Ethics in Deaf Education 4/29/2002 Rod G. Beattie, Acting Head of College, Renwick
College, Royal Institute for Deaf and Blind Children, Australia
Ethics in Deaf Education

Rod G. Beattie
Acting Head of College/Senior Lecturer in Hearing Impairment
Renwick College
Royal Institute for Deaf and Blind Children
North Rocks, NSW 2151
and
University of Newcastle
Callaghan, NSW 2308
Australia

Email to: rbeattie@mail.newcastle.edu.au

Ethics in Deaf Education:

If ten special education teachers were asked to describe an ethical dilemma for children
with hearing impairments—it wouldn't be much of a surprise if they described some aspect
of cochlear implantation. If we expanded our informal ethical dilemma survey to a group
of teachers of the deaf, their nominations might feature oral or sign language options and
methods of instruction. This mental gymnastics exercise is probably where most people
both stop and start with the topic of ethics and the education of young children with
hearing impairments. Consider, however, the following dilemma of a professional
researcher.

*John has been a Project Manger for Access Demographics for the last four years. His
doctoral training in population studies has served him well.*

*Over the last four years, John's research projects reflected the spectrum of commercial
interests in population demographics: He was to determine the market potential for the
latest quirky twist in cross-trainers in the south to the acceptability of a political hack in
the north.*

*The studies followed a relatively simple pattern. First, define the area. Second, identify the
number and make-up of people living there, and third survey the people's predilections for
wavy shoe bottoms or wacky political ideas. Simple stuff—neat and clean.*

*The project concerning captioned television, for a coalition of a government department
and a consumer group, seemed much like others. Only as the project unfolded did the
complications become obvious and the hidden agenda surface.*

*Defining the "area" was simple, defining the consumer group, however, was not. Who were
they? Were they the deaf and hard of hearing people who had decoders and used*

captioned television? This certainly was the interest of the government department, who could use lower "numbers" to make a case for keeping the lid on expensive caption development programs.

In contrast, the consumer agenda was equally obvious. Their interest in identifying the size of the consumer group included not only the current users of caption television but also those who had not, for whatever reason, partaken or used captioning at this time. The larger the number of potential consumers—the greater the pressure they could bring to secure government funding.

John had not experienced this "push-me—pull-me" game with demographics from an unholy alliance before. Past demographic studies, commissioned by a single entity, were looking for data to support a yea or nay question. Yes or no... hundreds of thousands of young males between 15 and 24 in the south will or will not toss themselves off cliffs like lemmings to buy wavy-soled cross-trainers. Yes or no... necks with blue and white collars like those with red underneath will or will not vote for the quirky political hack with odd ideas.

This time John was experiencing very obvious pressure. Was quantifiable pressure exerted to falsify demographic findings? Certainly no bribes or threats were offered or given. Still, there were subtle pressures to "cut the cloth" one way or another in the questions and queries during the interim briefings with the coalition partners.

The pressure was not pleasant. John realized that defining demographic variables for the sale of goofy shoes and quirky hacks is an easier way to make a buck than satisfying the desires of alliances and coalitions who have different agendas. The task was not without interest, but perhaps the only appropriate way to deliver this potentially derisive demographic data would be from a researcher who's funding for the project was separate from the interested parties.

With experience, sustained reflection, collection, and exploration, the numerous real and possible ethical dilemmas in this area, like the demography of deafness example above, become obvious. An expanded collection might include—genetic counseling and medical intervention; effects of science and technology; assessment and measurement; educational placement; application of curriculum; and preparation of personnel.

This list suggests that serious consideration should be given to deafness and ethical issues from a collection of professional fields—medical science, audiology, rehabilitation, psychology, education, and perhaps politics - if it fits the professional definition. To date, it is easy to see, as Newell (1991) suggested in a critical evaluation of a paper from the National Health and Medical Research Council, that the general bioethics literature has been too dominated by medical discourse. Newell's argument "that their paper has neglected to account for the social nature of disability and handicap" should serve as a warning and a motivation (p. 46). Even a quick review of the literature concurs that the ethical debates involving deafness are also too dominated by medical discourse.

Yes, the ethical discussion concerning cochlear implants in children is growing, but largely it rises from the theatre of the medical and Deaf communities "aided" by the popular media

who seem to be looking for something emotional or alarmist, rather than issues discussed or argued with reason. Seemingly, the larger/longer term arena of education fails to make good sound bites, but this does not mean that the ethical dilemmas don't exist. Indeed they do. Unfortunately, the outcome seems to mean that growth of information on ethics and deafness falls into the too little and too slow basket.

