
Clinical Ethics Forum: An Examination of Principle-Centred Decision-Making in Human Communication Disorders

Tribune de déontologie : Un examen de la prise de décision dans le domaine des troubles de la communication

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Abstract

The clinical ethics forum provides an opportunity for clinicians in the field of human communication disorders to reflect on their experiences while considering the legal and ethical responsibilities of the profession. Each scenario presents a dilemma from the clinician's perspective which is followed by commentary from a lawyer and an ethicist. Issues highlighted include conflicts with team members over treatment decisions, determination of best interests, conflicts of interest, and distribution of scarce health care resources.

Abrégé

La Tribune de déontologie offre aux cliniciens dans le domaine des troubles de la communication humaine une occasion de se pencher sur les responsabilités légales et déontologiques rattachées à la profession. Chaque scénario présente un dilemme du point de vue du clinicien suivi du commentaire d'un avocat ou d'un spécialiste des questions relevant du domaine de l'éthique. Parmi les sujets traités, mentionnons les conflits portant sur le choix de traitement à prodiguer, la détermination du meilleur intérêt, les conflits d'intérêts et la répartition des maigres ressources médicales.

Ethical dilemmas, if left unresolved, are often found in those situations which linger in our memory long after the event. Each dilemma provides us with a window on our values at both a personal and professional level. The following scenarios were composed from a collection of narratives shared with the first author by her colleagues in clinical practice. While some of the clinical details are lacking, an attempt was made to present a central focus on the ethical dilemma. Commentary from a lawyer and an ethicist follows each scenario.

In the first scenario, the speech-language pathologist finds herself in a conflict with a physician over a diagnostic recommendation and is left wondering about her legal and ethical obligations to the client. The conflict theme is continued in the second scenario where the clinician is locked in a debate with a parent over the "best interests" of his child. In the third scenario, the complexity of childhood language disorders plays a part in creating a concern surrounding a conflict of interest for a private practitioner. Finally, the ethics forum concludes with a scenario which highlights the tension over resource allocation when an audiologist recommends amplification for a severely multiply disabled client. While these scenarios have placed the clinician in the favourable position of defending a "right" decision, we must be cognizant that clinicians' actions are not always morally right and, thus, open to debate.

We invite the reader to the exploration of this arena of clinical practice with the intention of providing a perspective on legal responsibilities of our professions and application of the principles of bioethics in speech-language pathology and audiology. The principle-centred approach taken in this forum is but one approach among several approaches taken in bioethics. Other theoretical approaches include utilitarianism, casuistry, character ethics, and the ethic of care. There are no easy solutions to the dilemmas arising in health care at this time. Each approach to bioethics provides a framework that facilitates the careful analysis of the relevant aspects of the dilemma. The clinical ethics forum creates an avenue for the discussion of the many ethical issues we face as we strive as a community of health care professionals to act in accordance with the ideals expressed in our *Canon of Ethics*.

Scenario A

Mike

Mike is a 21-year-old who sustained a closed head injury during a motor vehicle accident. As a result of his injuries, he is a quadriplegic who has limited use of his upper body in supported positions. At three months post-injury, Mike was transferred from an acute care hospital to a rehabilitation centre. The psychologist conducted a neuropsychological assessment and concluded that Mike demonstrated normal cognitive functioning.

A communication assessment was completed. Mike's language comprehension was found to be intact. However, as a consequence of his injury, Mike presents with severe dysarthria rendering his attempts at speech unintelligible. Mike was provided with a Canon Communicator which allowed him the ability to type his communication. He used this alternate communication system successfully to converse in brief exchanges.

During the communication assessment, an oral mechanism examination was conducted. The speech-language pathologist observed slow, weak oro-motor movements. During feeding, Mike demonstrated poor control of the bolus and possible delay in swallowing. Episodes of aspiration were reported by the nursing staff who assisted Mike at mealtimes.

At the team conference, the speech-language pathologist presented her findings and recommended that a modified barium swallow be performed. This procedure could only be done at a large regional hospital in another city one-and-a-half hours away. Therefore, Mike would have to be transported to that location. The physiatrist, who directs the team, disagreed with the recommendation and would not authorize the testing.

The speech-language pathologist left the meeting feeling frustrated and confused about the physiatrist's decision. In reviewing her notes from the assessment, she felt sure that Mike was at risk in oral feeding. Yet she was unclear about what would be an appropriate course of action and who should make that decision.

