Communication Outcomes for Children who are Deaf-Blind with Cochlear Implants

Charlotte Ruder CCC SP/A

Cincinnati Childrens Hospital

Susan Bashinski EdD

Eastern Carolina University

Michael Scott AuD

Cincinnati Childrens Hospital

Session Outcomes

* Discuss communication outcomes for children who are deafblind and receive cochlear implants (DB-CI)
* Describe MAP strategies and adaptations that may be necessary for children DB-CI
* Compare the effects of vision impairments and deafblindness on a child's language and communication
* Describe parent coaching and therapy adaptations that may be necessary for children DB-CI

Sponsor

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Opinions expressed within are those of the project / authors and do not represent the position of the U.S. Department of Education.

IDEAs that Work
Office of Special Education Programs

Acknowledgements

- We wish to extend a special thank you to all of the children and their parents who are participating in the study.
- We also wish to thank the many State Deaf-Blind projects and private consultants who assisted with the research
- We couldn’t have accomplished this task without you!

Cincinnati Children's
change the outcome

IDEAs that Work
Office of Special Education Programs

East Carolina University

Influencing Outcomes for Children with Cochlear Implants
Who have Deaf-Blindness

Kids DB CI Project Staff

Teaching Research Institute Western Oregon University - Kat Stremel Thomas (PI); Mark Schalock;

East Carolina University - Susan Bashinski, EdD

Cincinnati Children's Hospital Medical Center - Susan Wiley, MD & Charlotte Ruder, CCC SP/A

2010 National Child Count for Children Who Are Deaf-Blind

- Overall, 4,291 children have a mod-severe, severe or profound sensorineural hearing loss
- States increased their identification of children with implants from 251 in 2005, to 622 in 2010
- An increased number of children are receiving bilateral implants
- 774 children have been identified as having CHARGE Syndrome, of which 83 have confirmed implants

Outcomes of Project

- To collect data on the outcomes and related factors for children so parents / guardians can make more informed decisions about implantation, services, types of therapy for their children
- To identify factors correlated with more positive child outcomes, with the long-term objective of improved intervention and access to opportunities for language growth

Participating States (27 + DC)

*children with CHARGE

Arizona	**Maryland***	**Oklahoma**
California*	**Massachusetts (Perkins)**	**Oregon**
Delaware	**Mississippi**	**Pennsylvania***
Florida*	**Missouri**	**South Carolina***
Georgia*	**Nebraska**	**Tennessee***
Illinois*	**New Jersey***	**Texas***
Indiana	**New York***	**Virginia**
Kansas	**North Carolina***	**Washington***
Kentucky	**Ohio (CCHMC)***	**Wisconsin***

National Cochlear Implant Studies (2004 – 2011)

- The Teaching Research Institute / Western Oregon University
  Kat Stremel Thomas & Mark Schalock

- East Carolina University
  Susan M. Bashinski, Ed.D.

- Cincinnati Children's Hospital Medical Center
  Susan Wiley, MD & Charlotte Ruder, CCC

Research Studies

* Study A – What effect does age at implant and hearing age have on child outcomes?
* Study B – What are the differences in the caregiver’s verbal interactions before and after implant?
* Study C – What are the effects of individualized interventions carried out by the caregivers post implant in natural environments? (In Progress)

Research: Children Who Are Deaf-Blind With Cochlear Implants

- Participants Status: How many children are participating?
- Demographics: Who are these children?

Participant Demographics

Status	Number of Assessments[1]							Total
	0	1	2	3	4	5	6	
Post CI Only	1	16	29	15	6	--	--	**67**
Pre CI Only	--	14	2	--	--	--	--	**16**
Pre-Post CI	--	--	7	11	3	1	1	**23**
Total	**1**	**30**	**38**	**26**	**9**	**1**	**1**	**106**

•Participants with bilateral implants = 24
89 children are included in post CI results
23 children are included in pre-post CI results

Participant Demographics*

ETIOLOGY	PARTICIPANTS
CHARGE Syndrome	29.5%
Complications of Prematurity	18.1%
Infections	14.3%
Other	25.7%
No determination of etiology	12.7%

Participant Demographics*

RACE / ETHNICITY	PARTICIPANTS
Indian / Alaskan Native	3.8%
Asian	---
Black/African American	9.6%
Hispanic / Latino	8.7%
White	72.6%
Native Pacific Islander	---
Two or more races	3.8%
Not reported	7.6%

Participant Demographics*

GENDER	PARTICIPANTS
Male	58%
Female	38%
Not Reported	4%

Participant Demographics

Participants' Age at Implant

Range = 6 months to 7 years 1 months

12 months or younger	= 14
13 - 24 months	= 37
25 – 36 months	= 23
37 – 48 months	= 5
over 48 months	= 10

(Participants ranged up to 8 years of age at time they joined study)

Participant Demographics

<u>Participants' CI Duration at last Assessment Time in Sound/Hearing Age</u>

Range = 3 month to 6 years 11 months

12 months or less	= 12
13 - 24 months	= 23
25 – 36 months	= 13
37 – 48 months	= 12
over 48 months	= 29

* A large number of our young participants have had little "time in sound."

Participant Demographics

Vision Impairment	Participants
Low Vision (<20/200)	28.6%
Legally Blind	27.6%
Light perception only	6.7%
Totally Blind	6.7%
CVI	15.2%
Diagnosed progressive loss	2.9%
Variations of field loss	12.4%

Vision Loss

* Totally Blind
  * Cannot perceive even light/dark differences
* Light Perception Only
  * Individuals who are without vision, but can perceive light
* Cortical Vision Impairment
  * A problem in the visual cortex or visual pathways in the brain resulting in varying visual impairments
  * The eye itself is not impaired

Vision Loss

* Legally Blind
  * Central visual acuity of 20/200 or less in the better eye after correction or central visual acuity of more that 20 / 200 if there is a visual field defect in which the peripheral field is reduced to an angle of 20 degrees or less in the better eye

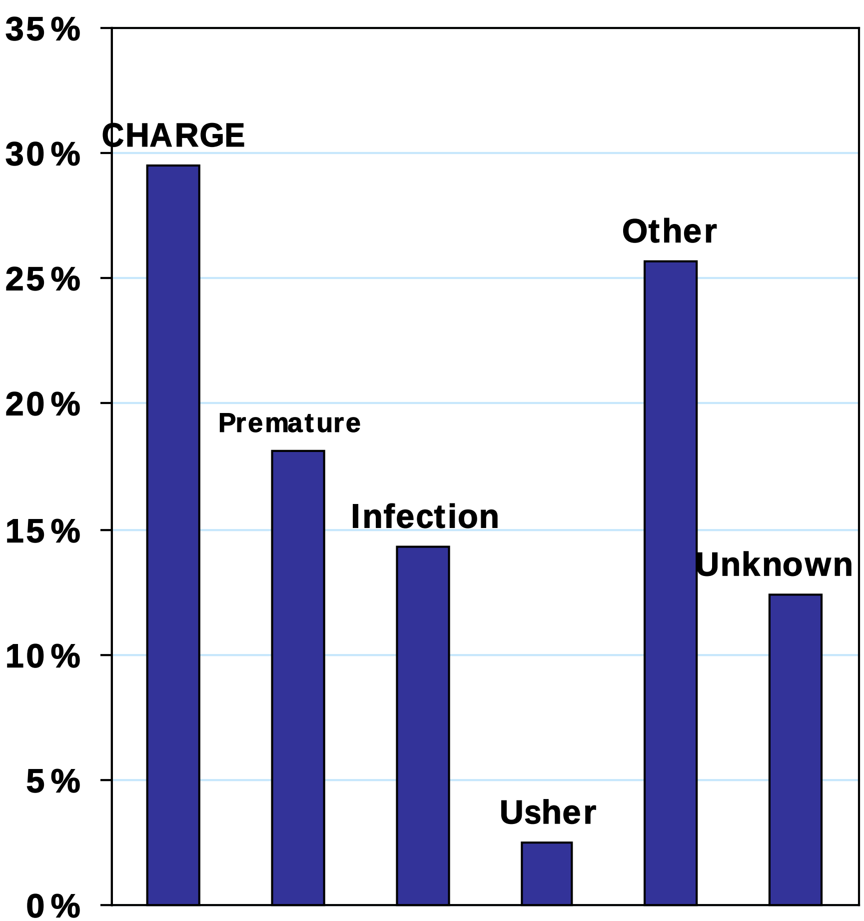
* Low Vision
  * This is a broad term which is used to refer to individuals who have significant visual impairments, but still have usable vision

