HANDS & VOICES

FAMILY LEADERSHIP IN LANGUAGE & LEARNING (FL3)

FL3

FAMILY-TO-FAMILY SUPPORT

FAMILY-TO-FAMILY SUPPORT PROGRAM GUIDELINES FOR ADDRESSING THE NEEDS OF FAMILIES WHO HAVE CHILDREN WHO ARE DEAF/HARD OF HEARING (D/HH)

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Family-to-Family Support Program Guidelines for Addressing the Needs of Families who Have Children who are Deaf/Hard of Hearing (D/HH)

Thank you to our reviewers for their feedback in development of the Guidelines.

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I. Working Definition of Terms:

To frame this discussion, it is important to describe the terminology that will be used within the Guidelines.

Deaf/Hard of Hearing (D/HH): The term used to describe all children and adults who are deaf and hard of hearing whether from birth or hearing loss occurred later, unilateral, and bilateral, all degrees from minimal to profound, sensorineural, auditory neuropathy, conductive and mixed, DeafBlind, and D/HH Plus additional health concerns.

Family-to-Family Support Program: Family to family support program consists of services and supports provided in response to the needs of a given family through a family-led organization. Types of support and services provided will be based on the capacity of the family-led organization and may include, but are not be limited to: direct parent-to-parent support, information, education, technical assistance, training, and referral.

Parent-to-Parent Support: Specially trained Supporting Parents sharing their lived experience of raising a child who is deaf or hard of hearing with other families who have just learned of their child's hearing condition, or who have older children and need the unique support that comes from someone else who has walked this path him/herself and can share from direct experience and wisdom.

Learning Parent: A parent (includes those who are hearing, hard of hearing, and deaf) who is new to or inexperienced in a situation of raising a child who is D/HH or may be experiencing a transition in the child's or family's life.[1]

Supporting Parent: A coaching, nurturing and encouraging parent (includes those who are hearing, hard of hearing and deaf) who has the lived experiences of parenting a child with hearing loss. May also be characterized as someone who is teaching, modeling, empowering, and mentoring.[2]

Parent Choice: The moral, ethical, and legal responsibility of parents to make decisions for their child that is protected by law and is their right as parents. Parent choice is a flexible discovery process allowing parents to consider many different opportunities, resulting in an appropriate fit for their child's unique needs. Parents may modify choices over time, if needed, or as the parents gain more information and as the child can provide input. Parent choice includes informed decision making and the importance of having consistent, accurate, comprehensive, up-to-date evaluation of the child's progress and well-being.

Informed decision making: A broad and inclusive phrase that captures the many decisions parents must make over time. It's the process of parents obtaining information and knowledge from a full range of sources and perspectives in order to assess benefits consistent

with the values and individualized needs of their child and family, and to then take action. Information provided to families should be accurate, comprehensive, up-to-date, and evidence-based, as appropriate, to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies, language acquisition, and communication modalities.

II. Introduction:

Why the Guidelines were Created

On April 1st, 2017, Hands & Voices entered into a co-operative agreement with the Health Resources and Services Administration (HRSA) to establish the Hands & Voices Family Leadership in Language and Learning Program (FL3). The cooperative agreement goals are to support the development of statewide newborn and infant hearing screening, evaluation, diagnosis, and intervention (EHDI) programs and systems by promoting the inclusion of families, parents and caregivers of deaf or hard of hearing infants/children identified through the Universal Newborn Hearing Screening Program as leaders in their statewide EHDI system. As a program objective of the FL3 program, Hands & Voices seeks to support Family Based Organizations with the development, establishment, and sustainability of family-to-family support programming for families who have children who are Deaf/Hard of Hearing (D/HH).

"Who would've thought what a wonderful world was waiting for me?"

Who are these Guidelines for?

The intended primary audience of these Guidelines are state and community organizations and organizers who wish to implement a family-to-family support program. Hands & Voices chapters and programs such as the H&V Guide By your Side (GBYS) program already have written specific guiding principles and operating policies and procedures of which they follow.

The Goal of the Guidelines

Whether you currently are operating a family-to-family support program with or without parent expertise in D/HH focused services and/or you are seeking to implement a program, we hope you find the guidelines informative and insightful. The Guidelines are designed as a resource for those interested in playing an active role in the development and implementation of high quality, sustainable parent-to-parent support unique for parents who have children who are Deaf/Hard of Hearing (D/HH). We believe underscoring core components of appropriate programming specifically for this population will provide consistent D/HH-focused support for all families.

Why Family-to-Family Support Programming?

The opportunity for a family to meet another family in the journey of raising a child who is D/HH through direct parent-to-parent support can have a profound impact for everyone involved. Raising a child who is D/HH is a delicate, complex and beautiful journey. There is something incredibly unique and important in receiving support from other parents and families who have children that are deaf or hard of hearing and have experiential knowledge of both raising/parenting a child who is deaf or hard of hearing and navigating the systems available to support them.

