Family Support & Empowerment Considerations within Humanitarian Efforts

Dr. Sheila Moodie, PhD Faculty of Health Sciences
Western University, School of Communication Sciences & Disorders
and the National Centre for Audiology

Janet DesGeorges, Executive Director
Hands & Voices Headquarters

Candace Lindow-Davies, President
Hands & Voices Headquarters and MN Hands & Voices

Lisa Kovacs, Director of Programs
Hands & Voices Headquarters
Session Overview

- **9:00 – 9:15** Opening remarks and meet the presenters
- **9:15 – 10:30** Parent to Parent Support for Parents with Children who are Deaf or Hard of Hearing – A Conceptual Framework – Sheila Moodie, PhD
- **10:30 – 10:45** Break
- **10:45 – 12:00** Hands & Voices Parent to Parent Support Model
  Janet DesGeorges, Candace Davies, Lisa Kovacs
What are ‘Low Resourced’/Developing/Developed Countries?

• According to the United Nations Statistics Division, there is no established convention for the designation of "developed" and "developing" countries or areas in the United Nations system. The designations "developed" and "developing" are intended for statistical convenience and do not necessarily express a judgment about the stage reached by a particular country or area in the development process.


• Kofi Annan, former Secretary General of the United Nations, defined a developed country as "one that allows all its citizens to enjoy a free and healthy life in a safe environment."

• Today, let’s think about ‘developing’ countries where Family Involvement needs to evolve....
Parent-to-parent support for parents with children who are Deaf or Hard of Hearing: A conceptual framework

Sheila Moodie, PhD
Western University, Faculty of Health Sciences, School of Communication Sciences & Disorders and the National Centre for Audiology
sheila@nca.uwo.ca
October 8, 2015
Coalition for Global Hearing Health, Gallaudet University, Washington, DC
Contributors to this presentation

- Rebecca Henderson, MSc. (MSc Project)
- Andrew Johnson, PhD
- Publications:
  
  
Acknowledgements

• The MCYS Ontario Infant Hearing Program provided funding for this work

• We appreciate the researchers, parents, and advocates who continue to contribute to FCEI literature

• We appreciate the professionals and parents who participated in the eDelphi study
Outline

• Family centered early intervention
• EDHI in Ontario Canada
• Development of a conceptual framework of parent-to-parent support for parents with children who are Deaf or Hard of Hearing
• Limitations
• Future directions
• Joyful, playful communicative interactions
• Self-efficacious
• Engagement
• Family well-being
• Overall enjoyment
• Skills-based

Flexible & Holistic
Strength-based
Supports Development
• Joyful, playful communicative interactions
Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

(Moeller et al., 2013, p. 435)

Principle 4: Family Social & Emotional Support Service providers

- Families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH children.
EHDI in Ontario Canada

Parent-to-parent support

For parents of children who are D/HH, what thematic content is central to the constructs and components of a conceptual framework of parent-to-parent support?
A scoping literature review

Scoping Review Methodology (Levac et al., 2010)

1. Identify the research question
2. Identify relevant studies
3. Study selection
4. Charting the data
5. Collating, summarizing, and reporting results
6. Consultation
Reporting results
Consultation: An eDelphi Study

• Derived a list of 100 potential participants and selected 30 for inclusion
• Round 1: 21 respondents from ~ 7 countries
• Round 2: 17 respondents from ~ 5 countries
• 8 countries represented including: Australia, Austria, Belgium, Canada, Germany, United Kingdom, United States
Parent-to-Parent Support for Parents of Children who are Deaf / Hard of Hearing: Revised Conceptual Framework
Parent-to-Parent Support for Parents of Children who are Deaf / Hard of Hearing: \textit{Revised} Conceptual Framework
COMPETENCE & CONFIDENCE

PARENTING, ADAPTATION, ENGAGEMENT, DECISION MAKING, PROBLEM SOLVING
Promoting a common understanding

• can help decision-makers understand context and content better, and facilitate interventions

• 20/21 respondents agreed with significant certainty that the conceptual framework has the ability to serve as a model for parent-to-parent support for parents of children who are D/HH.
“This exercise has me thinking so much about moments in my life of being supported and supporting other families.... So at the end of the day, there is a component of parent-to-parent support that I believe cannot be written about, researched, labeled, frame worked, or defined. It just is. Maybe it's the listening part, the laughter, the tears, the humor and the wine that just got me through to the next thing, the next day, etc. in this thing we are calling a 'framework' it just is.”
Limitations

• Comments of uncertainty generally focused on environmental factors of parent-to-parent support.

