

## **Ethical Issues Related to the Use/Non-Use of Assistive Technologies**

**Albert M. Cook**  
**University of Alberta**

*Assistive technologies (AT) can provide significant assistance in accomplishing the tasks of daily living for persons who have disabilities. Five types of ethical principles underlie the distribution and use of AT: beneficence, nonmaleficence, justice, autonomy and fidelity. Beneficence, nonmaleficence, and justice, most directly affect the distribution of AT, leading to increased autonomy for persons with disabilities. In this paper, I develop the premise that it is principles of distributive justice that both inform and shape equitable assistive technology application and ultimately affect use and non-use of these technologies.*

### **Introduction**

In the last thirty years, the evolution and application of assistive technologies (AT) have greatly aided individuals with disabilities. Advances in the technical sophistication of these assistive technologies parallel the progress made in information and computer technologies. However, the effective application of these technologies to meet the needs of persons with disabilities tends to develop at a much slower rate as clinical experience and research studies yield increased understanding of the issues underlying successful assistive technology application. Success in the application of assistive technologies to ameliorate the problems faced by persons with disabilities is not universal, and there have been reports of significant disuse or abandonment of assistive technologies (Phillips & Zhao, 1993). Underlying this growth in the availability of assistive technologies and the emerging picture of both use and non-use by individuals with disabilities are some significant ethical issues. This paper will highlight some of these issues and place

the role of assistive technologies within the larger ethical view of disability.

### **Assistive Technologies defined**

There are many ways to define assistive technologies (Cook & Polgar, 2008). One widely used definition is provided in Public Law (PL) 100-407, the Technical Assistance to the States Act in the United States:

Any item, piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities. (Cited in Cook & Polger, 2008, p. 5)

Several aspects of this definition are important in the current context. First, by including all types of devices, an extremely wide range of applications is addressed. Second, the focus on *functional* capabilities of *individuals* with disabilities places the emphasis on real world outcomes that increase the autonomy of individuals with disabilities. Functional abilities underlie the most fundamental human activities of self-care, recreation and productivity through employment or education. Assistive technologies support these activities in specific ways that are matched to the needs of an individual (Cook & Polgar, 2008).

Public Law 100-407 also defines an assistive technology service as “any service that directly assists an individual with a disability in the selection, acquisition or use of an assistive technology device.” The law also includes several specific examples that further clarify this definition. These include (1) evaluating needs and skills for assistive technology; (2) acquiring assistive technologies; (3) selecting, designing, repairing, and fabricating assistive technology systems; (4) coordinating services with other therapies; and (5) training both individuals with disabilities and those working with them to use the technologies effectively. Each of these invokes consideration of ethical principles. Further, assistive

technologies are distinguished from educational or rehabilitative technologies that are typically used as one modality in an overall education or rehabilitation plan including development of skills for the use of assistive technologies (Cook & Polgar, 2008).

In order to provide a context for the combined aspects of assistive technology devices and services, Odor (1984) distinguished between *hard technologies* and *soft technologies*. The term hard technology is used here to describe the tangible assistive technology devices defined above. Soft technologies are the human areas of decision making, strategies, training, concept formation, and service delivery included within assistive technology services (Cook & Polgar, 2008). Soft technologies, without which the hard technologies are ineffective, are much harder to obtain than hard technologies because they are highly dependent on human knowledge rather than tangible objects.

### **The ethical context**

Kitchner (2000) describes the following five types of ethical principles. Underlying all of assistive technology development and application are the concepts of *beneficence*, ensuring that actions lead to good results that benefit others and *fidelity*, faithful, loyal, honest, and trustworthy behavior. A further important aspect of beneficence applied to assistive technologies is the identification of potential consequences of such application and the balancing of positive and potentially harmful aspects to maximize benefit to the individual. Nonmaleficence refers to the principle of not causing harm to others directly or through avoidance of actions that risk harming others. This concept is fundamental to clinical practice including that focusing on assistive technologies. A major goal for all assistive technology application is the increase in the independence of the individual. The clinical decision making process around the choice of particular assistive technologies for a given individual must also be true to the ethical principle of *autonomy*, i.e., focus on freedom of action and choice. Finally the ethical principle of *justice* deals with the issue of fairness in individual, interpersonal, organizational and societal contexts. In this paper, I will focus on three of these areas of ethics beginning with a discussion of the application of

beneficence and nonmaleficence to the use or non-use of assistive technologies. The implications for autonomy will be briefly addressed as well. With this background, I will focus on distributive justice principles and their application to the use of AT.