Parents with children who are deaf and hard of hearing (D/HH) often report feeling isolated from others sharing a similar experience. They also often report they lack the information, tools and resources to effectively support their child's specific needs and desire more opportunity to build the leadership skills necessary to provide important feedback to the systems serving their child and family. One proven strategy to address these issues is the development of formal parent-to-parent support designed to address the unique challenges and impact hearing loss has on the developing infant/child. Research supporting this practice state "Families rank family-to-family support as one of the most helpful forms of support for the family."[3] [4] "Parents/families reporting participation in social networks with other parents/families of D/HH children had less isolation, greater acceptance of their child, and improved interactional responsivity."[5] Ensuring all families have the opportunity to meet with other trained parents who are part of a formal, organized program embedded into their local system is critical.

Creating a family-to-family support program to serve children who are (D/HH) can be a challenging endeavor and requires careful planning, execution and evaluation. Programs must be built on the foundation of respect for informed parent decision-making and delivery of unbiased information to families. Recognizing this, the U.S. based Joint Commission on Infant Hearing made a recommendation in their 2013 "Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing" under Goal 9 "All Families Will Have Access to Other Families Who Have Children Who Are D/HH and Who Are Appropriately Trained to Provide Culturally and Linguistically Sensitive Support, Mentorship, and Guidance". They proposed Early Hearing Detection & Intervention (EHDI) Systems would "develop and implement guidelines that address family-to-family support. These guidelines should outline the background and training necessary for family support providers to inter-

"[This program] has been an amazing help. I must call my [supporting parent] three times a month. When I have a question, she is the first person I call because I know I will reach her right away. It really helps when a parent who doesn't know anything about hearing loss can ask another parent anything. She's more like a friend, someone who understands, another mom who knows. If I didn't have someone to talk to, I'd be lost and not aware of where to go for help. This is a great connection. I know I can call her anytime. The program has helped me so much with my daughter. I love it. Of all the programs out there, this has been the most helpful."

act with families of infants/children newly identified as D/HH, including the importance of objective, unbiased information."[6]

The evidence-based *Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement* includes the recommendation for ensuring that all families have access to parent-to-parent support from other parents of children who are D/HH, recognizing the key role of parent-to-parent support in promoting social and emotional well-being for families.[7]   (Principle 4)

Why Deaf/Hard of Hearing Specific Support?

Families require different types of support based on their unique needs. They also need specialized forms of support because of the "disability" itself. It is commonly recognized that over 90% of children who are born with hearing loss have hearing parents. Because there are different perspectives on the experience— from deafness being a "medical condition" to a "culture and community"—new families need a full range of perspectives from different viewpoints to come to a conclusion abou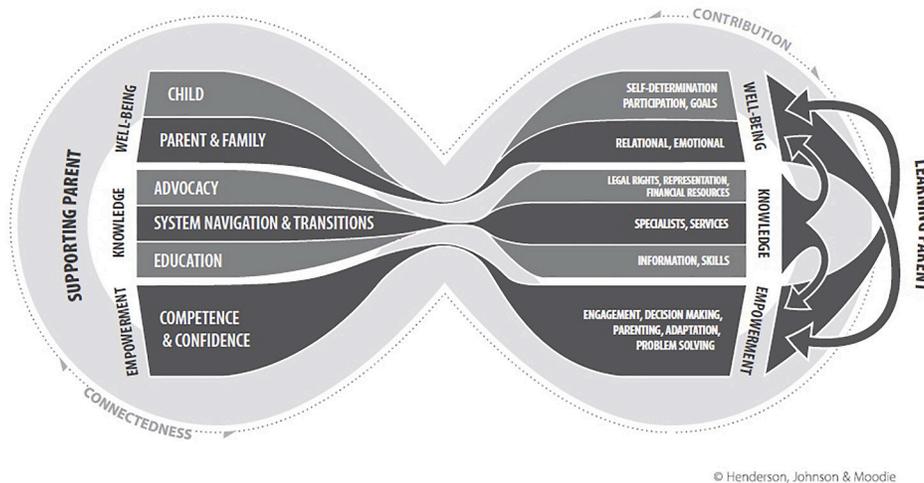t their own personal perception of their child's journey. The continuum of perspective is not an either/or experience for many families. They may choose to seek medical intervention for their child, while at the same time begin to explore the social, educational, and cultural implications of the population that their child is now a part of. The quality and quantity of information a family needs to form their own sense of what this experience means for them and their child comes from a variety of sources. The cultural identity and belief system of a family influences and gives meaning to this process.[8]

"Our region's [supporting parents] have not only been guides and support for our parents of deaf/hard of hearing children; they have been guides for me, as a teacher, in working with parents. The [supporting parents] are the first contacts that are given to our parents, so that they can establish a relationship with someone who's been there and done that. Before this program, we as teachers were doing our best to connect families. It was the piece that was fragmented or missing when a newly identified baby and family came to us. They have filled the gap. I believe that we have only just begun this already successful journey of parent-to-parent connections."

