

PERSONS WITH DISABILITIES

Health Services Literature Review And Community Consultation

**Healthy Diverse Populations
Alberta Health Services - Calgary Health Region
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GLOSSARY OF TERMS

Best practice: A process or methodology that has been proven to work well and produce good results, and is therefore recommended as a model.

Communication Disability: Involves difficulty in communicating with others and can “arise from problems with speech, using and understanding language, voice, reading, writing or hearing”(adapted from Speech Pathology Association of Australia, undated).

Comorbid Condition: Concomitant but unrelated pathological or disease processes that have an adverse impact on health (Krahn et al., 2006: 71).

Deaf (capital ‘D’): Refers to the cultural community of persons communicating primarily in American Sign Language; deaf (lower-case) refers to the audiologic lack of hearing (Steinberg et al., 2006).

Developmental Disability: The term most commonly used in Canada to refer to lifelong limitations in intellectual and adaptive functioning initially identified in people younger than 18 years (Sullivan et al., 2006: 1411).

Disability: Impairment, activity limitation, or participation restriction that substantially affects one or more life activities (Richman, 2007: 421).

Health: A state of complete physical, mental, social well being, and not merely the absence of disease (Krahn et al., 2006: 71).

Health Literacy: The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course (Rootman and Gordon-El-Bihbety, 2008: 11).

Intellectual Disability: An umbrella term referring to “those who have known learning disabilities, severe and enduring mental health problems whereby cognition is affected, dementia cases, people with acquired brain injury. It also encompasses those people who are not known to learning disability services, have lower intellectual ability and problems coping with their day-to-day living” (Clark and O’Toole, 2007: 154).

Learning Disability: “Learning disabilities refer to a number of disorders which may affect the acquisition, organization, retention, understanding or use of verbal or nonverbal information. These disorders affect learning in individuals who otherwise demonstrate at least average abilities essential for thinking and/or reasoning. As such, learning disabilities are distinct from global intellectual deficiency.” (Learning Disability Association of Canada, 2008).

Physical Disability: Refers to “any degree of physical disability, deformity, malformation or disfigurement that is caused by injury, birth defect or illness. This includes, but is not limited to, epilepsy; paralysis; amputation; lack of physical coordination...” (adapted from Alberta Human Rights and Citizenship Commission, 2007).

Psychological Disability: Results in limitations “in the amount or kind of activities that one can do due to the presence of an emotional, psychological or behavioural condition.” (Statistics Canada, 2006).

Secondary Conditions: Refers to those conditions that a person with a pre-existing disability experiences at higher rates than the general population and are generally regarded as preventable (Krahn et al., 2006: 71).

EXECUTIVE SUMMARY

The purpose of this literature review and community consultation was to identify barriers to health care experienced by persons with disabilities and ways in which the Calgary Health Region may become more competent in meeting the needs of persons with disabilities. The literature focused on articles published since 2001 and the community consultation involved four focus groups with a total of 34 participants, including persons with disabilities (including communication, developmental, intellectual, physical and psychiatric disability), support workers, family members and representatives of organizations who work with persons with disabilities.

The research found that persons with disabilities, as a group, are more likely than able-bodied counterparts to have multiple and complex health care needs, in some cases leading to proper care not being provided; perceive their health status as poor; report having unmet health care needs (including reduced rates of preventive health care services); and have lower levels of satisfaction with health care. Focus groups, however, also revealed that many persons with disabilities have had exceptionally positive experiences with individual practitioners/providers. This suggests that actions already being taken are helping to reduce barriers.

Barriers to health care experienced by persons with disabilities were identified and organized into three types: environmental, process, and individual barriers. Each type of barrier was explored in depth and recommendations are made for enhancing the disability competency of health care systems.

Environmental Barriers

Environmental barriers refer to characteristics of health care settings that are known to impede access to health care among persons with disabilities. Environmental barriers include inaccessible facilities and equipment, inappropriate practices and procedures, transportation barriers, inaccessibility of health information, and disparities in accessing aids, devices and human support for the activities of daily living.

Facilities and equipment: The absence in health care facilities of adjustable-height examination tables, appropriate lifting devices, and weight scales that can accommodate wheelchairs, and the inaccessibility of much diagnostic equipment (e.g. mammography machines) present significant barriers for persons with physical disabilities; in addition, some people with cognitive disabilities view health care environments as complex, confusing or difficult to navigate. Additionally, some health care environments fail to provide signage that is appropriate for persons with cognitive and sensory disabilities. It is recommended that health care systems adopt principles of universal design, wherein physical environments are designed in ways that they can be efficiently and effectively used by all people; that existing facilities be modified to ensure accessibility, and that accessible equipment be made available. An innovative approach identified in a focus group was a collaboration of a group of disabled

women in the Calgary area with the Women's Health Resource Centre to provide accessible Pap test clinics.

Procedural accommodation: Procedural accommodation refers to the extent to which the usual practices of health care encounters facilitate or impede access to health care among persons with disabilities. Inadequate length of appointments, inappropriate routine practices, prohibiting support workers from accompanying clients during health visits, and inappropriate discharge practices are salient barriers. Providing longer appointment times, using coloured lights to signal Deaf or hard of hearing patients to perform required actions in radiology units, allowing support workers to accompany their disabled clients throughout their health care system experience and examining the safety and appropriateness of discharge practices are examples of recommendations to improve procedural accommodation.

Transportation: The accessibility of health care is also impacted by the availability of transportation that is accessible, efficient and affordable. Public buses are often not equipped with wheelchair lifts, drop-off points are not always close to health care facilities, and the cost of public transit can be prohibitive to persons with disabilities on moderate incomes. The rising cost of gas has also resulted in some support workers being less willing to transport clients to appointments. Disability transport services are available but scheduling can be problematic. Persons with disabilities may be discharged from health facilities without appropriate arrangements for transportation. Health care staff should become aware of the transportation issues of clients with disabilities, financial issues concerning transportation should be addressed, transportation services should solicit feedback from users to enhance services, and health care should be provided in such a way as to avoid unnecessary transportation.