A Lawyer's Perspective

Mike's case presents two areas of legal concern: the issue of informed consent and the disagreement with the physician. Regarding the issue of informed consent, a lawyer would ask, is this patient competent to give consent? Yes: Mike has not been legally declared incompetent by a court. Also, we know as a result of both the neuropsychological and communication assessments that Mike demonstrates intact cognitive and language comprehension skills.

Therefore, the speech-language pathologist, following the guidelines for informed consent, would have discussed her findings and recommendations with Mike at the time of the assessment.

In the second area of concern, the disagreement with the physician, we need to examine team decision making, scope of practice, and duties owed to the parties involved. Regarding team decision making and team dynamics, it is important to have an understanding of the relationship between the various health-care professionals who are providing care. In some jurisdictions the speech-language pathologist and other allied health-professionals are viewed as peers, while in other jurisdictions the relationship is hierarchical, with the physician viewed as the captain of the team. So this factor has to be considered. In Alberta, only the physician can order the modified barium swallow test, so that the speech-language pathologist must: a) persuade the physician of the need for this test; b) persuade other team members and have the team make the decision on a majority vote; or, c) seek a second opinion from another physician.

Regarding scope of practice, we must ask if the assessment and recommendation are within the scope of practice of the speech-language pathologist alone, or is it within the scope of practice of the physician, in this case the physiatrist, as well? There will be issues that are peculiar to the practice of one profession, while others may be within the scope of practice of two or more professional groups. Clinicians should be aware that the scope of practice for each professional group may be found in provincial legislation governing the profession in question and/or may be stated in professional codes and position statements. It is incumbent upon clinicians to become familiar with the applicable legislation and policies that define the scope of practice within the province in which they practice. There will be variations in legislations across provincial jurisdictions in Canada. There will also be issues that are more generic, that all members of the team should have input on.

So, the question that has to be asked of the medical director in this case example is whether this treatment recommendation is within his sphere of competence (practice). If the answer is yes, then the speech-language pathologist has two options: a) to go along with the decision, if she views it as a reasonable alternative, albeit not the alternative she would recommend; or, b) she can review her own assessment, have it reviewed by another speech-language pathologist and physiatrist, and if their assessments are in accordance with hers then seek to persuade the medical director of the disagreement with his opinion. Obviously, since this is the medical director, this may be risky to do, but if the speech-language pathologist honestly believes that the patient's life or health may be at risk then

she has a legal obligation to her patient to see that the patient receives appropriate care.

If the answer is no, that this issue is not within the scope of practice of the physiatrist, then it must be pointed out that he is potentially running a risk in overruling this recommendation. If the patient suffered harm because the test was not done, the physician's insurer could refuse to provide him with coverage in case of a lawsuit. It might also be tactfully pointed out that physicians have both an ethical and a legal duty to consult with and refer to other healthcare professionals in appropriate cases.

The issue of scope of practice is significant in the context of a lawsuit brought against one or more health care professionals. In Mike's case, were he to aspirate and suffer further injury, both the physiatrist and the speech-language pathologist could be sued. The speech-language pathologist could raise scope of practice as a defence; namely, that the final decision was the physiatrist's and that she did all that she could reasonably do to recommend a different course of action than the one that was taken.

In the event of litigation, the court will first consider whether the intervention was within the scope of practice of the speech-language pathologist, the physiatrist, or both groups. Then, the court will determine whether or not the speech-language pathologist in question acted in accordance with the standard of care expected of a reasonable speech-language pathologist under all of the circumstances in question. Each health care professional's conduct will be assessed by the court and either or both party's conduct may be found to be negligent.

Obviously, there is an advantage to patients in having their cases reviewed and recommendations made by a team. So it is imperative when a team approach is used to set out the mechanisms for decision making. For generic issues, probably the decision should be made by the majority vote in cases of disagreement. For issues that are within the special sphere of competence of one (or more) of the professions represented on the team, that or those individuals should have primary responsibility for the decision(s) made.

Finally, we need to consider duties to the client, to other health care professionals, and to the employer in analyzing the speech-language pathologist's obligations. He or she must be cognizant of his or her duties towards the patient, to his/her profession, to the team and to his/her employer.

An Ethicist's Perspective

Mike's case is made difficult because we lack some of the most important information about it. We are told that the

physiatrist disagrees with the speech-language pathologist's recommendation, but we are not told why. Without this crucial information it is impossible for us to decide what the speech-language pathologist should do.

Not only is it impossible for us to decide, but it would also be impossible for her to decide in any rational way. This reveals a first step. She should ask the physiatrist why he will not authorize the test. Any further actions depends upon the answer she receives to this request. Different answers are possible, and different responses are appropriate for each.