Participant Demographics*

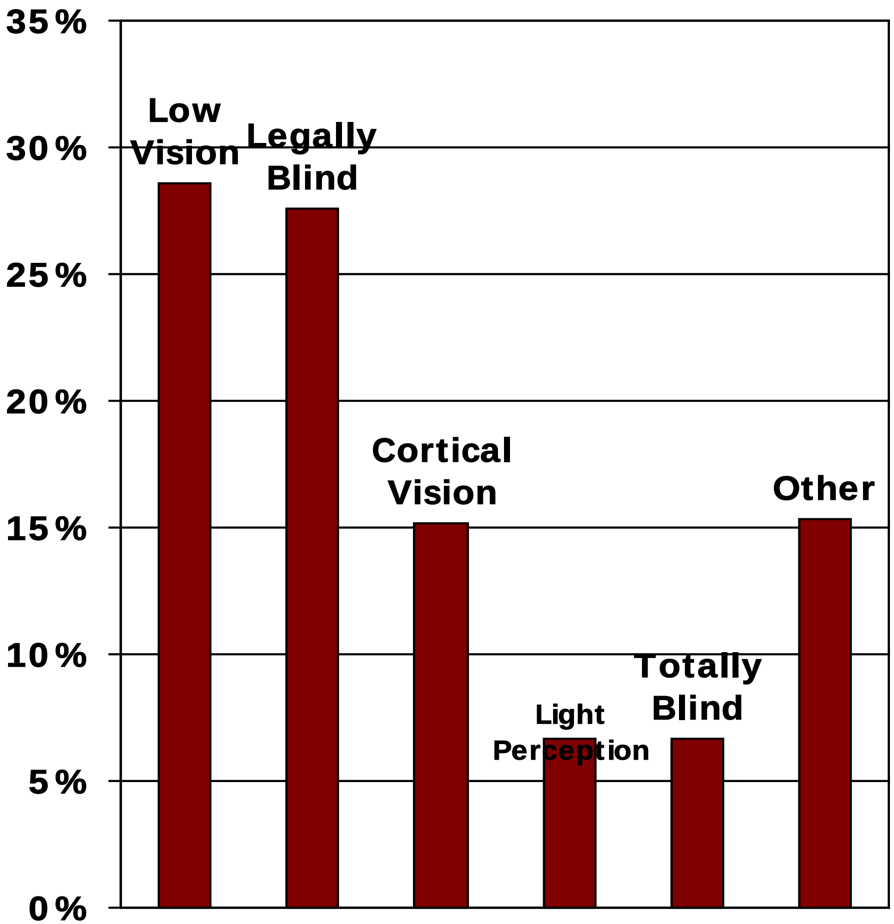
<u>In addition to a Dx of Deaf-Blindness</u>:

- 63.5% - complex health care needs
- 61.2% - physical challenges
- 56.5% - cognitive challenges
- 24.7% - behavior challenges

Characteristics

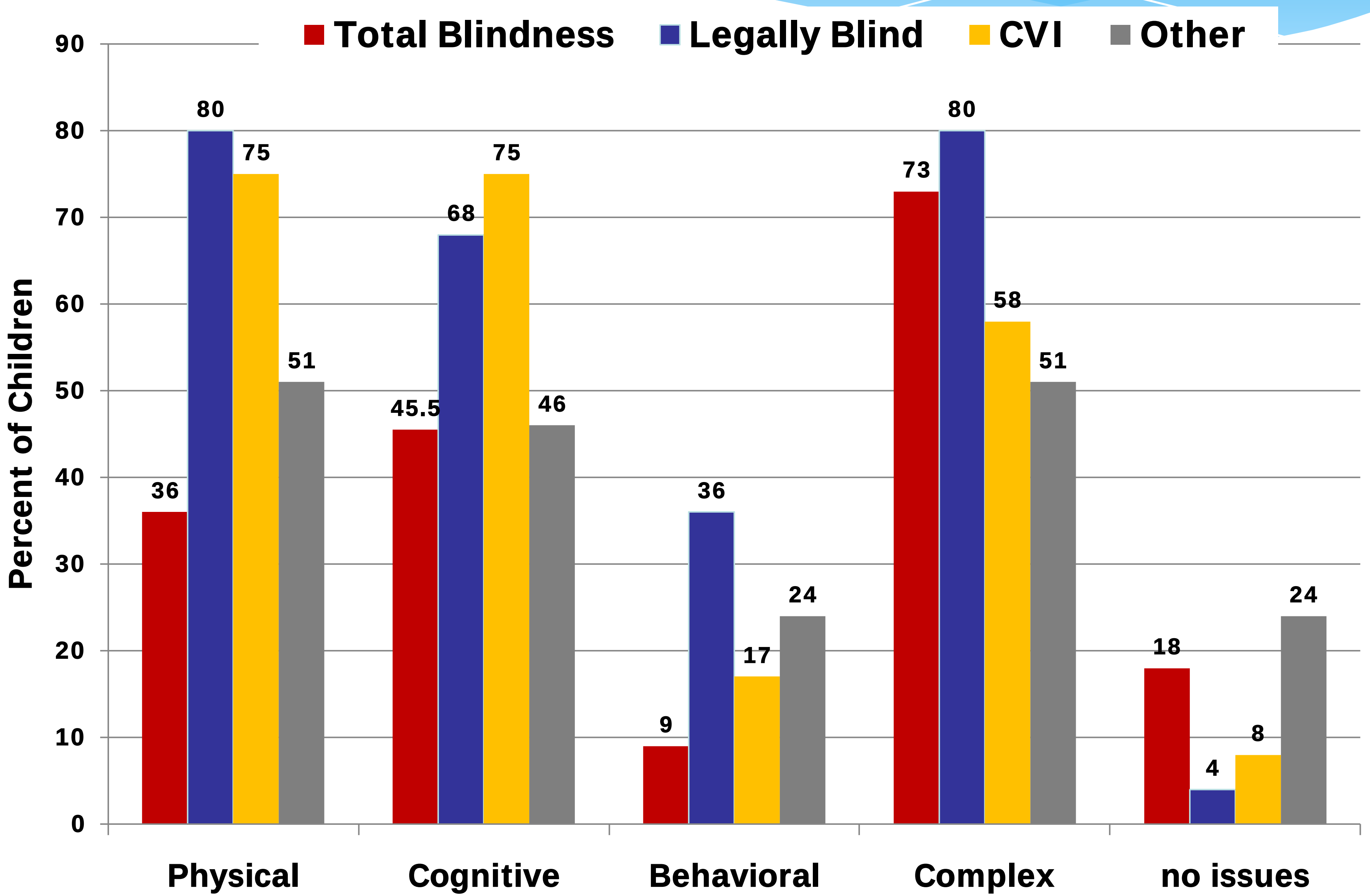


Etiology



Vision Status

Additional Developmental Issues



National Cochlear Implant Grants, Children with DB (2004 – 2011)

- TWO multi-center studies
- Enrolled children with deaf-blindness:
  - #1 - 12 months to 13 years
  - #2 - 12 months to <8 years who had, or were preparing to receive, a cochlear implant

National Cochlear Implant Grants, Children with DB (2004 – 2011)