- Teacher of the Deaf/Hard of Hearing

In a research study of Qualitative Analysis of Parent-to-Parent Programs Ainbinder, J.G. et al (1998) found that parent-to-parent support is particularly helpful when reliable allies have the following four components: (a) perceived sameness, (b) comparable situations for learning relevant skills and gathering useful information, (c) availability of support, and (d) mutuality of support.[9]

The following Guidelines include suggestions for how family-to-family support programs can be established either as a new program or within a larger non-disability focused program to execute and maintain quality parent-to-parent support to families who have children who are Deaf/Hard of Hearing (D/HH).

III. D/HH Specific, Evidence-based Support Elements for Programs

Evidence Based Conceptual Framework of Parent-to-Parent Support for Parents of Children who are Deaf or Hard of Hearing (Rebecca J. Henderson, Andrew M. Johnson, and Shelia T. Moodie)

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When considering the creation of parent-to-parent support for families, it is important to understand why supports should be specialized for this unique population. Additionally, program components should strive towards the types of supports that are evidence based in the parent-to-parent construct.

In the above model, researchers Moodie, Henderson, Johnson did a scoping review of 39 peer reviewed articles published from 2000-2014.[10] The study sought stakeholder opinion and feedback – 31 experts from 7 countries with experience in provision, research, or experience in the area of parent-to-parent support. Participants completed an online questionnaire that informed an initial framework and revisions to the final framework. The findings from this dual stage scoping review and e-Delphi study provides a conceptual framework that defines the vital contributions of parents in a family-to-family supporting role. The constructs and components are presented in a closed helix visual design with the Supporting and Learning Parents at opposite curves. The two descriptive words— "connectedness" and "contribution"—describe the underpinnings of the relationship. Three overarching themes (constructs)—well-being, knowledge and empowerment—are mirrored in the roles of the Supporting and Learning Parents. In the flexure of the Learning Parent, arrows indicate that relationships exist between the defining constructs, namely that knowledge and well-being promote empowerment and empowerment and knowledge increase well-being. Under each construct, broad descriptive elements are found on the Supporting Parent's spiral. Finally, specific key elements (components) itemize specific parental needs by the Learning Parent.

Programs would benefit by incorporating these elements in the assessment, design, implementation and evaluation of services delivered for this unique population, anchoring their model on evidence-based practices.

IV. Creating a Stakeholder Group

Identifying a group of stakeholders, from the start, who reflect the comprehensive systems that serve families who have children who are D/HH is essential to assist you with establishing the goals and objectives to meet the parent-to-parent support needs of families. This stakeholder group would be formed with the goal of being advisory during the program establishment and on-going implementation, as needed, and should include professionals from diverse backgrounds and working in different aspects of the systems that serves families and include parents of children who are D/HH and Adults who are D/HH.

Assessment of Community/Family Needs

To provide appropriate parent-to-parent support meeting the unique needs of diverse families with children who are D/HH, assessing the needs of families and the services that already exist is critical. By implementing this practice, you will identify strengths, avoid duplication and competition for funding, as well as identify gaps and create programming complementary and supportive to existing services, spanning the full continuum of family experiences.

Recommendations

1. The stakeholder group should consist of parents of children who are D/HH, adults who are D/HH with diversity of lived experiences, and professionals with diverse experiences serving families. Recommendations to consider but not limited to:

    a. Parents with different ages of children, various language and communication modalities and from cultural communities representative of the demographics served

    b. D/HH Adults with different lived experiences and cultures who access their family, friends, work, and community through spoken language and/or visual language

    c. Early Intervention providers

    d. Pediatric Audiologists

    e. Health Care clinicians (Pediatricians, ENT, etc.)

    f. Professionals from Schools for the Deaf, mainstream programs, and private programs

    g. IDEA Part C representative(s) [11]

    h. Department of Education representative(s)

    i. Representative from another established non-disability specific organization

2. The stakeholder group may participate in the development and/or review of local and

other needs assessment information to make recommendations about how to proceed based on:

The needs of parent-to-parent support for families with children who are D/HH and if they are:

   a. met with current programs and funding is adequate.

   b. met with current programs, but funding is not adequate.

   c. not met with current programs and additional programming is needed, and adequate funding exists.

   d. not met with current programs and additional programming is needed, and adequate funding does not exist.

3. Review needs assessments done by other sources such as the Hands & Voices FL3 Needs[12] Assessment, NCHAM SNAPSHOT[13] , and Washington State Gap Analysis.[14]

4. Initiate local needs assessments if your stakeholder group feels as if you need more information by conducting surveys, focus groups and/or interviews with diverse families and stakeholders to determine what families need and what services exist.

"We were so relieved to speak with another parent who had 'been there.' Our [supporting parent] helped us realize we were not alone on our child's journey with hearing loss."