Health Information: Health information that is not available in accessible formats, as well as the failure of health care providers to orally communicate sufficient and appropriate health information, create barriers to health care for persons with disabilities. Health information should be available in Braille, large print and audiotape formats, and should use simplified language and graphic depiction of health information. Health care providers should examine their own assumptions and biases that might lead them to consider certain types of health information that may be irrelevant to persons with disabilities. As the focus groups revealed considerable communication barriers between support workers and health care providers, it may be beneficial for the Region to work more closely with support workers, perhaps through regular meetings and in-services. Finally, health providers should enhance their knowledge of communication strategies that are effective and appropriate for communicating health information to persons who have communication disabilities or behavioural issues affecting communication.

Aids and devices and support for the activities of daily living: The health and wellness of persons with disabilities is influenced by the accessibility of aids and devices as well as human support to accomplish the activities of daily living. Though many of the focus group participants did not report experiencing barriers to obtaining needed aids, devices and supports, the literature identified cost, lack of locally available resources, and not knowing where to obtain

needed aids, devices and supports as the most commonly reported barriers. It is recommended that increased/improved effort is made to better communicate to persons with disabilities the means of acquiring needed items/supports, as well as information about community agency programs providing items/supports at low or no cost.

Process Barriers

Process barriers refer to characteristics of interactions between health care providers and persons with disabilities that may impede access to adequate and appropriate health care. Process barriers may be related to the knowledge, experience and attitudes of health care providers, the extent to which the disability is the focus of the health care encounter, communication, and coordination of care.

Knowledge and experience: A lack of disability-specific knowledge and experience is known to play a role in the provision of inadequate and inappropriate health care to persons with disabilities. It is recommended that health care providers enhance their knowledge of the medical care needs of persons with disabilities seen in their practice, become knowledgeable in how symptoms of health problems are expressed in persons with certain disabilities, and examine their own beliefs for biases about health information and care relevant to persons with disabilities.

Attitudinal influences: Unwelcoming attitudes conveyed through verbal and non-verbal communication compromise rapport- and trust-building, reduce patient satisfaction, and decrease service utilization. It is recommended that health care providers examine their personal attitudes toward and belief, become aware of how messages of acceptance are communicated or inhibited in their interactions, and enhance their ‘disability etiquette’ skills, including sensitive, courteous and respectful interpersonal skills in relating to persons with disabilities. Respecting and enabling independence and ‘ability’ is further recommended. Focus groups revealed concern over “do not resuscitate” (DNR) orders being suggested or assumed in some situations with persons with disabilities and education for health care providers around DNR orders and persons with disabilities was recommended.

Focus on disability: An inappropriate focus on the disability can result in overlooking illnesses and conditions unrelated to the disability and can reduce the time available during the consultation to address preventive health care needs. When health conditions unrelated to the disability are ignored or minimized, or when additional symptoms are not investigated, persons with disabilities are at greater risk for poor health, are less likely to be satisfied with their care, and may be reluctant to seek further care. It is recommended that health care providers be encouraged through education sessions to avoid over-focusing on the disability.

Communication: Communication is often cited by persons with disabilities as the most important factor in quality health care. When communication is impaired, physicians report difficulty understanding symptoms, making health assessments and diagnoses, and determining appropriate treatment plans. Miscommunication can also impair the understanding of health

information and contribute to feelings of frustration among persons with disabilities, leading to the under-utilization or avoidance of health care services. Communication may be improved by adapting communication style to individual need, building rapport, using plain language and using a step-by-step method of explaining medical procedures. Persons with disabilities should be consulted to identify preferred and effective modes of communication with care taken to avoid the assumption that communication barriers signify a lack of intelligence or cognitive deficit.

Sign language interpretation: While sign language interpretation is available in the Calgary Health Region through Interpretation and Translation Services, the literature review revealed that a significant barrier to quality of care for persons who are Deaf, is the lack of the provision of qualified sign language interpreters in the health care system. Failing to arrange for an interpreter may result from erroneous assumptions held by some health care providers that lip reading and note-writing are adequate modes of communication. Providers should become aware of the differences in grammar and syntax in American Sign Language (ASL) versus English and the relevance of facial expressions and body posture in ASL. Steps should be taken to ensure interpreters are available for the duration of the health care consultation.

Coordination of care: A well integrated and coordinated system of care can enhance service delivery and utilization by reducing the fragmentation of services, reducing service gaps, and reducing bureaucracy by simplifying processes, thereby making it easier for persons with disabilities and their families to navigate the health care system and obtain services. A number of studies, however, have found persons with disabilities cite a lack of service coordination and integration as a major barrier to quality health care. Research suggests that care coordination be the designated responsibility of a key worker or care coordinator. Key worker programs have been found to enhance relationships with health professionals, improve morale, decrease social isolation, reduce the burden on family members and reduce the prevalence of unmet health care needs. While many participants in the focus groups were satisfied with the coordination of care, several expressed frustration over the lack of service coordination and integration with the primary concern being a lack of information sharing among members of the health care team.

Individual Barriers

Individual barriers refer to challenges that persons with disabilities may experience in identifying and communicating health issues, as well as barriers associated with lack of empowerment.

Identifying and communicating health issues: Effective health care requires that health consumers be able to identify symptoms of ill health and to provide an accurate and comprehensive description of symptoms, concerns, and preferences for treatment. It is not uncommon, however, for persons with disabilities and their caregivers to have difficulty identifying symptoms requiring medical attention. It is important that persons who may have difficulty identifying and communicating symptoms of poor health have routine medical check-ups and regular preventive health screening. It is also recommended that when appropriate, persons with disabilities should be encouraged to bring their support worker to health care encounters to assist with identifying and communicating health issues.

Empowerment: Having a disability can influence feelings of empowerment or ability to act to create or maintain a healthy lifestyle, and to pursue primary and preventive health care services. Disempowerment may be associated with adopting an external locus of control and with feelings of disenfranchisement associated with being dependent upon others for day-to-day needs, as well as a lack of assertiveness skills and health and health care system literacy. It is recommended that health care providers work alongside persons with disabilities to facilitate feelings of empowerment and enhance the health literacy of their clients. Persons with disabilities should be encouraged to garner information that enables informed decision making, participate in support groups, and explore the use of the Internet as a source of information on health and health services. Also, persons with disabilities should further be encouraged to become 'self-advocates,' or active participants in their own health care planning and decision making, and also in the planning and implementation of disability-competent health care services. Financial cost of achieving health and wellness is also an issue related to empowerment and ability to act. This was a major point of discussion in the focus groups, with concerns being raised about the consequences of rising prices (of gasoline and nutritious foods for example) for accessing health care and achieving a healthy lifestyle.

