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Sandra G. Leggat\* Gaétan S. Tardif\*\* The Impact of the Purchaser Provider Funding Model in the United Kingdom on the Independence of Persons with Disabilities: Implications for the Canadian Health Care System

Through large-scale system restructuring, a number of jurisdictions around the world have adopted a purchaser provider approach to the funding and delivery of health care services. In this model, a decision-making body, such as a regional board, is provided with a budget to purchase health care services on behalf of, and in response to the identified needs of a defined population. This paper reviews the purchaser provider funding model of the United Kingdom and comments on the impact of this system on the health needs of individuals with disabilities. Generally, the purchaser provider split in the U.K. appears to have resulted in greater fragmentation and inequity in care among the disabled population. The implications of the use of this type of funding method on individuals with disabilities residing in Canada are then discussed in relation to the Canadian Charter of Rights and Freedoms.

La restructuration à grande échelle des systèmes de santé a résulté, dans de nombreuses juridictions, en une approche acheteur-fournisseur pour le financement et la provision des services de santé. Avec ce modèle, une autorité, telle un régie régionale, reçoit un budget pour l'achat de services de santé au nom d'une population définie et en réponse à leurs besoins identifiés. Cet article fait une revue du système d'allocation de ressources acheteur-fournisseur en place au Royaume-Uni et commente sur l'impact de ce système sur les besoins de santé des personnes handicapées. En général, la séparation acheteur-fournisseur au Royaume-Uni semble avoir résulté en une fragmentation accrue et une iniquité de soins parmi les personnes handicapées. Les implications de l'utilisation de cette méthode de financement pour les canadiens atteints d'une incapacité sont par la suite discutées en relation de la Charte canadienne des droits et libertés.

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#### Introduction

Throughout history, people with disabilities have faced physical, systemic and attitudinal barriers not experienced by non-disabled members of the population in gaining access to health care. The purpose of this paper is to focus specifically on the impact of the implementation of a purchaser provider model of health care planning and delivery on the access of the disabled population to health care services.

Through large-scale system restructuring, a number of jurisdictions around the world have adopted a purchaser provider approach to the funding and delivery of health care services. In this model, a decisionmaking body, such as a regional board, is provided with a budget to purchase health care services on behalf of and in response to the identified needs of a defined population. It has been suggested that through the market competition which is thereby created, the purchaser provider model promotes greater accountability within the health care system, redistributes power from health care providers to health care consumers, and facilitates the achievement of cost efficiencies. Conversely, purchaser provider systems have been described as elaborate mechanisms to co-opt the public into rationing of health care services.<sup>2</sup> Rationing of health care is perceived as being culturally unacceptable and politically dangerous in many jurisdictions, as it has the potential to create inequity in access to health care. In a system with a purchaser provider split, the purchasing authorities may meet the expenditure targets assigned by the provincial government through service rationing, at arms length from the government. Other authors have suggested that splitting purchaser from provider increases transactional costs required for negotiating and monitoring contracts within the system with limited operational benefits.<sup>3</sup>

Although there is debate about the real and potential impacts of a purchaser provider system of health care planning and delivery, there has been no comprehensive evaluation of this method of organizing a health care system. Yet, more jurisdictions restructure their health care systems with market competition as an ostensible underlying principle. For example, in Canada, the province of Ontario recently established a purchaser provider split for community-based and long-term care ser-

<sup>1.</sup> See C. Ham, "Managed markets in health care: the U.K. experiment" (1996) 35 Health Policy 279.

<sup>2.</sup> See S. Harrison & G. Wistow, "The purchaser/provider split in English health care: towards explicit rationing?" (1992) 20 Policy & Politics 123.

<sup>3.</sup> See P. Howden-Chapman & T. Ashton, "Shopping for health: purchasing health services through contracts" (1994) 29 Health Policy 61.

vices. This model introduces competitive bidding for services for a vulnerable sector of the population who require in-home and long-term care services. Its introduction presumes that competition will enable quality health care to be provided for this population at lower cost to the system. However, the focus on cost reduction in competitive bidding may result in inequitable access to health care by vulnerable and marginalized segments of the population.

A purchaser provider system has been in place in the United Kingdom (U.K.) since 1990. This paper will review the purchaser provider health system in the U.K. and analyze its impact on persons with disabilities receiving health care. Generally, the analysis will suggest that implementation of a purchaser provider split in health care has the potential to create significant inequities in access to health care services among individuals with chronic and disabling conditions.

## I. The Definition of Disability

Before the rise of organized medicine in the 19th century, legal authorities carried responsibility for judging who could be classified as disabled.4 As the medical profession advanced, based on principles of scientific objectivity, physicians became the authority to pronounce on disease and disability. Individuals with disabilities comprise a vulnerable, but growing sector of society and there is often still a need for a legal definition of disability or handicap. The World Health Organization (WHO) defines disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." This definition of disability is used in many areas. For example, Statistics Canada uses this definition in the Health and Activities Limitation Survey (HALS), a postcensual survey in which individuals identify their limitations in activities of daily living. The WHO definition of disability is considered by many to reflect a medical perspective that suggests there is a normal state and deviations from normal are abnormal. Use of a definition of disability that is based on a normal/abnormal distinction has been challenged because what is considered normal may change depending on the culture, time period or perspective used by the observer. 6 Normal and abnormal are not

<sup>4.</sup> See J. Craddock, "Responses of the Occupational Therapy Profession to the Perspective of the Disability Movement, Part 1" (1996) 59 Br. J. Occupational Therapy 17.