V. Funding for Programs

Adequate, sustainable funding is important for specialized services to be delivered to families who have children who are D/HH. Funding should provide services to all families regardless of their geographic location, language of origin in the home, socio-economic status, child's language(s) and communication modalities, level of hearing, etc. Funding is used to hire parent-to-parent support staff, program operation and expenses, provide ongoing training, and program evaluation.

Recommendations

1. Collaboratively identify potential funding mechanisms for sustainable parent-to-parent support services.[15]

2. Adequate funding to offer all families of children who are deaf or hard of hearing the opportunity to access trained parents in a formal program at no cost to families.

3. Paid staff at all positions: Parent coordinator, parent staff, etc. including staff reflecting the adequate level of diversity of families in the community also including diversity of the language and communication modality experiences of the Supporting Parents.

4. Support participation of Learning Parent whose first language is not English (funding for interpreters, translators, translated materials, etc.).

5. Paid initial training for all positions including funding for on-going training.

6. Funding to cover expenses for travel etc.

7. Trained parent participation in systems level advisories and committees is funded.

8. Funding to provide program evaluation including family satisfaction, family outcomes, quality improvement, and reporting.

VI. Program Design and Components

Family-to-family support programming should include opportunities for families to connect with a trained Supporting Parent with a child(ren) who are D/HH and include opportunities for families to meet other families with children who are D/HH through social or educational events. Components you will want to consider when designing family-to-family support programming should include; peer parent-to-parent emotional support, system navigation and engagement, social networking opportunities, education on a variety of topics including the impact of hearing loss on language/literacy/social- emotional development, parent leadership training, and engagement with a wide variety of adults who are D/HH.[16] Clear communication about what kinds of supports are available is helpful for families to understand and for professionals/systems to refer in a timely and appropriate manner.

Recommendations

1. Deaf and Hard of Hearing specific family-to-family support programming designed with parent leadership, stakeholder input, and embedded into the local systems that serve families with children who are D/HH. The family-to-family support program coordinator works in partnership with local system leaders to co-create[17] the program's contract, scope of work, goals, budget, and evaluation.

2. Program will have a referral system that ensures all families regardless of residence, culture, language of the home, etc. will have an opportunity to receive parent-to-parent support.

3. All positions should be paid and filled by parents of children who are D/HH.

4. Program designed based on an understanding of the diverse needs of adult learners.

5. Program created to support families' participation through a variety of platforms including, passively, anonymously, through one-on-one connections and through group interaction. (see appendix n)

6. Provide resources, including training and mentorship, for families to obtain the necessary knowledge and skills to participate in systems and policy development and demonstrate that training is provided.[18]

7. Program will be founded on respect for all language and communication opportunities for families including, parent choice and delivery of unbiased support specific to D/HH.

8. Implement strategies to reach low resourced and challenging to engage families.

9. Family-to-family support program coordinator and staff are integrated into local systems by serving on advisory boards, serving in leadership positions, participating in quality improvement efforts/learning communities etc.

10. Establishment of family-to-family program policies and procedures, some items you may want to include:

    a. Parent-to-parent support services abide by the policies and procedures outlined in their contract and by the organization where the program is housed.

    b. Determination of when parent-to-parent support will be offered, what ages of children will be served, how often services will be offered to families, when and how families with be referred, and how this service differs from other non-D/HH-specific parent-to-parent or professional-to-parent support.

    c. A procedure for responding to parent inquiry, assisting with a program enrollment process which is simple, easy and avoids unnecessary barriers to enrollment.

    d. Careful determination of which staff will provide support to a family, for example by region or by a culturally or language-specific Supporting Parent.

    e. Procedure for scheduling meetings between families and staff including confirmation of appointments, rescheduling, and documentation.

    f. Guidelines for successful initial and follow-up calls, home visits, etc. including how to convey their own personal/family story in an unbiased manner.

    g. Strength-based programming and support for positive child/family relationships.

    h. Develop a system that ensures that neither geographic location nor socioeconomic status limits access to staff. Should consider utilization of technology, including virtual meeting opportunities and social media to support connecting families while ensuring security and privacy.

    i. Ensure access and cultural sensitivity to families whose first language is not English.[19]

    j. Develop and implement program guiding principles that address providing families with access to trained parents who can provide parent support (these guiding principles should outline the background and training necessary for support personnel to interact with families of infants/children identified as D/HH; these supports should guarantee that families have access to the services regardless of audiologic status, hearing levels or type, and the geographic location of the family).

    k. Safety training regarding staff and families and especially children, including mandatory reporting considerations.[20]

    l. Delineation of the types of supports offered: loss to follow up contacts after hearing screening, contact following identification of hearing loss, educational advocacy, or any restrictions to the amount of support that can be provided to families.

m. If an identified parent resource is followed, citation and training on the delivery of information is established.

n. Collaboration with other programs, such as early intervention, family support programs, advocacy centers and health information centers. If the services are limited in duration, programs provide resources for families to stay engaged with other families over time.

o. Periodic review of staffing, policies, procedures and the services provided to reflect current practices and responses of parent satisfaction feedback. This may include modifying service delivery to provide better program access to families and meeting their needs.