1.0 INTRODUCTION

Disability affects one-in-seven Canadians, or 14.3% of the population (Statistics Canada, 2007). Adults (aged 15 years and older) with disabilities comprise 16.5% of the population¹, and children with disabilities comprise 3.7% (Ibid)². Of Canadians with disabilities, one-third has a mild disability, while 14% and 18.9% of adults and children, respectively, have a disability that is severe (HRSDC, 2006).

The share of the Canadian population with disabilities increased by 1.9 percentage points between 2001 and 2006 (Statistics Canada, 2007). This increase is attributed to Canada's aging population (Statistics Canada; Marks and Teasell, 2006), increased longevity of persons with disabilities (Ouellette-Kuntz et al., 2005; Ramirez et al., 2005), and an increase in the share of young people developing chronic and disabling conditions (Marks and Teasell).

Additionally, a greater number of persons with disabilities now reside in the community and depend on community- and hospital-based sources of health care. Prior to the shift to a community model of care and the subsequent downsizing and closing of institutions that was widespread in the 1980s, persons with disabilities residing in institutions had relatively uninhibited access to health care. Community living, in contrast, means that persons with disabilities are more likely to rely on general practitioners to have their health care needs met and these practitioners may lack experience and specialized knowledge of complex disabling conditions (Parish and Saville, 2006; Sullivan et al., 2006; Jenkins, 2005; Ruddick, 2005). While the adequacy of efforts to plan for the care of persons with disabilities in the community is debated (Ouellette-Kuntz et al., 2005), barriers to preventive health care and rehabilitation services have been associated with the shift to community care (Marks and Teasell, 2006; Parish and Saville, 2006). The shift from institutional to community models of care has also resulted in an increased burden of care on informal supports, including family members, friends and community agencies (Peter et al., 2007; Ouellette-Kuntz et al., 2005).

Efforts to reduce health care barriers among persons with disabilities are not unique to Canada. There is currently an international movement toward identifying and eliminating physical, social and cultural barriers experienced by persons with disabilities. In the United States, the Americans with Disabilities Act was introduced in 1990 (Reeves and Kokoruwe, 2005; Barnett, 2002) and in 2005 the Surgeon General issued a "Call to Action to Improve the Health and Wellness of Persons with Disabilities" (U.S. Department of Health and Human Services, 2005). In the UK, the Disability Discrimination Act was introduced in 1995, with further phases introduced in 1998 and 2004, and the Disability Rights Commission was established in 2000 (Pain and Wiles, 2006; Reeves and Kokoruwe, 2005). In 2001, the UK government published

¹ Pain, mobility and agility limitations are the most common forms of disability among adults, affecting 11% of the population (Statistics Canada, 2007). One-in-twenty adults with disabilities report a hearing disability, 3.2% report a seeing disability, and 1.9% reports a speech disability (Ibid). Persons with psychological disabilities comprise 2.2% of the Canadian population; 1.9% has a learning disability, 1.8% a memory impairment, and 0.5% has a developmental disability (Healthy Diverse Populations, Calgary Health Region, 2008).

² The majority of school-aged children (aged 5-14 years) with disabilities report having multiple disabling conditions (73.7%), with learning disabilities, chronic conditions, and speech disabilities the most common forms of disability (Statistics Canada, 2007).

“Valuing People: A New Strategy for Learning Disability in the 21st Century” (O’Hara, 2006). In addition, a European manifesto is being developed on basic standards of health care for persons with intellectual disabilities (Jenkins and Davies, 2006).

In this country, the Canadian Charter of Rights and Freedoms prohibits discrimination based on mental or physical disability and the Canadian Human Rights Act requires service providers to accommodate special needs, including those of persons with disabilities, short of undue hardship (HRSDC, 2006). While the federal government does not yet have a national policy concerning the care of persons with disabilities, task forces, subcommittees and published reports have begun to address the needs of persons with disabilities, including “Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenships” (1999); “In Unison” (2000); and “Advancing the Inclusion of Persons with Disabilities” (2002). According to the latter, the Government of Canada will develop a National Disability Act to improve accessibility and inclusion of Canadians with disabilities (HRSDC).

Following the lead of the World Health Organization, Canadian health care systems are increasingly shedding the view of disability as an ‘individual defect’ or ‘impairment’ that must be ‘corrected’ by the medical system, and adopting the view that disability is a social construct. While the former view would focus on ‘correcting’ or ‘fixing’ persons with disabilities as the main mode of increasing participation in mainstream social institutions (health, education etc.), the current view emphasizes the inadequacies of social institutions themselves. From this perspective, the participation of persons with disabilities in Canadian health care systems will increase when the systems themselves become more ‘disability competent,’ by recognizing and eliminating systematic barriers to health care (HRSDC, 2006; O’Day et al., 2004).

To this end, the Calgary Health Region has commissioned a review of the literature and a community consultation to identify barriers to health care and ways in which the Region may become more competent in meeting the needs of persons with disabilities.

In this report, we present the findings of the literature review and community consultation. Barriers to health care for persons with disabilities and recommendations to eliminate barriers, are organized into three main categories: environmental barriers (barriers related to the physical environment and practices and procedures known to impede access to health care); process barriers (barriers related to characteristics of health care providers and their interactions with persons with disabilities); and individual barriers (physical and cognitive impairments to health, wellness and access to health care). Data from the community consultation is interspersed with the findings of the review of scholarly and gray literature in each section.

2.0 METHODS

2.1 Literature Review

The literature review was prepared with computer-assisted database searches (PubMed Restricted, Ovid Medline, Web of Science, Scopus, CINAHL, Native Health Databases) with key words “disability and health care access, disability and health care barriers, disability and health care planning, disability and health care consumers, low vision, blind, deaf.” These terms were combined with “family practice, delivery of health care, health services, evidence based, best practice,” using wild card and MeSH headings, to identify North American and international articles published between 2001 and 2008. Articles were also identified through Internet search engines (Google and Google Scholar).