The physician may refuse to authorize the test because he does not believe that it would be in Mike's best interest. The give and take of discussion between professionals may lead to a consensus regarding the test. The speech-language pathologist may convince the physiatrist to authorize the test, or he may persuade her that it is not indicated. Discussion may, that is, dissolve the ethical dilemma. But, it may also transform it. At the end of the day the two may remain committed to their original positions. Given the current structure of power within the system, where the physician's signature wields enormous power, the speech-language pathologist's options are seriously limited. The immediate question she must confront is whether to take it upon herself to inform Mike about the barium swallow.

The physiatrist may refuse because he or she believes that only the physician is morally responsible for the client's care. This misunderstanding may cause the physician to override the speech-language pathologist's recommendation failing to recognize her moral obligation as well. It is hardly novel to note that the medical world has long been hierarchical, structured on a military model with the physician at the top in the role of commanding officer. Physicians trained in this model may see any recommendations as insubordination which ought to be resisted.

The physiatrist may refuse because of the cost involved, feeling that the expense of transporting Mike to the regional hospital and performing the test does not produce adequate benefit. The physiatrist may believe that, although the test would benefit Mike, greater benefit for other patients could be purchased with the same expenditure.

The second rationale is theoretically more difficult. The burning question is what role health care professionals should take in this. One standard view, perhaps the traditional one, is that the professional ought not to think about costs when he or she is at the bedside. The 'client' terminology captures this, perhaps inadvertently. The professional ought to advocate on behalf of the client, and let the social consequences fall where they may. Others contend that it is just this sort of attitude which makes the problem of

cost containment intractable in the arena of health care. Moreover, health care providers are already involved in rationing at least one very valuable resource at the bedside: their own time.

Even if there is a team working together, it may be strained to say that the team made a decision. Here the sports analogy for teams in health care may get in the way, for there are many team sports which are anything but collegial. Too many sports, like football, have a quarterback who gets to call the play.

Does the client get better care when the team has a captain who calls all the plays? Changing the nature of the game is a long-term goal, and not a strategy for resolving an immediate problem.

Scenario B

Jennifer

Jennifer is an eleven-year-old girl with spastic cerebral palsy. She has attended speech and language treatment at a local rehabilitation unit since she was an infant. A picture symbol system was introduced when she was a preschooler and evolved into a 120-symbol system contained in a book. Jennifer's hand skills are sufficient for her to turn pages and point to the 1/2 inch symbols. Jennifer attends a regular grade four class in her local school where she receives assistance from an aide.

Jennifer's oro-motor skills are severely impaired. She exhibits tongue thrusting and undifferentiated movements of the jaw and tongue. There are associated movements of the oral musculature when Jennifer is engaged in physical movements.

In terms of speech, she is able to produce an undifferentiated vowel on demand with great difficulty. This is her only vocalization other than crying and laughing.

A recent cognitive evaluation was carried out as part of the multidisciplinary followup clinic at the regional children's hospital. The results indicated that Jennifer's cognitive skills were commensurate to the two year level. John, Jennifer's father and a teacher, was one of the parents who lobbied for service in their community which was a six-hour drive from the major children's hospital coordinating services for the region. John, the director of the rehabilitation unit who is a physiotherapist, and the occupational therapist have all known each other since Jennifer was an infant. The speech-language pathologist is new to the program and a recent graduate whose graduate work focussed on neuromotor communication disorders.

A meeting was held with John and the speech-language pathologist to discuss treatment plans for Jennifer. John stated that he no longer wanted Jennifer using the symbol board because she was relying on it too much and would not learn to read. He strongly stated that he wanted Jennifer to talk and that it was the speech-language pathologist's job to work on that.

The speech-language pathologist explained Jennifer's oro-motor limitations and the implications for speech. She emphasized how well Jennifer could communicate specific intentions using her symbol book. In anger, John responded, "Who are you to tell me that my daughter won't talk. There are doctors who know more than you do who would never say that. Besides, you only have a job because my wife and I established this clinic." The matter was not resolved at this meeting.

The following week, Jennifer arrived for her physiotherapy session. She was crying when the physiotherapist met her, so the physiotherapist looked for her communication book and found instead the Macaw communication device that had been ordered independently by her parents and programmed for sentences by her classroom teacher. The physiotherapist placed the device on Jennifer's lap tray while Jennifer continued to cry. Jennifer pushed several buttons but her communicative message was not clear to the physiotherapist. The physiotherapist found a symbol board belonging to another child and gave it to Jennifer who then indicated that she felt sick and had a sore tummy.