VII. Hiring Practices and Personnel

The strength of a program lies in its strong people with positive attitudes and their ability to respect the needs, values and perspectives of families. Your careful attention to hiring staff who can model effective strategies to acquire knowledge, work collaboratively with professionals and who can see beyond the needs of their own child to deliver unbiased support to other families is crucial.

Recommendations

1. Ensure Supporting Parents' experience represent the diversity of the D/HH population (e.g., children who are deaf, hard of hearing, cochlear implant and hearing aid users, unilateral, cultural diversity, deaf/hard of hearing plus other health concerns).

2. Recruitment efforts are made to ensure staff diversity including, but not limited to, race, ethnicity, sex, disability, education, socioeconomic background, and geographic location.

3. Written job description for staff detailing job requirements, candidate qualifications and scope of work.

4. Hiring practices are in accordance with the organization where the family-to-family support programming is housed.

5. Interview questions will assess the applicant's ability to provide support according to expectations including the ability to support families without bias, experience and knowledge of D/HH specific supports and resources.

6. Ensure that program staff can accept, without judgment, a family's decisions for language and communication, educational placement, technology use, etc.

7. Utilization of a diverse interview team and scoring rubric will assist with creating fair and consistent hiring practices.

VIII. Program Coordinator

Developing a successful family-to-family support program starts with your ability to hire a committed, skilled and strategic parent leader to coordinate the program and advocate for the diverse needs of parents of children who are deaf and hard of hearing. The program coordinator plays a critical role in establishing parent-to-parent support that meets the needs of families, is responsive to family feedback and community needs using information obtained from the assessment recommendations in section III, collaborates well with other stakeholders, oversees comprehensive and on-going staff support, provides financial oversight, program evaluation and reporting.

Recommendations

1. Coordinator is an adult who is the parent of a child who is D/HH with experience navigating the systems that support families.

2. Position has a written job description outlining responsibilities such as:

    a. Establishing policies and procedures.

    b. Recruiting, hiring, training, and on-going supervision of the staff.

    c. Debrief and mentally process with staff their interactions with families.

    d. Promoting the Family Support Program throughout the state/province/territory.

    e. Financial oversight of the program in context to how the program is structured and funded.

    f. Program evaluation, quality improvement, and reporting.

    g. Constant vigilance in delivery of unbiased support and comprehensive information about choices, services, and education.

3. Coordinator is accountable to a larger stakeholder group or committee of the organization where the program is housed, who can provide feedback about the effectiveness of the program related to deaf/hard of hearing-specific work.

4. Coordinator works collaboratively with other professionals, agencies, and organizations.

5. Coordinator is innovative with new ideas and utilizes quality improvement practices.

6. Coordinator has an annual performance review and plan for on-going professional development.

IX. Supporting Parents

Supporting Parents are parents of children who are deaf or hard of hearing who have received specialized training that prepares them to function in this important capacity. The training you provide should offer them with a solid foundation in supporting families with-

out bias towards language or communication modality as well as a functional understanding of formal systems and services available to families and their children. Supporting Parents bring their direct experience, specialized knowledge, and personal compassion to their role while making the family's needs their prime focus.

Recommendations

1. Supporting Parents are experienced parents of a child who is D/HH.

2. Position has a written job description outlining responsibilities such as:

    a. Providing families with the opportunity to establish a relationship of trust and emotional support with an experienced parent of a child who is D/HH.

    b. Knowledge of local and regional resources for families with children who are D/HH.

    c. Assist with the family's navigation of systems and services designed to support their child and family.

    d. Understanding all levels of the Education system with knowledge of the D/HH specifics within these systems.

    e. Ability to represent diverse family experiences within the system beyond their own family experience.

    f. Meeting identified protocols in a timely manner.

    g. Maintaining standards of confidentiality.

    h. Communicate effectively with the Program Coordinator and other Supporting Parents on their team.

3. Supporting Parents have an annual performance review and plan for on-going professional development.

*possible other staff who are not the Coordinator or Supporting Parent (such as admin, data analyst, event coordinator, D/HH Mentor, Role-Models, or Guides) may also be included. Additional staff will need to abide by the same principles of the program and whenever possible consider parents of children who are D/HH or D/HH adults for these additional positions.

X. Training Practices

Quality family-to-family support programs have a D/HH specific training curriculum in place to provide consistent and superior support, tailored to the needs of families with children who are D/HH. The thoughtful design of your training will ensure families receive guidance by Supporting Parents who understand and honor the complexity of a family's journey, adhere to a consistent level of professionalism, and have the experience and training about the systems and community resources available to families. Training customized for families with children who are D/HH is key, as the needs of this population can vary greatly from other families with children with other conditions due to the dramatic impact hearing loss may have on a child's language, literacy, academic and social-emotional development.