### *Beneficence and Nonmaleficence*

The term beneficence connotes acts of mercy, kindness, and charity in everyday understanding. In ethics, the concept is broadened to effectively include "all forms of action intended to benefit or promote the good of other persons ...helping them to further their important and legitimate interests..." (Beauchamp, 2008).

Nonmaleficence and beneficence are very different with different obligations. Rules of beneficence state positive requirements for action that is voluntary and is typically more demanding than rules of nonmaleficence. In contrast to nonmaleficence, failure to abide by the rules of beneficence rarely carries legal punishments. The rules of nonmaleficence are negative prohibitions of action that must be followed impartially. Failure to abide by these rules can have legal implications.

In health systems nonmaleficence and beneficence are typically viewed from the point of view of a physician's roles and responsibilities. As Beauchamp (2008) has observed:

there is no manifest reason why physicians' hands are tied to the single benefit of healing, complying with terminally ill patients' requests for physician-assisted suicide, and the like. If these are bona fide medical benefits, how far does the range of benefits extend? If a physician runs a company that manufactures wheel chairs for the elderly, is this activity one of supplying a medical benefit?

This extension of the physician's role to include assistive technology provision bridges the gap between discussions narrowly related to medical practice and those more broadly focused on the provision of hard and soft assistive technologies.

The principle of beneficence has specific features that relate to obligations that it invokes. Beneficence requires that we be responsive to the needs of others. While some of these needs are universal (the integrity of life and limb; disease and disability; the necessities of human sustenance), others are more local and context dependent (Herman, 2001). Herman argues that deficits in welfare sometimes are the result of social deficiencies and sometimes of natural deficiencies. The former constitute injustice, which there is a perfect duty to rectify (meaning it has to be done), whereas the latter don't constitute injustice, meaning that to rectify those is a matter of beneficence. On a Kantian scheme, beneficence is an imperfect duty, meaning that being beneficent some of the time is required, but there is no requirement to be beneficent whenever someone else needs assistance.

Assistive technology applications fall into the natural deficiencies category. Herman (2001) describes needs in this category as encompassing "the range of things a person might require to be an effective member of her community: from literacy to clean and presentable clothes" (p. 231). Assistive technologies are used to address needs across this broad spectrum of activities. In many cases, they are also employed to ameliorate chronic conditions. Obligations incurred through beneficence are much more difficult in cases of chronic need (Herman, 2001). Herman uses this analogy to illustrate her point: Consider, by way of analogy, a family with two children, where one child has such enormous physical and psychological needs (for health care, special training, and the like) that there are no non-subsistence resources in the family that could not be absorbed in bringing the first child toward normal self-sufficiency. Beyond some baseline of reasonable care, it is not obviously impermissible to expend resources on some of the higher-order needs of the second child (piano lessons, college). And this may be done without having to balance overall costs and benefits. If this intuition can be generalized, it would suggest that something like moral triage may have a role to play in adjudicating claims of need. If there are good reasons for families to take primary responsibility for some kinds of needs, there are equally good reasons for the community to be responsible for extreme conditions of individuals (p. 254). It is a community responsibility to provide hard and

soft assistive technologies as one response to the “extreme conditions of individuals.”

A specific case regarding assistive technology application serves to illustrate the role of beneficence and nonmaleficence in AT application.<sup>1</sup> The case involves a man (mid-late 30s) who has ALS. He was provided with an AAC device for communication. The man used his assistive technology system to indicate two things: "I would rather choke on a piece of good cod fish (very popular in Portugal) than have a GI tube" and "I do not want to be put on a mechanical ventilator at any time." He made the second request from a position of having worked as a volunteer with persons suffering from ALS and with the knowledge that the end stage of the disease results in the inability to breathe independently. If we consider this case from the point of view of beneficence--that is, what must be done to meet obligations--then, as AT practitioners, it is clearly within both our capabilities and our obligation to provide this individual with a means of communication. Are we obligated to continue to provide additional AT as his needs change as a result of the degenerative nature of the disease? Herman (2001) clearly believes that we are so obligated:

Normally, in providing aid, we take on new responsibilities. While just such extensions of responsibility often make people hesitate to help in the first place, they also mark out the contours of what it means to be members of a community. In some contexts, responsibility can be extended simply by embarking on a course of action. (p 231)

Thus, we are obligated to continue to meet his needs for communication within the capabilities of existing assistive technologies. This might include technology that is capable of detecting the last voluntary movements of which our patient is capable. Our obligation under the principle of beneficence only ceases when there is no possible AT that can be used with the individual's remaining physical ability.

