

Engaging Parents in System Design to Reduce Loss to Follow-Up

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Abstract: This article provides an overview of Virginia’s 1-3-6 Family Educator Project involving the induction and integration of parents of children who are deaf or hard of hearing as leaders in systems change, and the investment of Virginia’s Early Hearing Detection & Intervention program in the project. The article describes the role of the 1-3-6 Family Educators and their success in collaborating with audiologists and hospitals, helping parents get timelier rescreenings of infants who did not pass the newborn hearing screening, and providing peer-to-peer support to parents. Details are provided about the 1-3-6 Family Educator Project to allow other states to consider replicating Virginia’s efforts to empower and support parents as an integral part of system change.

Key Words: EHDI, deaf or hard of hearing, family involvement, family support, leadership

Acronyms: CFI = Center for Family Involvement; CYSHCN = children and youth with special health care needs; DCFH = Division of Child and Family Health; EHDI = Early Hearing Detection & Intervention; ENT = Otolaryngologist (Ear, Nose, Throat Doctor); FE = Family Educator; F2F = Family to Family Network of Virginia; GBYS = Guide By Your Side®; LTF = loss to follow-up; OFHS = Office of Family Health Services; VDH = Virginia Department of Health; VEHDIP = Virginia’s Early Hearing Detection and Intervention program; VISITS = Virginia Infant Screening and Infant Tracking System.

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Introduction

There is an adage in the disability field of “nothing about us, without us” that speaks to the conviction that people with disabilities and their families know what is best for them when planning for their personal supports and services and as stakeholders in designing the systems that support them (Bartha & Smith, 2017; Charlton, 2000). This sentiment of end-users contributing as active participants in systems design is not new. The result of their participation yields richer understanding of a system from different perspectives, helps organizations build practical empathy—a mindset of serious listening—that influences its design, and provides invaluable feedback on what works and what doesn’t (Sloan, 2016; Young, 2015).

Early Hearing Detection and Intervention (EHDI) programs have a history of including parents of children who are deaf or hard of hearing on their advisory groups and sometimes as staff assisting with follow-up from newborn hearing screening or parent involvement issues. However, true family engagement goes beyond activities to a process of induction and integration. Pulling family members from the sidelines to a seat at the table in a way that is not tokenism

takes demonstrating the values for authentically engaging parents and for co-powering with parents. It requires commitment to transparency about the results we find from their work and pledging to provide funding that supports parents paid as professionals. It also takes acknowledging that there are systemic barriers (Yarbrough, 2017a; Frank, 2016). In the case of EHDI programs, the barriers may perpetuate loss to follow-up.

Parents of children diagnosed as deaf or hard of hearing are information seekers, not only when they first receive their child’s diagnosis, but throughout their child’s life. From the beginning, parents and caregivers have to learn about communication options including communicating with their family and others. They also must decide how to help their child fit into society. All these decisions are made while parents are encountering new systems and dealing with often-difficult funding streams. Parents want their children to have the same opportunities as other children, though there may be challenges, so they develop a level of advocacy. As these parents become advocates for their own children, many develop a desire to help and support other parents of children with hearing loss. They may also aspire to help others avoid some of the more challenging

experiences their family encountered. And, some of these parents want to share their stories and ideas with policy-makers to improve the system for those that follow.

Meaningful relationships, shared leadership, and power are at the core of genuine parent engagement. The process of family engagement called induction occurs when families move from the periphery to the center of the system: They begin to take notice, speak up, and intervene in ways that change the nature of the parental relationships with the system. Rather than viewing professionals as final authorities, families begin to see them as partners. In addition, professionals and systems benefit from viewing parents as assets, not liabilities. This takes letting go of the established agenda and creating a shared agenda with families. This takes co-powering. When we co-power, we acknowledge the power families innately carry—power that too often has been dismissed. Co-powering recognizes the power of families in telling their own stories. Co-powering shifts perspectives about what families are capable of doing so they are seen as assets and professionals meet them where they are (Vargas, 2008; Yarbrough, 2017b).

This article provides an overview of the innovative use of parents of children who are deaf or hard of hearing as leaders in systems change within Virginia's EHDI program, the collaboration with a statewide family-led program (Center for Family Involvement) which facilitated the induction and integration of these parents, and the Virginia EHDI program's perspective on this investment.

