Science, Not Philosophy, Will Help Deaf and Hard-of-Hearing Children Reach Their Potential

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Survival, developmental outcomes, and quality of life have been transformed over the past 30 years for infants suffering a wide range of previously devastating conditions. Children affected by prematurity, cystic fibrosis, and congenital heart disease now survive and indeed thrive into adulthood. Technical advances have proceeded alongside coordinated programs of multicenter registries and trials, driven by clinicians and researchers motivated to not only continually push the boundaries of postdiagnosis treatment but to show that children reap the benefits.

The past 30 years have also heralded astonishing advances for children born deaf and hard of hearing. The first pediatric cochlear implantation in 1985 was followed by the discovery of the first of many genes for nonsyndromic hearing impairment in the 1990s. Widespread implementation of universal newborn hearing screening programs in the early 2000s means that hearing impairment is now routinely diagnosed in the first 3 postnatal months. For the first time in history, we have the opportunity to learn how to prevent language delay, so that development never falls behind that of hearing children.

The systematic review by Fitzpatrick et al uncomfortably illustrates that we may not yet have seized this opportunity. Noting that “no consensus exists on optimal interventions for spoken language development,” they examined the effectiveness of early sign and oral language intervention compared with oral language intervention only for children with permanent hearing loss. Only 11 observational studies could be included. Not one randomized trial was located; indeed, not a single article reported any kind of experimental design. Eight of the 11 articles focused solely on cochlear implant users, where the large majority of children use standard hearing aids. The total evidence rested on 320 children with implants and a further 207 in samples heterogeneous for hearing aids and implants. For every language, speech, and speech reception outcome, the quality of evidence was rated as “very low.”

The need for better intervention is real and present. So many questions remain unanswered. Is there a hearing threshold below which amplification has few benefits? Do children with unilateral losses benefit from hearing aids? How is language best learned in the presence of hearing that is not normal, even with the best modern technology? How is it best taught? What are the most effective ways for parents to promote communication? Does sign language help, hinder, or make no difference to oral language outcomes? Even the simplest question of “Are we making progress, year on year?” remains out of reach.

Given these questions, what underlies the dearth of high-quality randomized trials? Perhaps the advocacy for universal newborn hearing screening and cochlear implantation were just

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DOI: 10.1542/peds.2015-3443

Accepted for publication Oct 7, 2015

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: Dr Wake is supported by Australian National Health and Medical Research Council Senior Research Fellowship 1046518. Mr Carew is supported by a PhD stipend from the Centre for Research Excellence in Child Language (National Health and Medical Research Council grant 1023463). Research at the Murdoch Childrens Research Institute is supported by the Victorian Government’s Operational Infrastructure Support Program.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

too persuasive, our job seemed done! Unfortunately, it is becoming very clear from large-scale epidemiologic studies that, on average, language and learning outcomes still fall well below both population norms and the children’s own cognitive potential.5 The Australian Statewide Comparison of Outcomes of Hearing Loss quasi-experimental study reports incremental gains of ~0.3 to 0.5 SDs in language scores with each step from statewide opportunistic to risk factor to universal screening. Nonetheless, even in the latter group, mean language scores for young schoolchildren born in 2003 to 2005 without intellectual disability still hovered just below 90 (~1 SD below their cognitive ability).6 These figures neatly mirror those of the observational Longitudinal Outcomes of Children with Hearing Impairment7 (following >400 Australian children across the full range of hearing loss) and Outcomes of Children with Hearing Loss8 (following >300 hard-of-hearing children from multiple US states) studies.

Whatever the reason, the lack of intervention trials is deeply troubling. Contrast this with childhood cancer, whose cumulative childhood incidence of ~1.0 to 2.5 per thousand9 is similar to that of congenital hearing loss. Acute lymphoblastic leukemia was invariably fatal in the 1950s; now 90% of children survive. Today, one might argue that hearing impairment is the more disabling condition. Like cancer, gains for childhood hearing impairment will happen only with painstaking comparative trials that are powered for incremental benefit and rigorous in avoiding confounding.

As noted by Fitzpatrick et al.,3 the debate about optimal outcomes has resulted in a plethora of philosophy-driven interventions. Winston Churchill said that “However beautiful the strategy, you should occasionally look at the results.” A coordinated international investment is needed to support and incentivize randomized trials, ideally springing from harmonized, web-based registries that can both monitor secular year-on-year improvements and provide large numbers of parents eager to make tomorrow better than today. Science, not philosophy, will optimize the future for countless unborn children with permanent hearing impairment.

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*Pediatrics* 2016;137;
DOI: 10.1542/peds.2015-3443 originally published online December 18, 2015;
Science, Not Philosophy, Will Help Deaf and Hard-of-Hearing Children Reach Their Potential
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Pediatrics 2016;137;
DOI: 10.1542/peds.2015-3443 originally published online December 18, 2015;

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