<sup>5.</sup> World Health Organization International Classifications of Impairments, Disabilities and Handicaps (World Health Organization, 1980) 143.

<sup>6.</sup> See e.g., I. Illich et al., Disabling Professions (London: M. Boyers, 1977).

objective measures. However, it is this perspective that is taken in the *Ontario Human Rights Code*, where section 10(1) of the Code provides:

"because of handicap" means for the reason that the person has or has had, or is believed to have had,

- a. any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, including diabetes mellitus, epilepsy, any degree of paralysis, amputation, lack of physical coordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a dog guide or on a wheelchair or other remedial appliance or device,
- b. a condition of mental retardation or impairment,
- c. a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- d. a mental disorder, or
- e. an injury or disability for which benefits were claimed or received under the *Workers' Compensation Act*.

Illustrating an alternate view, the Institute of Medicine in the U.S. defines disability as "a limitation in performing certain roles and tasks that society expects of an individual." This definition suggests that disability is not inherent in the individual, but results from the interaction between the biological and psychological make-up of the individual and his or her environment. The extent of a disability is therefore dependent upon the social and physical environment of the individual. This perspective is reflected in the U.S. Rehabilitation Act of 1973 which defines a handicapped individual as

"any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."9

Notwithstanding the *Ontario Human Rights Code*, <sup>10</sup> the bio-social interpretation of disability has been supported by the Supreme Court of Canada, in *Andrews v. Law Society of British Columbia*, where McIntyre J. stated that the "accommodation of differences ... is the essence of true

<sup>7.</sup> R.S.O. 1990, c. H.19.

<sup>8.</sup> E.N. Brandt & A.M. Pope, eds., Enabling America. Assessing the Role of Rehabilitation Science and Engineering (Washington: National Academy Press, 1997) S-5.

<sup>9. 29</sup> U.S.C.A. §706 (West 1985).

<sup>10.</sup> R.S.O. 1990, c. H.19.

equality" and in Eaton v. Brant Board of Education, where "it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled persons from participation, which results in discrimination against them."12 These judgements provide support for a bio-social view of disability over the medically-based normal/abnormal perspective.

In law, mental disability has been identified in statutes and in the Constitution as distinct from physical disability.<sup>13</sup> Within the health care sector, definitions of disability have generally been ambiguous for political reasons, often related to service funding. 14 Typically, emotional and cognitive impairments resulting in disability are considered separately from physical disability based on the medical perspective of the duality of mind and body. 15 Mental health is organized and funded separately from physical health within the health care system. For this reason, the analysis in this paper is limited to individuals with physical disability, although it would be surprising if the experience of people with mental disabilities were markedly different.

With developing medical technology, more people with disabilities are surviving with more severe impairments, for much longer life spans. 16 The effectiveness and appropriateness of any health care system change in meeting population needs will be reflected through the impact on the disabled population. A number of authors have stressed that a test of the adequacy of a health care system is its ability to maintain the vital margin of health of individuals with disabilities.<sup>17</sup> This group is more vulnerable to health problems than persons in the general population and maintenance of their health has importance in ensuring their quality of life within the society in which they live. In addition, a focus on the health of the disabled population has financial implications, in that the overall costs of care may be reduced. The analysis in this paper will address three areas of importance: equalization of opportunities for the disabled population

<sup>11.</sup> Andrews v. Law Society of British Columbia, [1989] 1 S.C.R. 143 at 169, 56 D.L.R. (4th)1.

<sup>12.</sup> Eaton v. Brant County Board of Education, (1997) 142 D.L.R. (4th) 385 at 406 [hereinafter Eaton].

<sup>13.</sup> Battlefords District Co-operative Ltd. v. Gibbs, [1996] 3 S.C.R. 566 [hereinafter Gibbs].

<sup>14.</sup> D.M. Fox, "Policy and Epidemiology: Financing Health Services for the Chronically Ill and Disabled, 1930-1990" (1989) 67 Milbank Q. (Supp. 2, Pt. 2) 257.

<sup>15.</sup> P. Roberts, "Theoretical Models of Physiotherapy" (1994) 80 Physiotherapy 361.

<sup>16.</sup> Craddock, supra note 4.

<sup>17.</sup> See A.I. Batavia et al., "The primary medical needs of people with disabilities" (1988) 14 Am. Rehabilitation 9 and G. DeJong, A.I. Batavia & R. Griss, "America's Neglected Health Minority: Working-age Persons with Disabilities" (1989) 67 Milbank Q. (Supp. 2, pt. 2) 311 at 320.

addressed both by decree of the United Nations and through national legislation preventing discrimination against people with disabilities, the primordial importance of an integrated system for individuals suffering from chronic or disabling conditions, and the impact of existing financial constraints within the health care system on the evolution of the purchaser provider model.