Virginia's EHDI Program

Virginia's Early Hearing Detection & Intervention program (VEHDIP) resides within the Virginia Department of Health's Division of Child and Family Health (DCFH) in the Office of Family Health Services (OFHS). The DCFH operates numerous programs serving the maternal and child health populations including, but not limited to, the children and youth with special health care needs (CYSHCN) programs, home visiting, newborn blood spot screening, and child development services. DCFH is the hub of the Title V Block Grant.

The VEHDIP is committed to the 1-3-6 national EHDI goals—all newborns receive a hearing screening by 1 month of age; all newborns who do not pass their screen receive a diagnostic audiological evaluation by 3 months of age; and all infants with hearing loss receive early intervention services by 6 months of age. VEHDIP staff follow-up with parents during each stage in the EHDI process: screening, diagnosis, and early intervention. With over 100,000 births per year, VEHDIP tracks children who need follow-up and/or who have risk indicators through almost 500 letters and approximately 100 phone calls per week to parents or providers. There are currently six VEHDIP staff: a full-time EHDI program manager, follow-up coordinator, and follow-up specialist; and two part-time follow-up specialists and a part-time quality improvement

coordinator. All the staff members are in Richmond, the capital of Virginia. In their work, the VEHDIP staff collaborate with approximately 70 hospitals and birthing facilities, over 120 audiologists, and 40 local early intervention systems throughout the state.

Improvements in data collection and the Virginia Infant Screening and Infant Tracking System (VISITS) have led to a decrease in Virginia's loss to follow-up (LTF) rate. In 2009, Virginia's LTF rate was 78%, but it steadily decreased to 34.1% in 2015. VEHDIP staff have long been committed to authentically engaging with families and providers to improve these rates. The staff make visits to those hospitals and audiologists that appear to be having the most difficulty with LTF after a failed screen or throughout the diagnostic process. In 2014, the staff recognized there was a need to visit more hospitals and audiologists than staff alone could accomplish in getting to the desired decrease in LTF rates. This recognition led to the inception of the 1-3-6 Family Educator project.

The Center for Family Involvement

Under the federal Developmental Disabilities Assistance and Bill of Rights Act, Virginia Commonwealth University's Partnership for People with Disabilities has received funding since 1985 from the U.S. Administration on Intellectual and Developmental Disabilities to act as the Commonwealth's university center for excellence in developmental disabilities research, training, technical assistance, and dissemination. One of the largest projects at the Partnership is the Center for Family Involvement, or CFI. The CFI has a mission of working with families to increase their skills as advocates, mentors, and leaders so that family members with disabilities can lead the lives they want. The CFI has grown from one full time and three part-time staff operating two grants (\$500,000) in 2005 to a little over \$1.1 million in funding in 2017 that supports one full-time and 19 part-time staff running 12 initiatives backed by four state and two federal agencies. The CFI staff are all parents or family members of CYSHCN or are themselves people with disabilities. Annually, the CFI provides one-to-one enhanced emotional, informational, and systems navigational support to approximately 750 diverse families of CYSHCN and participates in informational and educational opportunities that reach over 8,000 families and professionals.

The CFI's largest initiative is the Family to Family (F2F) Network of Virginia that provides evidence-informed parent to parent support through eight local coordinators, five cultural brokers, three disability liaisons, five 1-3-6 Family Educators, and over 100 volunteer Family Navigators. The F2F Network is Virginia's federally recognized Family to Family Health Information Center and a nationally recognized Parent to Parent USA alliance member.

VEHDIP and CFI Collaboration

In 2007, the VEHDIP collaborated with the Partnership for People with Disabilities and CFI to pilot a family to family support program using the Guide By Your Side® (GBYS) model from Hands & Voices. The program connects parents of children who have been newly diagnosed with hearing loss to other parents who have already had that experience. Data from the CFI's three-year pilot of GBYS demonstrated the need for such services:

- Approximately 250 families requested emotional support and unbiased informational support on communication options from another parent.
- Ninety-four percent of the families who were matched with a family guide and responded to a survey reported being satisfied or highly satisfied with the support received from the CFI/Virginia GBYS program.
- Eighty-two percent of parents found the information they received useful.
- Ninety-five percent found the information on communication options helpful in making their decisions.

