Enhancing support for early identified deaf children and their families using Deaf and hard of hearing professionals

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Looking back: Stephanie

- **Personal Experience:**
  - Identified at the age of three years old, severe to profound hearing loss, fitted with hearing aids, cochlear implant 2006
  - Grew up oral, other options were not offered
  - Public school, speech therapy
  - Learned sign language as an adult
  - Parents met and had a life long friendship with a deaf woman
  - Family did not have opportunities to meet deaf/hard of hearing professionals

- **Professional Experience:**
  - Special Educator
  - Preschool Director
  - Involvement as a Deaf/hard of hearing person in the system
  - Role Model/Early Intervention with Colorado Home Intervention Program CHIP
  - Involvement on committees/task forces and presentations
  - Hands and Voices Colorado and National
  - Children’s Hospital Colorado- Family Consultant
Looking back: Katherine

Personal experience:
- Born deaf to hearing parents.
- Attended oral deaf schools
- Learned sign language from early age
- Parents had no opportunity to meet d/Deaf adults and no d/Deaf professionals were involved with me or my family.
- It was not until my mother obtained a student placement at the local Deaf centre that she met Deaf professionals.

Professional experience:
- Worked as Youth Service Co-ordinator, working with d/Deaf young people in local Deaf organisation
- Full time academic since 2006
- Sessional lecturer
- Research Internship, Deaf Studies Laboratory (DSL) at National Technical institute for the Deaf, Rochester Institute of Technology, USA in 2009
- Currently doing doctoral research fellow at University of Manchester
Involving Deaf/hard of hearing professionals enhances:

- Family Systems
- Communities
- Early Intervention Systems
What will this connection do for families?

- Normalizes experiences and feelings in a positive light
- Ability and credibility to speak for the child’s upcoming needs
- Opportunities to ask questions that families might not otherwise be able to ask or know the answers to
- Parents may feel that their child has lost a modality - assist parents in building a relationship with the modalities at hand
When we first received our son’s diagnosis, I looked at the doctor, he was hearing... I looked at the audiologist, she was hearing... And as we walked out, I looked back at the receptionist and she was hearing. I had no idea what this (raising a deaf child) would look like until you, (Deaf adult) walked in the door.

-- Shelley Strickfaden - parent
Examples of previous research on the benefits of meeting d/Deaf adults

- Positive attitudes toward d/Deaf people and Deaf culture (Mohay et al., 1998)
- Feeling more able to parent their deaf children by reducing their feeling of isolation (Hintermair, 2000)
- Learning more sign language (Takala et al., 2000)
- Making improvements to their deaf children’s communication competence (Watkins et al., 1998)
- The findings from the evaluation of the Deaf Role Model (DRM) project (Rogers & Young, 2008)
Social capital of families with deaf children: Parents’ social networks and coping

(Hintermair, 2000)
The findings from the evaluation of the Deaf Role Model (DRM) project (Rogers & Young, 2008)

- The DRM project was set up by an organisation in UK, The National Deaf Children’s Society (NDCS) in 2007

- Aims were:
  - Share info and experiences of being deaf
  - Enhance positive attitudes towards deafness
  - Increase deaf children’s confidence/self-esteem

Evaluation study (Rogers & Young, 2008)

Aims of the evaluation:
1. Monitoring
2. Benefits and outcomes – from the perspectives of parents, deaf young people, professionals and DRMs
3. Learning for the future
Perceived benefits for service users
- Parents – see that d/Deaf people can achieve and become more positive about deafness
- Deaf young people – reduction in feeling of isolation and expanding their concept of ‘deaf’
- Professionals – expand understanding of the diversity of deaf people

Difficulties for DRM’s
- Parents’ expectations – e.g. parents chose DRMs that match communication choices and not benefit from diversity of DRMs
- Coping with parents’ attitudes to deafness – e.g. low expectations of their deaf child

Experiences of being a DRM
- At a professional level:
  - gaining new skills, knowledge, and confidence
- At the personal level:
  - Feeling worthwhile – e.g. feelings of satisfaction and achieving something worthwhile
  - Feelings of pride – e.g. reinforce own feelings of pride in being d/Deaf
- Personal impact on identity
  - “It’s been a little journey and hopefully it will continue.”
“A community that excludes even one member is not a community at all.” Dan Wilkins

- “These are the places where the foundations for self worth are created” -The Circle of Courage Bendtro, Brokenleg, Van Brocken
- Families who see Deaf and hard of hearing professionals as valuable members of their community, begin to understand and see the potential in their child.
"I met a professional who was Deaf in the early days of our journey with my daughter Sara. He accepted me where I was at, and encouraged my decisions and stood by those decisions even if they were different from his own path. But mostly when I was around him, I began to see past the label of 'deafness' and saw a kind human being, a good husband and father. I began to be able to look past my own daughter's 'label' and begin dreaming for the future like I had with all my other kids."