Casting a wider net, ethics in special education has been an important and recognized topic for many years. Reynolds and Fletcher-Janzen (1990) in their *Concise Encyclopedia of Special Education* summarized the key elements:

Special education professionals are responsible for knowing the ethical standards of the profession and must be knowledgeable about the rights of exceptional children and their parents. Parents of special education children need to be informed of these rights, including the granting of consent for evaluation, diagnosis, and education. The right to privacy of the individual youngster and the family must be protected and all records and pertinent information kept confidential. When delivering an intervention, special education professionals are mainly responsible for choosing an educational alternative that would not be harmful, physically or mentally, to the handicapped youngster. (pp. 413-414)

It is unlikely that professionals involved with children with hearing impairment and their parents would find fault with this statement. Most would see the importance of ethics and a need for an extended discussion concerning the early management and education of young children with hearing losses—because they've faced awkward situations and difficult decisions relating to the points made.

Professionals recognize that parents of deaf children have many difficult decisions to make. For example; decisions regarding medical procedures - often being queried shortly after diagnosis, decisions regarding assistive listening equipment and amplification, vast and diverse educational options (once restricted to often-distant residential schools, may now span the service range from the same residential schools to partial or full integration in the home community), additional decisions regarding language and methods of instruction complicate decision-making roles even more. Language choices span auditory-verbal to bilingual-bicultural: From one or more auditory-oral languages of the hearing majority to the natural visual-manual languages of the local Deaf community. Simply, the choices, alternatives and responsibilities are enormous and difficult, and they interact in a complex fashion that impacts and determines a somewhat unpredictable outcome.

Consider now another dilemma—this time reflecting a parent's perspective.

Frank is four and a half and I'm struggling with yet another educational placement decision for him. Which kindergarten program should he attend? He's a child who has been in home school, clinic school, play school, and even preschool—a time longer than some people take to get a degree.

My Frank's special. Beautifully blond: fine strong build. Handsome face, one that turns heads even though he's a child. Deaf! Ah did I forget to mention that? Yes deaf as the oft-described post. Certainly deaf if that fridge magnet is stuck anywhere but on the side of his head. But technology is not my issue here. Those decision-demons have been dealt with.

The battles of keeping his cochlear implant on his head and persevering to the point where we both can recognize its benefits have been conquered—at least for now! No, my struggle is once again with another school placement for my Frank.

I can't say how jealous I am of parents with young kids who can hear and see and move and think unfettered. So fortunate! Perhaps a day-care decision, so they can return to work, is tough. From my perspective it doesn't seem that difficult. I suppose, laying a guilt trip on oneself or having a wallow in the pity-pot is a possibility, but weighing the plusses and minuses on little Stewart Willy or Jasmine Periwinkle seem inconsequential.

Not only do the long and short-term outcomes frighten me after a placement decision has been made… I am almost struck dumb by what needs to be done to make the decision. The standard developmental screening tests are non-issues in Frank's life. He's had those in spades: More than I can remember since losing his hearing from meningitis at six months. Since then, I've given more "yesses" and "nos" to those parent-report questions than Kellogg's has corn flakes. There have been auditory-perception levels; discrimination values; visual-motor integration results; receptive and spoken vocabulary numbers, language comprehension and expression ages; IQ's verbal, performance, and combined; not to mention the drawing of a person, house, and tree, which I'll sing if I need to make my point clearer.

Still, I've only made one of my points here. Frank has been tested more that any innocent should be, but this doesn't even touch on the greatest of my burning issues. Will my beautiful child when he is older, resent me for his childhood lost as I quested for the "least restrictive environment" or an "appropriate placement"? Will the peers and teachers I surround him with in these educational settings be the ones he would select or gravitated towards as friends and mentors given time and free choice? Over the years, will the inevitable collection of good and bad Ms. Verbals or Ms. Signs equip Frank to cope in work and life? Simply, would school "A" be better than school "B" for him?

Selfishly, will the school placement decision I make and the teachers, mentors, and friends that that decision entails meet my needs? Will I be supported in my decision through the good times and the bad? Might I happen to hear or feel their doubts about what I hoped and believed was the best decision at the time it was made? What of the casting of stones to mark an educational failure and the need to re-evaluate options? I've seen and heard the hyphenated epithets from both sides: oral-failures—sign-ghettos. I know where they have come from and for whom they were intended. I've listened to and observed bruised egos and souls. Cruel remarks from people who should know better—best interests at heart be-damned. Not at the moment the remarks were made. My beautiful Frank does not deserve that. And neither do I.

Technological development has spurred many decisions with ethical implications, but there are also implications arising from neonatal screening programs.