Success of this pilot indicated the continued need for family to family support with the same objectives to connect newly diagnosed families with experienced parents and to expand supports to culturally diverse families. From 2011 to 2014, the EHDI program contracted with the CFI for evidence informed parent to parent support from its F2F Network. It is important to note that during this timeframe, families in Virginia were trying to establish a sustainable chapter of Hands & Voices and that some funds in the contract with CFI supported those efforts.

The scope of work between the VEHDIP and the CFI was expanded in 2015 to focus on families participating in data collection, policy discussions, and leading stakeholder learning. Prior to this expanded contract, the challenges of distance and time limited the VEHDIP staff to only completing about six hospital visits and six audiology visits each year. The VEHDIP needed boots on the ground or ambassadors who lived in various parts of the state and could extend VDH's outreach to EHDI stakeholders (i.e., hospitals, audiologists, early intervention programs). Six parents were hired to educate stakeholders about EHDI programs, processes, and best practices. Additionally, and more importantly, these parents were able to share personal experiences of their child's hearing journey with the stakeholders, as well as with other parents in need of support. This initiative became known as the 1-3-6 Family Educator (FE) project.

As shown in Figure 1, the VEHDIP has progressed from 2000 to 2018 in its efforts involving families. It began with families attending EHDI Advisory Committee meetings to receive information for themselves, evolved into a system of paying it forward by providing peer support to other families, which in turn led to families actively participating in systems change efforts.

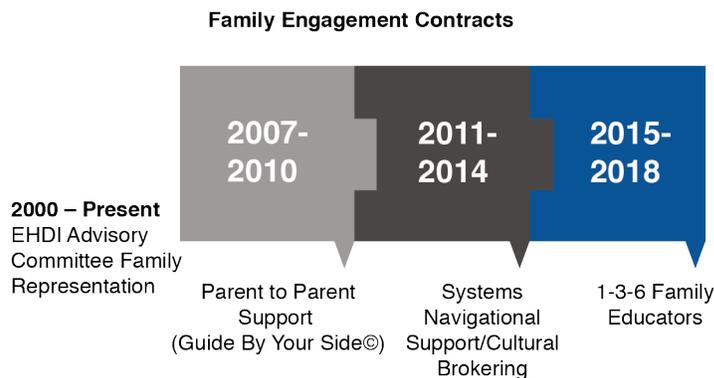


Figure 1. Family engagement contractors

Virginia's 1-3-6 Family Educator Project

1-3-6 FEs are parents of children and young adults diagnosed as deaf or hard of hearing who can commit 16 to 20 hours per month to the 1-3-6 FE project. They receive compensation as contractors. The FE role is three-pronged with the following responsibilities:

- Visit local hospitals and audiology practices to conduct short surveys and discuss the processes used for testing and for sharing hearing testing results with families, and maintain contact with the stakeholders following the initial visit;
- Acquire information about and distribute resources regarding hearing loss and services to professionals and families within their region; and
- Provide emotional, informational, and systems navigational support to families of children recently diagnosed with a hearing loss.

The parents chosen as FEs participate in an interview, submit to a criminal background check, and are required to have transportation to visit hospitals, audiology practices, and other providers. In 2016, the CFI contracted with six parents for the role of a 1-3-6 FE. Two resigned during the first year; one of them was replaced in 2017. The red stars highlight the FEs current geographic distribution in Virginia (Figure 2).

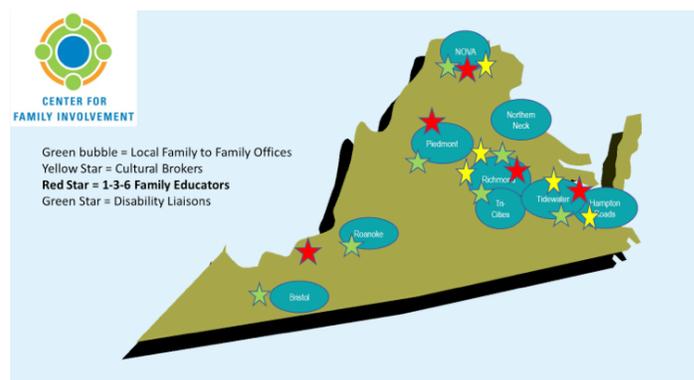


Figure 2. Current geographic distribution of Family Educators in Virginia

FEs complete the eight-hour CFI training required of volunteer F2F Family Navigators. An additional eight hours of training is also required for the FEs. This training includes

- An overview of the history of EHDI and the importance of a systematic way to identify infants with hearing loss;
- Screening equipment used for infants;
- Expected procedures for screening, diagnosis, and referrals;
- The types of hearing loss (including deaf-blindness);
- An overview of the EHDI program in Virginia and a review of recent data;
- The role of a 1-3-6 FE;
- How to use various EHDI/CFI products with families, hospitals, and audiologists;
- The process used to match a 1-3-6 FE with a referred family;
- Role-playing providing unbiased family support; and
- Role-playing hospital and audiology site visits (including conducting a survey and sharing of resources).