Four possible mechanisms for purchasing of health services for disabled people were identified in the literature:

- 1) a budget is provided to a care manager to purchase on behalf of the individuals;
- 2) a budget is held by a region and practitioners apply to the region for reimbursement for services provided;
- 3) the budget is used by the region to fund services directly through mechanisms such as block grants to providers; or
- 4) the budget is distributed to the service users for them to purchase their own care.<sup>18</sup>

Although all of these purchasing mechanisms have been tried to some extent, the most common approach within the purchaser provider models implemented to date involves purchasing by a regional health authority through contracts or grants to providers. A purchaser provider system structured around service users obtaining the funds and purchasing their services directly or in association with a care manager might have resulted in different outcomes from those discussed in this paper. However, few jurisdictions are likely to give up control of the purchasing budget to individual consumers. Government funders and service providers maintain professional control of assessment and care purchasing, and management for control of finances, but also because the medical model suggests that persons with disabilities are dependent, requiring care. <sup>19</sup>

# II. The Purchaser Provider Model in the United Kingdom

The National Health Service (NHS) was created in the U.K. in 1948,<sup>20</sup> with the result that all public and voluntary hospitals were transferred to direct control of the central government. Funding of the system is through general taxation (81%), payroll taxes (14%) and user charges (4%). Like Canada, the NHS maintains a long standing separation between primary

<sup>18.</sup> A. Petch, J. Cheltham, R. Fuller et al., *Delivering Community Care Initial Implementation of Care Management in Scotland* (Edinburgh: The Stationery Office, 1996).

<sup>19.</sup> See e.g. A. Kestenbaum, *Independent Living*. A Review (Layerthorpe: York Publishing Services, 1996) at 4.

<sup>20.</sup> National Health Service Act 1946 (U.K.), c. 81.

physician care and secondary hospital care. In 1962, the NHS planned hospital development around district general hospitals, directly controlled by the government, serving one hundred to one hundred and fifty thousand people. In 1990, the NHS had undergone a series of reforms that resulted in health authorities and general practitioner fundholders carrying responsibility for purchasing health services from hospital and community trusts.<sup>21</sup> The Government announced that "to include greater flexibility and the more effective matching of patient needs and care, decision making was to be delegated to the local level".22 The NHS contracts between purchasers and the health care providers are management documents that specify the cost, quality and quantity of service purchased. These contracts are 'understandings' among the participants, rather than contracts enforceable by law.<sup>23</sup> Critics of the NHS reforms have suggested that the changes are leading to commercialization and privatization of health service provision within the U.K., as the purchasers can purchase from both public and private providers.

From 1988 to 1993, individuals with disabilities could apply to the Independent Living Fund (ILF) for funding to purchase their own personal assistance services. The original ILF was then replaced by a Fund which was much smaller in scope and had greater criteria which had to be met for support. The 1990 National Health Service and Community Care Act gave local authorities the funding responsibility for community care services. Critics have suggested that the Act eliminated the opportunity for people with disabilities to control their own lives by increasing their dependency on others to plan, purchase and evaluate needed community services.<sup>24</sup> In 1991, responsibility for wheelchair services was also devolved to the district level within the NHS, with each regional authority independently planning and purchasing wheelchairs and other assistive technology.

As part of the 1990 U.K. reforms, the Patient's Charter<sup>25</sup> was introduced to stress the priority of the health needs of the population. The Secretary of State for Health in the U.K. continues to stress that "patients must always come first."26 The Charter sets out the rights (which all

<sup>21.</sup> National Health Service and Community Care Act 1990 (U.K.), 1990, c. 19.

<sup>22.</sup> A. Maynard, "Can competition enhance efficiency in health care? Lessons from the reform of the U.K. National Health Service" (1994) 39 Soc. Sci. & Med. 1433 at 1437.

<sup>23. (</sup>U.K.), 1990, c. 19, s. 4(3).

<sup>24.</sup> V. Finklestein & O. Stuart, "Developing new services" in G. Hales, ed., Beyond disability: towards an enabling society (London: Sage, 1996).

<sup>25.</sup> U.K. Dept. of Health, The Patient's Charter & You (London: NHS, 1995).

<sup>26.</sup> V. Bottomley, Secretary of State for Health, as quoted in ibid.

patients receive all the time) and the expectations (which are standards of service the NHS aims to achieve, but not guarantee). The *Patient's Charter* <sup>27</sup> indicates consumers can "expect" the NHS to make it easy for everyone to use its services, including people with physical or mental disabilities. This suggests that individuals with special health care needs do not have a "right," but only an "expectation" of care. However, in 1995, the U.K. passed the *Disability Discrimination Act* "to make it unlawful to discriminate against disabled persons in connection with employment, the provision of goods, facilities and services or the disposal or management of premises . . . ."<sup>28</sup> This Act may elevate health and social service care from an "expectation" to a "right" for people with disabilities, as the Act specifies.<sup>29</sup>

- 19. (1) It is unlawful for a provider of services to discriminate against a disabled person -
- (a) in refusing to provide, or deliberately not providing, to the disabled person any service which he provides, or is prepared to provide, to members of the public;
- (b) in failing to comply with any duty imposed upon him by section 21 in circumstances in which the effect of that failure is to make it impossible or unreasonably difficult for the disabled person to make use of any such service;
- (c) in the standard of service which he provides to the disabled person or the manner in which he provides it to him; or
- (d) in the terms on which he provides a service to the disabled person.

# III. Equalization of Opportunity

In 1993, the United Nations General Assembly adopted the "Standard Rules on the Equalization of Opportunities for Persons with Disabilities", to ensure that they are accorded the same rights, freedoms and obligations as other members of society. Following from the *United Nations Decade of the Disabled* (1982-1993), the standard rules express strong moral and political commitment to the equalization of opportunities for people with disabilities.<sup>30</sup> Under this framework, people with disabilities should receive the same access to health and social services as the general population. Many jurisdictions have gone further in protecting the rights

<sup>27.</sup> Supra note 25.

<sup>28. (</sup>U.K.), 1995, c. 50.

<sup>29.</sup> Ibid.

