

# Attitudes and access: advancing the rights of people with disabilities

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## Abstract

BARRIERS TO MOVEMENT AND COMMUNICATION in the physical environment prevent people with disabilities from enjoying the same rights, privileges and opportunities as other members of society. The guidelines presented by Drs. Karen E. Jones and Itamar E. Tamari in this issue (page 647) remind us that access to physicians' offices is one area in which improvement is greatly needed. But, as Jones and Tamari acknowledge, accessibility involves more than the removal of physical barriers. The greatest obstacles faced by disabled people are often attitudinal ones. Programs that place responsibility for rehabilitation and integration within the community can foster a better understanding of the issues. Family physicians and other professionals must work with communities to change the attitudes, beliefs and behaviours of policy-makers and the public. Until significant progress is made on this front, problems of access that serve to marginalize people with disabilities will persist.

## Résumé

LES OBSTACLES À LA CIRCULATION ET À LA COMMUNICATION dans l'environnement physique empêchent les personnes handicapées d'avoir les mêmes droits, privilèges et possibilités que d'autres membres de la société. Les lignes directrices présentées par les D<sup>rs</sup> Karen E. Jones et Itamar E. Tamari dans le présent numéro (page 647) nous rappellent que l'accès aux bureaux des médecins est un domaine où des améliorations s'imposent vraiment. Or, comme les D<sup>rs</sup> Jones et Tamari le reconnaissent, l'accessibilité va plus loin que l'élimination des obstacles physiques. Les attitudes sont souvent les plus grands obstacles auxquels font face les personnes handicapées. Des programmes qui placent dans la communauté la responsabilité de la réadaptation et de l'intégration peuvent aider à mieux comprendre les enjeux. Les médecins de famille et les autres professionnels doivent collaborer avec la communauté pour faire changer les attitudes, les croyances et les comportements des décideurs et du public. Tant que l'on n'aura pas fait des progrès importants sur ce front, les problèmes d'accès qui marginalisent les personnes handicapées persisteront.

**M**ost of the common practices of society have a "non-disabled" bias, and the norms by which everyday life is perceived are based on the experience of non-disabled people. This bias has the effect of marginalizing people with disabilities, who are prevented from enjoying equal opportunities in health care, education, employment and recreation. The exclusion of disabled people is not always intentional, but it has a negative impact on their quality of life and that of their families.<sup>1</sup>

Because people with disabilities are often denied their basic human rights, in 1993 the United Nations General Assembly adopted a set of standard rules<sup>2</sup> to ensure that disabled people were accorded the same rights, freedoms and obligations as other members of society. These rules grew out of experience gained during the United Nations Decade of the Disabled (1982–1993). Although they are not compulsory, the rules express a strong moral and political commitment to the equalization of opportunities for disabled people. The rules deal with a host of issues related to disability and rights, and specifically address the question of accessibility:



## Editorial

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States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. For persons with disabilities of any kind, States should introduce programs of action to make the physical environment accessible and undertake measures to provide access to information and communication.<sup>2</sup>

Barriers to movement and communication in the physical environment prevent people with disabilities from contributing fully to the economic and cultural life of their communities. Such barriers, while being problematic in themselves, also cause financial strain. Many activities of daily living that are physically and financially accessible to most people are costly for those with some form of disability. Expenses related to alternative means of transportation, communication aids, recreational, educational and vocational activities and assistance with personal care contribute to a reduced quality of life and can perpetuate a state of dependence.<sup>3</sup> In presenting guidelines for improving the accessibility of physicians' offices, Drs. Karen E. Jones and Itamar E. Tamari (page 647) raise the question of whether improved access to health services will increase the "economic burden" for society as a whole. However, as they point out, improvements in access would increase the functional and social capacities of disabled people and thus improve their ability to contribute to the economy. The high financial and social cost of maintaining people in institutional settings must also be taken into account. Money has been spent on facilities, technology and programs that foster dependence, rather than on measures to promote independence.<sup>4</sup>

Although Jones and Tamari discuss accessibility primarily in terms of "being able to use, enter or reach a structure or office" they acknowledge that accessibility is a broader issue. With respect to employment, for example, disabled people are affected not only by the physical inaccessibility of the workplace but also by the negative attitudes of the able-bodied. Traditionally, they have been "the last to be hired and the first to be fired."<sup>5</sup> Studies have consistently shown that disabled people as a group are poorer than nondisabled people and have fewer years of schooling, fewer occupational skills and higher rates of unemployment.<sup>6</sup> Their situation can often be described in terms of a reduced level of performance, lack of employment and income, and exclusion from participation in the community. In addition, disability can adversely affect the employment opportunities of family members who provide care.<sup>1</sup>

Within the last decade many countries have become more aware of their limitations in providing the health and social services necessary to advance the rights of people with disabilities.<sup>6</sup> In many societies, even basic health care and rehabilitation services are not available to everyone. The lack of accessibility to health care in general is

related to the concentration of resources and personnel in urban centres. In addition, increased competition for financial resources has limited the development of many health and social services for disabled people. As Jones and Tamari report, until the Decade of the Disabled international development of health and social policies largely ignored the needs of people with disabilities.