A CFI staff person (a woman who is hard of hearing and is herself the parent of a young adult who is hard of hearing) and a VEHDIP staff person provide ongoing support for the FEs. These two staff members conduct the initial and on-going training, regularly provide coaching and mentoring to the FEs, and are available when questions or concerns arise about their role or assignments.

1-3-6 Family Educator Site Visits

In February 2016, FEs began visiting hospitals and in May 2016, the first audiology site visit was conducted. Prior to each visit, the VEHDIP staff emails a letter to the hospital or audiology practice that describes the 1-3-6 FE project and introduces the FE who will visit that site. At the same time the letter is sent, VEHDIP staff provide the FE with the pertinent information about the facility, including who to contact and how to best reach that person. The FE schedules the visit through emails or phone calls to the facility; a letter is mailed if there is no response. The visits typically last between 20 and 60 minutes, depending on the availability of the provider. In general, the hospitals have been able to schedule more time to meet with a FE than audiologists have. The average length of time between the FE receiving the hospital information and completing a visit was 18 days while the average time for audiology practice visits was 41 days from time of referral.

Over a 22-month span in 2016 and 2017, FEs conducted site visits with 35 hospital newborn screening teams and 32 audiology practices. They also assisted 89 families seeking support. Additionally, they participated in 10 meetings and trainings with VEHDIP and CFI staff and presented at or participated in 20 community or educational events. All the FEs are members of the EHDI Advisory

Committee and participate regularly in quarterly meetings.

Visits by FEs to the first 12 hospital newborn hearing screening teams occurred between March and September of 2016. For these hospitals, the average 2015 LTF rate was 51%, as compared to the overall state LTF of 34.1%. For 2016, the average LTF rate for these 12 hospitals was 46.6%; a decrease of 4.4%. The six hospitals that showed the greatest improvement in LTF received visits by FEs between March and June 2016, allowing more time for the effect of the visit to influence the LTF rate.

The information gathered from the FE site visits goes beyond the surveys they complete. Because of the FE site visits, the VEHDIP has learned about pockets of need that they would not know of otherwise. And, hospital staff have witnessed how FEs can impact parents, hospital staff, and even the community. For example, one hospital shared concerns of the lack of information about newborn hearing screening provided to expectant mothers who were receiving prenatal care at a free clinic near the hospital. The hospital screener suggested the FE train staff at the nearby free clinic on newborn hearing screening, so clinic staff can share information with expectant mothers. Another facility helps new parents focus on take-home information most essential to hearing screening follow-up (e.g., documents on how to obtain a birth certificate and the hearing screening results are placed in an easy to locate purple folder).

The hospitals anecdotally reported that they value the FE site visits. One hospital hearing screening coordinator has requested that the FE return to their hospital to share her experiences with her own child with the nursery staff. The screening coordinator shared that staff were afraid of giving bad results to a family and that it would help them be more willing to let parents know their child did not pass the hearing screen if the staff were to hear the success story only the FE could share.

The VEHDIP has also learned useful information about audiology practices from the site visits, including:

- Audiologists found the follow-up calls from the EHDI team to be helpful.
- Parents come to their appointments with CFI follow-up postcards that were designed by the FEs and shared with hospitals.
- Audiologists are frustrated because they lose money when parents cancel at the last minute.
- Some audiologists were not aware of the VDH-funded Hearing Aid Loan Bank.
- If a child is diagnosed with hearing loss, audiologists are most likely to refer to an otolaryngologist (ENT), early intervention, genetics, and ophthalmology in that order.
- The average number of infants seen is one per week at most audiology practices.

