

# 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

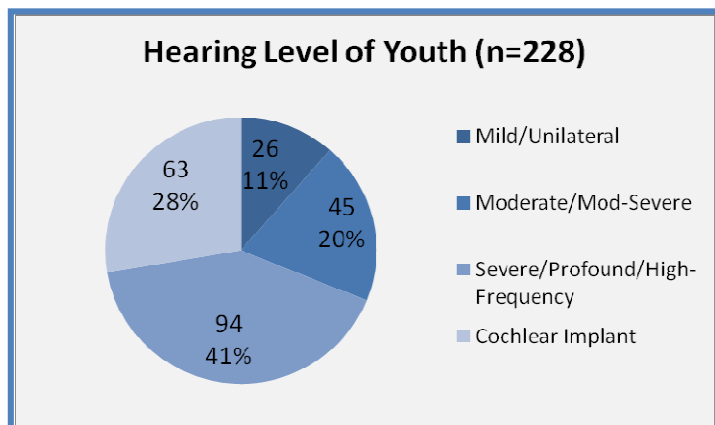
### Box 2. Definitions of Quality of Life for Youth

- 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.

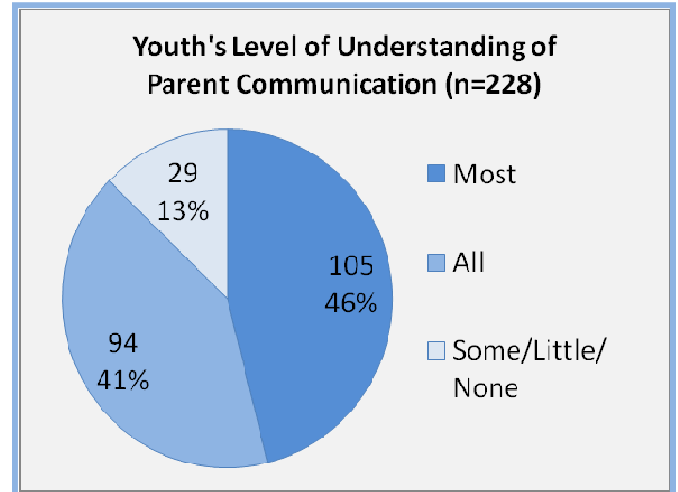


- Specific findings suggest that the greater the presence of depressive mood in youth, the lower the youth's feelings of Self-Acceptance/Advocacy and Participation and the higher the youth's feelings of Stigma.
- Youth Participation was significantly higher (better) and Stigma was significantly lower (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.

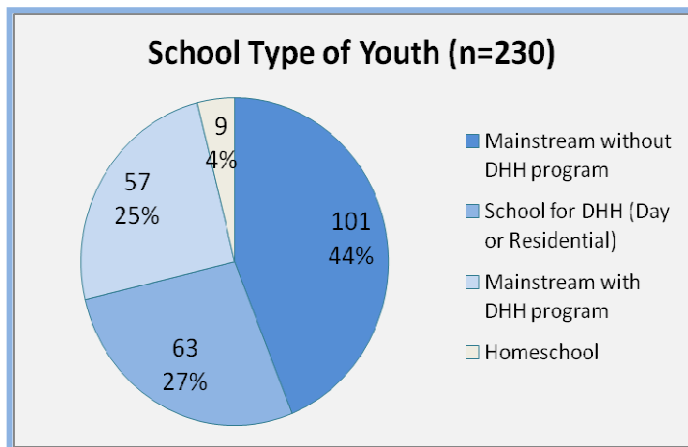
## Communication between Parent and Youth

- 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

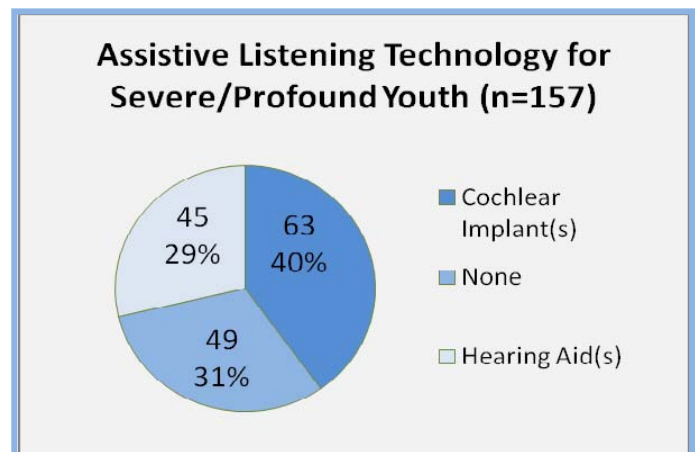
- We found that there is no relationship between what school youth go to and QoL related to being DHH.
  - Among youth who are deaf in mainstream schools with no DHH program, there seem to be no significant differences in QoL between those who have hearing parents and those who have deaf parents.
  - 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 CI<sup>1</sup>, 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 quality of life scores compared to youth with hearing aids.