A Lawyer's Perspective

This situation appears to centre around the parents' (father's) inability or unwillingness to appreciate his daughter's limitations as well as lack of trust on the part of the parents with the speech-language pathologist who conducted Jennifer's assessment.

The parents are entitled to obtain a second opinion. Since the father appears to believe that physicians have the greatest amount of expertise, it may be advisable for the speech-language pathologist's supervisor or director to discuss arranging a second consultation done by a senior speech-language pathologist and a physician. One might hope that the physician would indicate that speech-language pathologists have the appropriate expertise to make this type of assessment and that most physicians would generally accept a qualified speech-language pathologist's assessment.

Parents, as the legal guardians of their children, have the right to make the care and treatment decisions and choices they want for their children. The state will not interfere

unless parental choices subject their children to a serious risk to life or health. If there is a range of alternative therapies, clinicians may recommend the one(s) they believe would be the best, but it is up to the parent to choose. On the other hand, if the parent(s) want to choose something that goes against the clinician's judgement - as being harmful or of no utility whatsoever - the clinician should disclose this to the parent, along with the reasons why the clinician holds this view and therefore cannot provide the child with the treatment the parent wants. In this situation, the clinician should not "abandon" the family, but should offer to send the parents to another speech-language pathologist or to send them to a clinician of their choice.

An Ethicist's Perspective

Many of the everyday problems in clinical ethics turn on issues of communication. Jennifer is not the only one in this case who has problems in communication.

Who should set the goals of therapy? The hallmark of a family-based approach is that the client and his or her family should be the primary decision makers. The professional's first role is to inform those whom they serve about the situation, about the forms of therapy which are available and about the outcomes that are attainable. After this is done and the family has made its decision, the professional can provide the requested service.

In very many instances, this division of labour works reasonably well. However, there are at least two ways in which it can run off the tracks. In the first place, the client or the family may doubt the professional's competence to make the diagnosis and prognosis. In the second, they may reject all of the proffered treatment plans. Both of these problems appear in Jennifer's case. Once the problems crop up the central questions change dramatically.

What is a therapist to do when the client's family sets unrealistic treatment goals? How should the speech-language pathologist react when the family pursues a course of action which seems unlikely to offer any benefit, and which might even be detrimental to the client?

At the very outset of the discussion we must recognize the possibility of genuine differences of professional opinion. The judgments that a parent's cherished goal lies out of their child's reach, or that a particular therapeutic approach offers no hope of attaining the goal, should never be the idiosyncratic opinions of the lone practitioner. These clinical judgments must be supported at least by a consensus of professionals in the appropriate field, and preferably by solid scientific argument.

John obviously distrusts the newly graduated speech-language pathologist's judgments about Jennifer's limitations. An immediate problem is to restore his trust in her clinical judgment since it will be impossible to maintain a stable therapeutic relationship without trust. The first step toward restoration would be to convince John that the speech-language pathologist's judgments are not idiosyncratic, and the standard way of doing this is by recommending a second opinion. Here the form is probably as important as the content. One might make the recommendation grudgingly, leaving the unspoken message "You don't trust me, so why don't you ask someone else?" It would be far better for the speech-language pathologist to view the second opinion as a way to confirm her own diagnosis and to ensure that there are no therapeutic options which she has overlooked.

It is also important to try to understand why the family continues to hold on to seemingly unrealistic expectations after so many years. One unfortunately common by-product of increasing specialization is the fragmentation of care, and with it the fragmentation of communication. It is impossible to ignore the possibility that Jennifer's parents' expectations have been built up over the years by a host of professionals, both within and outside of the health care system.

False expectations can be created in any number of ways. The teacher who helped John by programming the Macaw for sentences certainly led him to believe that Jennifer was now capable of communicating effectively without her symbol board. Many other professionals may have contributed to his beliefs, not by what they said or did, but by what they did not say. John's comment that no doctor would say that Jennifer won't ever talk is a telling one. The fact that no doctor has ever said this does not indicate that those who have treated her believe she will speak someday. This bleak prognosis may have been withheld because no one wanted to be the bearer of bad tidings, or because no one wished to destroy his hope prematurely, or simply because the physicians did not feel competent to make that prognosis.

The appropriate course of action is clear, at least for the immediate future. The speech-language pathologist should assist John in obtaining a second opinion about his daughter's abilities. The clinician should also ensure that all of those who care for the young girl, including her teacher and the aide, understand the situation.