2.2 Community Consultation

Four two-hour focus groups were held with a total of 34 participants, which included persons with disabilities, support workers, family members and representatives of organizations who work with persons with disabilities. In several cases, the organization representative was also a person with a disability. Group participants were recruited with the assistance of community organizations and, with the exception of support workers and organization representatives, received a \$50 honorarium for participating.

Persons with disabilities who participated in the focus groups experienced disabilities in different areas, including:

- Communication disability
- Developmental disability
- Intellectual disability
- Physical disability
- Psychiatric disability

The Calgary Health Region and the project consultants are grateful to the persons with disabilities and their support workers who participated in the focus groups, as well as the representatives of organizations who work with persons with disabilities. The Region also extends its appreciation to the Calgary Scope Society, the Canadian National Institute for the Blind and the Developmental Disabilities Resource Centre of Calgary for hosting the focus groups

Focus group participants came from a range of backgrounds and levels of ability. Some receive 24-hour care; others live independently and are employed outside the home.

Organizations working with persons with disabilities that participated in the focus groups included:

- Calgary Scope Society
- Calgary Society for Person's with Disabilities
- Canadian Paraplegic Association
- Cerebral Palsy Association of Alberta
- Canadian National Institute for the Blind

- Developmental Disabilities Resource Centre of Calgary
- Deaf and Hard of Hearing Services
- Renfrew Educational Services
- Vocational Rehabilitation Research Institute

A limitation of the research is the use of a small sample size and convenience (non-probability) samples, which provide a depth of understanding but are not highly generalizable. While persons with disabilities in a number of different areas were included in the focus groups, the full range of disabilities were not represented. These limitations should be taken into consideration when reviewing the report.

3.0 HEALTH ISSUES OF PERSONS WITH DISABILITIES

Persons with disabilities do not constitute a homogeneous group; differences in the type and severity of disability as well as age, gender, socioeconomic status, race and ethnicity and other factors influence how persons with disabilities experience their health and access to health care (Sullivan et al., 2006; Alborz et al., 2005). For example, Canadian seniors with disabilities are more likely than younger counterparts to receive the help they need to accomplish the activities of daily living (Fawcett et al., 2004) and are more likely to seek help for mental health and substance dependence problems (Statistics Canada, 2003). On the other hand, being older and having a disability presents additional risks for unmet health needs; Alborz et al (2005) report that dementia and depression in older adults with learning disabilities are often undiagnosed and untreated because symptoms of these conditions are attributed to the learning disability. Young adults with disabilities are less likely than their able-bodied counterparts to have a usual source of health care and less likely to access health services (Callahan and Cooper, 2006). Canadian women are more likely than men to have unmet needs for devices or aids related to learning disabilities and to speech, and are less likely to have adequate help with activities of daily living (due to cost and lack of help from family and friends; Fawcett et al., 2004); women with disabilities are also more likely than their male counterparts to have very low earnings (19.6% earn less than \$5,000 compared to 14.6% of men; HRSDC, 2006). Racial or ethnic minority status presents additional barriers to health care among persons with disabilities (Iezzoni, 2006), as does having limited English language proficiency (Alborz et al., 2005).

It should be borne in mind, then, that the health issues and barriers to health care presented in this report are not experienced equally or in similar fashion by all persons with disabilities. The issues, barriers and recommendations presented here are meant to serve as a starting point from which health care systems may begin or continue to identify and eliminate barriers to health care relevant to the populations they serve.

Before examining the barriers to health care commonly experienced by persons with disabilities, it is useful to garner an understanding of some of the health issues that may be of particular relevance for persons with disabilities. While not experienced by all, research does indicate that persons with disabilities, as a group, are more likely than able-bodied counterparts to have multiple and complex health care needs; to perceive their health status as poor; to report having unmet health care needs; and to have lower levels of satisfaction with health care.

The support worker for of a developmentally disabled client who had a kidney transplant remarked that her client has received exceptional health care throughout the entire process. Now several years post operative, her client continues to receive respectful and considerate follow-up care from all health care personnel to the point where she "feels good when she comes out of the appointments."

Focus group for persons with disabilities

3.1 Multiplicity of Health Issues

In addition to health care for general health and to disabling conditions, persons with disabilities often require additional care for the prevention and treatment of secondary and comorbid conditions (Krahn et al., 2006a; Sullivan et al., 2006; Wei et al., 2006; Alborz et al., 2005). For

example, about 30% of Canadians with intellectual disabilities develop comorbid physical disabilities (such as hearing impairments (10%), vision impairments (20%) and communication disorders (30%)), and roughly 30% have comorbid mental health issues (Ouellette-Kuntz et al., 2005). Persons with physical disabilities have been found more likely than the general population to have been treated for anxiety and depression (Dryden et al., 2004; O'Day et al., 2004).

Persons with disabilities in the focus groups accessed the health care system for a wide range of health issues, some of which were related to their primary disability (e.g., psychiatric services and health care for complications related to a physical disability) and some of which were unrelated (e.g., heart disease and arthritis). While many individuals were well connected with health care providers to address their multiple issues, some organizational representatives said it was difficult to find family physicians for their disabled clients because of the “high refusal rate.” They said this was a growing problem in Calgary where there is already a shortage of family physicians and because “doctors who are willing to serve clients like this are bombarded.” As a result, the disabled client sometimes ends up at a walk-in clinic where the doctor has no history with them and “has to start from scratch.”

The “high refusal rate” among family physicians for disabled clients is a growing problem in Calgary where there is already a shortage of family physicians.

Focus group for organizations that work with persons with disabilities

Informal networking does occur among organizations that work with clients with disabilities so that information about available physicians is shared. However, some organizations admit to being protective of this information for fear of overloading the physicians.

When family physicians are not accessible, walk-in clinics and emergency rooms often become the point of entry to the health care system. This issue came up in almost all of the focus groups. In a few situations, a health crisis developed when clients were not seen by a medical specialist in time. In other situations, support workers had been told by family doctors to use the emergency department if they were unable to get the care they required or if they needed more rapid access to a specialist than they were able to get through physician referral.