Evaluation Instruments included:

- Communication and Symbolic Behavior Scales
- **Reynell-Zinkin (developmental assessment for children with visual impairments)**
- **MacArthur-Bates Communication Scale**
- Infant-Toddler Meaningful Auditory Integration Scale or Meaningful Auditory Integration Scale (ITMAIS / MAIS)
- Speech Intelligibility Rating

Studies

* TWO Multi-center studies
* Enrolled deaf-blind children: #1 - 12 months to 12 yrs; #2 - 12 months to <6 years who had or will receive a cochlear implant
* Evaluated language outcomes
* Assessed language, development, auditory skills
  * Communication and Symbolic Behavior Scales
  * **MacArthur-Bates Communication Scale**
  * **Reynell-Zinkin (developmental assessment for DB)**
  * Infant-Toddler Meaningful Auditory Integration Scale or Meaningful Auditory Integration Scale (ITMAIS-MAIS)
  * Speech Intelligibility Rating

Reynell Zinkin: Response to Sound

Detection Skills	1: Listens to sounds 2: Orientation towards sound of source 3: Selective response to sound 4: Reaching for source of sound in any direction 5: Reaching for source of sound in correct direction 6: Recognition of familiar sounds (own toys, parents voices)
Response to simple words/phrases	7: Recognition of familiar words or phrases 8: Appropriate response to familiar phrase or words 9: Appropriate response to simple direction (give it to me, give it to mommy, where is your nose)
Word Identification	10: Selection of familiar object in response to naming 11-15: selection of objects from choice of 3
Simple Directions	16-20: directional commands with items (put the spoon in the cup)
Understands functional use of objects, spatial concepts, size	21-36: Which one do we drink out of, Find two things we can use for eating dinner, Show me the longest pencil, the smallest cup Put the short pencil in the biggest cup

Vocalization and Expressive Language

Sound Production	**Some meaningful words**
1: vocalization other than crying	9: 2-3 meaningful words
2: single-syllable sound	10: 4-6 words
3: two different sounds	11: 6-12 words
4: four different sounds, including consonants	12: word combinations
5: double syllable sounds	13: 20 or more words
6: repetitive double syllable babble	**Sentences**
Word	14: appropriate use of words other than nouns or verbs
7: one definite words	15: Sentences of 3 or more words
Expressive jargon	16: Appropriate use of prepositions
8: expressive jargon	17: appropriate use of pronouns

Vocalization and Expressive Language

Complex sentences
18: any appropriate use of past tense
19: mature forms of past tense
20: appropriate use of future tense
21: nearly all sentences correct and complete
22: use of complex sentences

Findings

- Great variability in outcomes for children in who are deaf-blind with cochlear implants

- etc

Reynell-Zinkin Response to Sound

- Little relationship between age at implant and receptive language
- Significant, but weak relationships between hearing age and age at assessment and receptive language
- Children's receptive language DOES improve significantly over time post implant
- Children's receptive language DOES improve significantly from pre to post implant

Example Data Analyses Correlations

	Age at implant	Age at most recent assessment	Time with CI at last assessment
Response to Sound	-.019	.433 (.031)	.501 (.001)

	Pre Implant	**Post Implant**	**Change**	**t-score**	**p. value**
Response to Sound **Mean** **S D**	**5.09 (7.08)**	**13.04 (9.00)**	**+7.96**	**5.18**	**.001**

Reynell-Zinkin Vocalization and Expressive Language

* Little relationship between age at implant and expressive language
* Significant, but weak relationships between hearing age and age at assessment and expressive language (p =   )
* Children's expressive language DOES improve significantly over time post implant (.001)
* Children's expressive language DOES improve significantly from pre to post implant

Example Data Analyses Correlations

	Age at implant	Age at most recent assessment	Time with CI at last assessment
Vocalization and Expressive Language	.059	.449 (.024)	.468 (.018)

	Pre Implant	Post Implant	Change	t-score	p. value
Vocalization and Expressive Language **Mean** **S D**	**5.52** **(4.03)**	**8.17** **(5.35)**	**+2.65**	**4.31**	**.001**

Data for Post Implant Children N=89

RECEPTIVE LANGUAGE		EXPRESSIVE LANGUAGE	
Response to sound	96.6%	Sound production	98.9%
Response to words and phrases	64.0%	One-word production/jargon	46.1%
Word identification (out of context)	48.3%	Meaningful words	41.6%
Simple directives	28.1%	Simple sentences	24.7%
Complex directives	22.5%	Complex sentences	12.4%

Data for Pre-Post Implant Children N=23

RECEPTIVE LANGUAGE			EXPRESSIVE LANGUAGE		
Response to sound	Pre 63%	Post 100%	Sound production	Pre 11%	Post 100%
Response to words and phrases	16%	68%	One-word production/jargon	0%	47%
Word identification (out of context)	5%	42%	Meaningful words	0%	47%
Simple directives	5%	16%	Simple sentences	0%	16%
Complex directives	5%	16%	Complex sentences	0%	0%
Marginal Homogeneity Test (Chi-Square equivalent)	MH = 3.82	p. = .001	Marginal Homogeneity Test (Chi-Square equivalent)	MH = 2.84	p. = .005

Reynell Zinkin – Response to Sound 103 participants july slide format better?

Relationships with **RECEPTIVE** language outcomes:

* Weak relationship with **age at implant**

* Significant correlations with:
  * **Duration with implant ("time in sound")**
  * **Age at assessment**
  * **Developmental level**

* Receptive language **DOES** improve significantly from pre- to post-implant AND over time, post-implant

Reynell Zinkin – Expressive Language 103 participants july slide format better?

Relationships with **EXPRESSIVE** language outcomes:

* No relationship with **age at implant**

* Significant correlations with:
  * **Duration with implant ("time in sound")**
  * **Age at assessment**
  * **Developmental level**

* Expressive language **DOES** improve significantly from pre- to post-implant for *some but not all* children

MacArthur Communicative Inventories

Parent Questionnaire

Words and Gestures (oral/signs)	Words and Sentences (oral/signs)
Understanding of Phrases	Words produced
Understanding of Words	Mean 3 Longest Utterances
Words Produced	Sentence Complexity
Early Gestures	
Later Gestures/Play	
Total Gestures	

MacArthur Communication Development Inventory (MCDI)