Assuming that the second opinion confirms the first, John may accept that his daughter's potential is more limited than he had hoped and become more willing to negotiate a treatment plan that will optimize the potential she does have. However, there is no guarantee his beliefs and aspirations will change in the face of this additional information. Should

he remain adamant in his opinions, the speech-language pathologist must reconsider whether the maintenance of her relationship with Jennifer continues to serve any of this young client's interests. She should keep two points in mind as she undertakes this reevaluation. The first is that she is under no moral obligation to acquiesce in a treatment plan which offers no hope of producing the desired outcome. If John insists on conditions which doom all therapy to failure (e.g., if he insists that Jennifer can not use symbols for communication) then it would be acceptable to withdraw from the case.

The second point creates an unavoidable tension. Negotiation with the family may produce a new treatment plan which, although not an optimal one, still promises to benefit Jennifer. In this instance it is much more difficult to justify withdrawing from the case. The downside of family-centred care is that it occasionally calls on professionals to achieve less than they might.

Scenario C

Nicholas

Nicholas, a four-year-old boy, was assessed by a speech-language pathologist at a local community health centre. The results of formal testing indicated that he presented with a language disorder characterized by word finding problems, response latency, and unusual pragmatics. Using general guidelines for rating severity of language problems in preschoolers, the speech-language pathologist described Nicholas' language disorder as moderate in severity.

Nicholas was being considered for a community preschool program for children with special needs. This program received block grants from the department of education to secure services for eligible children. The department's guidelines specify that a language problem fall into one of three categories: mild, moderate, or severe. No distinction is drawn between the terms "delay" and "disorder". Children who present with multiple concerns (e.g., fine motor, gross motor, cognitive, sensory) in the moderate range are eligible for the complete grant. Children like Nicholas who present with a singular concern are eligible when their concern is described as severe.

As a result of the assessment, Nicholas was ineligible for funding. His parents, Don and Marie, want him to attend the community preschool where he would receive daily structured language intervention in a less restrictive environment rather than attend once weekly outpatient treatment at the local health centre.

Don and Marie approached a private speech-language pathologist and expressed their concerns regarding the funding criterion as well as their desire to have Nicolas attend the preschool program. This speech-language pathologist agreed to reassess Nicolas with a view to assisting in securing funding by qualifying his language disorder as severe. The same speech-language pathologist has contracted services with the department of education where she currently provides treatment and consultation to community preschool agencies, though not the specific program proposed for Nicolas.

A Lawyer's perspective

First, it is not inappropriate for the parents to seek a second opinion, nor is it inappropriate for an speech-language pathologist to provide a second opinion. What is problematic from a legal perspective is conducting a reassessment with a foregone conclusion in mind. That cannot be construed as the proper exercise of the clinician's professional judgement and could be construed by a professional licensing body as "unbecoming conduct" that could bring the profession of speech-language pathology into disrepute.

On the other hand, if the speech-language pathologist makes it clear to the parents that she will do a reassessment, but her diagnosis will not be influenced by the parents funding wishes, she is exercising her professional obligations to both patient and her profession in an appropriate fashion.

There is a potential conflict of interest if the speech-language pathologist in question is conducting assessments for the Department of Education. She should examine her contract with the government as she may be contractually precluded from doing private assessments for families who may wish to or need access to government funding.

Even if she is not contractually precluded from doing private assessments for families to access government funding, the speech-language pathologist should consider her obligation to each of her clients. Both the government and the family are her clients. She has an obligation to act in the best interests of her client(s). In this case, these interests may conflict. The speech-language pathologist should disclose to both the parents and the Department that she does assessments for the other. In the case of the disclosure to the Department, the family should not be identified, but the fact that the speech-language pathologist is providing a second opinion to a family should be disclosed. In some cases, disclosure of the potential conflict may be all that is necessary, while in other cases, the speech-language pathologist should not act for one of the clients.

An Ethicist's Perspective

This case illustrates a problem health care professionals will have to face with increasing frequency over the coming years as governments trim the amount of money available for health care and social programs. Responding adequately to the challenge requires a serious reconsideration of the moral responsibilities of health care professionals.

It is useful to begin by considering the position of Nicholas' parents, Don and Marie. They want what is best for their child, and they are willing to work the system to get that. There is nothing wrong with their advocacy for their child. Indeed, we expect responsible parents to vigorously pursue their children's welfare. And in most instances we expect parents to do this without paying particular regard to how their actions will affect other people's children. That is, we do not expect parents to worry about issues of distributive justice when they are being advocates for their child.

