Published in final edited form as:

Am Ann Deaf. 2012 ; 157(3): 249–250.

Representativeness in Studies of Early Cochlear Implantation

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We read with interest the review by Belzner and Seal (2009) on demographics in research samples of children with cochlear implants (CIs). We applaud the authors' effort in evaluating and promoting the awareness of representativeness of research study samples in this pediatric population as reported in the peer-reviewed literature. In Belzner and Seal's review, one of the longitudinal outcomes reports that were examined was Quittner et al. (2007), which reported on a subset ($n=88$) of CI recipients from the Childhood Development after Cochlear Implantation (CDaCI) Study ($N=188$). While the subsample of CDaCI participants demonstrated some racial diversity, the chi-square value led to the conclusion that the subsample was not representative of the national pediatric deaf population. It is surprising, however, that the authors referred to the Fink et al. (2007) publication, which provided a detailed description of the CDaCI Study's design and participants as well as nonparticipants, but they did not choose to examine the representativeness of the full CDaCI cohort.

In designing and conducting the CDaCI Study, tremendous efforts were put in place to ensure the diversity and representativeness of the children enrolled in the CDaCI Study. These efforts included enlisting multiple implant centers from diverse geographic locations across the nation and carefully documenting and comparing the participants to those who were eligible but declined participation. In response to Drs. Belzner and Seal's comments regarding the representativeness of the CDaCI Study sample, and thus the generalizability of the CDaCI Study results to young children with sensorineural hearing loss fitted with CIs, we provide the race/ethnicity distribution for the CI cohort of the CDaCI Study (Table 1). As can be seen, the percentages for the race/ethnicity categories of the CDaCI Study are similar to, and in fact, the demographic distribution of children with CIs in the CDaCI Study does not significantly differ from, the 2000 U.S. Census data, as was reported in Drs. Belzner and Seal's review.

We agree with Drs. Belzner and Seal that generalization of outcomes has to be done very carefully. Though the CDaCI Study was also shown by the authors to not be representative of the larger deaf population in terms of disabilities and socioeconomic status, our study design and comprehensive data collection regarding these and other important confounds have enabled us to track critical outcomes and correlates of successful CI use while controlling for these confounds with multivariable-adjustment in data analyses (Fink et al., 2007; Markman et al., 2011; Niparko et al., 2010). We believe this approach is critical in assessing real world comparative effectiveness and share Drs. Belzner and Seal's appreciation for the representativeness of the study population.

Acknowledgments

The CDaCI Study was supported by grant R01 DC004797 from the National Institute on Deafness and Other Communication Disorders, National Institutes of Health.

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Table 1

Representativeness of Children with Cochlear Implantation in the CDaCI Cohort.

Race/Ethnicity	N, CDaCI	%, CDaCI	%, 2000 Census*	N, Expected
White	117	64	63	115
Black	17	9	15	27
Hispanic	37	20	17	31
Asian	10	6	4	7
Other	1	1	1	2
Subtotal	182	100	100	182
Unknown/Refused	6	--	--	--
Total	188	--	--	--

*
from p 312 of Belzner and Seal, 2009.

Chi-square goodness of fit test = 6.5065, with 4 degrees of freedom; **p = 0.1644**