

Physician Experiences Providing Primary Care to People with Disabilities

Expérience des médecins offrant des soins de santé primaires aux personnes présentant une incapacité



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Abstract

The 2003 Statistics Canada Health Services Access Survey found that 12% of Canadians polled did not have a family doctor, and 18% reported access problems such as long waiting times and difficulty contacting the doctor. Research has repeatedly shown that where a problem with access exists in the general population, it is considerably more severe in subsets of the population that are most disadvantaged. Statistics at both the national and local levels confirm that although people with disabilities have greater need for health services, including both institutional and community services, they also experience significant disadvantages in attempting to access service. The question explored in this study is how physicians' perceptions of disabled patients and behaviour towards them might affect access to primary care for adults with disabilities. The study used a qualitative interpretive approach to uncover physicians' perspectives on working with people with disabilities. Semi-structured interviews were conducted with a sample of 34 physicians in Eastern Ontario. Physicians were asked:

- How are disabled patients similar to/different from non-disabled patients?
- How are you as a physician different with disabled patients?

Physicians' perceptions, as revealed by their responses to these questions, were interpreted in terms of four types of barriers to access to primary care for disabled adults: physical, attitudinal, expertise-related and systemic. These barriers were examined for their impact on finding a doctor, getting an appointment, getting into the office and receiving a reasonable standard of care.

Résumé

L'Enquête sur l'accès aux services de santé (Statistique Canada 2003) montre que 12 % des Canadiens interrogés n'avait pas de médecin de famille et que 18 % d'entre eux ont signalé des problèmes d'accès tels que les temps d'attente et la difficulté à entrer en contact avec le médecin. Les recherches ont maintes fois démontré qu'il y avait un problème d'accès pour la population en général. Ce problème est d'autant plus sévère pour les secteurs de la population les plus désavantagés. Les statistiques nationales et locales confirment que bien que les personnes présentant une incapacité ont davantage besoin de services de santé, que ce soit des services institutionnels ou communautaires, ce sont également celles qui souffrent le plus de désavantages dans l'accès aux services. La présente étude pose la question à savoir si les différences dans la perception des médecins envers les patients présentant une incapacité et si leur comportement face à ces patients mènent à des iniquités d'accès aux soins primaires pour les adultes ayant une incapacité. La méthode qualitative/interprétative a été employée pour connaître le point de vue des médecins sur leur travail avec des personnes présentant une incapacité. Des entrevues semi-structurées ont été menées auprès d'un échantillon de 34 médecins de l'Est ontarien. On leur a demandé :

- En quoi les patients présentant une incapacité sont-ils semblables ou différents des autres patients?
- En tant que médecin, agissez-vous différemment envers les patients présentant une incapacité?

La perception des médecins, tel que le montre leurs réponses, a été interprétée en quatre types d'obstacles à l'accès aux soins primaires pour adultes présentant une incapacité : physique, psychologique, lié à l'expérience et systémique. On a étudié ces obstacles selon leur impact dans la recherche d'un médecin, dans la prise d'un rendez-vous, dans l'accès au cabinet du médecin et dans l'obtention normale de soins acceptables.

THE HEALTH SERVICES ACCESS SURVEY (STATISTICS CANADA 2004) clearly shows that Canadians experience problems with access to primary care. According to the survey, 12% of Canadians polled did not have a family physician, and 18% reported problems with access, such as long waiting times or difficulty reaching the doctor. Problems that delay access to primary care can result in higher downstream costs of health services. Sanmartin and Ross (2006) found that the lack of a family doctor was one of the most significant determinants of failure to receive necessary care. Research has repeatedly shown that where a problem with access exists in the general population, it is considerably more severe in subsets of the

population that are most disadvantaged (Brownell et al. 2001). Sanmartin and Ross (2006) confirmed that the presence of a disability (operationalized as activity limitation) increased the odds of failing to receive necessary routine care by more than 50%.

“Access,” a term that typically refers to human resources shortages or problems in geographic distribution of providers, has become one of the most pressing issues for health policy; however, for people with disabilities, access is a much broader and more important issue (Neri and Kroll 2003). It includes:

1. the physical configuration of the practice – e.g., stairs, doorways, examining tables;
2. the attitudes of providers and staff towards people with disabilities;
3. expertise about the natural course and typical complications associated with disability;
4. systemic factors that act as disincentives or obstacles to access or equity (McColl 2006).