A more difficult question is raised by the principle of nonmaleficence. Given his two requests, have we done harm or created the possibility of harm by providing autonomy through the use of the AAC device? If my colleague had not provided the AT in the first place, would the dilemma of how to deal with the individual's choices still exist? One view is presented by Gillon (1985), writing about obligations of the physician:

the principle of nonmaleficence may conflict with the principles of respect for autonomy. For example, the patient may want to take bigger risks of harm in the pursuit of benefit than the physician would advise... (It is important here to distinguish between benefit to the patient - the primary special obligation of a doctor - and benefit to others, whether these be the patient's family, other patients, or people more generally). (p 131)

Gillon is addressing a medical responsibility, but we can extend this concept to the role of the AT provider. What is the role of the AT and its provision in this situation? For example, my colleague indicated that the use of the AAC device by the patient rather than his normal speech to make the two requests cast doubt on whether the statements were valid. Does the AT practitioner's responsibility extend to demonstrating the authenticity of the patient's utterances or does it stop at the provision of a reliable communication system? Appropriate AT practice would dictate that the accuracy and reliability of any system provided would be evaluated as a normal course of service delivery (e.g., by demonstrating that the patient can use AAC to answer simple questions and establish his cognitive competence). Thus, the validity of the utterances is established as a part of the obligation of beneficence. Failure to provide an accurate and reliable system would result in nonmaleficence. If we accept the fact that the obligation relative to the AT extends only to the establishment of reliability and accuracy, then we are left with the conclusion that the AT is neutral in the dilemma created by the patient's two requests: i.e., the patient's utterances should be treated as they

would have been if uttered by his natural voice. Discussion of the issues raised by his request are beyond the scope of the present paper.<sup>2</sup>

This case illustrates challenges associated with the claim that avoiding harm has priority over doing well: a concept that is vigorously contested in moral philosophy (Gillon, 1985). In many clinical circumstances involving assistive technologies it is not feasible to separate beneficence and nonmaleficence. Application of either or both of these ethical principles may also conflict with personal autonomy (Gillon, 1985). In the case of AAC and ALS this is certainly evident.

As this case illustrates, beneficence cannot be reduced to obligations of nonmaleficence. However, the distinction between obligations of social justice and obligations of social beneficence is much less evident (Beauchamp, 2008). Justice and beneficence both focus on human welfare, but they each have distinct domains of concern (Herman, 2001). While justice and beneficence can both complete and limit each other, when discussing need, questions of injustice overwhelm other issues. In the remainder of this paper, I will focus on how the functionality and availability of assistive technology is affected by the notion of distributive justice.

### *Distributive justice*

“Principles of distributive justice are normative principles designed to guide the allocation of the benefits and burdens of economic activity” (Lamont & Favor, 2008, p. 10). There are a number of principles of distributive justice: (1) What is subject to distribution (income, wealth, opportunities, jobs, welfare, etc), (2) What is the nature of the subjects of the distribution (natural persons, reference classes (e.g., persons with disabilities), and (3) What should the basis of the distribution be (equality, maximization according to individual characteristics, according to free transactions, etc.)?

While there are many principles of distributive justice that differ in a variety of ways, assistive technologies have an impact in two broad areas: egalitarian and difference principles (Lamont & Favor, 2008). There are a number of different formulations of egalitarianism. The simplest is *strict egalitarianism* in which each person should have the same level of material goods and services. Major issues with this principle are indexing (i.e., how to count goods and services) and time frame (i.e., when to start the count). This approach also assumes equal need, a concept that is clearly violated in the case of persons with disabilities. Individual disabling conditions can lead to significantly different needs for support from technology. In the area of mobility, for example, there are a range of needs from canes to walkers to manual powered wheelchairs to powered wheelchairs. All serve the same basic need of mobility, but each places different demands on the user to satisfy that need and accomplish the desired end result of independent mobility. Thus, *strict egalitarianism* is not useful as a basis for considering distributive justice for AT.

*Resource-based principles* (also Resource Egalitarianism) prescribe equality of resources with outcomes determined by people's free use of resources. In this approach, unequal natural endowments (e.g., a disability) should attract compensation to avoid creating a disadvantage in life prospects. Several principles of distributive justice focus on difference. One of the most widely discussed of these is the *Rawls Difference principle* (as cited in Lamont & Favor, 2008). Here, the main motivation is equal respect for persons and each person has an equal claim to a fully adequate scheme of equal basic rights and liberties. Social and economic inequities must be such that they are of the greatest benefit to the least advantaged members of society. Rawls also assumes that his representative "person" is rational and able to rationalize his or her own self interest. His argument, then, is based on recognition of inequality that negates the rights of citizens who might be deemed "irrational." The notion that someone who is rational should decide for those deemed "irrational" is problematic when considering persons with disabilities and the distribution of assistive technologies.