The central moral obligation of the health care professional is sometimes portrayed as similar to that of a parent. This idea is captured in what appears as the overarching precept of the Canadian Association of Speech-Language Pathologists and Audiologists *Canon of Ethics*: "The ethical responsibilities of the members require that the welfare of those served professionally be considered paramount" (1992).

At its worst, this portrait of the professional's role leads to paternalism, in which the professional usurps the decision-making prerogative of the client — the attitude roundly and justly criticized in much recent literature in bioethics. But at its best, this portrait holds the professional to an admirable high standard of single-minded devotion to the welfare of the client. But the precept requires careful interpretation if it is to provide guidance in hard cases. What does it mean to consider the client's welfare paramount?

At a minimum, the precept means that professionals should not place their own interests above those of the client. They should strive to avoid conflicts of interests; and, when this proves impossible, the interests of the client should be given primacy. But there is no reason to think that either of the speech-language pathologists in this case have personal interests which conflict with Nicholas'.

The precept might mean that, like the good parent, the good therapist should focus exclusively on the welfare of the client and ignore the interests of all others. On this interpretation, there is only one question a good speech-language pathologist should consider: "Does placement in the community-based program offer greater benefit to Nicholas than outpatient treatment offers?" If the answer is affirmative then the clinician ought to advocate for the boy's

placement in the program. Acceptance of this interpretation makes the actions of the speech-language pathologist who does assessments for the Department of Education ethically questionable. Instead of working for the welfare of the client, this professional appears to work as a gatekeeper for the system.

The interpretation would condemn the actions of this individual and of any other professional who performs a similar function. Yet this function of providing diagnoses in order to determine eligibility for special benefits is often performed by health care professionals. Who else could perform the function adequately?

There are limits on what professionals ought to do in promoting the welfare of their clients. Making the client's welfare paramount does not include misrepresenting their condition so that they qualify for special treatment. Misrepresentation would be a misuse of professional authority even if it was clear that the treatment would be of great benefit.

In the case at hand, there is some suspicion that the private speech-language pathologist has misused her professional authority. It appears that she has accepted the parents' money, not for conducting an independent objective reassessment of Nicholas' condition, but as payment for labelling the boy's condition 'severe'. It will remain hard for the private speech-language pathologist to climb out from under this shadow of suspicion as long as the funding guidelines use such vague descriptions as 'severe disorder' without providing a scale for evaluating severity.

But we should not overlook the fact that the first speech-language pathologist's evaluation falls under a very similar shadow. Parents and others will wonder whether she has labelled the condition 'moderate' simply to shelter her paymaster from an increased financial burden. The fact that both speech-language pathologists fall under suspicion suggests that the real solution to this case lies at a different level. What is needed is a more reliable method of determining who is entitled to special benefits. Creating such a method is a two-step process. The first step would be the development of a set of clinical guidelines for the classification of language disorders. The second step would be to ensure that these guidelines are used is setting the funding policy.

Neither of these is a task for the lone practitioner. The first is clearly a job for the professional community of speech-language pathologists. Good clinical guidelines should cover the entire gamut of language disorders and developmental delays; that is, they should be complete. The guidelines should also be reliable in application. Any two professionals who use them in assessing the same client

should usually come to the same diagnosis. Since the development of reliable and complete clinical guidelines requires considerable scientific and practical expertise, this task is primarily the responsibility of the relevant professionals.

Ensuring that the guidelines developed by the profession are actually used in deciding who receives various benefits requires engagement in the political process. In order to achieve this, professionals must lobby and negotiate with those who have the political authority to make such decisions. While such political activism is far removed from our traditional picture of the health care professional, it may be precisely what is now required if the welfare of clients is to be adequately served.

Scenario D

Jacob

Jacob, a three-year-old with severe global developmental delay and generalized hypotonia, was assessed by an audiologist, Stephen, as part of a team assessment at a tertiary care hospital. Using ABR, responses were elicited to unfiltered click stimuli presented monaurally at a rate of 31.1 clicks per second. The lowest level to which responses were obtained was 60 dBnHL bilaterally. Stephen recommended a trial of amplification with a view to reassessment in one month.

At the team meeting, Stephen presented the ABR results, their interpretation, and the recommendation for trial amplification. One team member then commented, "What's the point of putting hearing aids on this kid? He's so delayed that he's going nowhere." Stephen explained the clinical and professional reasons for his decision. However, the team member persisted by stating, "I know what you're saying, Stephen. But my point is that we can't keep pouring public money into cases where the outcomes are so dismal. So this child will hear something. So what? He's not going to talk. He's likely mentally retarded." Following this statement, the team erupted into a heated discussion over the issue of using public funds in cases where the benefit is not clearly agreed upon.