For people with disabilities, access issues can actually prevent their receiving service, not simply delay or inconvenience it.

One of the key determinants of access to health services for people with disabilities is provider perspectives and understanding of disability. Even unrecognized perceptions can influence physicians’ judgments and interventions, and have profound effects on the treatment process (Duckworth 1988). Sanchez and colleagues (2000) observed that attitudes of providers towards people with disabilities remained a significant deterrent to good-quality care. Furthermore, the issue of physician attitudes towards disability was complicated by a perception that attitudes were already all that they should be (Sanchez et al. 2000). Unfortunately, negative attitudes among physicians mirror those of society in general, creating obstacles for people with disabilities (Antonak and Livneh 2000).

Negative attitudes towards disability can assume a number of different forms. The simplest is the view that a person’s disability is a negative trait (Tervo et al. 2002) or an abnormality (Office for Disability Issues 2004). Equally unhelpful is to view the disability as an illness. Jorgensen (2005) found that physicians looked at disability as illness, whereas the disabled patient considered the disability a condition of life. While illness and disability may (and often do) co-exist, the two call for quite different responses from clinicians (Paris 1993). Whereas illness elicits an acute, curative response, this approach is not applicable to a condition that is a part of everyday life for the patient. It inappropriately perpetuates the “sick” role and is ultimately disempowering for people who are often struggling with conditions that are already challenging (McColl and Bickenbach 1998).

There is an interesting paradox in physicians' perceptions of disability. Veltman et al. (2001) reported that one-fifth of doctors did not take adequate account of the disability, while another fifth tended to attribute everything to the disability, and therefore did not explore new complaints as thoroughly as was warranted. Misunderstandings and discordant expectations between physicians and disabled patients exist regarding patients' overall health, potential for recovery and even life expectancy (Iezzoni et al. 2003).

There are four points at which patients experience barriers to access in primary care: finding a doctor, getting an appointment, entering and using the facilities in the practice, and receiving a reasonable standard of care. The purpose of this study was to describe the issues and challenges confronting family physicians in providing excellent care to their patients with disabilities, and to assess the impact of those issues on access to primary care for people with disabilities. The four types of barriers (physical, attitudinal, expertise-related and systemic) and the four access points (signing up, getting an appointment, being examined, obtaining quality care) can be grouped into a matrix that offers a framework for subsequent discussions of our results (see Table 1).

TABLE 1. Matrix of barriers and access points

Areas of access	Types of barriers			
	1. Physical	2. Attitudinal	3. Expertise-related	4. Systemic
a) to a doctor		×		×
b) to an appointment		×		×
c) to the office	×	×		
d) to a high standard of care	×	×	×	

X = Cells where our findings provide evidence of the presence of barriers for people with disabilities.

Methods

Design

The goal of this study was addressed using a qualitative interpretive approach to uncover physicians' perspectives on working with people with disabilities. The study was part of a larger quantitative study looking at the effect of payment type on quality and access to primary care for people with disabilities. The semi-structured interview administered to a subsample of physician participants permitted exploration of issues arising at the level of the individual physician in providing primary care to his or her patients with disabilities.

Sample

Physicians in Eastern Ontario were invited to participate in this study if they:

- had been in the same practice for at least one year;
- provided ongoing comprehensive care to patients (practices that were limited to a specific component of care, e.g., psychotherapy, were excluded);
- were located in a community setting;
- had patients with one of a list of severe physical or cognitive disabilities (spinal cord injury, acquired brain injury, intellectual disability, cerebral palsy, rheumatoid arthritis, post-polio, other mobility-related disability).

Of 241 practices in the region, 503 physicians were initially identified. On the basis of the criteria above, 125 were deemed ineligible. Of the remaining 378, 305 declined or did not respond to the letter of invitation, mostly owing to issues of time or space. The remaining 73 physicians participated in the larger study of which this was a part, and 34 participated in this qualitative study. Practices with more than one participating physician were encouraged to select one person to participate in the interview so as not to overweight the responses by one organization.

The 34 physicians who volunteered to participate in the qualitative study were evenly distributed across three payment types – 11 each for salaried and capitation practices and 12 from fee-for-service (FFS) practices. Twenty-three (67.6%) of the physicians interviewed were female, and 21 (61.8%) were from rural areas. Twenty-four physicians (70.6%) worked full time. Most of the FFS and capitation physicians interviewed worked full time at one practice, whereas only three of 11 salaried physicians worked full time at one location.