- DATA all participants

Summary MCDI all participants

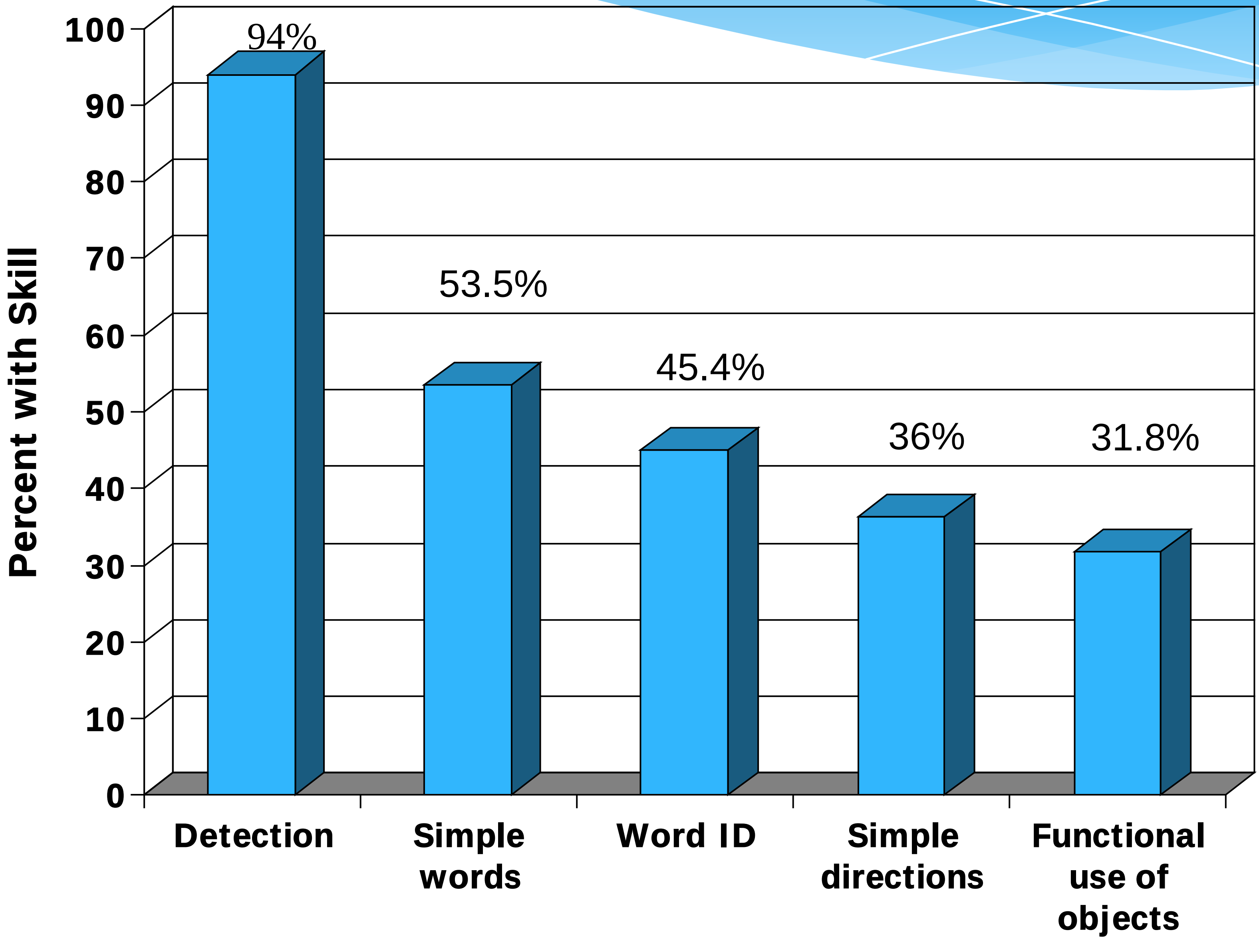
MCDI

MCDI cont'd

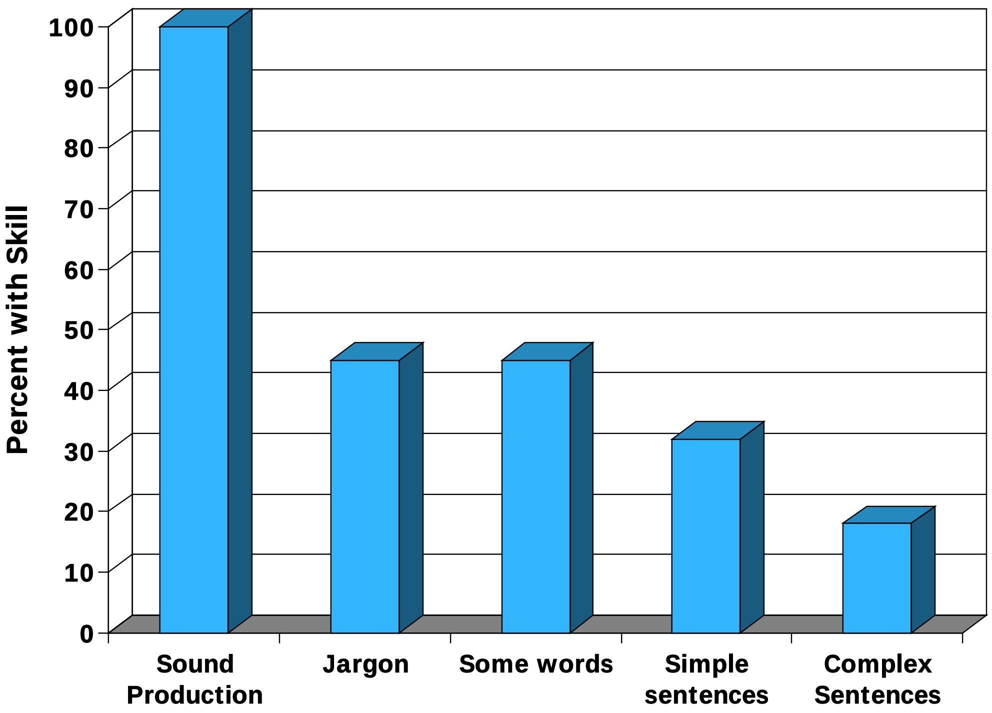
CHARGE Syndrome

* Based on 2009 National Deaf-Blind Child count, **747** children have been identified as having CHARGE Syndrome, of which **72** (9%) have confirmed implants
* Children with CHARGE syndrome have a wide range of medical and developmental needs
* Many have challenging inner ear anatomy as well as aberrant facial nerve course which can impact full insertion of implant and/or activation of electrodes

Reynell Zinkin Response to Sound



Reynell Zinkin Expressive Language



MacArthur Communicative Development Inventory

- Data /CHARGE

Reynell Zinkin - CHARGE

* **Age at implant** was **not** correlated with receptive (rho=-.205, p=.359) or expressive (rho=-.117, p=.603) language outcomes

* **Duration with implant** was significantly correlated with receptive language (rho=.693, p=.0001) and expressive language (rho=.792, p=.0001) outcomes

* **Developmental Level** was significantly correlated with receptive language (rho =.782, p=.0001) and expressive language (rho=.792, p=.0001)

CHARGE Summary

* The children in the study are a very diverse group with highly varied outcomes
* Children with CHARGE Syndrome experience improvements in receptive and expressive language post implant
* Duration of implant and developmental level correlated with language outcomes more so than age of implantation

Limitations to Progress – 3 Studies

- Many participants did not have prelinguistic communication skills
- Many participants did not have skills of functional object use
- Auditory - verbal programs were not individualized
- Many participants did not wear their implants consistently
- Many participants were not mapped frequently (and, possibly, accurately)

Limitations to Progress – 3 Studies

- Many children were "dropped" from auditory-verbal programs, due to lack of progress
- Parents reported not being taught effective strategies that could be used at home
- Frequent use (in therapy and in-home interactions) of toys / objects with "high" tactile, vibratory, an visual properties—but ***not*** sound
- Many children do not have the opportunity to frequently hear speech directed to them in close proximity

Hearing Management

* Cochlear Implant Candidacy
* MAPping Tips and Tricks
* Device Considerations
* Expectations and Outcomes

Implant Candidacy

"Candidacy criteria for cochlear implantation have evolved and expanded over the years to include younger children, children with congenital abnormalities, and those with multiple disabilities."

-Trimble et al. 2008

"Success" defined

a : degree or measure of succeeding

b : favorable or desired outcome;

also **:** the attainment of wealth, favor, or eminence

* Merriam-Webster Online

How do you want to define "success"?
How do the parents want to define "success"?
Do they match up?

Issues to Consider

* Some disabilities are not easily identifiable at the time of consideration for candidacy
* In more complex cases, hearing loss may not be the first priority
* Even in children without additional disabilities, outcomes depend on significant factors such as chosen mode of communication

"Despite the best efforts of many professionals, it is often difficult to diagnose learning disabilities, reduced cognitive function, and soft neurologic deficits in very young children…"

- Walzman, B. 2000

Special Populations

* Studies have shown that 40-50% of children with hearing loss will have an additional disability. (Wiley et al, 2004)
* It is important that <u>realistic and appropriate expectations</u> are discussed and understood by the family and professionals involved.
* Since it is ideal to implant a child at an early age, there will be children who receive implants prior to the identification of additional disability.
* Disabilities such as autism or apraxia may not be identified until a child is 2-4 years of age.
* A language, learning, or cognitive disorder will still be present after a child gets a CI. It is important that everyone understands that the implant is not going to resolve all issues.