- Janet DesGeorges
Why do we need Deaf/hard of hearing professionals? (1)

‘Seeing is believing’ (Sutherland, Griggs, & Young, 2003)
- Envisioning the child as an adult/in the future
- Positive messages

Engagement with decision making
- Basic idea is that we make decisions through experience, not just through information
- Role models can be an active part of decision making processes (parents or young person) – through answering questions, talking about life
- DRM information may be valued for being outside the professional/professionalised arena
- However, there is a need for more Deaf professionals to demonstrate to parents what Deaf people can achieve
Why do we need Deaf/hard of hearing professionals? (2)

Promoting communication
- Specifically in relation to signed languages/early sign acquisition
- In relation to other communication approaches/languages
- Generally in terms of deaf awareness in families, regardless of communication choices

Build deaf child’s social capital
- Definition of social capital:
  “networks of people and community resources. These peer and other social contacts can provide both instrumental and emotional support to navigate through society’s institutions” (Yosso, 2005)
- could expand social network knowledge and reduce the risk of isolation (Wilkens & Hehir, 2008)
Why do we need Deaf/hard of hearing professionals? (3)

**Indirect/coincidental engagement**

- Very few d/Deaf professionals, therefore d/Deaf people are not involved in decision and policy making
- Deaf children (and their families) need to see d/Deaf people in position of influence and power
- d/Deaf professionals can also show hearing professionals what a deaf person can achieve thus impacting on that hearing person’s perception of d/Deaf people
Other considerations....

- Cultural perspectives
- Technology
- Changes the identity of the family
In policies/law:

- In the USA:
  - Joint Committee on Infant Hearing (JCIH) 2007 statement – the fourth principle of early intervention practice:
    “Intervention programs should ensure opportunities for involvement of individuals who are deaf or hard of hearing in all aspects of EHDI programs.”
  - The Deaf Child’s Bill of Rights – state law (Inc. South Dakota, Colorado, New Mexico, California, and Georgia)

- In the UK:
  - Unusual for hearing families with deaf children to meet d/Deaf people as a routine element of family support or in more general professional roles.
How do we involve Deaf / hard of hearing professionals in the systems?

Begin with a FAMILY CENTERED SYSTEM
- Families are the center of the early intervention team
- Families are partners, not just recipients of services
- Outcomes for children improve when families access a comprehensive support system
“After I met several deaf/hard of hearing adults, the importance of the early intervention providers involved in our lives, and the goals for our child started to make sense.”
Comprehensive Support Systems

Infusion of Deaf/hard of hearing people at all levels:

- Build powerful intervention teams
- Move beyond asking deaf/hard of hearing people to help at certain times (personal to professional)
- Locate connections within the organization and outside the organization
- Become open and flexible to unique ideas
- Empower families and children to succeed in real life with deafness
- Assist parents in becoming the experts
- Families do need to be in a crisis to benefit from ongoing interactions with Deaf/hard of hearing professionals
Embedding family-centered principles in program activities can lead to improved family outcomes

**Family-Centered Principles**
- Shared philosophy
- Families as partners
- Focus on strengths
- Family choice of goals and services
- Collaboration and coordination of service
- Effective communication
- Flexibility
- Community-based

**Program Activities**
- Referral and intake
- Determining eligibility
- Child assessment
- Family assessment
- Team meetings and decision-making
- Service provision and coordination
- Parenting practices
- Community support

**Family Outcomes**
- Understand child’s abilities and special needs
- Know rights and advocate effectively
- Help child develop and learn
- Have support systems
- Access the community

Possibilities....

Collaboration in Colorado
Multiple opportunities
Medical System
Collaboration in Colorado~
Families and children will most likely graduate from early intervention services meeting more than one Deaf/hard of hearing adult

- CHIP Coordinator: Dhh, signs, oral and English and Spanish
- Early Interventionists: 5 out 54 early interventionist are dhh
- 25-30 Sign language instructors
- Three pediatric audiologists
- Colorado Hands and Voices Board: 2 dhh professionals, 1 professional and parent
- Early Years: Parent child early literacy groups in five locations led by or teamed with Deaf adult professionals
- Educational settings: Early childhood, teacher of the Deaf, Special education teachers, general education
- Director of Client Relations for community center based (district/county) ~Early Intervention Services and Family Support Services for Boulder, Colorado
- Family Consultant: Children’s Hospital Colorado
Family Consultant: Children’s Hospital Colorado

- Serves as a liaison between the clinical professionals and the families
- Facilitate connections between parents, support organizations and mentors
- Establish supportive relationships with families
- Provide resources and information
  - Clinic-specific resources
  - General community-based resources
- Discuss unbiased communication choices and options
- Lend a personal perspective into the day to day issues of a deafness
Current challenges:

- Values and beliefs of hearing professionals currently involved
- Parents' fears
- Barriers for Deaf/HoH access to professional training
- Priorities of the funding bodies
The future:

- Ideas to enhance Deaf / hard of hearing professionals in early intervention
  - Examine your current systems and collaborate
  - Enlist the support and empowerment of parents of d/Deaf children (including those parents who are d/Deaf themselves)
  - Identify and work with current university Deaf/HoH students
  - Work in partnership with the Deaf community and empower them
  - Training opportunities need to include supporting without bias, cultural awareness, communication options and more
  - Move systems one person at a time and one program at a time
  - Use FCEI 2012 as a foundation What are other countries doing that work well?
  - Research and establish evidence based practices and share at future FCEI conferences
  - Liaising with, for example, the FCEI Deaf/HoH Leadership group
“I am only one, but still I am one. I cannot do everything, but still I can do something; And because I cannot do everything; I will not refuse to do something that I can do.”

Helen Keller: American author, political activist, first deafblind person to obtain a college degree 27th June 1880- 1st June, 1968
Selected references:


Thank you FCEI!

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