<sup>30.</sup> M. Peat, "Attitudes and access: advancing the rights of people with disabilities" (1997) 156 Can. Med. Assoc. J. 657.

of people with disabilities in legislation. For example, the U.S. enacted the Americans with Disabilities Act of 1990.31 As discussed above, the U.K. passed the Disability Discrimination Act 32 in 1995. In Canada, the Canadian Charter of Rights and Freedoms<sup>33</sup> and the Canadian Human Rights Act 34 prohibit discrimination based on mental or physical disability. However, this legislation does not directly address systemic discrimination, and recently the Federal Task Force on Disability Issues made a strong recommendation for the Government of Canada to establish a Canadians with Disabilities Act as a complementary measure to existing human rights legislation. This Task Force stated that "Canadians have the right to expect inclusiveness, equality and the opportunity to achieve equal outcomes, no matter where they live."35 Based on the principle of equality of opportunity expressed above, individuals with disabilities should have equitable access to health care.

An objective of the purchaser provider model is to transfer power within the health care system from physicians and other providers to consumers.<sup>36</sup> The purchaser provider funding model is expected to promote greater system accountability among providers. Purchase of services in response to local needs suggests the end of provider domination in the planning and development of health care services. The purchasers set out clear expectations by which providers can be assessed, and if the contract terms are not met, the sanction is that contracts will not be renewed. This equalization of power within the system should be beneficial to individuals with disabilities requiring services. However, this has not proven to be the case. Implementation of a purchaser provider model requires the purchaser to focus on meeting the needs of the broader population within a fixed budget. The assessment of need by the regional authority is influenced by resource availability, and resource levels are centrally determined and based to a large extent on historical financial allocation.<sup>37</sup> Although the NHS reforms stressed

<sup>31. 42</sup> U.S.C.A. §12111.

<sup>32. (</sup>U.K.), 1995, c. 50.

<sup>33.</sup> Canadian Charter of Rights and Freedoms, Part 1 of the Constitution Act, 1982, being schedule B to the Canada Act 1982 (U.K.), 1982, c. 11. [hereinafter Charter].

<sup>34.</sup> R.S.C. 1985, c. H-6, s. 2.

<sup>35.</sup> Canada. Federal Task Force on Disability Issues, Equal Citizenship for Canadians with Disabilities: The Will to Act (Ottawa: Minister of Public Works and Government Services, 1996) at 12.

<sup>36.</sup> B. Salter, "The politics of purchasing in the national health service" (1993) 21 Policy & Politics 171.

<sup>37.</sup> M. Browne, "Needs assessment and community care" in J. Percy-Smith, ed., Needs Assessments in Public Policy (Buckingham: Open University Press, 1996).

that "to meet patients' needs, money was to follow the patient," in a regional purchasing model there is a shift in planning and service philosophy from care for individuals to care for the community. Individuals with special needs become members of a larger community pool and resources tend to be allocated to meet what is thought to be the greater good of the community. Resource allocation within purchaser provider systems is often based on needs assessment. Shortell et al. have stressed the importance of an outside-in approach to needs assessment to ensure a complete continuum of service is available to meet the needs of the population.<sup>39</sup> However, needs assessment techniques are only useful in identifying relative need, in that one need is greater than another need. Other than 'the greater the need, the greater the funding allocation', needs assessments do not provide resource allocation rules that lead to maximizing benefits to the community given the existing resource constraints.40 In fact, in relation to the U.K. system, Day and Klein state that needs assessment might prove to be a political and technical morass for the purchasers. 41 Needs assessments, by their nature, focus on the greatest needs within the population and not on the special needs of smaller constituency groups.

The existing wheelchair services in the U.K. are a clear example of lack of equalization of opportunity. A 1994 survey found that varying regional authorities had allocated service funding for wheelchairs to reflect very different priorities. This survey found annual budgets for wheelchair services ranged between 25 pounds per wheelchair user to 123 pounds per wheelchair user. Twenty-five pounds per annum is not sufficient for the maintenance of a single wheelchair, let alone purchase of new wheelchairs, and residents with disabilities served by authorities with this allocated level of service funding would receive substantially less wheelchair service than individuals in other parts of the U.K. Furthermore, health authorities adopted different systems for wheelchair assessment and prescription, and different staffing mixes in the wheelchair centres. This illustrates that even within the population with disabilities in the U.K. there is inequity in access to wheelchair resources.

<sup>38.</sup> Maynard, supra note 22 at 1437.

<sup>39.</sup> S.M. Shortell et al., Remaking Health Care in America (San Francisco: Jossey-Bass, 1996).

<sup>40.</sup> See C. Donaldson, "Economics, public health and health care purchasing: reinventing the wheel" (1995) 33 Health Policy 79.

<sup>41.</sup> P. Day, Accountability: Five Public Services (London: Tavistock, 1987).

<sup>42.</sup> Prosthetic and Wheelchair Committee. *National Prosthetic and Wheelchair Services Report 1993-1996*. (London: College of Occupational Therapists, 1996).

<sup>43.</sup> P. Jelier & A. Turner-Smith, "Review of Wheelchair Services in England" (1997) 60 Br. J. Occupational Therapy 150.

