



August, 2011

Hope! Dream! Achieve

www.myparentlinks.com



Getting Ready for the School Year

Excerpt taken from Boys Town National Research Hospital

Some parents sing with joy at the commencement of school even calling it the "Most wonderful day of the year". Others face this day with a bit of anxiety, especially for those who are sending their deaf or hard of hearing child to their first day of an early intervention program.

Below are some tips on what to expect

- It's ok to feel anxious. This is very normal. It is not only a new experience for your child but for you as well.
- Let the interventionist know how you are feeling.
- Remember your child is there to learn and improve his or her skills in listening, signing etc.
- You and your child will make it through the first day and begin on the exciting adventure of learning.

How Intervention Works for you Deaf or Hard of Hearing Child



All children learn from their environment. Babies absorb language, thinking skills, and social skills as they experience the world with their caretakers and others. Most children acquire these skills, especially language, effortlessly, because others are fluent in the language and use it all the time. Sometimes children are not able to acquire language easily and need teachers who use special methods. Children who are deaf or hard of hearing can usually acquire language in the same way as hearing children, but they need a teacher and they need parents who can help them access the language environment.


Helping Deaf children is often different than helping other children needing special education. Your infant/family specialist has special training to give you and your baby access to language. For example, they know about hearing aids, implants, and audiograms and they can help parents turn their home into a good visual and auditory environment. Infant/family specialists can recognize the cues our children give us about how to best communicate with them. And they can help parents meet deaf or hard of hearing adults, and involve these individuals in the children's development. Infant/family specialists understand the unique needs of deaf or hard of hearing child. They are here through Early Start Programs to work WITH the family to ensure that the child's language, social, and cognitive growth develops according to plan!

**Parent
Links
Hope!
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Achieve!**

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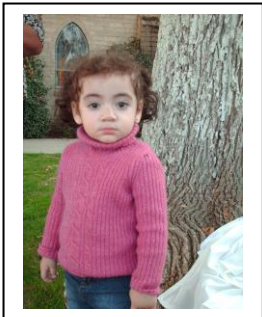


Acronyms



Acronyms are words formed from the initial letters of a name or by combining initial letters of a series of words

Our world is full of acronyms. They are used in texting, in news articles and even in our schools. As parents of a child that is deaf or hard of hearing, you are required to learn these acronyms that pertain to your child's hearing loss, education and hearing equipment. Below is an acronym *cheat sheet* that just may help you.



- **IEP: Individual Education Plan** - a legally binding document that spells out exactly what special education services your child will receive and why. It will include your child's classification, placement, services such as a one-on-one aide and therapies, academic and behavioral goals, a behavior plan if needed, percentage of time in regular education, and progress reports from teachers and therapists.
- **IFSP: Individual Family Service Plan** - The IFSP is a written plan which is the framework for meeting the unique needs of a child and a family. This plan is developed at the IFSP meeting by a team which includes the parents/guardians, the service coordinator or anyone who has evaluated the child. Parents may also invite other family members, friends, advocates, or other supportive people.
- **ASL: American Sign Language** - a full, signed language with its own grammar, word order, and idioms. It is the primary language of many Deaf persons in the United States. It is associated with Deaf culture, which has customs, beliefs, and mores unique to itself.
- **SELPA: The Special Education Local Plan Area** - coordinates with school districts and the County Office of Education to provide programs and services.
- **CI: Cochlear Implant** - a Cochlear Implant is a device that can be surgically implanted into a person's cochlea to stimulate it to cause hearing. It consists of a tiny receiver which is placed under the skin in the bony part behind the ear. The receiver has a probe with several electrodes that is implanted into the cochlea. A cochlear implant can be useful if the hearing loss is caused by problems with the cochlea (usually damaged hair cells) or where the loss is caused by problems with the middle ear that cannot be corrected.
- **HCC: Hearing Coordinating Center** - a government program that tracks and monitors children referred from hospitals from the New Born Hearing and Screens program.
- **DHH: Deaf or hard of hearing**

Types of deafness

(Deaf Child Worldwide: [www. http://www.deafchildworldwide.com](http://www.deafchildworldwide.com))

The main types of deafness are conductive and sensori-neural. If you are told that your child has mixed deafness, it means that your child has a combination of both conductive and sensori-neural deafness.