A week later, Stephen fitted Jacob with hearing aids. However, he still felt unease in light of the team's discussion. Stephen approached the hospital's bioethics committee requesting their input on the issue.

A Lawyer's Perspective

The legal issues in this case are concerned with the issue of "medically appropriate" treatment and possible discrimi-

nation. It is up to an audiologist to determine whether in his or her professional judgement, a patient would benefit from a particular treatment or therapy and to make a recommendation based upon this judgement and what would be in the best interests of the patient. In this case, Stephen has concluded that a trial of amplification should be conducted and if warranted - then the child should be fitted with hearing aids.

The view of the team member that hearing aids are wasted because of the child's mental disability and physical disability is problematic. Both the *Charter of Rights and Freedoms* and federal and provincial human rights legislation prohibit discrimination on the basis of physical and mental disability. So a lawyer would ask: Would the proposed treatment or procedure benefit this child? If so, it would be inappropriate not to provide it merely because the child has other handicaps.

Obviously, under some circumstances, a person would not benefit from a particular treatment or procedure precisely because of their handicap - for example, what if this child was comatose? Could it be said that the child would benefit from the amplification trial? Highly unlikely, and thus it would not be likely to be construed as discriminatory not to provide that service in such a case.

An Ethicist's Perspective

The central question posed by the team member can easily be stated: Does the benefit enjoyed by the client justify the expenditure? It is certainly a legitimate one to ask this question; indeed, asking it is unavoidable. But we must recognize both that the question is a dangerous one and that answering it is extremely difficult.

The question is difficult for a number of reasons. Often there is very little trustworthy information available regarding the effectiveness of treatments. In the absence of solid scientific data, clinicians are forced to rely on their hunches or unscrutinized experience. Unless well designed studies of the outcomes of interventions are conducted, the possibility remains that our health care resources are being wasted on procedures which simply do not work.

Determining effectiveness, while crucial, is only a preliminary stage in answering the central question. To say that a treatment is effective is not the same as saying it is beneficial. Whether treatment is judged beneficial depends upon how its effects (including its side-effects) are related to an individual's values, interests, and beliefs. Because values differ, the same treatment outcome may be considered beneficial by one client, met with indifference by another, and be seen as detrimental by yet a third.

Competent individuals can decide for themselves what outcomes they believe are worthy of pursuit, and at what cost. This provides the ethical underpinnings for the notion of informed consent. The clinician tells the client what outcomes are achievable, how likely the achievement is and at what cost; the client then chooses from among the treatment alternatives.

When the client is very young or as disabled as Jacob is the decision-making process becomes much more complex. The authority to give consent shifts to the client's guardians. Although they are not mentioned in the case, it is fair to assume that Jacob's parents should be fully informed and their consent secured before their son is fitted with hearing aids.

But this still does not bring us to grips with the full complexity of the team member's question. If the cost of fitting Jacob with hearing aids were borne entirely by his family, they could be left to decide whether the expenditure is worthwhile. When raised in the context of allocation of society's resources the issue becomes unavoidably comparative. Would the amount of resources spent to benefit Jacob bring greater benefits to another client? This is not the kind of query we are accustomed to, and there is a possibility that it will induce intellectual paralysis.

We are only just beginning to face the difficult questions of allocation as a society, so it is not yet clear how we should answer the challenge. However, past experience points out the dangers lurking in the questions. The first is that those whose disabilities prevent them from advocating for their own interests are most likely to have those interests disregarded. It is altogether too easy for those who have not experienced a disability to underestimate the benefit that a treatment can bring to a life. Moreover, once we attempt to compare benefits conferred on different individuals by similar expenditures of resources, there is an ever-present danger that the decision makers will tip the scales in favour of those who are most like them. Thus the team might decide to withhold treatment from Jacob so that the resources will be available to another child who is not mentally disabled.

There are no ironclad guarantees against discrimination. The most we can hope for is to craft an appropriate decision-making process, one that makes discrimination unlikely. When viewed from this perspective, the troublesome feature of the case is not the team member's question; rather, it is the forum in which he asked it.

When the issue in dispute is only about the effectiveness of a treatment, the meeting of the clinical team is the appropriate place to discuss it. Had the team member merely wondered whether the hearing aids would allow Jacob to hear anything, there would have been no cause for concern.

But his question went beyond the technical issue of effectiveness and into the realm of social policy. Decisions about social policy should not be made behind the closed doors of the clinical team's meeting.