Data collection

Qualitative interviews were conducted to solicit information about how family physicians work with and perceive their interactions with patients with disabilities (see Figure 1). The interview was semi-structured and permitted exploration of issues arising at the level of individual physicians in their relationships with disabled patients. The 15- to 30-minute interview usually took place in the physician's office or exam room. These interviews were taped and transcribed. The interviews were analyzed using NVivo software. Interview data were initially coded according to three core questions:

1. How are disabled patients different from non-disabled patients?
2. How are disabled patients similar to non-disabled patients?
3. How is the physician different with disabled patients?

Data were partitioned into three subsets according to these questions and then open-coded line by line for content. Codes were subsequently categorized into themes, and themes were developed when at least three interviewees raised the issue. This process generated a finite set of themes associated with each of the core questions.

FIGURE 1. Interview schedule for qualitative data on physicians' perceptions

1. In this study we are particularly interested in adults with physical or cognitive disabilities in your practice who are between 18 and 65 years of age.
(Please write down the names or initials of patients with the following diagnoses, so that you may refer to them in responding to subsequent questions: spinal cord injury; acquired brain injury; multiple sclerosis; cerebral palsy; post-polio syndrome; intellectual disability; rheumatoid arthritis; other disabling condition.)
2. How do their health complaints compare with your average non-disabled patients of the same age?
(Probe: How are they the same / different from their non-disabled contemporaries?)
3. How do you think your experience with these patients differs from that with your other non-disabled patients of the same age?
(Probe: Do they have a longer set of issues, types of services, number of visits per year, referral needs, amount of time per office visit, staff accommodations, etc.?)
4. Are there any special considerations that they require?
(Probe: These considerations may be things that you do provide, or things that you are not able to provide.)
5. Are there any primary care services that you are unable to provide to your patients with disabilities?
6. What else, if anything, do you need in order to be able to provide what you consider excellent care to your patients with disabilities?

Ethical considerations

The research protocol and consent form were submitted to and approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board in December 2003.

Results

This section summarizes the comments made by physicians about their experiences with disabled patients in their practice. The discussion is augmented with verbatim quotations taken from the transcripts.

Question #1: How are disabled patients different from non-disabled patients?

In response to inquiries about how disabled patients differed from other patients in the physician's practice, interviewees offered a number of very consistent observations.

MORE TIME REQUIRED

It was consistently reported that disabled patients needed more of the physician's time than non-disabled counterparts. The explanation for this included physical, communication and cognitive aspects of disability. In terms of physical factors, disabled patients were often slower in their movements, taking more time to dress and undress themselves, requiring more time for the physician to position and examine them, and taking longer to enter and leave the office. Physicians noted a need to physically rearrange office space before and after an office visit from a patient with physical disabilities.

Communication with disabled patients was also noted to be more time intensive for several reasons. Depending on the disability, patients might experience dysarthria, causing them to communicate more slowly, or they might use technological aids, slowing the process. Family physicians noted that they tended to question the patient with a disability in a different way – they asked more probing questions and gave more attention to circumstances of the complaint and whether doctor and patient had understood each other accurately. When family members or caregivers attended appointments, three-way conversations were more time-consuming. Patients with a cognitive disability required either more detailed or simplified instructions and explanations. Some also required written material to support verbal directives.

PREMATURE AGING

Some physicians noted that their disabled patients seemed to age prematurely. That is, at mid-life they seemed to have problems more usually associated with old age. Patients with developmental disabilities in mid-life were observed to experience dementia and other medical conditions typically associated with an older age cohort:

“She is just in her early 60s, maybe late 50s even, but the complaints are, I think, more similar to someone who might be in her 70s or 80s, and she looks older as well. In the sense of just getting around, she seems frailer than people of her age.”

SPECIFIC HEALTH ISSUES

Physicians noted a number of common health problems that people with disabilities typically encounter. These pertained mostly to those patients with mobility impairments. Physicians noted specific health concerns, including pain, bladder, bowel and skin problems. Limited sensation was also noted as the source of a number of presenting problems common among disabled patients.