Associated with the transfer of power, the purchaser provider system might be seen to facilitate greater consumer input into the services required. However, this would be dependent upon consumers participating or providing real input to boards and staff of the purchasing authorities. In the U.K., the regional authorities comprise a maximum of eleven members: as the executive staff of the organization is included in this total, there are only five spaces available for non-executive members. There is little opportunity for consumer participation on these decisionmaking bodies, and even less opportunity for individuals from marginalized groups, such as those with disabilities, to have a voice in resource allocation. Generally, the 'politically powerful' dominate bodies responsible for health care resource allocation, 44 and it is likely that the health care needs identified by these participants will be very different than those expressed by members of society who are faced with disabling conditions. Even the 'general public' tends to put greater emphasis on technology and acute care services and less emphasis on services for disadvantaged populations.45 A 1994 survey of young people with physical impairments living in Inner London revealed decreasing access to necessary services.46

### IV. Integrated Service Delivery

Individuals with chronic conditions require integrated and coordinated care that treats chronic disease as an evolving condition, not a series of events. "Successful chronic illness programs ... maintain regular contact and prevent losses to follow-up, collect critical data on health and disease status regularly, meet educational and psychosocial needs, and respond appropriately to clinical needs."47 Integrated health care delivery is important because consumers with chronic conditions tend to be the most vulnerable in society: the frail, the elderly, and persons with physical or cognitive disabilities. The needs of these groups for service are greatest at a time when they may be unable to search out personally the best

<sup>44.</sup> See S. Lewis, "Regionalization and devolution: transforming health, reshaping politics?" Paper based on a presentation to the Robarts Centre Symposium, April 1-2, 1996 [unpub-

<sup>45.</sup> See J. Lomas, Reluctant Rationers: Public Input to Health Care Priorities, Policy Commentary C96-2 (Hamilton: McMaster University Centre for Health Economics and Policy Analysis, 1996).

<sup>46.</sup> Y. Doyle, P. Moffatt & S. Corlett, "Coping with disabilities: the perspective of young adults from different ethnic backgrounds in Inner London" (1994) 38 Soc. Sci. & Med. 1491. 47. E.H. Wagner, B.T. Austin & M. Von Korff, "Improving outcomes in chronic illness" (1996) 4 Manag. Care Q. 12 at 16.

services. The split of purchaser and provider may, in fact, result in greater fragmentation of care to populations with long term needs. Researchers in the U.K. have suggested that the separation between purchase and delivery has strengthened boundaries around existing patterns of service delivery, 48 making it difficult to achieve integrated service delivery. For example, since the reforms, NHS hospitals have increased focus on the diagnostic and treatment phases with less attention to the recuperative and rehabilitation phases of care. 49

The existing health care system has been designed to respond to emergency and acute episodes with highly technological services. The structure is not well suited to individuals requiring ongoing or intermittent care for chronic or disabling conditions.<sup>50</sup> In fact, individuals with a chronic or disabling condition who had previously received health care for an acute illness were astounded at the inability of the health care system to respond to their chronic illness in the same manner. 51 A funding model which strengthens these inadequacies will not provide better care for individuals with chronic or disabling conditions. Therapy providers in the NHS have observed greater fragmentation of care throughout the system.<sup>52</sup> The purchaser provider split in the U.K. has resulted in inconsistent provision of rehabilitation, with service users, carers, practitioners and managers expressing "increasing dissatisfaction about access to rehabilitation opportunities."53 People with disabilities in the U.K. complain that because different purchasing patterns result in the provision of different services, their access to rehabilitation varies according to where they live and this is considered to be unfair.<sup>54</sup> This fragmentation of service has been shown to have an impact on the functional independence of individuals with disabilities. A 1993 study found that functional deterioration had been detected among individuals subjected to fragmented care delivery, which directly affected the ability of these individuals with disabilities to live as independently as possible in the community.<sup>55</sup> On the other hand, individuals with disabilities who

<sup>48.</sup> Ham, supra note 1 at 279.

<sup>49.</sup> A.J. Harrison, Hospitals in England (London: Kings Fund Policy Institute, 1997).

<sup>50.</sup> See e.g., G.H. Williams, "Disablement and the ideological crisis in health care" (1991) 32 Soc. Sci. & Med. 517.

<sup>51.</sup> S.E. Thorne, Negotiating Health Care. The Social Context of Chronic Illness (Newbury Park: Sage Publications, 1993).

<sup>52.</sup> E. Pringle, "Occupational Therapy in the Reformed NHS: the Views of Therapists and Therapy Managers" (1996) 59 Br. J. Occupational Therapy 401.

<sup>53.</sup> J. Robinson & G. Batstone, Rehabilitation A Developmental Challenge (London: Kings Fund, 1996) at 1.

<sup>54.</sup> Ibid. at 6.

<sup>55.</sup> M.H. Williams & C. Bowie, "Evidence of unmet need in the care of severely physically disabled adults" (1993) 306 Br. Med. J. 95.

experienced regular multidisciplinary contact had more of their needs met.56

It has been suggested that separation of the purchase from the provision of health care increases accountability, as the purchaser has a duty to set out clear criteria by which the providers will be evaluated. However, this separation also separates the flow of feedback and evaluative information which, consistent with the principles of total quality management, is used to continually improve services. This forced separation limits the capacity for learning<sup>57</sup> among both the purchasers and providers. Research by Lomas et al.<sup>58</sup> confirmed that clinicians were often mistaken about their understanding of their own practice patterns. indicating that feedback was necessary to stimulate change. Researchers have found that a feedback loop, linking standard setting, information gathering, and service provision is essential for improvement in clinical practice, and that this feedback is most effective when presented close to the time of decision making.<sup>59</sup> Without this feedback, the purchaser provider system may discourage innovation in care delivery. Within the system there may not be sufficient incentives to ensure ongoing and integrated care of people with chronic or disabling conditions.