Dworkin (1981a, b) uses a wider concept of resources to include both external resources, such as money and physical objects and internal resources, such as physical and mental capacities. In his view, if two persons have the same amount of external resources, but one of them is disabled, then the distribution of resources between them is not equal. However, assistive technologies can alter this “internal/external inventory” by augmenting physical or sensory or cognitive function and thereby increasing the allocation of internal resources. While this is attractive in the context of hard and soft assistive technologies, it fails to recognize fundamental differences in the required external resources given variation in internal resources.

*Welfare-based principles* emphasize that what is of primary importance is the level of welfare of people, but it is hard to define “welfare.” One variant, *utilitarianism*, substitutes utility for welfare where utility is defined as pleasure, happiness, or preference-satisfaction. A difficulty is that utilitarianism fails to take individual differences of persons into account.

*Desert-based principles* of distributive justice are based on what people deserve in light of their actions as distinguished from entitlements. Differing versions identify differing bases for deserving. The primary ones are Contribution (contribution to social product), Effort (effort in work activity) and Compensation (reward by the recovery of costs incurred in work activity). Finally, the wide variety of Feminist theories of distributive justice are also based on difference, but the focus is on consideration of what difference gender makes to the subject matter or study of justice.

As Johnstone (2007) points out, none of the resource-based principles of distributive justice capture the full range of factors that must be considered. Individuals with disabilities may derive very different degrees of benefit from the same set of resources. As she states:

Very often simple redistribution fails because it is not resources alone that determine the achievement of

valued states, and people are often unable to benefit from redistribution programmes for the very same reasons they cannot access resources on their own account. (Johnstone, 2007, p. 75)

In the next section, I will argue that capability theory (Nussbaum, 1992; Sen, 1982) provides a much more appropriate base for discussion of the distribution of assistive technologies.

There are three aspects of distributive justice that are relevant to considerations regarding the distribution of assistive technologies: (1) what is subject to distribution, (2) the nature of the subjects of the distribution, and (3) what the basis of the distribution should be. In what follows, I will relate the current understanding of assistive technology devices and services to the principles of distributive justice in order to examine two basic questions. (1) What are the implications of varying principles of distributive justice for fairness in the availability of assistive devices to those individuals who could benefit from them? (2) How does the availability of assistive technologies influence principles of distributive justice, both negatively and positively? In what follows, I will discuss the ways in which assistive technologies can change the perspective of egalitarianism and reduce perceived and real differences in capabilities and functions. I will also discuss how assistive technologies can lead to greater difference and decrease the perception of capability and participation by person with disabilities, concepts central to distributive justice.

### **The Distribution of Assistive Technologies - what is subject to distribution?**

When discussing distribution of assistive technology devices and services the initial point of reference is typically the device (i.e., hard technology) or service (i.e., soft technology) that is viewed as the commodity to be distributed (Cook & Polgar, 2008). AT as the “what is distributed” includes both hard and soft technologies because success depends as much on the support received by the individual as on the appropriateness of the device itself (Scherer, 1998).

One of the major indicators of the failure of assistive technologies to meet the needs of disabled people is for the individual to stop using the technology. This situation has been described as device abandonment. Phillips and Zhao (1993) surveyed more than 200 users of assistive technologies and identified four factors that were significantly related to the abandonment of assistive technologies: (1) failure of providers to take consumers' opinions into account, (2) easy device procurement, (3) poor device performance, and (4) changes in consumers' needs or priorities. In this context there are models for service delivery as well as for assessment and selection of AT to meet needs of an individual with a disability (Cook & Polgar, 2008). AT abandonment has also been shown to be dependent on the personal meaning attributed to assistive devices and how this influences integration of AT into the user's daily life (Pape, Kim, & Weiner, 2002). Users of assistive technologies were primarily concerned that AT use did not stigmatize them as disabled and detract from their autonomy, i.e., their identification as individual persons. Other factors contributing to successful use were expectations of how the device would function and the social costs of using the device (i.e., cost/benefit of device use). These considerations clearly indicate that, from the point of view of the person who receives and uses the technology, there are social and emotional factors that have a very significant impact on the sense of well being of the individual. Soft technology is often required in order to make an assistive technology system useful. For example, a device is more likely to be used properly when adequate training in its use is provided to both the individual user and caregivers, and there is less likelihood of abandonment (Chen, Mann, Tomita, & Nochajski, 2000).