Evaluation for Cochlear Implants

* Challenges:
  * Obtaining accurate audiometric information
  * Understanding family expectations
  * Available resources

* Tools:
  * Objective measures (ABR, ASSR, OAE, etc.)
  * Speech perception- not always possible to obtain, much less with great reliability
  * Questionnaires and Profiles (IT-MAIS, ASC, etc.)

Other Considerations

* Evaluate for communication ability, not just hearing sensitivity

* Does this child make use of the information he receives from his intact sensory modalities?
  * Environmental involvement – vision and touch
  * Does the child accept or reject this input?
  * How might this relate to tolerance of device wearing or the stimulation it provides?

The Team Approach

* Evaluation and input from several disciplines
* A collaborative decision made on every case
* ChIP (modified from Hellman et al, 1991):
  * Objective tool for evaluating potential cochlear implant candidates
  * Criteria to determine areas of "no concern," "mild to moderate concern," and "great concern"
  * The team meets to discuss their finding for each child evaluated
  * The team members complete the Children's Implant Profile (ChIP)
  * Recommendations to proceed with surgery or for other services are made following the completion of the ChIP

Special Populations

- Children with additional handicaps *need* an experienced multi-disciplinary team to assist in determining appropriate expectations

- These children <u>can</u> benefit from the evaluation whether or not they proceed with a CI as they will receive a developmental evaluation and appropriate educational recommendations

Evaluation Benefits

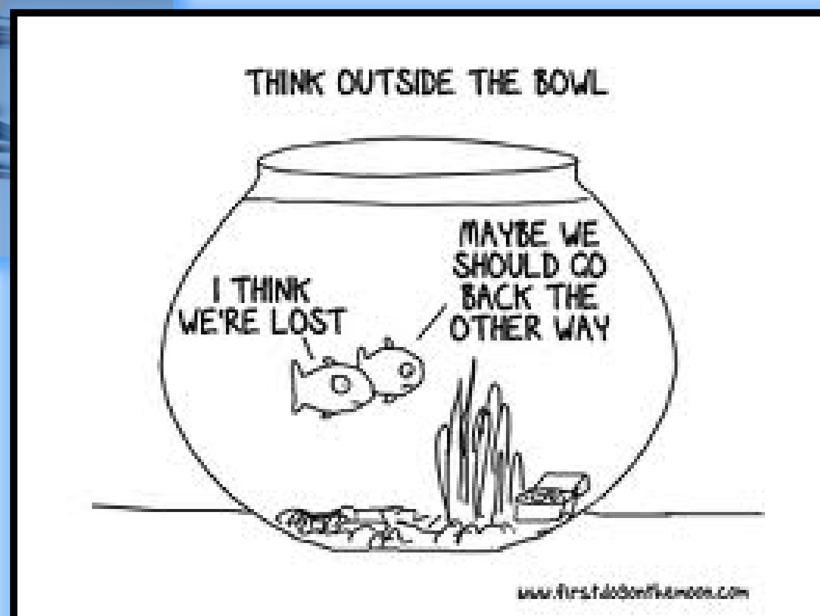
* Ability to provide more appropriate counseling
* Application of outcome data to future decision making
* Possibly provide better resources to parents/caregivers of children with multiple handicaps
* Investigate if the addition of a CI would help or *hinder* progress in other areas

After the Fact:
fitting and management

* **OK, we chose to implant… *now* what?!?**

* Similar issues with management of traditional amplification
* No way to measure sound output (such as with Verifit)
* Setting programming levels- two approaches:
  * Subjective: behavioral observation, behavioral response, loudness measures
  * Objective tools: eABR, eSRT, neural telemetry, ASSR?

Thinking Outside of the "Box"



Programming Tips and Tricks “Environmental Responsiveness”

- **Go to where the patient is more comfortable**

- The child may give you more feedback and/or be more willing to play listening games in a familiar environment such as:
  - the place he has weekly therapy
  - school environment
  - elevator? - in jest, but think outside the box!

Programming Tips and Tricks
Abnormal Cochleae

- **Scrutinize every channel**
  - Consider the patient with CHARGE:
    - Possible cochlear anomalies? → full electrode array insertion? → viable electrodes? → → → ???

One bad channel can mean the difference between a child willing to wear his device vs. constantly taking it off!

Programming Tips and Tricks Blindness

Visual Reinforcement

* May have to dim the lights <u>significantly</u>
* Light up toys for VRA placed in close proximity

Conditioned play

* Use toys that <u>entertain</u>, and have lots of them!
* balls and blocks may be less tactile than stars→
* Light up pointer/pen/flashlight/tap-light that the child can turn on when they hear sound

Programming Tips and Tricks Autism/behavioral opposition

* Follow the child around the clinic for an hour or so
* Let the child show you what <u>they</u> are comfortable with
* Perhaps you can only get the coil on, so the processor has to stay off of the ear for a while- an that’s ok!
* Try putting the device on <u>without</u> batteries in (no auditory stimulation) first, only to work up to consistent wearing followed by progressive programming

Programming Tips and Tricks
Active Involvement

- **Involve the child more than you typically would**
  - Show them the programming screen
  - Show them that they can hear a sound when they see something change on the screen
  - Of course, stop short of handing them the mouse and keyboard!

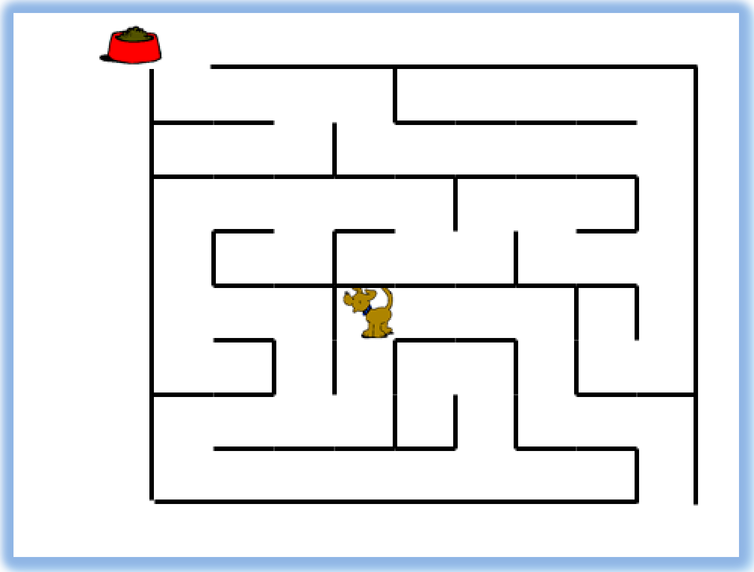
  - Sometimes, the child just needs to make a connection between what they are hearing and what they see

Programming Tips and Tricks
New Games

Get the parents/caregivers to help out

* Ask the parent what entertains their child
* Teach the parents how to play a listen-n-drop game at home that you could also play in the office
* Make up new "games" →

Flexibility is key!