Conductive deafness or Otitis Media is the most common type. It means that sounds cannot pass efficiently through the outer and middle ear to the cochlea and auditory nerve. This is most often caused by fluid building up in the middle ear. This condition is called Otitis Media with Effusion (OME) and can be referred to as 'glue ear' in some countries. Most conductive deafness is temporary but there is a chance that it can be permanent.

Sensori-neural deafness is caused by a fault in the inner ear or auditory nerve. This is sometimes called 'nerve deafness' but this term is usually not completely accurate. Most sensori-neural deafness is caused by a problem in the cochlea. Commonly, this is because the hair cells of the cochlea are not working properly. Sensori-neural deafness is permanent.





What's up with your Life?

Quality of Life of D/HH Children and Youth

Three research teams across the United States did an extensive research study of children ages 5 through 11 who are deaf or hard of hearing. The study entitled Quality of Life of DHH Children and Youth was conducted between the years of 2007- 2010.

Quality of Life of DHH Children & Youth



This newsletter provides information about study results from the University of Washington and University of Colorado's Hearing and Quality of Life study conducted from 2007-2010. We are sharing these results with you because you shared your experience with us as a young person who is deaf or hard of hearing or a parent of a child who is deaf or hard of hearing. Pages 1-2 highlight findings from data collected from 11-18 year old youth who are deaf or hard of hearing. Page 3 highlights findings from data collected from parents of 5-10 year old children who are deaf or hard of hearing. For more information about this study please refer to the website address provided on page 4. Thank you all for your contributions to this study!

What was the study?

- The study aimed to create an instrument to examine the quality of life (QoL) of DHH youth ages 11-18 and children ages 5-10, with mild to profound hearing levels.
- Because of the lack of previous research in this area, the study team initially conducted interviews with 49 DHH youth 11-18 years of age and 46 parents of DHH children 5-10 years of age to gather information about school, home life, friends, communication preferences, etc. From these interviews, two surveys were developed and tested, one for youth to report on their QoL (*Box 1*), and one for parents to report their observations of QoL-related topics in their child's life (*Box 3*).
- The questions in the youth survey cover three areas: **Self-Acceptance/Advocacy, Participation, and Perceived Stigma** (*Box 2*).
- The sample size of n=230 youth and n=271 parent study participants completed the survey questions about general and hearing-related quality of life.
- Parents of children ages 5-10 were asked about their young child's communication or how they interact with family members and children their own age and are presented on page 3.

Box 1. Sample Question from Youth Survey

96. As a person who is deaf or hard-of-hearing, it is **easy** for me to start talking to people I do not know ... (please circle one number)

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

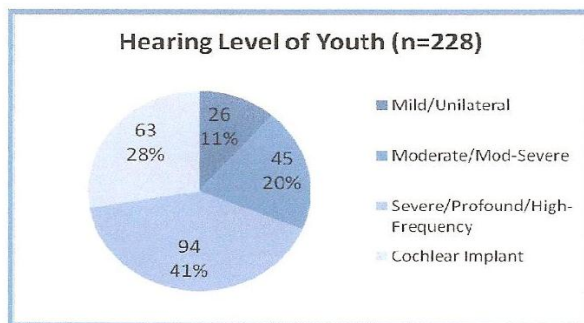
Box 2. Definitions of Quality of Life for Youth

- 1) **Self-Acceptance/ Advocacy:** happy with who I am, feeling satisfied with my communication, able to speak up for myself;
- 2) **Participation:** taking part in activities with family, friends, and in my community;
- 3) **Stigma:** feel like people treat me badly, feel like I am not as good as others.

General Quality of Life for Youth

What did we find?

- Results suggest that DHH 11-18 year olds generally share similar views and perceptions about their quality of life, regardless of the school they attend, whether their parents are deaf or hearing, or if they are male or female.