• "parents shape meaning-making with regard to Deafness and hearing loss within a discursive context and this is not well-illustrated or documented"."
Future Directions

- Environmental Context
  - Role of Supporting Parents
  - Professional Systems
  - Community Systems
  - Social Determinants of Health

Question & Answer?
Break
Family Support Model Similarities

Support  Information

Family

Modeling

© Hands & Voices 2015
H&V Program Goals – GBYS/ASTra

• Provide parents with the opportunity to establish a supportive relationship with an experienced parent of a child who is d/hh soon after they learn of their child’s hearing loss and through the education process

• Provide an understanding of the unique needs of infants who are deaf or hard of hearing

• Provide unbiased information regarding communication options and school placement options

• Link families to resources locally, regionally, and state/province wide

• Ensure that families are linked to their county Birth to 3 Program or local school district

• Ensure that families are connected to other parent to parent resources

• Ensure that families have an opportunity to create context for their own child’s life by connecting to Adult Role Models who are Deaf/Hard of Hearing.

• Ensure that families’ voices are heard in the systems that are serving them
H&V Program Structure

• Identify potential parent leaders
• Alignment with H&V philosophy
• Consistent initial training
• On-going training
• Keeping parent leaders engaged
• Program oversight and evaluation
• Connection to H&V HQ
• Collaboration with Professionals

© Hands & Voices 2015
Collaboration

Where Families Find Support

Parent-to-Parent
- Formal Parent Support Groups
  - Deaf Specific
  - General Disability
- Informal Parent Support

Information
- Internet Websites
- Brochures
- Books
- CDs/DVDs/Videos
- Resource Guides
- Curricula

Existing Communities
- Family
- Friends
- Neighborhood
- Places of Worship/Spiritual

Professionals
- Service Coordinator
- Parent Educator
- Early Interventionist
- Audiologist
- Medical Home/Physician
- Speech/Language Pathologists
- Teacher
- Hospital Staff
- Communication Instructor/Specialist

Adults Who Are Deaf/Hard of Hearing
- Mentor
- Role Model

© Hands & Voices 2015
Training Practices

- Vision, mission, and philosophical alignment
- Train the trainer model
- Individual stories and experiences
- Initial requirements
- On going activities of professional development
- Levels of recognition
- Evaluative measures
- Chapter level leadership
Secret to our Success – “What works for your child is what makes the choice right”

• It starts with one family story...
The single most important predictor of a newly identified child’s success is the meaningful and effective involvement of his or her parents and family. (2000 Journals of Perinatology, 20, S132-137. Yoshinaga-Itano, C., Coulter, D., Thompson, V.)

Parent to Parent Support is a proven practice to: meaningful and effective involvement of his or her parents and family
THE GPOD SURVEY: 587 Parents Speak from 23 Countries across the Globe 2009

An online survey was developed and distributed to parent groups, listservs, key individuals and organisations around the world.

- 84% wanted programs to connect them with other parents
- 60 % had used some kind of family-to-family support
- A third (33.6%) have not received any support or rated the support they have received as poor or very poor.
- When parents were told how to contact or be contacted by other parents, they were almost three times more likely to have followed through and used family-to-family support services.

And if this isn’t enough...
Issues Identified:
- Stigma
- Oppression
- Isolated
- Lack of Information
- Parents don’t see/understand their role
- Systems don’t recognize the parent role

Comments from the parents:
“We keep knocking until our knuckles bleed.”

“On days I cannot walk, I crawl.”

“If the parent believes there is stigma, so will the child.”

“The love and respect of the parents to the child is what can provide the example.”
Hands & Voices is working on an international policy to develop guidelines for how we respond to requests for assistance:

- **Tier Three:** Start-up of International Hands & Voices Chapter through formalized process
- **Tier Two:** International collaboration and support that includes funding and specific deliverables
- **Tier One:** Collaboration and support that does not require financial support and determined by availability of staff time and capacity
H&V Model Adapted

- Parent-Professional Collaboration
  - The power of 1 believer
- GBYS
  - Training
  - Mentoring/sharing the load
  - Unbiased support
- ASTra
  - Educational advocacy
  - Knowing what to ask for
Parent Involvement via international Documents

• GPOD Position Paper
  http://www.handsandvoices.org/resources/whitePapers/GPOD.pdf

• Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement
  http://jdsde.oxfordjournals.org/content/18/4/429.full

• WHO Report on UNHS 2009
  http://www.who.int/blindness/publications/Newborn_and_Infant_Hearing_Screening_Report.pdf?ua=1

Not about us without us
Similarities and Differences Between Countries

**Similarities**
- Love for our Children
- Desire to Communicate
- Empowerment Happens (even in cultural contexts where there is ‘deference to authority’)
- Hope and miracles
- Knowing what’s best for our Kids (when given information, support, and modeling)

