#### A Modular Curriculum for Practice

Social Work Practice with Families of Children with Hearing Loss: A family-centered approach

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#### **Curriculum Advisory Committee:**

Sarah Jane Dodd, PhD, Silverman School of Social Work, Hunter College, CUNY, NY, NY

**Jeanne Finch, DSW**, School of Social Work, Stony Brook University, Stony Brook, NY

Mary Ann Jones, PhD, Silver School of Social Work, New York University, NY, NY

Susan Mason, PhD, Wurzweiler School of Social Work, Yeshiva University, NY, NY

Lynn Spivak, PhD, Adelphi University and Hofstra Universities, Long Island, NY

**Brenda Williams-Gray, DSW**, Department of Social Work, Lehman College, CUNY, Bronx, NY

Wendy Zeitlin, PhD, Wurzweiler School of Social Work, Yeshiva University, NY, NY

# A family-centered approach to a child's hearing loss

- Review: 98% of children in the US are screened for hearing loss shortly after birth in Universal Newborn Hearing Screening programs
  - Slightly more than 1.5% of children do not pass this initial screening
    - Of those children, 8.5% are ultimately diagnosed with a hearing loss, but nearly 40% do not come back for recommended screening/diagnosis/intervention
    - These children are lost-to-follow-up or they do not return as recommended
- Family-centered practice provides an essential framework for including the child and family.
- Understanding a family-centered approach
  - The Social worker's role
  - The context and impact of the diagnosis
  - Assessing the child's and parental responses
  - Assessing system supports
  - Recommendations for policy

## **Topics**

#### A family centered approach to hearing loss

- o The social worker's role
- The context and impact of the diagnosis
- Loss of hearing and its meaning to the child and family
- The social worker family relationship

#### Understanding the nature of the child's hearing loss

- The importance of early intervention
- Tracking the child's developmental progress
- Anticipating implications for educational placement

#### Assessing the child's and parental response

- The family's role in facilitating learning
- Identifying and remediating challenges

#### System supports

- Parent to parent interventions
- Group work interventions for children and siblings
- Policy implications for practice

### **A Family-Centered Approach**

- The family unit is the focus of attention
- The aim is to strengthen the capacity of families to function effectively
- Families are partners in decision making and goal setting
- Interventions link families with resources suited to their needs

## Outreach, Advocacy, Education, and Capacity Building

- The social worker's role: Outreach, Advocacy, Education, and Capacity building
- Clinicians need self-awareness and identify potential barriers to forming a working alliance with families
- Consideration of cultural factors and family's resources are essential in order to proceed with each family

## The impact of the diagnosis and nature of the hearing loss

- Loss of hearing and its meaning: exploring myths, stigmas and barriers to service. Here are some examples:
  - Myth: it is not necessary to treat conductive losses because they are transient
  - Stigma: a child wearing hearing aids is likely to be bullied
  - Barrier: cultural norms that are supportive of noncompliance with treatment recommendations
- Timing and context: The importance of early intervention to encourage normal language and social development
- Clinicians need to deal with the impact of hearing loss on the child and family and on the working alliance

## Assessing the child's and parental responses

#### The social worker needs:

- To be sensitive to the family's response to their child's hearing loss
- To help families understand their child's unique response to hearing loss
- o To support the family's role in facilitating learning
- To identify and make recommendations to remediate challenges

### **Assessing System Supports**

- Understanding the family's context and strengths is an important task for clinical practice
- System supports need to be identified:
  - Making early provisions for identifying the child's educational needs and providing access to early intervention
  - Providing access to resources:
    - Assessing access to available services, including insurance coverage
    - Parent peer interventions/support
    - Group work interventions for children and siblings

#### **Policy Implications**

The social worker needs to be aware of policy implications related to infant hearing loss:

- Developing the need for advocacy from working with individual cases
- Accessing and developing needed community resources
- Making recommendations for change

### Case study:

## A Family-Centered Approach

Mr. and Mrs. Hernandez were thrilled with their first-born, a little girl. Baby Sandra appeared healthy and normal and was born at full-term. After her birth, the couple was told that their baby would be screened for a variety of health related issues, including hearing loss. Both Mr. and Mrs. Hernandez were surprised to hear that their baby had not passed the hearing screening done in the newborn nursery in either ear. Nurse Jones assured them that this happens often, and it does not necessarily mean that Baby Sandra has a hearing loss. An appointment was scheduled for a followup hearing screening in the couple's neighborhood. Mr. Hernandez insisted that Baby Sandra be brought to their pediatrician first in order to get the doctor's opinion.

## Beginning to work with the family

 You have on your calendar the Hernandez baby, who is scheduled for a re-screen in one week from today. You have the information provided on the previous slide.