3.2 Perceptions of Health

Though perceptions of health vary widely among persons with disabilities, there is some evidence that persons with disabilities are more likely, as a group, to perceive their health as poor. Studies have found for example that persons who are deaf or hard of hearing (O’Hearn, 2006), who are blind or have low vision (O’Day et al., 2005), or who have psychiatric disabilities (O’Day et al.), and women who have at least one functional limitation (Chevarley et al., 2006) are more likely than able-bodied counterparts to perceive their health status as poor.

3.3 Unmet Need

Because of vast differences among persons with disabilities, including type and severity of disability, it is difficult to determine whether persons with disabilities as a group are more or less

likely than able-bodied persons to utilize health care services. For example, persons who are prelinguistically deaf have been found to under-utilize health care services, while persons who are postlinguistically deaf have been found to over-utilize services (O'Hearn, 2006). There is conflicting data on the utilization of preventive health care services, though overall it appears that persons with disabilities utilize preventive services at a lower rate than able-bodied persons (O'Hearn; Rurangirwa et al., 2006; O'Day et al., 2005), with likelihood decreasing as severity of disability increases (Wei et al., 2006). It is only half as likely to enter publically sponsored treatment for drug and alcohol abuse (Krahn et al., 2007; Krahn et al., 2006b; West et al., 2007; Taggart et al., 2007).

On the other hand, there is some evidence that persons with disabilities are more likely, on average, to make health visits. For instance, data from the 1998/1999 National Population Health Survey show that Canadians with disabilities made an average of three times more family doctor visits than the non-disabled population (McColl et al., 2005, cited in Calgary Health Region, 2008). The literature suggests, however, that a greater frequency of health visits may be a function, in part, of persons with disabilities receiving inadequate health care during initial visits (e.g. inadequate understanding of treatment plans, missed symptoms of disease or illness), resulting in a need for repeat visits. There is indeed substantial evidence that persons with disabilities are less likely than the general population to have their needs fully met by health care services (Marks and Teasell, 2006; O'Day et al., 2005; Reeves and Kokoruwe, 2005); reasons for unmet health care needs are explored throughout this report.

Some of the focus group participants remarked on the reduced use of preventive health services by persons with disabilities, although other participants (or their support workers) said they receive regular screening tests, such as mammograms, and routine preventive health care, such as dental care. Examples of overlooked preventive services included:

- Some physically disabled women have not had Pap Tests on a regular basis because it is difficult to lift them from the wheelchair and position them for the test (a group in Calgary is working to establish accessible Pap Test clinics, which is discussed further under Section 4.0, Barriers and Recommendations).
- Some support workers said their clients do not always receive a thorough physical exam, including blood pressure readings.
- One support worker requested a mammogram for her client and the doctor responded, "Why do you want to do that?."
- Some participants felt that parents of children with disabilities with "difficult behaviour" avoid the doctor's office because of the stress of trying to control their children in the waiting room.

Persons whose disabilities caused them to exhibit antisocial behaviour are at a particular disadvantage in the health care system, illustrated by the following example. A focus group participant was concerned that her disabled roommate's abdominal pain was not being diagnosed in a timely manner because health care workers were refusing to see him because of his disruptive behaviour. The roommate had in the past been abusive to hospital staff and was

told he would not be seen in emergency unless brought in by ambulance. The participant said the staff “see him as an old drunk” when, in fact, his behaviour was related to his disability and not alcohol use. Unfortunately, the cost of ambulance transport to the hospital was a barrier for this individual. While the Calgary Health Region’s zero tolerance policy on abuse is in place for good reason, persons with psychiatric disabilities whose behaviour is sometimes abusive may not always receive the care they need because their own behaviour creates a barrier.

3.4 Satisfaction with Health Care

Dissatisfaction with health care among persons with disabilities is well-documented; for example, of persons with disabilities participating in a study conducted in Toronto, one-in-five (21.9%) felt their disability prevented them from receiving adequate health care (Veltman et al., 2001). Dissatisfaction with health care is attributed to poor communication (O’Hearn, 2006; Reeves and Kokoruwe, 2005) as well as perceptions of unmet health care needs (MacLurg et al., 2005), including unmet needs for preventive screening (Parish and Saville, 2006), accessible health information (Hoffman et al., 2005), and specialist health care (Jha et al., 2002). Dissatisfaction with health care is significant as it can lead to avoidance or delay in seeking health care, poor compliance with treatment recommendations, and reduced likelihood of seeking follow-up care (Hoffman et al., 2005).

While dissatisfaction with health care among persons with disabilities is well-documented, many of those who participated in the focus groups expressed satisfaction with accessing health care in Calgary and area. This suggests that actions already being taken are helping to reduce barriers. Some of the examples cited in the focus group were:

- adequate appointment length
- adequate physical space in some situations
- respectful communication with health care providers in many situations

Calgary Health Region

In contrast to the literature, many participants in the focus group expressed satisfaction with the health care system. In particular, participants with developmental disabilities and their support workers described exceptionally positive experiences, i.e., being able to access the care they needed, having appointment times of adequate length, being in physical spaces of adequate size and experiencing respectful and satisfying communication with health care providers. One support worker noted that her client’s “health care providers worked together as a team.” Another said, “the Dementia Centre at the Peter Lougheed Centre is a great service. They treated my client like a regular person...Figured out a baseline and went from there.” A person with a psychiatric disability said, “I feel I can talk to my psychiatrist anytime.”

That said, a number of focus group participants gave examples of frustrating experiences related to appointment times that were inadequate, unsatisfactory communication with care providers, lack of knowledge of care providers and non-accommodating procedures. While some of their concerns might be echoed by the non-disabled population (e.g., waiting time too long, inability to ask their family physician about multiple issues at one visit), some experienced difficulty because of their disabilities, e.g., doctor ignoring the disabled person and speaking directly to the support worker, nursing staff making incorrect assumptions about the extent of their disability (hesitant to discharge a disabled person because there was no one else at home,

although the disabled person was capable of looking after himself) and receiving print materials in formats that are not legible for visually impaired persons.