**Differences**
- Systemic structures
  - Dad from Uganda
- Educational Opportunities
  - Mom from Kenya
- Rights under the Law
  - Russian Federation
    - The Poverty Gap
      - What poverty means in different places
- Informed choice – when there is no choice
  - Story of family from South Africa

© Hands & Voices 2015
Goals and Objectives:

- **Parent mentorship and emotional support:** Parent Mentorship Program, Closed Facebook chat group, WhatsApp chat groups
- **Making unbiased information accessible and available:** We strive to find the best unbiased information from both national and international sources, and make this accessible through Social Media and an informative and up to date website.
- **Resource development:** SASL (South African Sign Language) and EI resources for families are extremely limited
- **Community Outreach:** A large number of families in South Africa who have deaf children live in remote areas. This results in these families being forced to send their children to boarding school where they see them infrequently and never learn to effectively communicate with them. THRIVE hopes to conduct outreach projects to support such families, through partnering with early intervention services to create FCEI (Family Centered Early Intervention) Satellite Units.
Enhancing Parent Leadership:

- Eight Scholarships were provided for international parent participation at the 2014/15 H&V Leadership Conference for Parent leaders from Canada; Completed on-site Training in British Columbia in October, Full day meeting with deaf educators; full day parent workshop for parents with over 95 in attendance.
- Provided Technical assistance to THRIVE in South Africa - Leadership Mentoring
- Supported full attendance of Kenya Parent Leader, Jackeline Oduor from Kenya to the H&V Leadership conference.
Outreach to Community Partners:

- H&V Parent Involvement/Leadership for the Global Hearing Health conference
- Support efforts for the Global Parents of Deaf Children (GPOD) to redevelop its resources/activities.
- 2015 Audiology mission to China - Candace Lindow-Davies
- Parent Involvement in Family Centered Early Intervention Conference - Austria

Development of materials:

- Continuation of Spanish Speaking Workgroup. Translated 26 articles into Spanish and now on H&V HQ website.
- 'How We can Help' letter for HTW funded projects. Survey is in process and plans to distribute in planning stages. (currently looking at translation for Cambodia)
Lessons Learned (learning) at H&V

• Learning from Others
  • Interviewing Existing Efforts
    • Discovering Deaf Worlds (sustainability on both sides of support)
    • The Stigma Conversation (Russia, China, Kenya)

• Expanding Opportunities to all Staff
  • Taking our collective skillsets to the international conversations (fundraising, programming, educational advocacy, etc.)

• The School of Hard Knocks
  - “I can’t find a Part C Representative, please help”
  - Adapting the model, not the country.....
Factors to Consider

- Newborn Hearing Screening/Early Intervention Stage of Development
- Educational Structure
- Financial Resources
- Social Environment
- Political and Governmental Support
- Parental Engagement
- Unique Opportunities and Challenges of the Community
China Experience

• Preparing for the collaboration by seeking expert guidance by those in that country and those who have immigrated to your country is critical

• International relations and political awareness is crucial

• Respecting the structures already in place and working together to empower the local stakeholders is imperative

• Accepting small incremental change and individuality based on that community keeps the project focused and flexible
“I’ve worked at the Center for 14 years, but never experienced this mission before. I hope we can do it more often. It was great to have training by a parent role model, the mother of a child who has hearing loss. I would love to see the parents organize a parent network to communicate with each other and share strategies and stories. The Rehab Center could provide help and a psychological professional to help them. We have benefited by a strong mother coming to China, a role model mom.”

- Teacher

“So when I started, I expected this to be a journey on many levels. And it most certainly has been. But the journey of self-discovery will be the most lasting. I have new skills and new experiences to bring back home and infuse into my work in the states. I’m have always been proud of the pioneering work of Hands & Voices. But I have never been so proud than at this moment. Our work is deep and powerful…and reaches across the globe. Pulling parents together and raising the bar for all children. What an honor to be in this field. And for me, it all started with the birth of my beautiful son. What an incredible journey.”


© Hands & Voices 2015
Dear Candace, I know the language of emotion between us can not be expressed ...... because we have a special mission!! I am willing to serve with a sincere heart for these lovely angels.

- Conversation with a Potential Parent Leader in China
Question and Answer

@HandsandVoices

EVERY PERSON YOU MEET LEAVES A FOOTPRINT ON YOUR SOUL.
Thank You

Thanks to the Hear The World Foundation for their Support of our International Projects

sheila@nca.uwo.ca

parentadvocate@handsandvoices.org