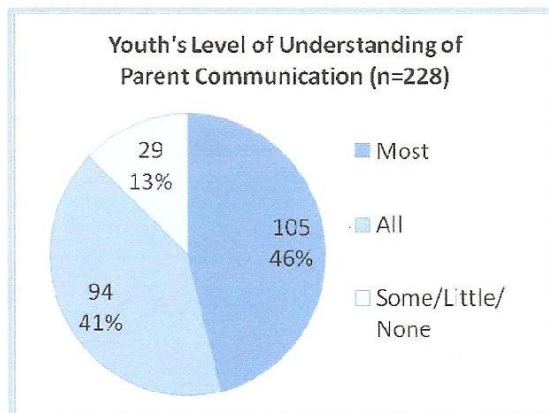
- Specific findings suggest that the greater the presence of depressive mood in youth, the lower the youth's feelings of Self-Acceptance/Advocacy and Participation and the higher the youth's feelings of Stigma.
- Youth Participation was significantly higher (better) and Stigma was significantly lower (better) for the 11-14 age group than for the 15-18 year old youth.

- There was no consistent relationship for youth between the level of hearing loss and Self Acceptance/ Advocacy, Participation, or Stigma.

- Youths' perceptions of their QoL did not differ for Self-Acceptance/Advocacy or Participation, whether they used sign language, spoken language, or speech and sign.
- Youth who only used speech reported worse Stigma about being deaf or hard of hearing than youth who used a combination of sign and speech.

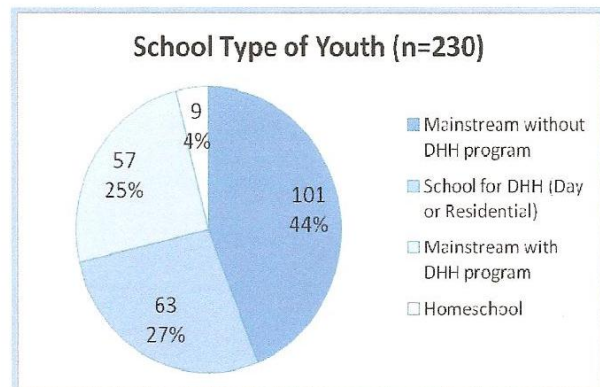
Communication between Parent and Youth

- Youth were asked: "How much do you understand when your parents communicate with you at home?"
- Youth who understand "most" or "all" of what their parents say reported higher Self-Acceptance/Advocacy and lower Stigma related to being DHH.
- Understanding all of what their parents say was associated with youth report of higher Self-Acceptance/Advocacy and Participation, regardless of the severity of hearing loss or use of Cochlear Implants (CI).
- Youth who are DOD or DOH had no differences in Self-Acceptance/Advocacy



School Environment for Youth

- We found that there is no relationship between what school youth go to and QoL related to being DHH.
- Among youth who are deaf in mainstream schools with no DHH program, there seem to be no significant differences in QoL between those who have hearing parents and those who have deaf parents.
- In mainstream schools with DHH programs, youth who are deaf with deaf parents had higher Participation.
- In mainstream schools with DHH programs, youth who are deaf with hearing parents reported lower Stigma than youth who are deaf with deaf parents.



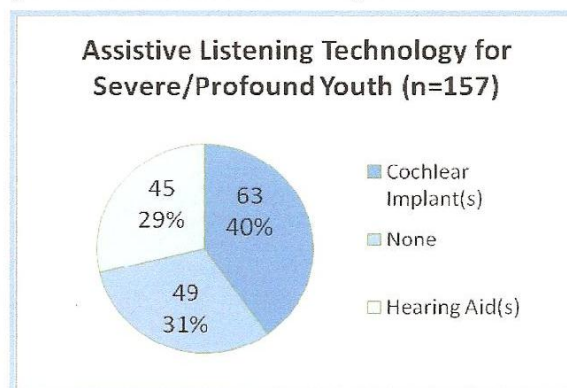
Assistive Listening Technology with

Severe/Profound Hearing Level

- 40% of the youth had a CI¹, 31% had no assistive listening device and 29% had a hearing aid.
- Youth with severe/profound hearing loss that had no assistive listening device reported higher QoL compared to youth with CI or HAs.
- Youth with cochlear implantation reporting higher

"The worst thing was when I did not have my cochlear implant and could not communicate with hearing friends."

-18 year old male, profound hearing loss



¹ Youth with CIs include only youth wearing CIs every day.

quality of life scores compared to youth with hearing aids.

Parent Observations of Child's General Quality of Life

What did we find?