The pressure to expand and develop services for disabled people stems from a number of factors, such as decreasing resources, increasing demand, population growth and a limited health care workforce.<sup>4</sup> The traditional "medical model" of health care and rehabilitation emphasizes a predominantly urban-based, specialized and institutional approach to care. Although this approach has significantly advanced the scientific base of professional practice, there has been an observable shortfall in the development and implementation of accessible and user-friendly programs and services.

Community-based rehabilitation stands in contrast to this traditional approach. It is

a strategy based on community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities themselves, their families and communities and the appropriate health, education, vocational and social services. Community based rehabilitation empowers persons with disabilities to take action to improve their own lives, and contribute rather than drain or deplete whatever scarce resources that are available, thereby benefiting all the community.<sup>7</sup>

Community programs are an attractive alternative to traditional hospital- and physician-driven systems, which are not necessarily the most appropriate, socially acceptable or cost-effective means to deliver services. Community-based programs ensure that people with disabilities are able to maximize their physical and mental abilities, have regular access to appropriate services and enjoy opportunities for full integration. Such programs emphasize the role of the family and the community and promote the right of disabled people to live within their communities and participate fully in all aspects of life. Nevertheless, people with disabilities can encounter the same barriers in community-based programs as they face in all their life experiences. Family physicians and other professionals must work with communities to change the attitudes, beliefs and behaviours of policy-makers and the public. Until significant progress is made on this front, economic and social barriers will persist.

In the realm of health care, advocacy groups have arisen from the basic need of disabled people to make informed decisions about issues affecting their lives. They are a response to the traditional medical approach, which neglects the involvement of people with disabilities in the decision-making process. Some action-oriented people have realized that the solution to many problems can be



found in the strengths and resources of the community of people with disabilities and in organizations that can lobby for equal rights and opportunities. A new sociopolitical model of disability has emerged, according to which "disability" results from society's failure to adjust to the needs of the person with a (perceived) disability rather than from that person's incapacity to meet the requirements of society. Through organizations such as the Canadian Council for the Disabled and Disabled People's International, people with disabilities represent themselves to decision-makers, advocating the adoption of public policies that facilitate the inclusion of people with disabilities and their families. With active members in more than 100 countries, Disabled People's International provides a united voice for people with disabilities in the international forum. Guidelines and policies are now being introduced with respect to accessibility on many levels. The advancement of rights and privileges for disabled people has, for the most part, resulted from their own efforts and determination. As a group, people with disabilities have not regarded health care professionals as being sensitive to their broader social and cultural needs.<sup>8</sup>

Sometimes the greatest barriers to community living for people with disabilities are presented by prevailing attitudes rather than by physical obstacles. Negative reactions, stereotyping and misconceptions remain major stumbling blocks. Placing the responsibility for rehabilitation and integration within the community can foster a better understanding of the issues. In many societies there is now a greater appreciation of the fact that people with disabilities possess the talents, skills and capabilities to be active in the community and competitive in the workforce.

In the long term, the most profound changes will result from education. Because community-based strategies for dealing with disability issues have largely been ignored at the undergraduate and graduate levels of health science education, the ability of health care professionals to understand and meet the needs of disabled people living in the community may be limited. To be responsive to the needs and values of the communities they serve, these professionals need to gain knowledge and experience outside of the institutional setting. Public education programs and vocational training initiatives have raised awareness in the private sector of the important contribution that people with disabilities make to our society. Attaining a similar awareness in the realm of health care remains an important challenge.

As Jones and Tamari argue, there are strong medical and ethical arguments for making physicians' offices more accessible to people with disabilities. They suggest that

many family physicians have not implemented such simple and inexpensive adjustments as dedicating space for a wheelchair in their waiting rooms. It would be interesting to know more about the context in which this information was provided — that is, whether the physicians they surveyed were reflecting on their own experiences in making their offices accessible or responding to suggestions for improvement. Indirectly, this may reflect the degree of importance that family physicians assign to the issue of office accessibility. The fact that no earlier studies exist on the question of office accessibility underscores the need for immediate attention to this issue. Jones and Tamari measure the need for accessibility in terms of "costs, benefits and potential harms; most important, they underscore the need for physicians to understand their responsibility to satisfy the basic rights of disabled patients and their families. In Helander's words,

If we could all act in a spirit of solidarity, recognizing the principles of human equality, if we could bring services to all in need, if we could contribute to a better quality of life, reduce the dependency and transfer power to them, then we would restore to disabled people their right to a life in dignity.<sup>6</sup>

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