

WEBWORDS 13

Low prevalence disorders: Finding the facts

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Big picture

Opportunities to work as a WHO volunteer are limited. The organisation provides humanitarian action on a scale (<http://www.who.int/dsa/cat98/epid8.htm>) that is almost too big to comprehend, and in situations (<http://www.who.int/disasters/>) that are distressing, even to contemplate. Accordingly, WHO only wants individuals with the experience and expertise to allow them to make a positive contribution to the world community.

Communities...

The information provided by epidemiologists (<http://www-nceph.anu.edu.au/>) is vital to the efficient operation of many humanitarian agencies. Epidemiology is concerned with the distribution and determinants of diseases and injuries in human populations. Whereas clinical medicine focuses on the individual patient, in epidemiology “community” replaces “patient”. A systematic approach is used to study the differences in disease distribution in subgroups, and causal and preventative factors.

...great...

Human genome epidemiology (<http://www.cdc.gov/genomics/hugenet/about/editorial.htm>) is an evolving field of inquiry into the impact of human genetic variation on health and disease. Many of the conditions (<http://www.cdc.gov/health/default.htm>) it concerns itself with are of pandemic proportions, overwhelming in their seriousness, reflecting, as they do, great and global heartache and intense personal suffering.

...and small

Just as heart-wrenching, at the other end of the epidemiological scale, are the sites devoted to low prevalence conditions. Low prevalence can be understood as being a prevalence that is generally recognised as less than 5 per 10,000 of population in the community. Around 6,000–7,000 diseases have been found and 5 new diseases are described every week in the medical literature.

Databases

The NORD (<http://www.rarediseases.org/>), Orphanet (<http://www.orpha.net/>) or BDID (<http://www.bdidi.com/>) databases, keyword searches, and personal home pages reveal that many low incidence conditions carry with them communication delays and disorders, posing a special information seeking challenge to speech pathologists.

Michael Giangreco

Michael Giangreco, a research Professor at the University of Vermont, is assigned to the Center on Disability and Community Inclusion. His professional and research interests encompass the why and how of planning, adapting, coordinating, implementing, and evaluating educational programs and services for students with disabilities who are included in general education classrooms. His work is highly regarded and widely published.

Particularly interesting, and inspiring, for speech language pathologists, is Giangreco, 2000. This article about low incidence and services to students, in PDF format, has been made available to ACQ Webwords readers by ASHA, the copyright owner, with the author’s kind support.

It is interesting to know that ASHA members, including international affiliates, now have access to all the association’s journal articles online (<http://professional.asha.org/resources/journals/>), as a member benefit.

Giangreco’s rambling labyrinthine website (<http://www.uvm.edu/~mgiangre/>), with its information about inclusion, paraprofessional support of students with disabilities, curriculum planning and the COACH and VISTA approaches, repays a few hours exploration, just to get a feel for his important work.

Unit

Closer to home, the Queensland Education’s Low Incidence Unit coordinates a range of specialised state-wide services which enhance and extend educational options for students with low incidence support needs. Its Internet site (<http://education.qld.gov.au/tal/liu/>) provides copious information, including a very good article on the IEP process.

Optimism

Back to the big picture at the World Health Organization (<http://www.who.int/en/index.html>). Idealism, enthusiasm and a positive outlook are not specified in the recruitment brochure as essential qualities for team members, but they would certainly help those individuals who stay the distance.

Maybe it was just such an optimistic group who formulated the organisation’s definition of health, as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

It makes a good motto, whether we are part of the big picture of world health, or the small picture of low incidence disability, whether we are part of a team involved in a rapidly expanding field like human genome epidemiology, or the slow-moving, low profile, hum drum that can be the reality of day to day solo SLP clinical practice.

For surely, this aim of ensuring the best possible outcome for all of our clients, is explicitly enshrined in the code of ethics that we all embrace as Speech Pathology Australia members.

Reference

Giangreco, M. F. (2000). Related services research for students with low incidence disabilities: Implications for Speech-Language Pathologists in inclusive classrooms. *Language Speech and Hearing Services in Schools*, 31, 230–239. (http://members.tripod.com/Caroline_Bowen/Low%20Incidence.pdf). Copyright held by the American Speech Language Hearing Association. Posted to Caroline Bowen’s website with permission.

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