There is increasing emphasis in the assistive technology literature on the outcomes obtained through use of assistive technology devices and services (Fuhrer, Jutai, Scherer, & DeRuyter, 2003). The shifting of emphasis from device provision to functional outcomes broadens the "what is distributed" question to one of "what is accomplished." The most meaningful perspective on effective outcomes is to view those that lead to the greatest independence and provide the greatest opportunity

for societal participation. This perspective transforms the “what” from the device and service to the vehicle for independence.

Peterson and Murray, writing about ethics and AT from the AT perspective, noted that,

In all of our discourse, it is important to remember that ethical AT service provision is not the ultimate outcome of all our collaborations, but a vehicle to help achieve more noble goals, including client skill and competency development, maximum independence, full participation in society, and integration into local communities. Success in these areas results in increased quality of personal and professional spheres of life for people with disabilities using AT service. (Peterson & Murray, 2006, p. 66)

Ethicists writing about this same subject have reached a similar conclusion, but grounded it in principles of distributive justice. The key ethical principle is attributed to Sen (1982) and Nussbaum (1992), who proposed that it is really “capabilities” that should be distributed equally, including the ability to move about and the power to participate in the social life of one’s community (Hansson, 2007). If one views assistive technologies as enabling and leading to expanded independence, then they in effect may be represented as “capabilities.” Short of being equated to capabilities they can surely be viewed as contributing positively to the capabilities of a person with disabilities. Elaborating on this concept, Becker (2005) observed:

The controlling idea is that our fundamental social institutions should be designed not only to permit but to promote, when necessary, the development of the physical and psychological capabilities that make human flourishing possible. (p. 35)

As Anita Silvers notes when describing the Americans With Disabilities (ADA) civil rights act:

... benefiting equally from public transportation means no more than being able to travel the same public routes with approximately the same expenditure of time and money as other individuals. ... persons in wheelchairs

use public transit with as much facility as able-bodied persons do. (Sillers, 1995, p. 46)

Silver's view is not directly a distributive perspective; rather she takes justice to require full access to social participation. Thus she does not formulate fundamental distributive principles, but rather takes distribution of access-making resources (such as assistive technologies) to be an instrument of participatory justice (Sillers, personal correspondence, 2009). Thus, the availability of assistive technologies can impact on participation and can help to increase the internal resources inventory for a person with a disability. The net effect of the availability of assistive technologies is the distribution of capabilities, not merely a distribution of resources or technologies. As Hanson concludes:

... there is no doubt that Amartya Sen's capability approach ... [applied to] assistive technology would therefore lead to priority-setting practices that are continuous with well-established ethical criteria for the distribution of resources for therapeutic technologies. (p. 263)

Nussbaum (1992) distinguishes three types of capabilities: (1) basic functional capabilities such as being able to see, hear, speak and move; (2) developed internal capabilities such as the ability to express a point of view or develop a social relationship, and (3) internal capabilities combined with an environment in which they can be expressed. Hard and soft assistive technologies can expand all three types of these capabilities. Writing about computer ethics and capability theory, Johnstone (2007) describes three dimensions of instrumental freedom, a concept central to capability theory that can be enhanced by technology-based intervention. These are the building up of internal capacities, providing resources and creating an empowering environment. Hard and soft assistive technologies, can address all three of these areas. An example used by Johnstone is that of an individual who needs a wheelchair. The hard technology, the wheelchair itself, addresses part of the resource provision. The soft technology (training, skill development,

strategies of use) bridges the resource provision and development of internal capacities dimensions. Universal design and environmental adaptation address the final category. Taken together, these aspects of AT have the potential to enhance capability for persons with disabilities.

Beauchamp (2008) has discussed the way in which “capabilities theory” merges concerns of justice and beneficence. Beauchamp references the work of Madison Powers and Ruth Faden in which they identify six distinct and core dimensions of well-being: health, personal security, reasoning, respect, attachment, and self-determination. In Powers and Faden’s view, “Each of these dimensions is an independent concern of justice, and the “job of justice” is to secure a sufficient level of each dimension for each person” (Beauchamp, 2008). The goal of social justice is to provide the social structures necessary to ensure that these dimensions exist for each individual. Beauchamp argues that “...this theory might just as well be stated as the job of beneficence.” It is the focus on distributions intended to enable persons to reach certain functional levels that closely links the ethical principles of beneficence and justice with the expressed intent of a capabilities theory.