Effective early identification programs for a hearing loss are not impossible dreams in developed countries. Political will, convinced by cost-benefit and/or quality of life research, can and will make it happen. These very early-identified babies will refocus the ethical concerns already mentioned. Their parents will need to make choices about

medical/surgical interventions, the application of assistive hearing technology, home/clinic intervention, language learning, teaching methods, early childhood educational placements. Unlike parents from even 20 years ago, they will have to make these decisions earlier—pressured by neurologic, audiologic and educational research on the effects of communication deprivation and the benefits of early intervention. Perhaps as well, modern parents make these decisions at a time when they are more "deaf naïve" than their forerunners.

Problems that parents face aside, involved professionals have a duty to serve them well. In a summary type statement to this area I noted (Beattie, 2001)…

Rightly or wrongly, criticism or blame has been oft directed at educational systems—especially those that drive it or provide support and those that deliver the programs. If we are inadequate let us hope it is because we are not yet sufficiently knowledgeable or competently trained or lacking in resources (although still unacceptable). Let us not hope that our inadequacies are based in ignorance of or disregard to proper ethical standards.

To minimize our inadequacies in ethical areas perhaps we could, as a starting point, consider the Tri-Council (1996) suggestions, "good ethical reasoning, like good scientific reasoning, must be more than a matter of the mechanical and dogmatic application of rigid rules to fact situations. Ethical reasoning requires thought, insight, and sensitivity." (Tri-Council, 1996, p. 2-14)

Knowledge about Ethics in Deaf Education

The contributions of educators, habilitation/rehabilitation specialists, medical personnel, and members of the Deaf community often "inform" the decisions that parents or guardians make on behalf of their children. As suggested earlier, these decisions are usually very difficult, obviously have long-lasting—even life-long implications, and not-surprisingly have obvious ethical aspects. The information regarding ethics in deaf education, however, is limited. Certainly, ethical dilemmas experienced by teachers of the deaf are commonly discussed, but few are au fait with a code of ethics for their profession, and how it may assist. Probably even fewer teachers or rehabilitation personnel have had formal course work in ethics in their professional training. Surely it is beyond question that professionals working with families with deaf children and children with hearing loss should have a fundamental understanding of topics like: respect for persons; dignity of risk; non-maleficence, beneficence, justice, coherence; responsibility as an individual or part of a collective; free and informed consent; harms and benefits; privacy and confidentiality; and exploitation.

Ethics Education—Where to Start:

In ethics education the definition of "ethics" and "morality" certainly warrant attention as a starting point. Although great debates exist for the term "ethics," as Jacob-Timm and Hartshorne (1994) describe for helping professionals it "generally refers to a system of principles of conduct that guide the behavior of an individual" (p. 2). And they continue, although ethics and morality are often interchanged "according to philosophers, the term *morality* refers to a subset of ethical rules of special importance" (p. 2).

Further, although some of the terms listed at the end of the previous section like "dignity" and "informed consent" arise in both pre-service and continuing professional training and development courses, a formal discussion of these and a larger corpus, should be explored in greater detail. Although many professionals may have a good understanding of privacy, informed consent, and the right to withdraw from participation from a research project or study, each take on a different nuance or "tone" when the child-parent-professional interaction is not arising from a research perspective.

Following a discussion of ethical terms and concepts, it would seem that professionals who will work with children with impaired hearing and their parents should have, at least, an introductory understanding of traditional ethical theories like deontology, consequentialism, and virtue ethics. Kuczewski's (2000) summaries of these three traditional theories can be found in Table 1.

Table 1
Brief Descriptions of Traditional Ethical Theories (al a Kuczewski, 2000)

Deontology
- This theory is duty-based. The goal of ethics is thought to be the fulfilment of one's duties—the carrying out of obligation without regard to one's desires or happiness. Suspicious of these desires as guides to moral action, adherents seek a general basis, an "a priori" principle, for duties.

Consequentialism
- This theory argues that actions are good or bad based upon their consequences. Adherents try to form basic rules to guide their actions. The best-known form, utilitarianism claims we need to take actions that generally lead to happiness. E.g., "Choose the action likely to produce the greatest good for the greatest number."

Virtue Ethics
- This theory considers the person's development and characteristics. Actions are so variable that they require a good deal of judgement—not inflexible rules. Adherents ask what character traits should we develop in order to become the kind of person who will judge well in these variable situations.

With this background knowledge educators should then acquire a basic understanding of principlism, which Stewart and Ritter (2001) note "is currently the most applied approach in bioethics" (p. 75). It is in principlism where the traditional theories are operationalized and where ethical decision-making occurs in particular cases by balancing the four principles of autonomy, beneficence, non-maleficence, and justice. Table 2 highlights the four principles.