VULNERABILITY

Family physicians were aware that their disabled patients were potentially more vulnerable. From a medical point of view, their health was considered more vulnerable to secondary complications, such as unattended minor infections that progress quickly to major infections. Physicians also noted that medical issues among people with disabilities were often influenced by financial issues and economic vulnerability. Disabled patients were perceived to be at increased risk of physical and sexual abuse:

“Many of our clients are not only disabled, they are also in a lower socio-economic group, so sometimes there’s the third component, which is sort of their interface with society and the variety of organizations and bureaucracy they have to contend with. ... These people are very vulnerable, very vulnerable in many ways. They’re vulnerable medically, they’re vulnerable to abuse, they’re vulnerable in their living situation.”

COMPLEXITY

In general, physicians perceived that their disabled patients had more problems than their non-disabled patients, and that their problems were often not amenable to the tools available to the family physician:

“They tend to have more problems, and those problems are often not usually solvable problems. Often their disabilities are fixed or they’re slowly progressive; there’s really very little you can do other than help to deal with that process – whereas if you had a diabetic, you could help to reverse that, stop it.”

Several interviewees felt they needed more training to assess and treat these patients properly. They were unsure how to properly position or examine a patient who lacked sensation, or who experienced spasticity or paralysis. Physicians indicated that they had not been trained in handling procedures relative to specific disabilities and were uncertain about them.

Several physicians also observed that their disabled patients had a greater need for medication than their non-disabled patients, and that finding the right medications for them was difficult. Concerns included difficulty finding medications that addressed chronic pain, interactions between medications, and conditions that did not respond as expected to treatment. There was further concern about treatment interactions for multiple problems and about the development of antibiotic resistance over time. It was also noted that disabled patients often required more office visits because they had multiple issues or problems, greater need for follow-up regarding these issues, and increased complications related to their specific disabilities.

COORDINATION

Interviewees observed that their disabled patients often required services that could not be provided in the physician's office, and they therefore referred them to a number of other community services and professionals. In addition, most disabled patients had specialists and were followed by community agencies where they received professional and non-professional services. Family physicians viewed themselves as the central coordinator for all these services. Not only did they refer and facilitate access to these services, they also provided follow-up and interacted with external care providers:

"Then there's a huge function of kind of being the receptacle for different reports coming in, and following and finding out what's going on. You have to be kind of like a traffic cop, directing them to the appropriate resources, is the way I look at it."

IMPORTANCE OF RELATIONSHIPS AND LIVING SITUATION

Physicians demonstrated an awareness of the importance of family and living situation for their disabled patients, to a greater extent than for their non-disabled patients. Depending on the patient's level of disability, physicians expressed an increased need to assess and be aware of who was providing care or support in the immediate living environment. Physicians were aware of the need for family members and caregivers to be involved in discussions regarding care of their disabled patients. They were sensitive to the financial and time commitments required of family caregivers. With regard to patients living in group homes, community support staff often provided a level of assurance of health supervision. These individuals could be a valuable source of information about health issues and often facilitated attendance at appointments.

SOCIAL ISSUES

In general, family physicians noted that their disabled patients needed physician assistance to complete forms for access to services and benefits for which they might be eligible. Family physicians also noted that their disabled patients experienced a variety of psychosocial problems and, although they were related to community care and relationships, these required the attention, time and concern of the family physician:

"So they come with a different kind, a set of different problems than somebody fully mobile does. ... They may be having difficulty getting certain things done through the system, so for instance they might need me to fill out forms. They may require some paperwork from some government ministry that needs to be filled out so that they can get a motorized scooter or get paid for some grab bars in their bathroom."

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LEARNING FROM PATIENTS

Family physicians noted that their disabled patients offered them an educational opportunity. Disabled patients taught them about specific medical issues, such as management of complex or repeated urinary tract infections, but also about assumptions made regarding health and wellness. Several physicians commented on the rewards of caring for patients with disabilities:

“They add a lot to the practice too, they teach me a lot. We all assume that we have four limbs, but one chap, he is a paraplegic because of a car accident, he teaches me stuff that I need to know.”

ADAPTATION

Physicians noted that their disabled patients were often able to adapt and cope better than their non-disabled counterparts. Physicians felt that their disabled patients were on the whole happier with their lives and less likely to complain than their non-disabled patients:

“And they seem to be happy with their lot, curiously, more than many of us. We should follow their example.”

Question #2: How are disabled patients similar to non-disabled patients?

Physician interviewees also reported a number of ways in which their disabled patients were no different from other patients.