*The Distribution of Assistive Technologies - the nature of the subjects of the distribution*

Having argued that it is actually capability that is being distributed, we can turn to the second question posed by distributive justice: that of the nature of the subjects of the distribution. Clearly, it is persons with disabilities for whom assistive technology devices and services are provided. Members of this group deviate from the norm by the existence of a physical or mental deficit sufficient to prevent them from performing one or more of life’s major activities (Silvers, 1995). Identification of distributive justice that is identified with equality would assume that all people are the same regardless of their individual circumstances, histories and positions (Silvers, 1995). Such distributive justice schemes are typically based on equality of opportunity or equality of outcomes. Both of these can be altered by assistive technologies,

perhaps reducing the marginalization of some individuals. However, as noted by Silvers, the dilemma for individuals with disabilities lies not in their personal differences but in how the sheer specificity of historical circumstance marginalizes them socially and, consequently, morally as well. (Silvers, 1995, p. 52)

Even within this broad group of persons with disabilities, there will be differences beyond the severity of the disability. For example, the undereducated or underemployed woman with a disability is unlikely to get the technology or training necessary to compete with her nondisabled counterparts educationally or vocationally (Parette & Scherer, 2004). Cultural aspects will also be important. For example, some families may want more immediate response, especially when advocating for children with developmental disabilities. Persons with more severe disabilities may require more extensive AT devices and services that also require more financial resources (Peterson & Murray, 2006). Impacting on the basic capabilities of a person who has a disability may also lead to other inequalities or to at least bring those inequalities into focus. Silvers (1995) provides an example of this situation:

In the everyday life of persons mobilizing in wheelchairs, their inequality, both as experienced by them and in the eyes of others, manifests itself not in the inability to walk but in exclusion from bathrooms, from theaters, from transportation, from places of work, and from life-saving medical treatment. Suppose that most persons used wheelchairs? Would we continue to build staircases rather than ramps? (p. 48)

The distribution of assistive technologies in itself is not sufficient to remove the inequalities faced by persons with disabilities. However, the distribution of opportunity through assistive technologies can provide some equalization of functional ability and thus positively alter the societal perception of dependence through this increased functionality.

Nonetheless, the subjects of the distribution of assistive technologies are also persons who have, as a group, been consistently shown to be the target of negative societal bias leading to a negative impact on interpersonal relations (Silvers, 1995).

Unfortunately, the use of assistive technologies can exacerbate this negative perception of people with disabilities by creating a stigma that calls attention to the disability rather than to the capability of the individual (Parette & Scherer, 2004). Specifically, the use of AT can stigmatize elderly people by making them appear less functional and more vulnerable. The degree of stigma differs according to the type of assistive technology, (e.g., hearing aids, wheelchairs, etc). Thus, in this case the assistive technologies contribute negatively to the desired equalization of the members of the subject group, actually increasing their difference from the majority of the population. Individuals who are already members of a token group may be less likely to use assistive technology if it singles them out and is perceived to reinforce stereotypes held by others (Parette & Scherer, 2004). Individuals with developmental disabilities and their families may feel that the use of assistive technologies generates heightened attention and scrutiny and therefore makes them less comfortable in community settings. These assistive technology factors tend to contribute to greater perceived or real difference between persons with disabilities and the norm. Policies based on justice ignore difference only up to the point at which it results in significant deviance from the norm (Silvers, 1995). Beyond that point, difference may be discounted (formal justice) or revalued positively (interactive justice). Stigmas associated with assistive technologies can also be dispelled if the technology becomes very familiar (e.g., the use of lap-top computers for augmentative communication or wheelchairs for mobility).

*The Distribution of Assistive Technologies - what should be the basis?*

The final question posed by distributive justice is what basis will be used for distribution. When considering this question, assistive technology specialists typically relate justice to government provision of sufficient funds. For example, Peterson and Murray (2006) refer to the equitable

distribution of goods and services in the presence of a limitation on those goods and services as fundamental to the principle of justice. Additionally, there is a recognition that persons with more severe disabilities will require more extensive technological intervention, and therefore will demand higher levels of funding, begging the question of what is an adequate level of funding, and what is used to determine that level.