Computerized Conditioned Play
-courtesy of Boys Town

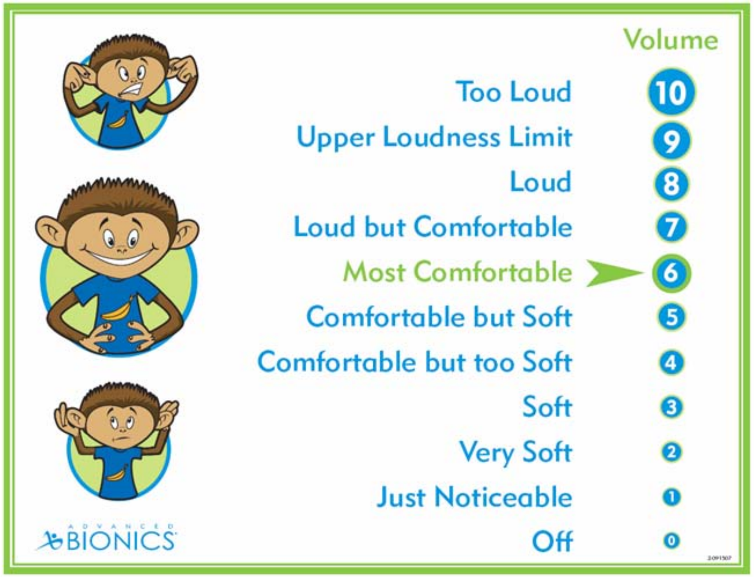
Programming Tips and Tricks Other Behavioral

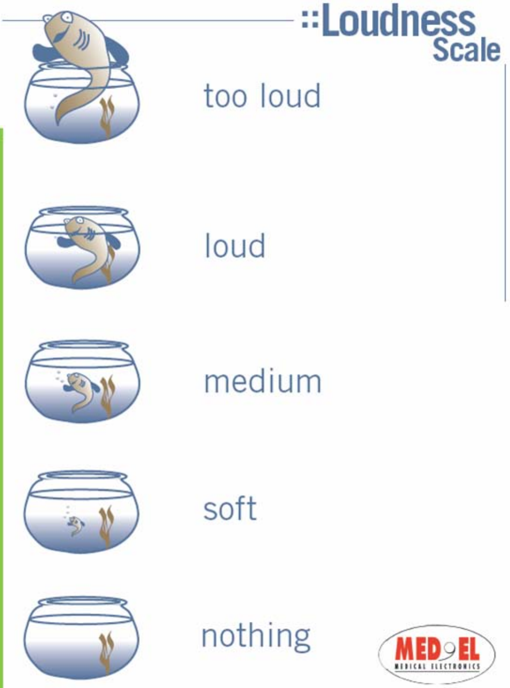
* Have a variety of toys for issues with dexterity
* Have a chair that spins/swivels for the child who needs that extra stimulation to stay on task
* Involve a common party (therapist/child life specialist, teacher, etc.)
* Pre- Medication (ADHD and others)
* Consider the most appropriate time for the child's schedule, and not the clinic's schedule

Verification during programming:

Comfort with loud levels

* Sweep across the upper levels and observe reaction
* Make various sounds and carefully observe reactions with use of the new program
* Try loudness scaling- you may be surprised!
* Adjust accordingly





Verification after programming:

Can check through the use of:

* Informal administration of Ling sounds, words, and phrases at various distances
* Formal aided detection of soft sounds in the test booth

Speech Perception Tests

* Ling thresholds
* ESP
* GASP
* MLNT
* LNT
* PBK
* WIPI
* Etc.

Beyond audiograms and speech perception measures…

* **Some thoughts and questions to ponder:**
  * Is there additional information that should be considered for closer analysis?
  * Are we already getting the information without evaluating it's value?

Other Methods!

Due to age, attention, etc., many children are not able to provide accurate feedback while the audiologist programs their cochlear implant, so there are several other **tools**…

Available Objective Measures

Clinically-Utilized

* Impedance Telemetry- checking for short and open circuits
* Neural Telemetry (NRT/NRI/ART)- action potential at the auditory nerve
* eABR- electrically evoked Auditory Brainstem Response
* eSRT- electrically evoked Stapedial Reflex Threshold

Research Tools

* Late evoked responses
* ASSR- Auditory Steady State Response

Neural Telemetry

* **When measuring neural telemetry, keep one eye on the child and one eye on the computer screen. Jot down the level that you observe a behavioral reaction. That's one more piece of information typically ignored.**

* **Advantages**
  * can be measured directly through the implant
  * not influenced by the movement of the patient
  * provides confirmation of implant function
  * provides a means for evaluating responsiveness over time
  * Can be used to help train the child for listening games

* **Disadvantages**
  * Unfortunately, not present 100% of the time- even in "normal" cochleae
  * does <u>not</u> tell you exactly where to set programming levels

Electrically evoked Auditory Brainstem Response (eABR)

* **eABR**: auditory brainstem response measured when stimulation is delivered to the auditory nerve electrically (ie: through the CI)
  * eABR measurements can provide information for fitting the cochlear implant processor by evaluating the responses at each of the different electrodes (ie: which electrodes should be switched-off?)
* **Disadvantage**s:
  * Set-up somewhat cumbersome
  * Child must be asleep
  * Intra-subject variability in study data
  * Unfortunately, not present 100% of the time- even in "normal" cochleae
  * does not tell you exactly where to set programming levels

Electrically evoked Stapedial Reflex Threshold (eSRT)

* **Stapedial reflex-** measured using the reflex decay option through a standard tympanometer when stimulation is delivered through the implant

* **Advantages:**
  * Once you have your eSRT, you can use this to set the upper programming levels (highly correlated)
  * For patients who are not able to provide accurate C/M levels, this will help in obtaining a more accurate measurement
  * May assist in creating programs that progress toward an acceptably loud level
  * Can be measured on a per-channel basis

* **Limitations:**
  * Set-up somewhat cumbersome (requires 2+ hands)
  * Child must be cooperative (a DVD works very well for this) or asleep
  * Cannot perform with abnormal middle ear status or PE tubes
  * Not present in about 30% of patients

Other Tools:

* Audiometric test measures
* Ling Sound Test
* Keen observation of the child during programming
* The audiologists’ past experience with other patients
* Parent/therapist/teacher reports

Device Modifications

* **Behaviors and conditions that warrant device modification:**
  * Pulling on device/falls off easily
  * Chewing on the device
  * Lack of head control
  * Lack of mobility
  * Moisture
  * Glasses
  * Etc.

Device Modifications

- **Chewing on the device:**
  - Purchase Dry & Store
  - Keep processor on the child's back (out of reach) if possible
  - Apply bad-tasting substance to headpiece
  - Apply bad-texture to headpiece
  - Supervision & Redirection
  - Always have extra cables on hand
  - Lots of positive reinforcement… or…
    - You may try not to draw attention to the device
    - Consider the child's personality and awareness of tactile/auditory stimuli

Device Modifications

* **Pulls on Device/Falls off Easily**
  * Consider location on the body
  * Keep cables behind child & under clothes
  * Huggie/Snugfit
  * Earmold (may have to try different styles)
  * Critter/alligator clip/barrett clip
  * Toupee tape
  * Headbands
  * others?

Device Modifications

* **Limited of Head Control:**
  * Placement of processor (off of the head if possible)
  * Soft headband
  * Lightweight hat
  * Wheelchair modifications: move headrest so child is not constantly knocking off the headpiece
* **Limited Mobility**
  * Consider the placement of the sound processor
  * Device choice/set-up
  * Refer back to the "retention options"

Device Modifications

- **Promoting independence**
  - It's hard to get that headpiece back on by yourself:
    - Give tactile assistance for appropriate orientation of the headpiece (example: rough side of hook-n-loop disk applied to outside of coil)
  - Are they telling you when the processor is working?
    - "sabotage" by not putting batteries in the processor, and see how they respond
  - Make the child an <u>active</u> part of wearing and managing the device

After the Fact: Outcomes

"Although the development of auditory skills was not as rapid or favorable for these subjects… the children in this study did obtain benefit. In addition to improved auditory skills, communication skills, social interactions, and general "connectedness" to the environment increased."

-Waltzman, S (2000)

After the Fact: Outcomes

* Similar issues with determining benefit from traditional amplification

* Will likely rely heavily on:
  * Parent/teacher/interventionist report
  * Observations of the child
  * Comparisons of the child to <u>themself</u> over time

* May not be able to see "benefit" for several years
  * Difficult to make sure programming is appropriate
  * Even with ideal implant programming, the child's performance ability is never fully known

After the Fact: Outcomes

"Even though children may not progress as well as their peers who do not have additional disabilities, they may nevertheless realize benefit from the additional auditory stimulation offered by a cochlear implant, representing sufficiently successful outcomes to justify the procedure"

- Trimble et al. (2008)

Evidence Based Practice

Knowledge of possible outcomes, and the collection of data as we evaluate and treat patients, can only contribute further to improved patient care.