BASIC PRIMARY CARE

Physicians felt that disabled patients experienced the same range of general health problems as their non-disabled patients. Family physicians were equally aware of the need for health monitoring and other regular health services among their disabled and non-disabled patients. They also noted that their disabled patients had the same need for prevention and screening as their non-disabled patients.

THERAPEUTIC RELATIONSHIP

Family physicians noted that there was the same need among disabled as non-disabled patients to form a therapeutic relationship that was unique and workable for each patient. Regardless of disability, there was a general need to think about a patient's personality and how best to work with him or her. For one interviewee, treating a patient

with a mental disability as if he were not disabled seemed to be the key to the therapeutic relationship:

“They’re the same because they’re human beings. We’re all the same at some point. There are the same issues in terms of how you forge that therapeutic relationship ... figuring out the key to each relationship and how to help people and how to understand how they are looking at and dealing with their own situations.”

EXPECTATION FOR RECOVERY

Physicians noted that their disabled patients were as likely as their non-disabled counterparts to expect a full recovery from illnesses or new conditions that brought them to the doctor. They expected to be treated as aggressively as anyone else, and to be given every chance to have optimum health despite their disability. In some ways, recovery from minor concerns is doubly important for individuals with pre-existing disabilities, so that new complaints do not further compromise independence and quality of life.

DIFFICULTY OBTAINING NECESSARY SERVICES

Physicians noted that all their patients had difficulty accessing a variety of services in the community, such as nutrition counselling, physiotherapy and occupational therapy. Systemwide shortages made access to needed services difficult for both disabled and non-disabled patients. Physicians felt that long waits were experienced by all patients and that there was a general lack of access to needed programs. Disabled patients had no advantage in terms of accessing services in short supply.

Question #3: How are you different with disabled patients?

Data were coded to uncover how interviewees felt they behaved differently towards their disabled and non-disabled patients.

EXTRA TIME ALLOWED

Just as interviewees noted that disabled patients typically take more time than non-disabled, some also noted that they allow more time. They routinely book double appointments for their disabled patients in order to ensure that their care is properly reviewed and that assessments can be done in a thorough and comprehensive manner. One salaried physician noted that salaried practice offered the economic luxury of discretion about the allocation of time.

“Sometimes we do have to book some extra time because we say, okay, I’ve got to get this person in and really review things and make sure we’re on track. ... [R]ightly or wrongly, there are often annual or periodic assessments booked for an hour rather than the usual half an hour.”

HOME VISITS

When asked, family physicians noted that they accommodated their disabled patients through making home visits. These visits ranged from occasional to regular to frequent occurrences as part of care provision. Reasons given for home visits included the patient’s lack of mobility, lack of transportation and difficulty getting into the office. Where allied health staff were available, home visits were often conducted by other members of the healthcare team, such as nurses or social workers:

“Well, certainly from the physical logistics of the office, which you are probably aware, there are some patients that I can’t see in the office because they are in a wheelchair. So those ones I have to make special dispensation for and I just visit them at home.”

TELEPHONE CONSULTS

Although telephone prescriptions and consultations are not how practices typically function, physicians reported that they made exceptions for their disabled patients. In recognition of the patient’s difficulty coming in to the office, and also in recognition of their own inability to schedule a home visit on short notice, physicians volunteered that they would use the telephone as a means of conducting a patient interview. In addition, several interviewees stated that they would call in prescriptions over the phone to save a disabled patient a trip to the office. They noted that they were much more likely to do this for patients with mobility issues as compared to intellectual disabilities. Some physicians also provided counselling over the phone.

MORE COUNSELLING/FOCUS ON COPING

Family physicians commented that they provided regular, and in some cases frequent, counselling to their disabled patients. Although they admitted that they lacked expertise in counselling specific patients, such as those with intellectual disabilities, they considered it an essential part of the care provided. Individuals with mental disabilities were perceived as requiring a great deal of counselling and support, as well as assistance with social relationships. Counselling sessions often included family members

and caregiving staff, and sometimes involved other professionals where available, such as the nurse practitioner or social worker.

INSISTANCE ON ATTENDANT

Not all reported differences in physicians' treatment of disabled and non-disabled patients made primary care more accessible for those who are disabled. Many of our physician interviewees volunteered that they required their disabled patients to bring someone with them who could help with access if required. For patients with physical disabilities, the required assistance typically related to dressing and positioning. For patients with cognitive disabilities, it related to both the provision and the receipt of information.