Tarvydas and Cottone (1991) proposed a four-level hierarchical model of ethical decision-making in clinical practice based on need. Their intent was to apply the hierarchy to ethics in education, supervision, and research. The first two levels in their model deal with service delivery through clinical activities such as the assessment and recommendation of assistive technologies and training. Level Three includes the institutional/agency level that is operationalized by the institutions and agencies, public or private, that are responsible for ensuring adequate provision of assistive technology services in an efficient and effective manner. Ideally, the ethical principle of justice is met when individuals with disabilities have their AT needs satisfied in a cost-effective manner. Systematic evaluation of outcomes achieved and the corresponding expenditures will allow efficient and effective use of resources which, they argue, "satisfies ethical considerations of justice" (Peterson & Murray, 2006, p. 65). From an assistive technology point of view, the application of appropriate distributive justice principles dictates that the needs of persons with disabilities will be met through the distribution of assistive technologies and this will be followed by reduced dependence upon governmental and other publically-funded services.

One commonly applied criterion for the distribution of hard assistive technology is medical necessity, in which funding for technology is prescribed by therapeutic need only not by social needs for employment, education or relationships (Canning, 2005). When the concept of medical necessity is applied to assistive technology distribution, it is often focused on finding the least expensive technology. This can be in conflict with an individual's needs based on quality of life considerations or the social perspective of disability. Further, independence and function are

not necessarily related to medical necessity. For example, Canning (2005) provides the example of the US Medicare failure to fund a powered wheelchair that is necessary for mobility in the community (including employment) if the person can use a manual wheelchair in the home. Thus, the outcome of a wheelchair evaluation will be influenced by available funding in the first instance, not the needs of the individual. The type of funding source will also play a role in what is available to the individual with a disability. Canning (2005) describes two separate scenarios in which the need of the individuals is nearly identical, but the outcome is dramatically different because of the funding available to them (public in one case, private insurance in the other). If the goal of distributive justice is the equal distribution of capability, then medical necessity fails to achieve that goal because it ignores family goals and life style preferences and focuses on meeting therapeutic needs with a minimum of public expenditures.

The question is whether AT is considered a basic commodity to be consumed by all who need it or a benefit only available through gate keepers like physicians and insurance companies who determine "medical necessity" as a generic concept. As long as persons with disabilities are viewed as recipients of care, the distribution will be driven by the concept of exceptional treatment, not equal opportunity (Silvers, 1995). Problems of resource distribution and resource limits are central in medical ethics, and these problems are accentuated by the consideration of assistive technology devices and services (Hansson, 2007). Despite the lack of ethical discussion on how assistive technologies should be weighed against other social objectives, Hansson concludes that "[u]nfortunately, full adaptation of all technologies to people with all kinds of disabilities would not be economically realistic in practice" (p. 261). Further, a physical or mental impairment that cannot be repaired by medical procedures leads to automatic reduction in eligibility for many kinds of care for an individual with a disability and represents recognition that to be disabled is to be relegated to a lower quality of life (Silvers, 1995).

As long as we focus on benefit or resource allocation as the key principle of distributive justice, disabled persons will be perceived as either

dependent or recipients of an unequal share of available resources. Becker (2005) takes an alternative approach by focusing on the “transaction” involving distribution of justice to disabled persons. He argues that a transaction involves reciprocity, and that the nature of that reciprocal arrangement is what should guide our discussion of distributive justice.

An underlying concept of distributive justice principles is fairness and equality for everyone (Lamont & Favor, 2008). However, theories of justice are built on notions of mutual advantage, aggregate welfare and participation. As Becker (2005) points out, social contract theory does not adequately or securely locate entitlement in the interests of the individual, and theories that maximize aggregate welfare discount unique interests such as those of persons with disabilities (especially cognitive). Becker builds the case for considering all of this from the point of view of reciprocity, stating: “I will argue that an adequate conception of reciprocity goes a long way toward answering the challenge that disability poses to theories of justice” (p. 12). An important element in distributive justice is the concept of mutual advantage in transactions. Often the mistake is made of restricting the franchise for transactions to healthy, property owning adult males (for example). Becker points out that these types of restrictions are self defeating but they can be easily corrected. More difficult is the restriction to free, independent and roughly equal parties in transactions of mutual advantage that appears to exclude or at least marginalize persons with disabilities. If assistive technologies are successful in increasing independence for persons with disabilities, their existence may reduce the marginalization of persons with disabilities. Becker acknowledges this possibility by describing assistive technologies in the context of offsetting the limitations of disabilities.