A preliminary survey conducted of the 1-3-6 Family Educator project in April 2017 (Murdock & Yarbrough, 2017)

found that the project was successful for six reasons. (a) The nine responding audiologists agreed that they were satisfied with the FEs and understood their purpose (89% strongly agreed; 11% agreed). (b) FEs felt they were prepared for their role (84% felt well- or very well-prepared; 17% felt prepared). (c) FEs conducted considerably more hospital and audiology clinic visits than EHDI staff were able to do. (d) FEs were pleased with their role and enjoyed nearly all aspects of their job, particularly improving the EHDI system, making a contribution, learning information, providing awareness to other families, visiting newborn screening teams, and providing support and information to families (100% of FEs strongly agreed that they enjoyed each of these roles). (e) FEs understood VEHDIP requirements, knew who to contact at VEHDIP and CFI, and felt supported in their role (83% of FEs had a large gain in knowledge and 100% rated the training/support very good or excellent). (f) When the average age of rescreen was determined for the three-month period prior to initiation of FE visits and for the same three-month period one year later, all but one hospital had decreased the length of time it took to have infants return for follow-up. The average age among all the hospitals visited had decreased from over three months of age to about two months (Figure 3).

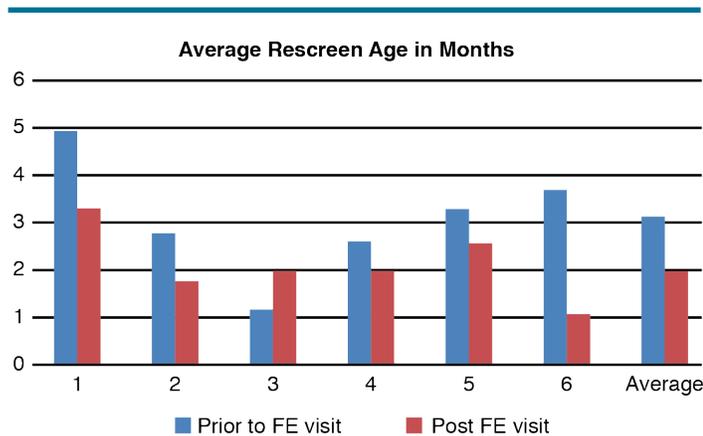


Figure 3. Average rescreen age in months.
FE = family educator

Conclusion

Embedding the 1-3-6 FE initiative within a well-established family-led program supported the VEHDIP’s goal of engaging parents in systems change efforts targeting Virginia’s LTF rate. FEs were supported by other parents of CYSHCN. The director of the CFI had the wisdom and expertise in building leadership behaviors in parents who may not have had lengthy employment histories or post-secondary education. And, on-going professional development for the FEs, particularly the use of technology (i.e., iPads, google products, cloud-based databases), was ensured through their integration with the CFI whose home was within a university.

The VEHDIP found that both the qualitative and the quantitative results from site visits provide information useful for short- and long-range planning, including where outreach or education would be beneficial, where there are pockets with specific needs or where there are specific requests, and which programs have successful processes that might be duplicated at other facilities. Though the preliminary data looks promising, it is too early to determine whether LTF has declined as the result of the FE visits. The usefulness of the information gathered is significant and has been helpful to enrich VEHDIP’s understanding of individual facility concerns and strengths.

Because the VEHDIP had a long history partnering with the CFI and trusted their ability to recruit, train, and mentor family members for the FE role, there were very few challenges encountered piloting the FE program. One helpful strategy to address the physical distance of FEs to the central CFI office was to continually state and reinforce expectations of the FE role. This was done through quarterly face to face meetings, email, video conferencing, and CFI/VEHDIP staff coaching sessions.

The CFI and VEHDIP recommend that state EHDI programs interested in replicating Virginia’s 1-3-6 Family Educator project invest in (a) an EHDI program liaison to the FEs; (b) on-going face to face meetings with FEs for clarifying processes and brainstorming solutions to challenges they encounter in their work; (c) a parent or a deaf person to coordinate the project and provide on-going coaching; (d) tools for the FE role that are available in multiple formats (i.e., hard copy, as Word documents, and as Google forms) for various learning styles; and (e) connections of FEs to larger family leadership and family engagement efforts so they are not isolated, but joined to other family leaders (who may or may not have children with the same disability/special health care need diagnosis).

Next steps for the CFI and VEHDIP include recruiting additional parents as FEs (with an emphasis on diversity—cultural and diagnosis, including deaf-blindness); establishing five regional EHDI Learning Collaboratives to support facilitation between VEHDIP staff and FEs; and expanding FE site visits to early intervention programs and pediatrician practices.

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