*"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



<sup>1</sup> Youth with CIs include only youth wearing CIs every day.

# Parent Observations of Child's General Quality of Life

## What did we find?

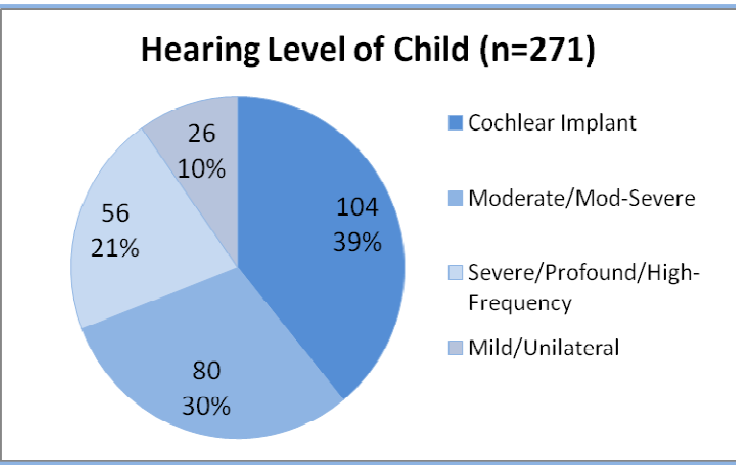
- Out of the 271 parents surveyed, 93% were female, and 82% were hearing. 52% of the DHH children reported on were male.
- The majority of the children reported on preferred speech as their primary mode of communication (66%).

**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
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*“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.”*

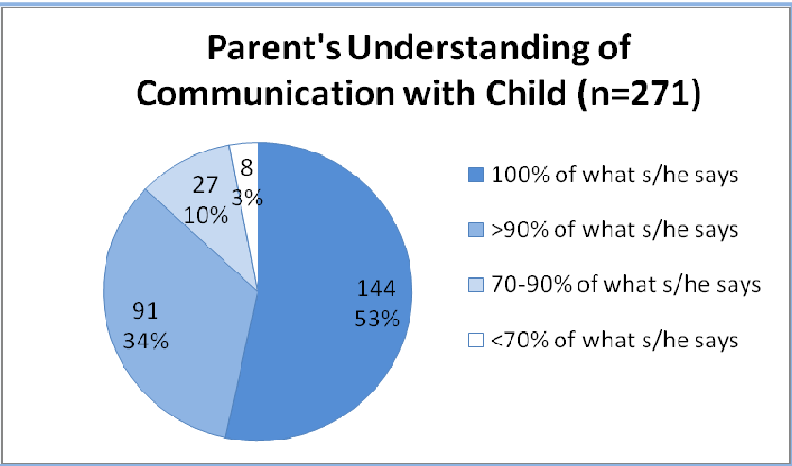
-Parent of 8 yr old boy with profound hearing loss

## 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

The Project HQL research team would like to thank the parents and young people that participated in this study. This project would not have been possible without your contribution.

## For more information...

Please check out the study website: <http://depts.washington.edu/projhql>

## References to publications:

Edwards, T. C., Huebner, C. E., Connell, F. A., & Patrick, D. L. (2002). Adolescent quality of life, Part I: conceptual and measurement model. *Journal of Adolescence*, 25, 275-286.

Patrick, D. P., Edwards, T. C., Skalicky, A. M., Schick, B. Topolski, T. Kushalnagar P., et al. (2010). Validation of a Quality-of-Life Measure for Deaf or Hard of Hearing Youth. *Oto Head and Neck*, 145 (1), 137-145.

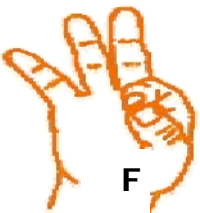
Kushalnagar P., Topolski, T. D., Schick B., Edwards, T. C., Skalicky, A. M., Patrick, D. L. (2011). Mode of communication, Perceived Level of Understanding and Perceived Quality of Life in Youth who are Deaf or Hard-of-Hearing. *J Deaf Stud Deaf Educ*, May 2 [epub ahead of print.]

Schick et al. School Placement and Perceived Quality of Life in Youth who are Deaf or Hard-of-Hearing. Manuscript in preparation.

Meyer A et al. Quality of Life amongst Youth and Adolescents with Severe to Profound Sensorineural Hearing Loss. Manuscript in preparation.



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