Summary

The preceding discussion has illustrated the greater likelihood of persons with disabilities to have multiple and complex health care needs, and has demonstrated that as a group, persons with disabilities are more likely to perceive their health status as poor, to report having unmet health care needs, and to report lower levels of satisfaction with health care (though in contrast to the literature, focus group participants generally expressed satisfaction with care). While these health issues are not experienced in the same way or to the same extent by all persons with disabilities, their examination does provide a context for understanding the various barriers persons with disabilities may experience in their efforts to access quality health care. These barriers are examined in the remainder of the report.

4.0 HEALTH CARE ACCESSIBILITY: BARRIERS AND RECOMMENDATIONS

When health care and health care environments are experienced as inaccessible, persons with disabilities are at risk of not having their health care needs fully met; moreover, these barriers subtly convey messages about the value and normalcy of persons with disabilities, possibly reinforcing feelings of deficiency and disempowerment:

Such internalized oppression, particularly when individuals are experiencing illness or injury, when their identities are fragile and in flux, can add unnecessary distress. At a minimum, such messages are not therapeutic, producing a preventable harm (Kirschner et al., 2007: 1122).

In this section we explore environmental, process, and individual barriers to health care commonly experienced by persons with disabilities, as well as recommendations for their elimination.

4.1 Environmental Barriers & Recommendations

Environmental barriers refer to characteristics of health care settings that are known to impede access to health care among persons with disabilities, and include the physical inaccessibility of facilities and equipment, inappropriate practices and procedures, transportation barriers, the inaccessibility of health information, and disparities in accessing aids, devices, and human support for the activities of daily living. Each of these environmental barriers, as well as recommendations for their elimination, is discussed in this section.

Accessible Environments

Persons with disabilities commonly experience physical access barriers in health care settings; for example, of persons with disabilities surveyed in Toronto, nearly one-third (32.3%) had experienced health care settings as at least somewhat physically inaccessible (Veltman et al., 2001). Of particular concern is the inaccessibility of medical equipment, such as examination tables and diagnostic equipment.

Many health care facilities do not have adjustable-height examination tables, appropriate lifting devices, and weight scales that can accommodate wheelchairs, and much of the diagnostic equipment, such as mammography machines, is inaccessible to persons with limited mobility (Kroll et al., 2006; Mele et al., 2005; Marks and Heller, 2003; Veltman et al., 2001). Research also indicates that hospital settings often fail to provide beds, hoists and chairs that can accommodate persons with obesity (Pain and Wiles, 2006). The inadequate provision of assistance with transfers (e.g. from wheelchair to examination table) is further experienced as a barrier by persons with physical mobility limitations (Kroll et al.; Pain and Wiles).

The physical space in doctors' offices, labs and similar places is usually too small to transfer non-ambulatory clients, even when they are accompanied by a caregiver who can do a one-person transfer. As one support worker said, "We had great difficulty helping my client with a urine test."

Focus group for persons with disabilities

Inaccessible environments are associated with unmet health care needs and with inadequate provision of preventive health care in particular (Kroll et al., 2006; Wei et al., 2006; Mele et al., 2005). Of physically disabled women surveyed in Ontario, 10% had never had a Pap test or pelvic exam, citing their inability to access the examination table as the main impediment (Cooper and Yoshida, 2007). The perception of inaccessible equipment, such as mammography machines, is often enough to inhibit women with disabilities from pursuing preventive health care (Schopp et al., 2002).

With the exception of the provision of accessible medical equipment, Canadian health care facilities have largely been designed to accommodate persons with limited mobility; however, there remains concern about the accessibility for persons with cognitive disabilities. Environments experienced as complex, confusing, or difficult to navigate may be perceived as intimidating and unwelcoming by persons with cognitive disabilities (Alborz et al., 2005; Brown, 2005). Inadequate signage is also a concern, including an absence in some clinics of signage indicating the location of wheelchair accessible entrances (Marks and Heller, 2003) and a prevalent absence of signage that is appropriate for persons with cognitive disabilities (e.g. with simple pictorial representation; Alborz et al., 2005) and sensory disabilities (e.g. Braille and raised letter signage; O'Day et al., 2004; Marks and Heller, 2003).

Recommendations

To eliminate barriers in the physical environment, health care systems are encouraged to adopt the principles of 'universal design,' wherein physical environments are designed in ways that they can be used, efficiently and effectively, by all people (Kirschner et al., 2007; Richman, 2007; Iezzoni, 2006). Existing facilities can often be modified at little cost, for example by purchasing removable ramps to facilitate access to the building, making cut-outs in the front desk to accommodate wheelchairs, and purchasing a lower desk at which persons in wheelchairs can more easily sign documents (Mann et al., 2007).

Appropriate signage can be installed to make it easier for persons with cognitive disabilities to find their way around health care facilities, and a consulting cubical can be designed using lighting and colour to minimize distress (Brown, 2005).

Adjustable height examination tables and accessible mammography machines are available that can be used by everyone (Mann et al., 2007; Richman, 2007; Iezzoni, 2006; Veltman et al., 2001), and hospitals may purchase a basic set of

Several disabled women in the Calgary area have teamed up with the Women's Health Resource Centre to offer accessible Pap Test clinics. They have already identified enough women for three clinics. An accessible location has been found but the group ran into an unexpected block when they discovered the doctors they had lined up to do the tests did not have a practice license at the hospital where the clinic will be based. The group will continue to work through these issues toward achieving their goal.

Focus group for organizations that work with persons with disabilities

Sometimes simple adjustments to a physical environment, such as a white sheet draped over a dark coloured table, can improve the situation for a visually impaired person.

Focus group for persons with disabilities

Aspects that influence readability of print material (e.g., colour contrast) vary among individuals so health care providers need to ask what works best for each person.

Focus group for persons with disabilities

heavy duty equipment, such as a bed, chair, commode and hoist, to accommodate persons with obesity (Pain and Wiles, 2006). Participants in the focus groups suggested ceiling tracks be installed in more places. Finally, personnel can be trained in patient transfer techniques that are safe and that maintain the dignity of the individual (Cooper and Yoshida, 2007; Richman, 2007; Veltman, 2001), can be trained in positioning techniques for mammography (Schopp et al., 2002), and physicians can learn how to conduct Pap tests in alternative positions (Veltman, 2001).