LESS LIKELIHOOD OF EXAMINATION

Physicians noted that they were less likely to examine disabled patients for a variety of reasons. Patients with mobility issues were difficult to transfer onto an examining table. Dressing and undressing sometimes took a considerable amount of time and required a skilled assistant. Physicians' offices often lacked equipment, such as transfer lifts or adjustable examining tables that facilitate moving patients. Physicians commented that they sometimes did partial examinations when a thorough examination exceeded the bounds of ability or efficiency. They admitted that many of their disabled patients had not had a complete physical examination for as long as they could remember. Further, they acknowledged that they were more likely to accept a verbal report from a disabled patient, and to proceed to treat without examination, than they were for a non-disabled patient:

"If it's difficult to do a physical examination because you have to transfer them, and you have to get someone to help you to do that, you are going to be more reluctant to do it. So you might do it less frequently than you would like to or than you ordinarily would."

LOSS OF FOCUS ON PREVENTION

For a variety of reasons, many of our interviewees noted that their disabled patients did not get the same consideration in regard to preventive healthcare as their non-disabled contemporaries did. For example, physicians noted that it was difficult to check blood pressure on patients whose arms were contracted. Some patients were not weighed because they couldn't get on the scale. Family physicians noted that they

sometimes lost track of regular preventive care issues with their disabled patients because of the volume of other health concerns. Long-term health and maintenance of regularly scheduled care was not a priority. Physicians also noted that their patients were concerned about the number of medical appointments they had and did not wish to come in for regular preventive care:

“And in all honesty, you may forget about some of the long term, health maintenance things, such as preventative manoeuvres, because you are focusing a bit more on the day-to-day management of their disability.”

LESS ATTENTION TO SEXUAL OR REPRODUCTIVE ISSUES

Patients' level of comprehension was identified as an issue that influenced the likelihood of some preventive care, particularly those tests related to reproductive or sexual issues. Patients with intellectual disabilities were less likely to be provided with Pap smears and breast, pelvic or prostate exams because physicians felt they would not understand the rationale behind these. Referring specifically to mammograms and Pap smears, physicians reported that they sometimes waived these tests in patients with intellectual disabilities for fear that the patient would not understand the need for the test or would not tolerate it. In addition, physicians' sensitivity about sexual abuse influenced their physical examination. One interviewee noted that doctors needed to be more aware of personal safety issues and about explanations for specific types of examinations, such as Pap smears.

Another issue was the assumption that disabled patients were not sexually active and therefore did not need to be treated the same as non-disabled persons of their age and gender. For example, disabled women might not be offered birth control or fertility counselling because of issues associated with their disability:

“There were some issues about birth control and things which of course are issues for any woman in her 30s. The concern was over why she needed it.”

Discussion

Our results showed that physicians noted numerous important differences between their disabled and non-disabled patients, and they were remarkably consistent in their views. They stated unequivocally that disabled patients took more time and were more complex. Furthermore, they noted very astutely that caring for a disabled patient required them to provide more social care rather than strictly medical care. Our interviewees employed a number of creative strategies for overcoming issues of access and

hardship for their disabled patients, yet they admitted that basic primary care, like physical examinations and preventive health measures, suffered because of logistical difficulties and constraints on physicians' time.

In several cases, physicians acknowledged that their offices did not permit wheelchair access, nor did they have special facilities to accommodate sensory or cognitive disabilities. Interviewees admitted that they were unaware of the correct manner of providing physical assistance to disabled patients, and in some cases were unwilling to do so. Given the time required to transfer, position and undress such patients, this meant that family doctors were less likely to examine a disabled patient and more likely to accept the patient's verbal report of a problem. There were varying views on this issue of providing assistance during the appointment, with some family doctors saying they simply provide the needed assistance themselves, and others saying they cannot be expected to do so. Several of our interviewees offered that they had no training in how to relate to or assist someone with a disability. They not only had personal discomfort with the issue, but also perceived potential professional liability if an incident, such as a fall, occurred.