Individuals receiving care in the U.K. have consistently indicated that their physicians are not able to provide them with sufficient information on services and benefits that would assist them in achieving greater independence in the community.60 This may have been reflected in the reported levels of satisfaction of NHS patients. Satisfaction surveys conducted since the NHS reforms have shown that, with respect to the care provided through GP fundholders, people with specific diseases expressed greater satisfaction, but people with less well defined conditions have become less satisfied with care. 61 Individuals with ongoing but less clear health care needs may not be well served in a system where the purchasers and providers are not receiving the information required to

<sup>56.</sup> Williams & Bowie, ibid.

<sup>57.</sup> J. Stewart, "The limitations of government by contract" (1993) Public Money & Management.

<sup>58.</sup> See e.g., J. Lomas et al., "Do practice guidelines guide practice? The effect of a consensus statement on the practice of physicians" (1989) 321 New Eng. J. Med. 1306.

<sup>59.</sup> M. Mugford, P. Banfield & M. O'Hanlon, "Effects of feedback of information on clinical practice: a review" (1991) 303 Br. Med. J. 398.

<sup>60.</sup> R.A. Chesson & A.M. Sutherland, "General practice and the provision of information and services for physically disabled people aged 16 to 65 years" (1992) 42 Br. J. General Practice 473.

<sup>61.</sup> J.G. Howie, D.J. Heaney & M. Maxwell, "Care of patients with selected health problems in fundholding practices in Scotland in 1990 and 1992: needs, processes and outcomes" (1995) 45 Br. J. General Practice 121.

change practices to better meet community needs. As health care system data becomes disaggregated in systems with a purchaser provider split, there is a concern that information will not be available for ongoing improvement in care delivery.

#### V. Financial Constraints

The experience of publicly funded health systems would suggest that the demand for health care will exceed that of supply available within the percentage of gross domestic product allocated to health care that is socially acceptable to most industrialized nations. This means that there needs to be a mechanism in place to determine how limited health care resources will be used to meet service needs. Purchasing authorities are responsible for identifying health care needs of the defined population, establishing health care priorities and standards, and purchasing health care services to meet their needs. The provider organizations are responsible for the provision of services to the defined population in accordance with the contract with the purchaser. The separation of purchaser and provider has, in fact, created a rationing mechanism, using the purchasers to explicitly ration health care through their purchasing patterns. The purchasing authority has the responsibility of "targeting scarce resources where they will achieve the most health gain for the population served."62 Early indications are that this has resulted in inadequate service for people with disabilities. Although the important role of occupational therapists in assisting individuals with disabilities to reach their maximal functional level has long been recognized by other workers in the health care system, 63 occupational therapists in the U.K. have expressed concern that purchasers, GPs, and commissioners have a poor appreciation of how occupational therapy actually contributed to quality of life. This has been translated into insufficient occupational therapy service for the community.64

Another objective of implementation of a purchaser provider split in the U.K. was to increase the efficiency of the health system by creating competition among service providers. The health authorities and GP fundholders purchase the services required to meet the needs of the population from a range of different providers. The intent of this competition is to encourage purchasing based on the most appropriate service,

<sup>62.</sup> Ham, *supra* note 1 at 289.

<sup>63.</sup> See Williams & Bowie, *supra* note 55, and F.C. Edwards & M.D. Warren, *Health Services for Adults with Physical Disabilities* (London: Royal College of Physicians, 1990).

<sup>64.</sup> Pringle, supra note 52.

for the best price. However, the purchase of health care assumes that purchasers have good information on the required quantity of various types of health care services that need to be purchased. A survey of individuals with disabilities residing in the U.K. found that individuals with similar levels of disability received very different levels of service. For example, an individual with multiple sclerosis who was wheelchair dependent had not been seen by her general practitioner for eight years, while a similar individual in a different area received monthly home visits from her general practitioner. 65 It may be possible to encourage efficiencies in service delivery through competitive bidding. However, a larger issue for the population with disabilities is the determination of appropriate levels of service provision required to promote maximal functional abilities. Only when the appropriate service requirements have been determined, can the focus shift to improving the cost-efficiency of these services.

### VI. The Implications for Canadian Health Policy

Although most Canadian provinces (British Columbia, Alberta, Saskatchewan, Manitoba, Quebec, New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland<sup>66</sup>) have adopted regionalized health care systems, none has established a purchaser provider split. The regional health authorities existing in Canada generally have responsibility for determining population needs, establishing regional health plans, allocating funding, and monitoring or managing the delivery system. In most of the provinces, the regional authority has become the direct service planner and provider, as hospital boards have been dismantled by the government and replaced by the regional authorities. In these structures, health care workers become employees of the region. The direct provision of care by the region may overcome many of the identified shortcomings in the purchaser provider model that reduce the independence of people with disabilities. Information flow to provide the neces-

<sup>65.</sup> Chesson & Sutherland, supra note 60.