Procedural Accommodation

Procedural accommodation refers to the extent to which the usual practices of health care encounters are experienced as facilitating or impeding access to health care among persons with disabilities, and include the amount of time allocated for appointments or consultations as well as practices and procedures occurring during the consultation and upon discharge from hospital.

Inadequate appointment time is a common concern among health care providers and persons with disabilities. A recent study found that nearly three-quarters of Canadian health care practitioners surveyed indicated that time restrictions during patient consultations compromised the quality of care they felt they could provide to persons with intellectual disabilities (Ouellette-Kuntz et al., 2005); of persons with disabilities interviewed in Toronto, 27% cited inadequate appointment time as a barrier to health care (Veltman et al., 2001). Appointment duration may be inadequate due to the extra time required to prepare for an examination (e.g. to access an examination table or undress) or the extra time required for communication (e.g. with the use of a sign language interpreter), but also because persons with disabilities often have complex medical conditions and multiple health issues, such as comorbid and secondary conditions and/or psychosocial concerns requiring extra time (Kroll et al., 2006; Marks and Teasell, 2006; Wei et al., 2006).

The implications of inadequate appointment time are significant. Time deficiencies can impair the ability of health care providers to deliver thorough and comprehensive care (Alborz et al., 2005; Marks and Heller, 2003); time deficiencies are considered to be a leading cause of the inadequate provision of preventive health care to persons with disabilities (Wei et al., 2006). Time deficiencies can reduce opportunities for building relationships of trust and rapport, and it is not uncommon for persons with disabilities to leave the 'hurried' encounter feeling as though their provider did not fully understand their condition or fully address their questions and concerns (Reichard et al., 2004; Iezzoni et al., 2003).

Addressing time deficits may be simply a matter of scheduling longer appointments for persons with disabilities; it is also important that health care providers be aware of the messages that may be conveyed to persons with disabilities when they act hurried or rushed, and make concerted efforts to ensure that patients' questions and concerns are fully addressed (Brown, 2005).

Focus group participants with psychiatric disabilities said they sometimes were unable to attend scheduled appointments because of mental health issues that arose unexpectedly. However, non-attendance can lead to being charged for the missed appointment or eventually refused future appointments, which would compromise their health.

Another procedural barrier concerns routine practices that are inappropriate for persons who are Deaf³ or hard of hearing. Reception personnel regularly summon patients from waiting rooms by calling their name, a practice which is highly inappropriate for persons who are Deaf or hard of hearing, and can result in patients feeling embarrassed or missing their appointment altogether (Iezzoni et al., 2004). The practice of radiology staff of providing oral instructions to X-ray patients from behind protective shields is also inappropriate for persons who are Deaf or hard of hearing (Ubido et al., 2002). The use of automated telephone menu systems used by some health care facilities present additional challenges for persons who are Deaf or hard of hearing, and the practice of issuing small appointment cards may be inappropriate for persons who are blind or have low vision (Iezzoni et al., 2004; O'Day et al., 2004).

Persons who are visually or hearing impaired may require an interpreter for medical appointments. In these situations, late appointments are problematic. As explained by one individual who requires a sign language interpreter, the interpreter can stay only for the length of time for which they have been booked. If appointments run late, she stands to lose her interpreter. Fortunately, in a recent instance when appointments were running late, the medical office was accommodating—she notified the care provider of the situation and they juggled the schedule to fit her in before the interpreter had to leave for her next booking.

Focus group for organizations that work with persons with disabilities

An additional procedural barrier was identified by participants in several focus groups: restrictions on support workers accompanying clients. While most support workers said they had been able to go with their clients in all situations, some spoke of instances in which they were told they could not accompany the disabled person beyond a certain point. In one instance, the support worker for a cognitively disabled client was prohibited from being with her for a rather routine 15-minute procedure in an emergency department. During the time they were separated, the disabled woman panicked, which resulted in her being sedated and strapped to a table while a male health care worker completed the procedure.

One support worker said, "I have to explain everything every time to every doctor. Communication between the doctors is not great. I keep ...a binder of everything so I can pass on the information from one doctor to the next."

Focus group for persons with disabilities

In a second situation, the support worker of a client with a developmental disability was told she could not accompany her client into the examining room. The support worker felt it was absolutely essential that she be present and insisted. The health care worker again said no. The support worker then threatened to call the media and was finally given permission for her and another support worker to accompany her client. The support worker said she has had to advocate for clients in such a way on several occasions.

A number of participants in the focus groups said they felt it was essential for disabled individuals to bring their own support workers whenever they are admitted to hospital in order

³ Deaf written with a capital 'D' refers to the community of persons who communicate in American Sign Language, who often have learned English as a second language, and who identify with Deaf culture (Reeves and Kokoruwe, 2005).

for proper patient transfers to occur. Some disabled participants also said they would appreciate the support of a staff member in the hospital whose job it was to help navigate them through the system.

Connected to the issue of support workers is the barrier of privacy legislation, e.g., sometimes a disabled person's support worker is not given important medical information and the provider cites privacy legislation as the reason. Focus group participants said, in some situations, health care providers have refused to tell support workers about the condition of the patient and were willing only to tell the person's legal guardian, although the guardian was not involved in the day-to-day care of the individual. As one support worker said, "I had to get aggressive to get the information."

Concerns related to inappropriate discharge from hospital were expressed in two of the four focus groups. One support worker gave the example of a disabled client discharged from hospital in the middle of the night, transported home by ambulance (for which they would have to pay) and delivered to a home environment where support workers were not available. This situation could have been avoided had the support agency been notified of the impending discharge and been able to properly prepare for the client.

