

Project ASPIRE: Empowering Families of Children With Hearing Loss

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Agenda

- Project ASPIRE
- o Exploring Health Disparities
- Developing A Best Practices Curriculum
- o The Modules
- Module Components
- o The Dream
- Research Protocol/Pilot Testing
- 0 Q & A



What is Project ASPIRE?

- Project ASPIRE: <u>Achieving Superior Parental</u> <u>Involvement for Rehabilitative Excellence</u>
 - A comprehensive interactive multimedia intervention
 - Imparts knowledge and skills for parents of economically disadvantaged children to aid in their children's listening, language and speech development after implantation
 - Empowers parents



Impetus for the Program: Implant Outcome Disparities

- Economically disadvantaged implant recipients have less favorable outcomes than their more affluent peers (Witkin, 2005; Easterbrooks, O'Rourke & Todd, 2000)
- Factors in Outcome Disparities
 - Access and Availability of Habilitation
 - Inadequate Parental Skills to support their child's language development (Geers, 2006; Moog & Geers, 2003, Easterbrooks, O'Rourke & Todd, 2000)



What Are Health Disparities?

- Unequal burden in disease morbidity and mortality rates experienced by ethnic/racial groups as compared to the dominant group
- Widening disparity in the United States affecting all aspects of healthcare
- Socioeconomic status (SES): the most frequently cited, and most consistent, contributor
 - SES=income, education, wealth or a combination
- Healthy People 2010 has designated the elimination of health disparities as one of its essential goal
 - Improved hearing health of the nation through prevention, early detection, treatment and rehabilitation
 - <u>Successful Implantation and Habilitation of</u> <u>Children Makes good economic sense!</u>

Children and Poverty

| RACE | BELOW 100% POVERTY** | BELOW 150% POVERTY** |
|--------------|-------------------------|-------------------------|
| White | 13.8% | 24.3% |
| Black | 32.6% | 46.9% |
| Asian | 11.3% | 18.9% |
| Hispanic | 26.6% | 45.6% |
| All Children | 16.9% | 28.1% |

** Percentages from 2006 data



Health Disparities in Pediatric Cochlear Implantation

- Disparities in Hearing-Impaired Ethnic Minorities: A Double Jeopardy
- Early Hearing Detection and Intervention (EHDI)
 - Loss to follow-up after failed initial screening occurs in 59.9% of the children
 - ethnic minorities or publicly insured are 1.5 to 2x more likely to be lost after failing the newborn screening
- Implantation Rates
- Auditory, Speech and Language Outcomes

Understanding and Addressing Disparities Horn & Beal (adapted)



Health Disparities in Pediatric Cochlear Implantation

- 2008 national survey of pediatric audiologists "Socioeconomic Determinants of Pediatric Cochlear Implant Success" (Kirkham, Perry, Baroody, Nevins & Suskind)
 - 78% (n=98) of pediatric audiologists noted a negative effect of SES on outcomes
 - This disparity attributed to internal & external factors
 parental self efficacy, advocacy and adherence
 - o access and quality of habilitation and resources
 - Overwhelming agreement that increasing parental involvement in habilitation would be most effective strategy for reducing outcome disparity



Project ASPIRE Collaborators

- Headquartered at the University of Chicago, Project ASPIRE collaborators include:
 - Medical Director & PI, Dana L. Suskind, MD
 - Educational Consultants, Lyra Repplinger, MS, Mary Ellen Nevins, Ed.D. & Jean DesJardin, Ph.D.
 - Health Disparities Expert, Sarah Gehlert, Ph.D.
 - Linguistics & Psychology Consultant, Amy Franklin, Ph.D.
 - Interactive Multimedia Expert, Dr. Cammy Huang
 - Research Associate, Renate Schultz, B.A.
 - Script Writer & Social Worker, Ms. Leslie Lewinter
 - Animator MIT, Fardad Faridi
 - Sean Adibs, Producer/videographer
 - Cree Rankin, Director
 - John Paro, Songwriter/medical student

Conceptualizing Project ASPIRE

- 8 Interactive Multimedia Sessions
- Professionally Supervised, Parentally Directed Group Sessions
- Project ASPIRE Module Components
 - Animated introduction
 - Modeled behavior video
 - Practice new behavior
 - Carryover activity



Developing a Best Practices Curriculum

- A number of parent education/skill building programs are already in existence
- These were consulted for developing the themes and key points of each of Project ASPIRE modules



Formative Studies Performed

- Parent Focus Groups and Individual Interviews
- Assess Barriers and Motivators
- Cultural Sensitivity of material
- Understand Baseline Knowledge and Beliefs

Identifying Module Topics

 Curriculum review and consensus building discussions with other educational experts yielded 8 areas for information dissemination and skill building for the Project ASPIRE pilot



Module One: What is Project ASPIRE?

o Core Instruction

- critical role of post implant habilitation
- key role of parent involvement
- o Key Points
 - parents are partners
 - implant activation is a beginning, not an end
 - wear time necessary for success



Module Two: Setting the Stage for Good Listening

o Core Instruction:

