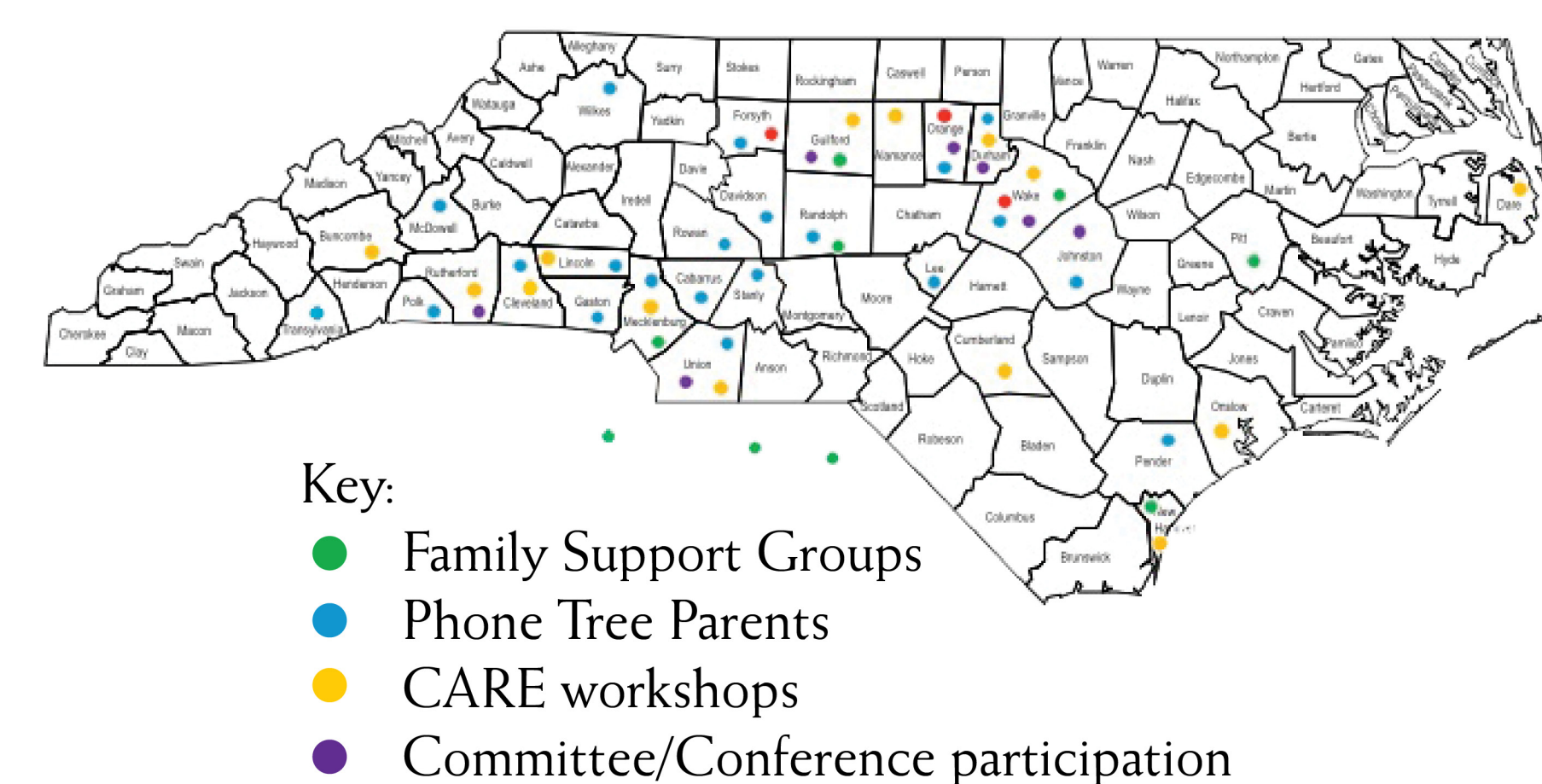
Potential Barriers to Family Engagement

- Parent leader barriers: tend to seek out families that are like their own; may be hesitant to cross cultural, linguistic and economic barriers
- Program barriers: funding to support parent leader and family participation in program activities
- Family barriers: resource issues (time, travel, child care, financial)

Family Engagement Model



Family Support and Family Engagement Activities Map



Meet Holly our Parent Consultant



Holly has a son that was diagnosed with hearing loss which led her to seek out support from other families of children with hearing loss.

Initially she requested other parents' contact information from the early professionals she encountered.

Inspired by the rewards of these connections to her family's journey she sought out ways to help other families find similar reprieve.

Holly made contacts and developed networks among both parents and professionals as she navigated her son through the system of services for children with hearing loss.

Further motivated by gratitude for her son's successes and meaningful relationships acquired along the way she sought out and served on many collaborative boards and committees including the EHDI Advisory Board where she learned about the successes and struggles of the EHDI program from different stakeholders' perspectives both at a state level and nationally.

Her participation on the EHDI Advisory Board showcased her passion and leadership skill set which was recognized as a good fit for the Parent Consultant position.

Holly is able to bridge together the EHDI program with families of children with hearing loss.

Holly has a unique skill set of a parent's perspective combined with interaction with a broad spectrum of stakeholders.

Conclusion

Hiring a paid parent consultant who is vested, experienced and passionate about her/his work increases the program's ability to provide the support families need, encourages other families to become involved and draws other potential parent leaders into the program. Holly has increased EHDI's visibility and has significantly increased the number of parents engaged.

In addition to feelings of satisfaction associated with helping others, parents have expressed that participating in EHDI activities is healing and rewarding. It has helped parents overcome their own hurt and fears. Moreover, engaging in EHDI activities has empowered them to take on leadership roles as they give back and help other families.

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