- Out of the 271 parents surveyed, 93% were female, and 82% were hearing. 52% of the DHH children reported on were male.
- The majority of the children reported on preferred speech as their primary mode of communication (66%).

Box 3. Sample Question from Parent Survey

During the past 4 weeks:

40. How often did you observe or learn that your child...
...was left out of activities because s/he could not follow what was going on because s/he is deaf or hard-of-hearing?
(please circle your answer)

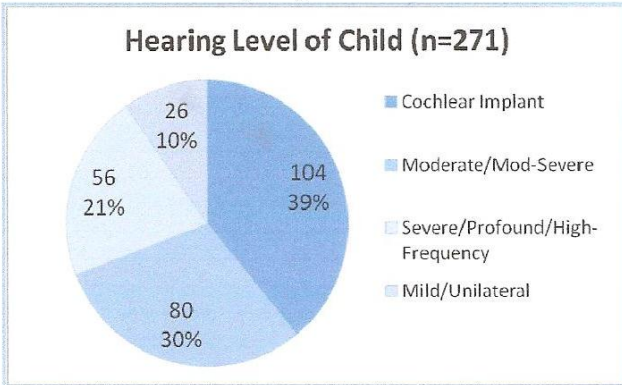
NEVER
0

RARELY
(ONCE IN 4 WEEKS)
1

SOMETIMES
(LESS THAN ONCE A WEEK)
2

OFTEN
(AT LEAST ONCE A WEEK)
3

VERY OFTEN
(MORE THAN ONCE A WEEK)
4



"My son needs to gain experience socializing with hearing and deaf kids. Equal balancing with both groups helps with better adaptation to both. Staying with only deaf peers all the times is not good. Mingling with both groups helps become better person."

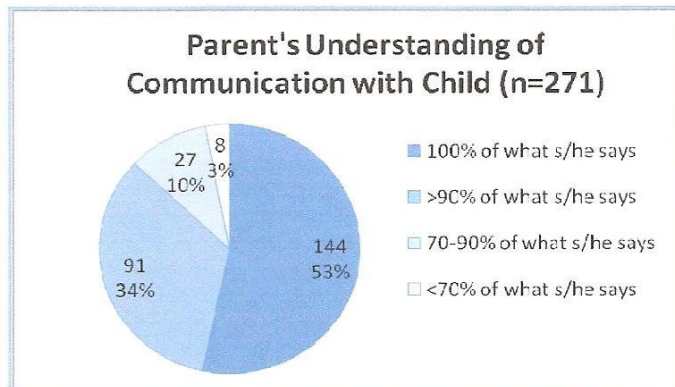
-Parent of 8 yr old boy with profound hearing loss

Participation

- Parents reported that their child participated in family conversations at meal times at least once per day (n=232; 86%).
- Most parents reported that their child daily initiated conversations with children his/her own age (n=197; 73%), and spent time enjoying his/herself with children of the same age at least once a week (n=114; 69.4%).

Communication Challenges

- Parents reported that their child sometimes needed to try several methods of communication before they were understood, though few had to do this very often (n=56; 21%). In addition, the parents reported they never or rarely observed their child giving up on something they wanted to do because of difficulties in communication (n=201; 74%).



"My daughter can switch the kind of communication modalities pretty easily...She already exists in a predominantly hearing world and a hearing family so we focus on how do we give her more opportunities to be connected to the deaf world."

"We make sure that she's supported both ways...so she can participate like a typical kid, not be left out of anything because of her hearing loss. And that she learns...to advocate for herself."

-Parent of 7 yr old girl with profound hearing level



Parent Mentors

Parent mentors are parents of children who are deaf or hard of hearing. From hearing aids, cochlear implants, sign language and speech, we have been there. Have questions? Give us a call.

Exceptional Parents Unlimited

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Fresno, CA 93726
559-229-2000 x 208

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Merced, Monterey
San Benito, San Francisco
San Joaquin, San Mateo
Santa Clara, Santa Cruz
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Family Focus Resource & Empowerment Center

Barbara Matusky
April Chauhan
Irma Sanchez
Cora Shahid
18111 Nordhoff Street
Northridge, CA 91330
818-677-6854 Office

Counties

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Rowell Family Empowerment Center

Kat Lowrance
Barb Ciukowski
962 Maraglia Street
Redding, CA 96002
530-226-5129

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