Recommendations

Training for Supporting Parents will be provided by individuals with the necessary qualifications to effectively train staff in: (this is not an exhaustive list, only suggestions)

1. Unbiased delivery of support and respect for informed parent decision-making, including honoring a family's decision around technology use or not, language and communication modalities or educational placement of the child.

2. How the Supporting Parent describes their personal/family story to minimize focus on the Supporting Parent's decisions, while helping the family understand the complexity of the circumstances surrounding decision-making for their child about their language acquisition and communication, educational placement, technology choices, etc.

3. How a Supporting Parent will share positive experiences from their family's journey to explain their story, refrain from sharing negative experiences or specifying people/programs/names related to negative experiences.

4. How the Supporting Parent can empower families to love, nurture, and bond with the child just as they planned to do prior to the identification of the child being D/HH.

5. Preparation to encountering the different emotions families may be experiencing, including siblings and extended family members.

6. Role play answering common questions of families.

7. Confidentiality and safety rules for Supporting Parent, Learning Parents and their children.

8. Appropriate expectations/professionalism by staff (appointments kept, professional boundaries established and maintained, staying within the scope of the Supporting Parent job description despite professional background in another area).

9. Knowledge of and referral process to community resources based on understanding the needs of parents with children who are D/HH. Initial and on-going training for staff in how to make referrals ensuring continuity of care, following the required confidentiality laws/practices while noting the potential exceptions for suicide intervention and mandatory reporting.

10. Understanding of the local Early Hearing Detection & Intervention system, follow-up health services, Early Intervention, Deaf Mentor, Role Model, or Guide Programs, and special education systems and laws. This can be obtained through informational interviews, reading diverse articles/books/blogs, participating in a wide range of stakeholder events/meetings/conferences, etc.

11. How to participate in systems work, representing the continuum of families beyond one's own personal or family decisions and experience.

12. Necessary documentation and reporting of activities to meet program and funding requirements.

13. Knowledge of resources and supports for families regarding language, literacy, and social development for their children and how to train families in the importance of on-going progress monitoring.

14. How to determine limitations of one's own experience, knowledge base, or training and when to refer families to someone else with more expertise or experience.

15. Respect for and access to referral to diverse adults who are D/HH.

16. Training and resources for responding with culturally appropriate supports and services.

17. Training and resources for responding with supports and services for families with children who are D/HH plus who have other medical concerns.

18. Guidance in how to assist families in advocating for their own child and building leadership skill development potentially for the system.

XI. On-Going Education and Training Development

Family-to-family support programs need established practices and processes for on-going support for staff education and training development, staff performance reviews, and personal goal setting. Your support of this practice will ensure staff continuously evolve just as the needs of the families they serve may change over time. The Program Coordinator should oversee this process with consultation from an advisory group or committee of the organization.

Recommendations

1. Ongoing professional training for program leadership and staff including;

   a. Opportunities for staff to meet D/HH adults with diverse life experiences.

   b. Opportunities for staff to meet families who have made diverse language and communication decisions, educational placements and technology use for their children who are deaf and hard of hearing.

   c. Exposure to vetted D/HH specific research.

   d. Opportunities to attend workshops and conferences.

   e. Access to virtual learning opportunities such as webinars, podcasts, etc.

   f. Case study evaluation with like-colleagues.

   g. Requested learning opportunities based on self-assessment of professional development needs.

    h.   Opportunities to participate in systems level family engagement.

    i.   Access to training opportunities specific to D/HH population that may be different from their personal experience (Unilateral Hearing Loss, Auditory Neuropathy, Deaf Plus, Syndromes associated with hearing loss, cultural communities, etc.)

2. Annual formal evaluation of leadership and staff through assessment of strengths and need for professional development can ensure alignment with the program's goals and offer feedback from team members to the design and delivery of services.

3. Participation in national network of family-to-family support coordinators and trained staff.

4. Access to leadership training opportunities including resources specific to D/HH.

XII. Program Oversight, Reporting, and Evaluation

Assessment of family satisfaction with the support they receive, and family outcomes is integral to ensuring programs respond to family's needs and continually improve services. Your program also will need to report your activities, family satisfaction, and outcomes to your funding sources and can assist your funding agency in meeting their grant requirements by reporting data.

Recommendations

1. Ongoing program oversight by program leadership continuously trained in management of human and financial resources.

2. Data collection on all program activities (number of families served, number of presentations given, number of events provided, materials shared, etc.).

3. Formal process to collect family satisfaction data including questions about the professionalism of staff, respect for parent choice, delivery of unbiased information, etc.

4. If a satisfaction survey identifies dissatisfaction with services or breach of unbiased delivery of services, process for addressing issue and an appropriate resolution for the family.