Table 2
Four Principles (al a Roeher Institute, 1999 & Tri-Council, 1996)

Autonomy	Beneficence
• … Every person has the right to be independent and to make his or her own decisions. This includes the right to make free and informed decisions.	• … In simple terms beneficence involves doing or producing good (performing acts of kindness or charity) to or for others (without implying it.).
Non-maleficence	Justice
• … Not harming others. Also in the light of the principle of autonomy and in terms of the harm-benefit ratio … there is an obligation to prevent or remove harm.	• … The principle of justice upholds that rights and equality of individuals and groups. It rejects economic efficiency and cost effectiveness as ethical principles.

Like the statement by the Tri-Council where the focus was on ethics in research, the rationale for the development of professional knowledge is to support the development of ethical thinking:

The intention is to guide and evoke thoughtful actions rather than to generate formulae or algorithms for ethical decision-making. This is very much in keeping with the best uses of the four familiar principles [respect for persons, non-maleficence, beneficence, & justice] of hearth care ethics. (Tri-Council, 1996, p. 2-2)

The Players, Their Positions, and Statements Implying Moral Obligation:

It is surprising how few people state their personal position in order to clarify ethically complex issues. Lynas (1999) while discussing the selection of a communication approach for a child with a hearing loss provides an example to consider. "The most important factor, in my view, is which of the alternative options available to the young child will be least constraining and will leave most options open to the deaf child on becoming an adult" (p. 124). Although Lynas did not italicise or bold "in my view" (above) it was clearly stated—separating the personal from the collective.

In contrast, Stewart (2001) illustrated a common experience of parents of deaf children—the collective "telling you … in a frank manner how you ought to be thinking about something, or more to the point, what you should be doing" (p. 181). Stewart reports;

- *Deaf children will not learn to speak if you sign to them.*

- *Learning ASL as a first language is the right of every deaf child.*

- *You are denying a child's deafness if you give them a cochlear implant.*

- *A deaf child attending a residential school will grow up and live in a deaf ghetto.*

Obviously there is no factual evidence supporting the finality of these (above) statements. Even if, as Stewart concludes, we accept the speaker's view that some of these statements hold true for a fraction of deaf children "their dogmatic tone leaves little room for discussion of alternative perspectives and consequently for discussions of what exactly teachers should know about how best to teach deaf children" (p. 181).

Conclusion and Summary:

The complexity of ethics, deafness, and education together can be overwhelming. Many ethical pitfalls are possible. To manage, there must be a struggle to keep things simple. In the classic, *An Introduction to Ethics* J. D. Mabbott simply stated, "The key words in morals are 'good,' 'right,' and 'ought.'" And the linkage between these words is "duty." This simple sentence and follow-up can serve us well. Each of Mabbott's key words can be used effectively for different topics in deafness: Is the choice of this or that language a *good* one for a specific child and family? Has the *right* educational program been chosen for a child and the child's family? Are there consequences for making a certain decision or choice of assistive listening equipment that we *ought* to inform the parents of? Certainly, it is not difficult to link these questions to our professional *duty*. It would be false to leave the impression that there are simple answers, indeed there are few, but it is possible, through the application of sound basic ethical reasoning.

References:
Beattie, R. G. (Ed.). (2001). *Ethics in deaf education: The first six years*. San Diego, CA: Academic Press.

Jacob-Timm, S., & Hartshorne, T. (1994). *Ethics and law for school psychologists* (2nd ed.). Brandon, VT: Clinical Psychology Publishing.

Lynas, W. (1999). Communication options. In J. Stokes (Ed.). *Hearing impaired infants: Support in the first eighteen months* (pp. 98-128). London: Whurr.

Mabbott, J. D. (1966). *An introduction to ethics*. London: Hutchinson.

Newell, C. (1991). A critical evaluation of the NH & MRC's "The Ethics of Limiting Life Sustaining Treatment" and related perspectives on the bioethics of disability. *Australian Disability Review, 4*, 46-57.

Reynolds, C. R., & Fletcher-Janzen, E. (Eds.). (1990). *Concise encyclopedia of special education*. New York: John Wiley & Sons.

Roeher Institute. (1999). *Genome(s) and justice: Reflections on a holistic approach to genetic research, technology and disability*. Toronto: Roeher Institute/Inclusion International.

Smith, D. D., Luckasson, R., & Crealock, C. (1995). *Introduction to special education in Canada: Teaching in an age of challenge*. Scarborough, ON: Allyn & Bacon.

Stewart, E., & Ritter, K. (2001). Ethics of assessment. In R. G. Beattie (Ed.), *Ethics in deaf education: The first six years* (pp. 67-87). San Diego, CA: Academic Press.

Stewart, D. A. (2001). Ethics and the preparation of teachers of the deaf. In R. G. Beattie (Ed.), *Ethics in deaf education: The first six years* (pp. 167-184). San Diego, CA: Academic
Press.

Tri-Council Working Group. (1996). *Code of conduct for research involving humans.* Ottawa, ON: Minister of Supply and Services.