Children Who Are Deaf-blind

Shanks: MAST Education Module, Eastern Carolina Univ

* Deafblindness imposes many limitations that affect child's internal understanding of the world.
* Varies with what a child can see, hear, touch. The greater the loss of hearing and vision, the more dependent the child is on others
* For some if not reachable, it does not exist for the child (Miles & Riggio, 1999)
* Over 90% of children with deafblindness have other deficits: motor, cognitive, medical

Deafblindness negatively affects all areas of development (Shanks)

* Cognitive skills: memory and concept development
* Social skills: cultural interactive skills (eg., smiling, eye contact, greeting, relationships with others
* Communication skills: having meaningful communication with others: including facial expression, pointing, gestures.
* Language skills: understanding through listening, speaking, reading, and writing
* Vocabulary learning: pairing object seen with verbal word/sign.
* Difficulty pairing other's lip movement for development of child's articulation skills
* Gross motor skills: muscular control of trunk, head, walking, running, movement
* Fine motor skills: eye hand coordination, movement of lips, tongue. Slow to learn to bring hands to midline, to reach and grasp.

General Adaptations for Children Who are Deaf-blind (Pam Shanks cont'd)

* Need extra time to process information, young children may need up to 15 seconds (Miles, 1999)
* Present information within a range that allows the child to perceive it
* Use touch cues and object cues that are distinctive prompts made on a child's body or hand to convey information and anticipation (eg., this is mommy, bottle on tummy)
* Present information consistently
* Present information slowly
* Wait for reactions that indicate perception or understanding
* Look for anticipation in the child that may be **subtle** but suggests understanding.
* Develop keen observation skills in self and parents

Language and Communication of Children who are deafblind

* Inability to hear vocal speech well delays both receptive and expressive language
* Inability to see and hear may limit a child's motivation and opportunity to communicate with others (Rowland, 2009)
* Dramatically reduced input to children who are DB requires thoughtful and planned input. (Pam Shanks)
* Limited opportunities to interact with objects and people results in the need for others to label objects, people, and experiences using multisensory input.

Kids DBCI need multimodal therapy approaches (purely CCR)

* Level of vision, hearing, and time in sound must be considered in all communication. CI must be worn!!
* All therapy approaches need to be individualized
* Every interaction needs to be in spoken words no matter what the targeted communication mode of the child

Auditory __________ Auditory

* Auditory sandwich can be utilized with gestures, touch cues, use of objects, pictures, manual and tactile sign, braille, aug com devices
* Speaker's facial expression, eye gaze, joint attention, mouth movements are important aspects of communication for children with dual sensory impairments
* Auditory-verbal therapy needs to be adapted as a technique for Kids DBCI

Potential Communication Systems: Deafblind (Shanks)

* Nonsymbolic: Unconventional modes to convey meaning (facial expressions, movements, postures, vocalizations, gestures, eye contact)
* Touch Cues: Systematic touches to convey meaning (Touch mouth to elicit vocalization)
* Object Systems: Objects to convey meaning (Time for bed: child puts small doll in bed on communication board)
* Picture communication systems to convey meaning
* Language Based Systems: Spoken language, written language, braille, tactile sign, fingerspelling, sign language
* Electronic Communications Systems: technological devices to convey meaning (Rowland, 2009, Crook, Miles, Riggio, 1999)
* Language is taught in **routines**

Communication Maps

* Communication mode is child specific and based on hearing, vision, fine and gross motor abilities, and cognitive functioning (Rowland, 2009)
* Child's learning level, preferences, interest, dislikes, temperament, sensory issues must be considered
* **Receptive and Expressive Communication Maps** (Stremel, K, 2005)

Receptive Map

Basic communication to symbolic communication

Natural context cues	Object cues	Gesture cues	Miniature objects	Visual sign cues
Movement cues			Associated objects	Tactile sign cues
Touch cues			Pictures	Speech
			Line Drawings	Written words
			Other tangible symbols	Braille

Stremel, K. Receptive Communication Map (as cited in January 2005 DB-Link). Used with permission

Expressive Communication

Basic communication to symbolic communication

Expressive Communication Map

Facial Expression	Vocalizations	Touch person	Extend Object	Complex gestures	Manual signs
	Body Movement	Manipulating person	Simple Gesture	Miniature object	Non-speech symbols
	Calling Switch	Touch Object	Pointing	Picture drawing	Electronic systems
			Two switch communication	Other Tactile symbols	Speech

Stremel, K. Expressive Communication Map (as cited in January 2005 DB-Link).
Used with permission

Many kids DBCI do not demonstrate pre-linguistic skills

* Early gestures indicate intention in context (ie., open handed reaching, reaching to be picked up, pointing, specific gestures of refusal.
* Representational gestures are symbolic and indicate an object or actions
* The ability to produce a gestural or vocal symbol is dependent on development of basic skills of intentionality, recall memory, concept formation, the ability to imitate, and reciprocal communication.
* Gesture skills are basic to the development of symbolic language skills

Gestural Development **Assessment**

Stremel Thomas, Schalock, Ruder & Bashinski, July, 2010

Teaching Research Institute Western Oregon University

Adapted from: Crais, Watson & Baranek (2009)

* To guide speech language pathologist, teachers, professional assistants to identify key components in prelinguistic communication.
* To collecting more information on gestures is relevant for children who have dual vision and hearing losses.
* To help guide specific goals for gestures development to be targeted for an individual child in all environments.

Use of objects as symbols for Communication MAST Modules Andrea Zody 2010

* Objects that are used in daily routines can become a reference to that routine
* Miniature objects can become a symbol of real object or routine activity
* Abstract objects can also reference an object or activity
* Objects should be consistent with child's preferred colors, textures, and sound.
* Objects should be **easily** discriminated from others used
* Objects must be consistently used across person, time and settings for child to derive meaning from those object cues and demonstrate appropriate responses

Use of Objects for Communication

* Level of abstraction of objects will depend on the child's cognitive skills and consistent experience in routines in multiple settings
* Objects that were originally used as receptive cues can eventually be used in expressive communication
* The object itself becomes the tool to affect the environment
* Objects can serve as a bridge to more abstract modes of communication, e.g., photograph, line drawing, sign or word
* Need to consider degree of vision loss, hearing loss, motor skills, and positioning of objects so child can respond to, access and utilize objects

Steps in Developing Interactions

(Andrea Zody)

* The child needs to display recognition of some objects in anticipation of what is going to happen in the daily routine
* When the child shows understanding that an object represents an activity, the child is ready to have a calendar box, in a set location, that contains an object related to an activity
* More objects can be added gradually with some that are more symbolic than being an actual part of the activity
* An object communication board can be used in a similar way

A-class time, container-game, CD-circle time, choicebox-mirror/book

Phase 1 – Parent Intervention Strategies

Partial Participation

Follow the Child’s Lead

Descriptive talk

Intervention Strategies (research in progress with 12 parent child dyads)

* 3 phases of intervention
* 12 to 15 in-home sessions with parent/caregiver and child
* Emphasis on demonstrating and coaching parents with child in the context of familiar routines chosen jointly by parent and researcher
* Written description of each phase is provided and discussed
* Weekly routine worksheet: goals, intervention strategies, vocabulary, and listing of potential dialogue including: "what to do/say", support level, targeted outcome for child, consequences-expansion/recasts
* Videos taken pre- and post-training for each of three phrases and parent and child targeted behaviors are analyzed