5. Formal process for collecting family outcomes as they relate to receiving parent-to-parent support.

6. Annual program evaluation and annual program goal development based on evaluation.

7. Utilization of Quality Improvement methodologies should be used to make improvements to family-to-family support programming. (Plan, Do, Study, Act)[21]

8. Assistance to the system in reporting all families having access to parent-to-parent support.[22]

XIII. About Hands & Voices

Hands & Voices is an organization with over twenty years of experience as a preeminent family-led and driven organization with specific parent-to-parent support and systems representatives who are experts as parents with children who are Deaf/Hard of Hearing. Hands & Voices has been able to build a strong network of families, professionals in all related fields, state/federal tech support resources, modality-based groups, institutions of higher education, service providers, and individuals who are deaf or hard of hearing. The foundation of their work is through development of formal family-to-family support programming that follow specific guiding principles and operating policies and procedures committed to the goal of each child who is deaf or hard of hearing achieving their highest potential. We hope these Guidelines have provided a framework for how to design, deliver and improve parent-to-parent support services. We welcome your feedback, suggestions, and innovative strategies. More information about Hands & Voices technical assistance can be found on the FL3 website, through a variety of webinars, on-line and in-person trainings, newsletter, and production of several materials and resources. For more information, please visit http://handsandvoices.org/fl3/index.html or contact fl3@handsandvoices.org. For additional resources provided by Hands & Voices, please visit www.handsandvoices.org or contact Parentadvocate@handsandvoices.org.

XIV. Frequently Asked Questions:

Q: Why is it important for parents with children who are D/HH to lead programs and provide support to other parents with children who are D/HH?

A: Whether parents have the opportunity to speak one-on-one, chat online, or attend support groups or other activities, communicating with other parents and families is a valuable component of the circle of support. Organizations, such as Hands & Voices (Guide by Your Side Program), Alexander Graham Bell Association, Family Voices, Hearing First, and American Society for Deaf Children have models for providing family-to-family support programming. Models range from formalized programs—where trained parents embedded in the system provide systematic, knowledgeable support—to the informal matching of families in a given community by professionals who know other families with a similar story. The most successful models of parent-to-parent support are programs that are parent-led and driven. Parent-to-parent support has an important role in helping parents new to the journey of raising a child who is Deaf or Hard of Hearing navigate a system that is new and unfamiliar to them and find their way in supporting their child in reaching their full potential. The parent of a child who is deaf or hard of hearing is the most effective and passionate advocate for d/hh-specific programming, by having a vested and long term interest in and deep understanding of important issues and nuances of the diverse range of needs of families.

Q: Why does support for families with children who are D/HH need to be unbiased?

A: Arguments of methodological superiority dismisses and dishonors the integrity and efficacy of all the languages and communication approaches, and it can derail a family's exploration of which mode or method will be a good match to their child's inclinations, abilities, and all the other considerations that play into this dynamic. Emphasis should be on how critical language acquisition is for children who are deaf or hard of hearing and whatever the strengths or weaknesses of a given language, mode or method, they will be realized differently for each child. Being unbiased means the Supporting Parent isn't committing to an outcome they can't control. Ultimately, the Supporting Parent will experience greater trust in the relationship with the family when they approach them with an open mind. Encouraging their independent thought serves the greater good: increased sensitivity and awareness of this child-driven process, deeper investment and ownership of their decisions, and more effective advocacy for their child. Careful attention while recruiting, training and evaluating the program and staff will ensure families have the opportunity to access unbiased support.

Q: How can one assess a program's ability to deliver unbiased support?

A. A diverse stakeholder group, governing/advisory board for a program can offer great insight about the design and delivery of unbiased support. Hands & Voices also created a "Checklist: Program Implementation of Unbiased Support for Families with D/HH Children"[23]

Q: Why is it important that parent leaders for families with children who are D/HH are linked to other parent leaders doing D/HH-specific work?

A: The work of supporting the full continuum of families with children who are D/HH and all the possible choices they can make is a rewarding and sometimes challenging endeavor. Frequent reflection about the delivery of unbiased support, continuous professional development, and exposure to the many possible strategies to engage, support and provide parent education through a peer relationship with knowledge of the D/HH specific experience is key to quality support. Networking with other parent leaders doing deaf or hard of hearing-specific work allows the parent leader to stay current on deaf or hard of hearing issues, learn from others' experiences supporting this population and spread ideas that have been proven to be successful with a diverse range of parents.

Q: What does co-production of parent support services mean?

A: As noted in *A Conceptual Model of Healthcare Service Coproduction* healthcare services should not be viewed as a 'product delivered' but is better conceived as a service. Services are always co-produced by service professionals and service users. Good outcomes are more likely if the patient (family/consumer/youth) communicate effectively, develop a shared understanding of the problem and generate a mutually

acceptable evaluation and management plan. This includes 'duality' of satisfaction by professionals and consumers (end users). This model encourages the idea of moving away from 'what's the matter with you' to 'what matters to you' and can create a culture where co-creation and generosity grows, and productive relationships form more naturally.