<sup>66.</sup> Regionalized systems have been created through the following enabling legislation: British Columbia - The Health Authorities Act, R.S.B.C. 1996, c. 180; Alberta - Regional Health Authorities Act, R.S.A. 1994, c. R-9.07; Saskatchewan - The Health Districts Act, S.S. 1993, c. H-0.01 (The Health Districts Amendment Act, S.S. 1996, c. 47); Quebec - An Act Respecting Health Services and Social Services, R.S.Q. 1977, c. 5-4.2; New Brunswick -Hospital Act, S.N.B. 1992, c. H-6.1; Nova Scotia - Regional Health Boards Act, S.N.S. 1994, c. 12; P.E.I. - Health and Community Services Act, S.P.E.I. 1993, c. 30; and Newfoundland -The Department of Health Act, R.S.N. 1990, c. D-15 as rep. by Executive Council Act, R.S.N. 1995, c. E-16.1, s. 23 and *The Hospitals Act*, R.S.N. 1990, c. H-9.

sary feedback to both purchasers and providers of health care services can be maintained within these regional models. However, it will be necessary for the regions to ensure coordination and integration of health services. British Columbia, Saskatchewan, Manitoba, and Prince Edward Island are the only provinces in which the provincial governments have explicitly given the regional authorities the responsibility for ensuring integrated service delivery. In those provinces where some health services are provided through contractual arrangements between the regional authorities and the providers (e.g., British Columbia and Saskatchewan), the regional authorities will need to structure their contracting processes to promote collaboration, and not the competition and confrontation that resulted from the purchaser provider split in other jurisdictions.

The majority of the Canadian provinces have structured health regions around the institutionally-based medical care sector. By not including primary care services, central provincial governments have limited the ability of the health regions to ensure that they function as a comprehensive health care system. The needs of people with disabilities go far beyond hospital care, yet, the regional systems in Canada are not structured to respond to these needs in a coordinated manner. In a large study of individuals with chronic and disabling conditions, the participants reported that they felt they had "fallen through the cracks of the health care system." If all of the components are included, the regional structures in Canada, unlike purchaser provider models, have the potential to eliminate the cracks experienced by individuals with disabilities.

Ontario is the only province to institute a purchaser provider model on a limited basis. The recently established Community Care Access Centres (CCAC) carry responsibility for purchasing long term care and community services, such as home care, for a defined geographic population.<sup>68</sup> The CCACs have not been in operation for long enough to make any statement about the impact on the Ontario system, but analysis of the impact of the purchaser provider split in the U.K. suggests that the success of the managed competition policy of the CCACs will rest on the ability of the CCAC Boards to balance the evaluation of the softer qualitative factors, such as quality of life and functional independence, against the harder economic reality of the cost of service delivery.<sup>69</sup> The

<sup>67.</sup> Thorne, *supra* note 51 at 131.

<sup>68.</sup> Long-Term Care Act, S.O. 1994, c. 26.

<sup>69.</sup> A.P. Williams, S.G. Leggat & J. Barnsley, "Defining, measuring and assuring service quality in community-based care: the case of long-term care reform in Ontario" (1997) at 5 [unpublished].

CCAC model, with focus only on long-term and community based service, has already created fragmentation of the services required by the population with chronic and disabling conditions. The imposition of the competitive focus of the purchaser provider split, which has been shown to impede integration in the U.K., will likely result in further fragmentation of health services for people with disabilities.

Based on the review of the purchaser provider model in the U.K., CCACs in Ontario risk the creation of unequal access to long-term and community services by the population with disabilities. Through the British North America Act, 70 responsibility for health care was assigned to the provinces, and the Charter applies "to the legislature and government of each province in respect of all matters within the authority of the legislature of each province."71 As the supreme law of the country, the Charter takes precedence over all other legislation. Changes in the organization and delivery of health care services which result in inequities in access to individuals with disabilities may be seen to violate the equality rights of the Charter. Under the Charter, "every individual is equal before and under the law."72 As such, equality rights are intended to protect the individual against discrimination, a guarantee which may assist persons with disabilities as health care purchasing may focus on the needs of the broader community at the expense of individuals with high needs. The Canadian Bar Association Task Force suggested that health care resource allocation decisions of physicians, hospitals, regional health authorities and provincial health ministries may infringe s. 7 or s.15 of the Charter.73

Section 7 of the Charter protects the right to life, liberty and security of the person. An individual with disabilities could challenge a resource allocation decision that results in decreased access to health care services on the grounds that the decision denies his or her right to life, to liberty or to security. In fact, a case in British Columbia held that when an individual died while waiting for heart surgery, there was a violation of the right to life.<sup>74</sup> It has been suggested that "[w]hile it [the *Charter*] does

<sup>70.</sup> Constitution Act, 1867 (U.K.) 30 and 31 Vict., c. 3.

<sup>71.</sup> Charter, supra note 33, s. 32(1).

<sup>72.</sup> Charter, supra note 33, s. 15. Section 15(1) states:

<sup>&</sup>quot;Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability".

<sup>73.</sup> Canadian Bar Association. Task Force on Health Care. What's Law Got to Do With It? Health Care Reform in Canada (Ottawa: The Association, 1994).

<sup>74.</sup> Sallis v. Vancouver General Hospital [1996] B.C.J. No. 758 (B.C.S.C.) (QL).

not give patients the right to demand any and all treatments, an argument can be made that it protects them from undue state interference with access to treatment."<sup>75</sup>

The Supreme Court of Canada has found that an infringement of s.15 requires:

- 1. that one of the four basic equality rights (e.g. equality before the law, equality under the law, equal protection of the law, and equal benefit of the law) be denied as a consequence of a legal distinction based on the enumerated prohibited grounds of discrimination or analogous grounds; and
- 2. that the denial results in discrimination in the sense of a burden, obligation or disadvantage to, or the withholding or limiting of benefits and advantages from, the claimant.<sup>76</sup>

This suggests that establishment of a provincial government health program which results in an individual with disabilities having access to health care which is less than that of the general public might be an infringement of s. 7 or s. 15 of the *Charter*.