Discussion

Several themes emerge from the preceding commentaries on these clinical scenarios. First, an understanding of the informed consent process will assist the clinician to clarify details of cases, such as those presented here, and therefore choose a course of action that maximizes outcomes while respecting the client's autonomy. However, as pointed out by our commentators, the distinction between results (i.e., clinician's perspective) and benefits (i.e., as defined by the client) deserves greater attention in discussions with clients and their families.

While the clinician's commitment to the client's right to autonomy is the hallmark of ethical care, there are inevitable conflicts with competing ethical principles. Commonly, clinicians feel this tension when faced with the additional commitments to act in the client's best interest (i.e., the principle of beneficence) and justify the use of scarce resources (i.e., the principle of distributive justice). As suggested by our commentators, the answer to these dilemmas may be found in the different levels of action available to us. Ethical care, then, becomes a matter of broadening our perspective to recognize our obligations to the client, the profession, and society.

Ethical care is demonstrated in the professional commitment to research investigating treatment efficacy, clinical guidelines, and decision-making. In another sphere, it is increasingly important for professional associations to direct efforts toward social and political action to secure recognition of the benefits of our interventions for people with communication disorders. This particular advocacy role will become significant as public debate turns to judgements of the worthiness of our clients and their claims to health care resources.

Finally, the interdependence of individuals in the health care system, as seen in the scenarios presented, is highlighted in trends such as team approaches, multiskilling, and family-centred intervention. Each trend impacts on traditional role assignments in ways that are not yet fully apparent. In the interim, clinicians can look to the legal-ethical foundation of the professions as a framework for change which will help to bring into focus a course of action in increasingly complex interactions.

Summary

Clinical ethics exploration cannot end with this one forum. Clinicians in the field of human communication disorders will pick up the threads of these themes and begin again the discussion with colleagues both formally and informally. The authors of this forum welcome input from clinicians and researchers to the ongoing dialogue regarding clinical ethics in speech-language pathology and audiology. Through this process we will arrive at a deeper understanding of the legal-ethical underpinnings of the *Canon of Ethics*.

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This classic text provides an overview of the field of bioethics with examination of the issues and analyses of the ethical underpinnings. Particularly useful to clinicians would be the second chapter, "Types of Ethical Theory", which describes and critiques the various theoretical approaches in bioethics.

Caplan, A., Callahan, D., & Haas, J. (1987). Ethical and policy issues in rehabilitation medicine. *Hastings Centre Report*, 51-20.

This special supplement represents the collaboration of rehabilitation professionals and ethicists and legal experts at the Hastings Centre, a research and educational centre dedicated to the examination of ethical dimensions of healthcare and related disciplines. The Centre regularly publishes *The Hastings Centre Report*, a source of scholarly discussion on these topics.

This supplement provides the reader with an introduction to the themes and ethical dilemmas particular to rehabilitation medicine. The authors point to the difficulty in defining and examining ethics in this area where there is little previous research, interactions are complex, and issues often seem illusive.

Haas, J., & Mackenzie, C. (1995). The role of ethics on rehabilitation medicine: Introduction to a series. *American Journal of Physical Medicine and Rehabilitation*, S3-6.

This article introduces a collection of papers exploring rehabilitation ethics. Various topics include the patient-provider relationship, resource allocation, team challenges, and goal-setting. This collection of articles introduced by Haas and MacKenzie are the result of the Hastings Centre research project on ethics in rehabilitation medicine. Though none of the articles specifically address issues particular to our professions, readers will be familiar with the topics and may find the perspectives offered educational insight.

Pellegrino, E., & Thomasma, D. (1988). *For the patient's good: The restoration of beneficence in health care*. New York: Oxford University Press.

These respected authors provide an extensive investigation of the inter-relationship between the principles of respect for autonomy and beneficence. Their examination of these two prominent bio-ethical principles has particular relevance for our field where we work with clients whose impaired communication impacts on their expression of autonomy.

Pellegrino, E., & Thomasma, D. (1993). *The virtues in medical practice*. New York: Oxford University Press.

Pellegrino and Thomasma offer a contemporary study of the virtues traditionally thought to exemplify the ethical health care professional.

Sherwin, S. (1992). *No longer patient: Feminist ethics and health care*. Philadelphia: Temple University Press.

Sherwin, a Dalhousie professor, presents a well written, thorough introduction to the various forms of feminist ethics. Her discussion of the role of oppression and political forces in health is enlightening to clinicians who wish to consider these points in working with minority groups and people with disabilities.