Parent leaders can play a key role in developing contract deliverables, work plan objectives and budgetary insight, and achievement of goals.

(Coproduction of healthcare service, Armstrong, Lisa et al. BMJ Qual Saf published online September 16, 2015) http://qualitysafety.bmj.com/content/early/2015/09/16/bmjqs-2015-004315.abstract

Appendix

Examples provided are of complementary and supporting documents from various organizations who are willing to share excerpts or entire documents with permission (needs assessments, funding sources, job descriptions etc.)

a. Hands & Voices FL3 Family Support: http://handsandvoices.org/fl3/topics/fam-fam-support.html

b. Conceptual Framework of Parent-to-parent Support: https://aja.pubs.asha.org/article.aspx?articleid=2527221

c. JCIH 2013 Supplement to 2007: http://www.jcih.org/JCIH-2007-Position-Statement-Supplement.pdf

d. Hands & Voices O.U.R. Project: http://www.handsandvoices.org/resources/OUR/index.htm

e. Parent-to-parent USA "Endorsed Practices for Parent-to-parent Support Summary" Document: http://www.p2pusa.org/wp-content/uploads/2017/03/Summary.EndorsedPractices.2.07.17.pdf

f. "A Framework for Assessing Family Engagement in Systems Change", Family Voices: https://www.lpfch.org/sites/default/files/field/publications/assessing_family_engagement_4.10.18.pdf

g. Partnership Continuum: http://qualitysafety.bmj.com/content/early/2015/09/16/bmjqs-2015-004315.abstract

h. Hands &Voices FL3 Needs Assessment: http://www.handsandvoices.org/fl3/resources/docs/HV-FL3_NeedsAssessment_19Jul2018_Final-opt.pdf

i. Washington State Gap Analysis: http://s406336064.initial-website.com/

j. EI SNAPSHOT: Early Intervention for Children who are Deaf or Hard of Hearing: Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities, and Trends: https://www.infanthearing.org/ei-snapshot/index.html

k. Quality Improvement in EHDI Programs: http://www.infanthearing.org/quality-improvement/index.html

l. Hands & Voices FL3 DHH Guidelines: http://handsandvoices.org/fl3/fl3-docs/DHH-Guidelines.pdf

m. Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement: https://academic.oup.com/jdsde/article/18/4/429/562489

n. Hands & Voices Uniquely Delivering Family to Family Support Within EHDI Systems and Beyond – 2018 EHDI Meeting Pre-Session: http://www.handsandvoices.org/fl3/resources/docs/UniquelyDeliveringFam-FamSupport.pdf

Endnotes

1   Conceptual Framework of Parent-to-parent Support. American Journal of Audiology, June 2016, Vol. 25, 110-126. doi:10.1044/2016_AJA-15-0059

2   Conceptual Framework of Parent-to-parent Support. American Journal of Audiology, June 2016, Vol. 25, 110-126. doi:10.1044/2016_AJA-15-0059

3   Jackson CW. Family involvement in early intervention for children who are deaf or hard of hearing. Early Childhood Services. 2009;3(1):77–97

4   Jackson CW, Wegner JR, Turnbull AP. Family quality of life following early identification of deafness. Lang Speech Hear Serv Sch. 2010;41(2):194–205

5   Hintermair M. Hearing impairment, social networks, and coping: the need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. Am Ann Deaf. 2000;145:41–53

6   JCIH Goal 9

7   Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

8   NCHAM eBook Citation: author: DesGeorges, J.

9   A Qualitative Study of Parent to Parent Support for Parents of Children with Special Needs. J Pediatric Psychology 1998 Apr;23(2) 99-109

10 Conceptual Framework of Parent-to-parent Support. American Journal of Audiology, June 2016, Vol. 25, 110-126. doi:10.1044/2016_AJA-15-0059

11 Early Childhood Technical Assistance Center http://ectacenter.org/

12 Hands & Voices FL3 Needs Assessment

13 NCHAM EI SNAPSHOT: Early Intervention for Children who are Deaf or Hard of Hearing: Systematic Nation-wide Analysis of Program Strengths, Hurdles, Opportunities, and Trends

14 Hands & Voices Washington State Gap Analysis

15 JCIH Goal 9 Recommendation 3

16 Hands & Voices FL3 DHH Guidelines

17 Partnership Continuum/Co-Production of Services

18 JCIH Goal 8

19 National Center on Cultural Competence "Cultural and Linguistic Competence Family Organization Assessment https://nccc.georgetown.edu/assessments/clcfoa.php

20 Hands & Voices O.U.R. Project

21 Quality Improvement in EHDI Programs (Model for Improvement)

22 JCIH 2013 Supplement Goal 9 Recommendation #4: "Report the number and percentage of families who have had access to appropriate family-to-family supports."

23 Hands & Voices "Checklist: Program Implementation of Unbiased Support for Families with D/HH Children"

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