Recent studies have suggested that use of regional authorities to garner public input on issues of rationing in health care may result in service limitations for disadvantaged populations. Public input into financial solutions for the health care system, either specifically through participation in the governance process or through consultative processes, has shown that members of the general public assign low priority to services for groups with high health care needs, 77 such as individuals with disabilities. Although not a purchaser provider split, the move within the Canadian system to involve the public in regional health system decision making may result in a reallocation of funding away from needed health services for people with disabilities. The purchaser provider model establishes a resource allocation process which results in a conflict between the rights of the presumed majority of citizens and the rights of some needy patients in the purchase of services. Observers of system change have identified the value conflicts generated with grassroots public involvement in allocation decisions<sup>78</sup> where there is this ability to

<sup>75.</sup> Canadian Bar Association Task Force, supra note 73 at 50.

<sup>76.</sup> J.R. Sproat, Equality Rights and Fundamental Freedoms (Toronto: Carswell, 1996) at 10-11.

<sup>77.</sup> See Lomas, *supra* note 45, and A. Bowling, B. Jacobson & L. Southgate, "Health service priorities. Explorations in consultation of the public and health professionals on priority setting in an inner London health district" (1993) 37 Soc. Sci. & Med. 851; C. Bowie, A. Richardson & W. Sykes, "Consulting the public about health service priorities" (1995) 311 Br. Med. J. 1155.

<sup>78.</sup> Lewis, supra note 44.

minimize the needs of some segments of the population. As illustrated above, the needs assessment approach to allocation decisions is weighted in favour of broader population needs. Generally, acute, highly technological life-saving medical interventions are seen as being more valuable by regional populations. However, a health system which focuses funding predominantly on acute interventions will not be able to respond to the objective of enabling people with disabilities to live an independent and dignified life in the community for as long as they are able and wish to do so, an objective that is a prime requirement of the goal of equalization of opportunity.

The philosophy of independent living by the population with disabilities favours solutions whereby individuals with disabilities are fully integrated within the community. However, the needs of some individuals may be better served through targeted or segregated strategies. In Eaton, the Court of Appeal and the Supreme Court of Canada illustrated different approaches related to the issue of integration versus segregation. The Court of Appeal suggested that segregation of a child with disabilities in a special class for children with disabilities against the child's wishes as expressed by the child's legal representatives, was discriminatory within the meaning of s. 15(1) of the Charter. However, the Supreme Court of Canada concluded that a segregated class would best meet the needs of the child in question and that this could not be construed as a violation of s.15. This suggests that a health care system has the opportunity to meet the needs of individuals with disabilities through both targeted and mainstream programs, and that not all general health care programs need to provide for the integration of individuals with disabilities if their needs can be found to be met more appropriately through segregated programs.

The commitment of Canadian society to equalization of opportunity requires access to services that protect or restore function without financial or other discriminatory barriers. In Gibbs, the Supreme Court of Canada found that an insurance plan that offered different benefits for physical and mental illness was discriminatory. 80 Sopinka J. wrote for the majority: "thus, a finding of discrimination on the basis of disability, even though only a subset of disabled employees is mistreated, is permissible according to case law".81 This suggests that in evaluating the impact of health care reforms, not only will the impact on individuals with disabili-

<sup>79.</sup> Eaton, supra note 12.

<sup>80.</sup> Gibbs, supra note 13 at 167.

<sup>81.</sup> Ibid

ties be compared with individuals without disabilities, but also the impact on individuals with different types of disabilities will have to be assessed. For example, a health authority which purchases physiotherapy services for individuals who have suffered a stroke, but provides inferior physiotherapy services for individuals who have multiple sclerosis, may be seen to discriminate against that subset of individuals with disabilities who have multiple sclerosis.

#### Conclusion

Although protected from discrimination by the *Charter* and human rights legislation, people with disabilities may find that current supposed reforms within the Canadian health care system reduce the ability of the system to respond to their health care needs. The analysis of the impact of the implementation of a purchaser provider model in the U.K. found that the incentives within the system were not consistent with good health care for individuals with chronic and disabling conditions.

Separating the purchase from the provision of health care does not support equalization of opportunity for those with disabilities, as inconsistent purchasing and provision practices are adopted by different regions. The purchaser provider model does not facilitate establishment of the integrated delivery system required by individuals with chronic and disabling conditions. As a mechanism to address the financial constraints within the health system, a purchaser provider model has the potential to result in inequitable rationing of services for disadvantaged populations such as those with disabilities. Canadian provincial governments are cautioned to identify and respect the needs of people with disabilities in future health care reforms and to be vigilant about protecting their entitlement to health care services in order to ensure that the tide of reform does not leave people with disabilities further disadvantaged in its wake.

The authors suggest the following as a statement of principles to guide the planning of health care reform in Canada in a manner which respects the needs of persons with disabilities:

- 1. There must be evidence that the proposed reform strives to eliminate systemic discrimination.
- Provision for meaningful involvement of persons with disabilities in the governance, planning and resource allocation activities must be assured.
- 3 There must be a recognition of the need to be accountable to the population with disabilities which is based upon a bio-social definition of disability appropriate for the Canadian context.

- 4. There must be evidence of the promotion of client independence, respect for consumer choice and a process for ensuring the ongoing evaluation of client satisfaction with services.
- 5. There should be opportunities for inclusion of both mainstream and targeted approaches as required to meet the needs of persons with disabilities.