In order to deal with the challenges of mutual advantage when disability is included, Becker develops the concept of reciprocity in the transactions that underlie mutual advantage. He relates reciprocity to justice: “Reciprocity is a matter of making a fitting and proportional return for the good or evil that we receive” (p. 18). He cites four over-

simplifications of reciprocity that limit its application in the current context. These are restrictions of reciprocity to:

- Direct one-to-one exchanges
- In-kind returns
- Scope restrictions
- Equal absolute value

Many transactions are actually indirect transactions in which the initial act is somehow reciprocated through a secondary transaction or at a later time. This is particularly true in consideration of assistive technology “transactions” in which a device or service is provided, and this results in a corresponding increase in capability. The increase in capability subsequently leads to greater participation in education or employment or other social activity whereby the individual makes a contribution resulting in some net gain for another person or persons or institution. Likewise, rarely does a transaction result in the initial “giver” receiving back exactly what she gave (i.e., an in-kind transaction). Scope refers to the type of interaction. Becker is particularly concerned that we not limit our considerations to voluntary transactions. When we require absolute equal value in transactions, we impose an unfair burden on persons with disabilities and can create hierarchical relationships in social and political life that disadvantage those with disabilities. Each of these restrictions has the potential to limit the ability of a person with a disability to participate in reciprocal transactions based on mutual advantage.

In order to deal with the perceived transactional imbalance between persons with disabilities and those without, Becker proposes the use of “marginal sacrifice” as the underlying concept in reciprocity. In this conception of reciprocity there is “...a return that is proportional to the sacrifice made by the givers rather than proportional to the benefit we have received” (Becker, 2005, p. 27). “Mutual advantage” is the “justifying aim” in marginal sacrifice reciprocity, which is mutually advantageous, unlike equal benefit. Marginal sacrifice does not imply equal suffering but, rather, a consideration of the comprehensive economic and non-economic opportunity costs.

... the response required by reciprocity to the burdens imposed (on the healthy) by other's disabilities. ... [is the provision of] ... capability-building rehabilitation wherever it can be effective in restoring or sustaining reciprocal social life. (Becker, 2005, p. 36)

For disabled persons, assistive technology devices and services will be included in a capability-building rehabilitation program.

### **Summary/Conclusions**

Principles of beneficence and nonmaleficence broadly define the scope of our responsibilities regarding the provision of AT devices and service. The broader medical and health system implications of these principles can also be impacted on by the provision of AT. Autonomy for individuals who have disabilities can also be directly impacted on by the provision of AT services and devices.

The distribution of assistive technology devices and services based on the perceived or real need of persons with disabilities is not justified on strict egalitarian ethical principles. When considering a difference-based rationale, there are also problems with such concepts as medical necessity, which fails to acknowledge need and focuses instead on available resources. Need is also weakened as a principle for distributive justice by the over-simplifications inherent in the consideration of reciprocal transactions. However, a reciprocity based on mutual advantage in which the distribution is of capability, not AT goods and services, provides a useful approach to distributive justice that offers a more complete view of the role of AT in the lives of persons with disabilities. By viewing distribution of capability, rather than devices or services, we can focus on the outcomes obtained by persons with disabilities. Peterson and Murray (2006) summarize the situation from an AT perspective:

In all of our discourse, it is important to remember that ethical AT service provision is not the ultimate outcome of all our collaborations, but a vehicle to help achieve more noble goals, including client skill and competency development, maximum independence, full participation in society, and integration into local communities. Success in these areas results in increased quality of personal and professional spheres of life for people with disabilities using AT service. (p. 66)

Silvers (1995), offers an ethicist's view:

What informs this mandate is recognition that accessibility would now be a commonplace, not a novelty, were the majority, not the minority, of the population disabled. (p. 49)

Distributive justice for persons with disabilities, based on the concepts of reciprocity through mutual advantage in the distribution of capabilities, has the potential to lead to the outcome desired by Peterson and Murray and the societal change desired by Silvers.

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### **Author Note**

Dr. Albert Cook is Professor of Speech Pathology and Audiology in the Faculty of Rehabilitation Medicine and Special Advisor to the Provost at the University of Alberta. He served as Dean of the Faculty from 1994 to 2007, and chair of the Health Sciences Council from 2000-2007. He was formerly Professor of Biomedical Engineering at California State University, Sacramento. Dr. Cook is currently a member of the Seniors Advisory Council of Alberta. Dr. Cook's research interests include augmentative and alternative communication, biomedical instrumentation and assistive technology design, development and evaluation. His most recent research has focused on the use of robotics with young children who have severe disabilities to develop and assess cognitive and linguistic skills

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<sup>2</sup> Discussion of the issues raised by his request are beyond the scope of the present paper.

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