Phases 1 – Intervention Strategy: Parent encourages Partial Participation

* Provide Opportunities for Partial Participation or full participation by helping your child assists in a routine activity (ie, pull the tray on chair, turn on water)
* Response to manipulation – full assist (ie, Placing child's hand on toy and helping her to push it
* Response to touch (Touching her under hand to get her to pick up something, touch back of her hand to cue pushing a toy)
* Response to gesture and point (ie, Say up and gesture with arms up, pause for her to imitate, or help her raise her arms by pointing up)
* Response to verbal (ie, Say help mommy push tray, push toy, turn on water and pause expectantly for a response.
* Mark beginning and end of each activity (ie, by helping your child put the spoon, wipe, soap in finish tub, or sing a song to mark start or end of an activity (ie, It's time for shoes on, shoes on, shoes on, it time for foot up, foot up, or time for shoes off, shoes off, etc)

Phase 1 - Follow child's lead Parent Responsiveness

* Interpret **eye gaze** (Say what you think she wants)
* Interpret **facial expressions** (Say what you think she is telling you)
* Respond to communication: **body movement, reaching, gestures, sounds, words**
* **Imitate** her sounds
* **Imitate** and e**xpand her** verbal production (ie, child says "mmmmm" interpret as more, more" or "wa" as water
* Point out **positive** child **behaviors** (ie., I like your smile, sitting, sounds, eating)
* Point out environmental sounds (ie., I hear daddy, doggy, water running, music box, noisy toy)

Phase 1 - NARRATIVE DESCRIPTION
Increase words that child hears

- Describe motor action (ie. Suzie walking, walking – pushing, pushing, good pushing Mommy washing hands, opening cereal, etc)
- Of your child
- Of yourself
- Of others
- Verbal Comment (ie., Suzie’s so happy today, Daddy’s home)
- Describe with object pairing (ie, While putting on shoe, get child’s attention, bring shoe to your face and say shoe, shoe, shoe, put on shoe. Getting ready to eat, bring spoon to your mouth saying “Spoon, spoon, Suzie needs

Phase 1: Parent child comparison

Parent

* Provides opportunities to participate
* Follows child lead in behavior, vocalizations, nonve rbal behavior
* Descriptive talk of objects and actions

Child

* Learns to participate in activities
* Child learns to initiate, make choices
* Learns to listen and notice what is being described in activity

Phase 2 - Parent Intervention Strategies

Increase receptive vocabulary

Auditory Sandwich

Object Identification

Phase 2 – Parent Strategy: Increase Receptive Language + Vocabulary

* Parent gives directions and commands
* Pauses (WAIT time) for response. If no response, assists child in understanding with touch cues, point/gesture cues, interacting with object
* Helps child not just listen, but understand words within the context of routines
* Increases child's coordination of objects and people
* Turn taking activities are increased in play and vocalizations

Phase 2 – Parent Strategy: Auditory Sandwich (receptive)

* Uses "auditory sandwich" **within the context of joint attention and joint activity**
* **Auditory-visual-auditory technique in which touch cues, gestures, signs, objects are used for visual support (if needed)**
* Parent always leads with verbal and PAUSES
* If no response adds visual support, PAUSES, then repeats verbal
* Context of routine also supports child's understanding

Phase 2 – Parent Strategy: Object Identification-from Verbal

* Parent provides the names of object as child is engaged with each
* a. Get the bubbles/Where's the bubbles
* b. Find your shoe
* c. Show me your tummy/nose
* d. Get your spoon (cup, cracker, apple, sauce)
* e. Where's Momma/Daddy?
* Focus on functional use of objects and sequential play with objects

Phase 2: Parent strategies to increase receptive vocabulary and object identification

* Joint attention, joint activity
* Use of Auditory Sandwich **(auditory-visual-auditory) in which gestures/signs/objects are used for support**
* **Coordination of objects, action, people**
* **Turn taking in play**

Phase 3 – Parent Intervention Strategies

Opportunities for Expressive Communication:

Choices

Model Sound Play, Gestures, Words

Phase 3 – Parent Strategy:
Opportunities for Expressive Communication (by child)

* Shift from giving directions to PROVIDING CHOICES "What do you want?"
* Analyze form and function of child's communications (i.e., **FORM**: eye gaze, joint attention, facial expression, body movement, reaching up, touching object or person, extending hand towards object, pointing, vocalizing, crawling towards/away, turning away, pushing away, saying "mmm or ma"/"more," putting objects in finish box; **FUNCTION**: request, reject, protest, "all done"

Phase 3 – Parent Strategy:
Opportunities for Expressive Communication (by child)

* Parent shapes communication forms to the next level of complexity
* Parent PAUSES and provides support to elicit communication from child
* Child is expected to listen, to respond, to communicate
* Parent provides more **models for vocal and verbal imitation**

Ph 3 Parent Child Comparisons

Parent

- Uses concentrated model of vowel & CV's
- Provides choices for food, toys, activities
- Provides more gestures to be imitated
- Provide opportunities for word imitation
- Uses "Up the ante" in cuing strategies
- Use more representational gestures with auditory sandwich

Child

- Begins to imitate more sounds
- More gestures to request objects/actions, protest
- Use of gestures more consistently
- Approximates more simple words: "wa/water," "ou/out"
- Changes body movement to gestures, word approximation
- Imitates representational gestures/word approximations more

Survey of Participants' Families

During the Fall of 2009, families of participants in the study were surveyed regarding their experiences with their child's cochlear implant.

The survey consisted of:

* 30 Likert-scale items
* 6 multiple choice items
* 2 short-answer items

Survey of Participants' Families

<u>Survey items addressed</u>:

* The decision to seek a CI
* Identification of vision loss(es)
* Pre-implant experiences
* Post-implant experiences
  * Challenges
  * Wearing Patterns
  * Communication Services
  * Child Outcomes

Family Survey Results

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I have noticed my child attending to common sounds in our home (e.g. water running, appliances, dog barking, telephone ringing) since receiving the implant	29	15	4	5	7
My child now responds to feelings expressed through vocal inflections that he or she did not seem to notice before (e.g. excitement, anger)	22	18	7	4	9
Since receiving the implant, my child now entertains himself/herself listening to music, watching television, or playing games more often.	22	15	3	6	14
My child's overall behavior has improved since receiving the	13	18	21	5	3

Family Survey Results

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
Progress during the first few months after my child received the implant seemed very slow.	21	19	8	11	1
Progress after implantation has exceeded my expectations.	19	5	13	10	11
The process of getting an implant for my child was no more intrusive in our family life than expected.	13	24	6	12	3

Family Survey Results

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I am confident my child's school knows how to meet his/her needs for learning to use the implant.	21	15	9	8	7
I worry that my child might not be receiving the support services he/she needs.	10	16	3	13	18
After my child's implant was activated, my family received direct training to teach us how to help my child learn to use the implant.	25	17	5	5	8

Family Survey Results

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
If I knew what I know now, at the time I was deciding whether to proceed with implantation for my child, I would make the same decision again.	40	11	4	1	3

Susan: parent perceptions of success

Thank You!

- **Charlotte Ruder: charlotte.ruder@cchmc.org**
- **Susan Bashinski: bashinskis@ecu.edu**
- **Michael Scott AuD: michael.scott@cchmc.org**

http://www.kidsdbci.org/

Children Who are Deaf-Blind with Cochlear Implants

Resources

Trimble et al. (2008) **Speech Perception Outcome in Multiply Disabled Children following Cochlear Implantation: Investigating a Predictive Score.** *Journal of the American Academy of Audiology*; 19:602-611.

Waltzman S, Scalchunes V, Cohen N. (2000) **Performance of Multiply Handicapped Children Using Cochlear Implants** , *American Journal of Otology;* 21:329-335.

Wiley S, Jahnke M, Meinzen-Derr J, Choo D. (2005) **Perceived qualitative benefits of cochlear implants in children with multi-handicaps,** *International Journal of Pediatric Otorhinolaryngology* 69, 791-798.