#### Questions:

- What do we know from the literature about families' willingness to follow-up with recommended re-screens?
- o From a family-centered perspective, what strengths emerge in this scenario?
- o What concerns emerge?
- On the strengths and concerns identified give any clues to your approach to forming an alliance with this family system?

## Case study: Baby Sandra's re-screen

The pediatrician told the Hernandez's not to worry about the recommendation for another screening, but that Baby Sandra should be re-screened. She told them that the need for a re-screen was fairly common and could be caused by other things besides hearing loss.

Mrs. Hernandez called her mother, still concerned about Baby Sandra not passing the screening in the hospital. Her mother suggested that she follow the doctor's advice and take the baby for her re-screen.

Baby Sandra is brought to the hearing and speech center affiliated with the birth hospital for the second screening.

#### Assessing the Family System

- What additional information has been presented that adds to your assessment of this family system?
- What questions are you forming to assess the match of services to this family's needs?
- How do issues of culture and socio-economic status affect your understanding of this family?

## Case study: Baby Sandra's screenings

Baby Sandra passes her second screening in her right ear, but still does not pass in her left ear.

Social Worker Sally, along with the audiologist, Clinician Craig, inform Mr. and Mrs. Hernandez that Baby Sandra needs to come back for an diagnostic assessment, which includes more in-depth hearing testing to determine why Sandra did not pass the screening in her left ear.

Mrs. Hernandez asks what this means and wants to know if Baby Sandra will need a hearing aid.

## Case study: The role of social work

Social Worker Sally must respond to Mrs. Hernandez's question:

- •How would you respond?
- •Why was this response chosen? What issues were you addressing in choosing this response?
- •Knowing that many children who do not pass their second screening do not come back for additional diagnosis or treatment, what would you do to encourage the Hernandez's to bring Baby Sandra back to the hearing and speech center?
- •How would you begin to assess whether the services offered are appropriate for this family's needs and expectations?

### Case study: Baby Sandra

Baby Sandra is brought back for the diagnostic testing in her left ear. After the testing is complete, Mr. and Mrs. Hernandez are informed that Baby Sandra has a moderate loss in her left ear only. At the end of their appointment, Mr. and Mrs. Hernandez are told by the audiologist that a hearing aid is recommended.

Mr. and Mrs. Hernandez have a dilemma: they want the best for Baby Sandra, but they are concerned about possible stigma – bullying, teasing, and looking different from other children – if Baby Sandra gets a hearing aid.

## Case study: The role of the social worker

Social Worker Sally also has a dilemma: if she pushes too hard for the Hernandez's to follow-up with the recommendation to fit Sandra with a hearing aid, she may lose them altogether. If she does not strongly encourage them to get Baby Sandra fitted, she is risking possible long-term deficits for the baby, including learning, social, and cognitive challenges.

What factors – ethical, social, clinical - exist that aid your analysis of how best to respond?

How would you advise Social Worker Sally? Explain your reasons for this choice of response.

### Case study: Baby Sandra

The Hernandez's can not figure out whether to get Baby Sandra a hearing aid. At six months old, she seems to be developing normally. She is sitting up, making some sounds and turns her head in response to noises.

At her six month check-up, the pediatrician asks what the Hernandez's are planning to do about the recommendation to get Baby Sandra a hearing aid. Mr. Hernandez tells the doctor that since Baby Sandra seems to be developing normally, they have decided to not get the hearing aid at this time.

#### Case study: Social worker role

Social Worker Sally notices that Baby Sandra has not returned to the hearing and speech center:

- What are the chances that, without intervention, Baby Sandra will continue to develop normally?
- What does the literature tell us about the connection between stigma and hearing aids in children?
- What would you advise Social Worker Sally to do at this point? How does viewing the roles of advocate, educator and capacity builder aid your response?
- What recommendations for service improvements emerge from your considerations?

## Suggested Assignment

- Utilizing family-centered practice principles design a program for families like the Hernandez's.
  - Provide your rationale and identify how this program addresses the concerns identified in your consideration of this case.
  - Your program design should include both structural and more direct clinical components.
  - Your program design should be linked to your understanding of both the strengths and challenges facing this family and others like them.
- Research whether such programs exist. If found, provide examples of how this resource might have responded to the Hernandez family and why. If not found, provide an analysis of why you believe this resource is lacking. Substantiate your reasons.

#### References and Resources

http://successforkidswithhearingloss.com/resources-for-parents-of-childrenwith-hearing-loss

A parent's guide to hearing: <a href="http://www.nationwidechildrens.org/hearing-guide">http://www.nationwidechildrens.org/hearing-guide</a>

Parent Interview Progress Report: Communication Development Monitoring Process for Young Children with Hearing Loss http://www.cehd.umn.edu/nceo/

http://www.deaflinx.com/DeafEd/OptionsGuide/EdLaws.html

http://deafchildren.org/

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