Attitudinal barriers potentially affect access at all four access points shown in Table 1. Although our small sample provided no evidence of it, there are suggestions elsewhere in the literature that disabled patients may be systematically excluded from family practices because of the burden they are perceived to impose on the physician's time (Batavia and DeJong 2001; DeJong 1997; McColl 2006). In our study, attitudinal barriers appeared only with regard to accommodating the special needs of disabled patients in the practice. Several physicians noted that they required their disabled patients to bring an attendant to assist with functions such as transferring, dressing and undressing, communication and follow-through. This requirement potentially diminishes the second type of access (to an appointment) because of the necessity to schedule appointments when the attendant or assistant can be available. While it may enhance the third and fourth types of access (access to the office and equipment, and access to a high standard of primary care), it may impede confidentiality and full disclosure because of the lack of privacy between patient and doctor.

Expertise-related barriers have their primary impact on the standard of care delivered. As several authors have pointed out, the inability to diagnose disabling conditions accurately and to anticipate further disabling consequences is a significant deterrent to high-quality primary care (Glazier 2004; Bernatsky et al. 2006). While our interviewees were clearly experts in primary care, many noted the need for more information about disability. They observed that the average practice would contain only a few patients with disabilities, and that it was difficult for doctors to develop an understanding of the issues on that basis. Particularly since disability can stem from a variety of diagnoses, and can be highly variable in its presentation from person to person, it is difficult for family physicians to achieve any sort of critical mass in a typical practice to permit them to acquire the necessary expertise. They admitted that they

had relatively little exposure to adult disability in medical school or residency training, and were more familiar with the concept of disability in their elderly patients (Claxton 1994). Recently, consensus guidelines have been published for primary care of adults with developmental disabilities (Sullivan et al. 2006). These make a compelling case for the need for special attention to disability-related issues, but they also serve as an acute reminder of the complexity and resource-intensive nature of providing excellent primary care to people with disabilities.

Systemic barriers include shortages and maldistribution of physician human resources, both of which can lead to difficulties finding a doctor and long wait times due to large caseloads. Recent data from the College of Family Physicians of Canada (2005) show that only 20% of family practices are open to new patients. Systemic barriers are experienced by all patients; however, barriers are potentially exacerbated for disabled adults, who physicians virtually unanimously report take more time. For physicians in volume-driven practices, whether fee for service or capitation, taking more time is inconsistent with the financial incentive system. Patients who require more time than the standard 10- to 15-minute appointment become an economic liability (Chisholm and Stewart 1998; Barros 2003). Furthermore, there are often no supports to assist physicians with complex patients in solo or small practices, such as other health professionals or even administrative staff, to fulfill some of the functions that are not strictly medical. Because of the additional time needed to treat disabled patients, the current rates of remuneration may make these patients financially disadvantageous for the physician.

Disability groups have argued that physicians should not need to be given incentives in order to provide the same standard of care to disabled patients that they provide to non-disabled. If we consider primary care a service to which all are entitled, there should be no need to explicitly reward provision to disabled people. This approach would represent horizontal equity – assuming that disabled people are equal to other citizens, they should be provided with equal access to resources. The alternative position, vertical equity, would recognize that where healthcare is concerned, disabled people are not like other patients (McCull et al. 2006; Mercer et al. 2003). They are high users of care and experience considerable unmet needs within the healthcare system (McCull 2005; McCull and Shortt 2006). Furthermore, they are acknowledged by physicians to require on average a greater investment of medical human resources. The way to achieve equity, therefore, is through resource allocation commensurate with patients' needs. This issue is one of the most difficult in service provision to people with disabilities: whether to adopt a universalist, human-rights approach and treat disabled people like everyone else, or whether to recognize the special needs of disabled people and treat them as a minority group whose needs are explicitly ensured. The rhetoric on disability policy reflects both these positions with equal force.

To date, the issues of people with disabilities have received little attention in most

jurisdictions in the process of primary care reform. Adults with disabilities are high users of primary care. They make three times as many visits to the family doctor as their non-disabled contemporaries, and yet they report three times as many unmet needs (McColl et al. 2005; McColl and Shortt 2006). The costs of providing service to this population may be higher than average, but the costs of ignoring them will surely be higher still. The recent emphasis on multidisciplinary provision and chronic disease management in primary healthcare may well address some of these problems. However, Canada lags behind other developed countries in implementing chronic disease management and multidisciplinary care. Morgan et al. (2007) refer to this as an “inconvenient truth.” While it may be inconvenient for many Canadians, like all access problems, it has potentially greater consequences for people with disabilities.

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