- Ling Six Sound check necessary to determine device functioning
- reducing background noise helps the child listen
- o Key Points:
 - daily equipment check is critical to success
 - good acoustic environment supports listening and talking



Module Three: Sound Safari/Be the Announcer

o Core Instruction:

- parents play an important role in calling attention to, labeling and describing sounds in the environment
- Key Points:
 - understanding what sound means is different from just hearing it
 - parents provide labels for the sounds the child hears to help create a sound/word inventory



Module Four:

How to talk so your child learns to listen and speak

• Core Instruction:

- use of Child-Directed Speech helps children listen and learn
- Key Points:
 - rate, pitch and acoustic highlighting are elements of CDS
 - using an "interesting" voice helps a child know when speech is being directed to him/her





Module Five: Be a CopycatTalking Starts with Imitating Sounds

• Core Instruction:

 speech production is assisted by imitating sounds that the child produces

• Key Points:

- imitating a child's sounds reinforces the conversational attempt and allows the parents to take a turn
- over time, parents help shape these sounds into meaningful word



Module Six:

Tell Her/Him About It. It's as Easy as 1, 2, 3

o Core Instruction:

- reprises the importance of CDS and conversational turns
- adds element of language expansion
- Key Points:
 - after labeling, parents provide more information about a word by using it in a phrase or sentence
 - using the word in yet another context helps broaden the child's understanding



Module Seven: Getting Ready for Reading by Book Sharing

• Core Instruction:

 it is important to build vocabulary from the start to get ready for reading

• Key Points:

- the words a child learns today prepare him/her for reading in later years
- Sharing and reading books is critical to language learning and later reading achievement



Module Eight: From Empowerment to Advocacy: Knowledge is Power

• Core Instruction:

- Through Project ASPIRE, parents gain new knowledge and skills to best help their child develop listening and spoken language.
- o Key Points:
 - Review Local Educational Resources, Parent Support Groups, etc
 - Don't be afraid to stand up for your child!



Animation: The Characters

- o Star
- Stella
- o Audi
- o The Doctor
- o Speak Lee
- o Moose the Mouse
- o The Camera Man





Star



- o Main character
- Young mother
- Provides

 information from
 an "I've been
 there" perspective





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- Bilateral implant recipient
- Animation depicts both a younger, newly-implanted Stella and Stella as an experienced listener





Audi



 The audiologist delivers important information to Stella and serves as her support





The Doctor



 Representative of the medical component of the process of implantation





Speak Lee



 This character is introduced as the director of the video recordings that parents will be asked to do





Moose the Mouse



 This "comic relief" character is a representation of the computer mouse that serves to gain access to the computer/DVD modules





The Camera Man



 This character assists the Director in capturing the images of parentchild dyads



Project ASPIRE

Videos



Project ASPIRE

The Pilot Study, Phase 1 The University of Chicago



Pilot study of Project ASPIRE

• Hypothesis: Within families of low SES background, completion of the Project ASPIRE pilot program will:

- Improve parental knowledge of their hearing impaired child's language development and listening needs
- Positively affect parental behavior increased adult language input, conversational turns, and decreased background noise





LENA (Language Environment Analysis) System

- 1. Adult Word Count (AWC)
- 2. Conversational Turn Count (CTC)
- 3. Television Exposure



Digital Language Processor (DLP)—

recording devices worn by the child for 16 hours







http://www.lenafoundation.org

THE INTERVENTION

- Powerpoint presentation format
- Coaching Method employed
- Therapist and family view it together
- Intervention is interactive
 - Questions
 - Role Play
 - Parent Involvement and Input

THE INTERVENTION

- The therapist visits the family at their home
- Intervention takes approximately one hour.
- At the end of the Intervention, the family is given another DLP and is asked to do a future recording.



The 3 T's

- 1. Talk more to child
- 2. Take turns talking
- 3. Turn of the TV

Results

Parental Knowledge Questionnaires

- o LENA System Outputs
 - Adult Word Count
 - Conversational Turn Count
 - Television Exposure
- Correlations between parental knowledge and behavior

Results Parental Knowledge Questionnaires Scores





Results

Questionnaire Scores and LENA Output

Change in AWC and Questionnaire Scores

Baseline to 1-week postintervention



Change in CTC and Questionnaire Scores

Baseline to 1-week postintervention



Results LENA Output: Television Exposure

Mean Duration of TV Exposure

Paired samples t-tests insignificant at 1-week, 2-week, and 4-week post intervention





Study Limitations

oSmall sample size (n=8)

- Low detection power
- High between-subjects variation in AWC, CTC, and TV exposure

oHawthorne Effect





Project ASPIRE

The Pilot Study, Phase 2 The University of Chicago



What's Next

 Participants will be given feedback reports with results from their LENA recordings

 Participants will create weekly goals and will see their progress through the LENA printouts



The 3 T's

- 1. Talk more to child
- 2. Take turns talking
- 3. Turn of the TV

Talk More

Adult Word Count





Take Turns

Conversational Turns





Turn off the TV

Audio Environment





Wh o Th

What we learned

- The Relationship with the family should be established prior to the administering the intervention.
- Interactive interventions were the most successful
- Don't PREACH...PLAN and be their PARTNER!