Recommendations

Persons with disabilities participating in research studies have provided some useful recommendations to eliminate these procedural barriers. Persons who are Deaf or hard of hearing recommend using a flashing light, vibrating pager, or number system to alert persons with impaired hearing that the clinician is ready to see them (Lieu et al., 2007; Iezzoni et al., 2004; Ubido et al., 2002). They also recommend installing coloured lights in radiology units that would signal patients with impaired hearing to perform required actions. Additional recommendations include providing adequate lighting and reducing background noise in examination rooms to facilitate sign language interpretation; ensuring TTY⁴ and TDD⁵ equipment is available and that staff are knowledgeable in their use; purchasing an audio sound system to facilitate communication with persons who are hard of hearing (such as Pocket Talkers, an assistive listening device that amplifies sound through a microphone); reviewing automated telephone menu systems for their suitability for persons who are Deaf or hard of hearing; considering the use of alternative forms of communicating appointment information, such as email or fax; and ensuring light as well as sound signals are used to alert individuals in the event of a fire emergency (Iezzoni et al.; O'Day et al., 2004).

It is also important that support workers be allowed to accompany their disabled clients throughout their experience in the health care system so that they may provide crucial assistance with communication between the client and the system, communication between health care workers and advocacy for clients in a variety of settings. Support workers in the focus groups suggested written notes (both support workers and health care providers) on the

⁴ Teletype

⁵ Device for text communication along a telephone line

blackboard in their clients' rooms would enhance communication. Privacy legislation as related to the provision of information to support workers, should be examined and, if possible, procedures put in place to facilitate information provision. While providers are legally and ethically bound to confidentiality guidelines, perhaps there are legal documents that the support worker can present to providers so the providers do not feel compromised.

Hospital routines around discharge of persons with disabilities should be examined so that safe and appropriate discharge occurs each time.

Transportation

The accessibility of health care is in part a function of the availability of transportation that is accessible, efficient and timely (Mele et al., 2005; Reichard et al., 2004; Marks and Heller, 2003; Scheer et al., 2003). Over one-third (38.8%) of Veltman et al.'s (2001) Toronto sample of persons with disabilities reported that transportation had at some point been a barrier to health care. Public transportation appears to present the greatest challenge; persons who are blind or have low vision may perceive public transportation as intimidating and to be avoided (Pollard et al., 2003). City buses often do not have the required lifts for persons with wheelchairs, or existing lifts do not work properly; drop-off points are not always close to health care facilities, and the cost of public transportation can be prohibitive to persons with disabilities on moderate incomes (O'Day et al., 2004). Disability transport services are available, but scheduling can be problematic; when appointments run late, transport services may not be able to wait; disability transport services have also been reported to run late themselves, resulting in missed appointments (O'Day et al.; Ho et al., 2007).

Transportation stood out as one of the most significant issues for participants in the focus groups. While they remarked on many positive aspects of disabled transportation arranged through Access Calgary (e.g., priority status is given to medical appointments, drivers are pleasant, dispatcher is able to give users a more accurate estimate of arrival time because of recently installed GPS units in the buses), they expressed frustration around sometimes experiencing unreliability and sometimes missing a bus because the driver did not go to the door of the building. Persons with disabilities who were able to ride public transit generally appreciated the opportunity to do so. One support worker who drives persons with disabilities in her agency's bus says handicap parking at health facilities is not always adequate. Several other support workers said, if the medical appointment is particularly important, they drive their disabled clients themselves rather than rely on Access Calgary.

Some visually impaired clients are not eligible for 24-hour Handi-Bus privileges because of their ability to see in the night time. However, some feel unsafe travelling independently in the daytime because of physical obstacles such as stairs and uneven sidewalks.

Focus group for persons with disabilities

Recommendations

Transportation barriers can be reduced by taking care to schedule appointments in consultation with the schedules of disability transport services (avoid scheduling appointments until after morning rush hour), and if appointments are running late, patients could be notified in advance

so that pick-up times can be altered (Veltman et al., 2001). Health care staff should be familiar with public transportation schedules, bus numbers and routes, and be able to provide concise directions from the bus stop to the facility to persons who may have difficulty navigating public transportation, such as individuals who are blind, have low vision, or have intellectual impairments (O'Day et al., 2004). Clients who use disability transport services should be encouraged to provide feedback to customer service representatives and take part in customer satisfaction reviews when they occur.

Focus group participants suggested providing health care in such a way as to avoid unnecessary transportation. In one focus group, it was suggested that persons with disabilities be given the option of being admitted to a "diagnostic bed" in the hospital rather than enduring many months of multiple appointments. However, other participants in this group cautioned segregating persons with disabilities like this, as it could be seen as a set-back, considering the long and difficult struggle for integration. Another suggestion from focus group participants was to use mobile clinics where possible, and they cited the example of a physically disabled and visually impaired person who received homecare services at his place of work and was able to provide a blood sample through a mobile lab. Another suggestion was to look at alternative ways of meeting health care needs through the assistance of others at home, e.g., the roommate of a visually impaired person was taught to give her injections, which she required three times a week.

Health Information

Health information that is not available in accessible formats, as well as the failure of health care providers to orally communicate sufficient and appropriate health information, create further barriers to health care for persons with disabilities. Deficits in the provision of health information in formats accessible to persons who are blind or have low vision are well-documented, including a lack of Braille, large print and audiotape information (Smeltzer et al., 2007; Mele et al., 2005; Ubido et al., 2002).

Health information is often written at a level that is not optimal for persons who are Deaf, who have, on average, a fourth- or fifth-grade reading level, and whose knowledge of medical vocabulary approximates, on average, that of non-English speaking persons (Steinberg et al., 2006), and for persons with intellectual disabilities, who may require simplified language and graphic depiction of health information (Brown, 2005). Focus group participants noted that plain language health information is also important when health care providers are relying on support workers to be the communication liaison with other health care providers in the system.

Persons with disabilities are further at risk of not receiving the same amount of health information from health care providers as able-bodied persons; research conducted by Armour

Health system paperwork is problematic for visually impaired persons. While some visually impaired persons are aided by computer technology (e.g., increase font size to be more legible), technology can also pose barriers (e.g., many documents are distributed in pdf format, which some software programs for the visually impaired cannot change to a more legible size).

Privacy legislation is creating new barriers for visually impaired persons because some documents cannot be sent by email due to privacy concerns.

Focus group for persons with disabilities

et al. (2007) found that compared to able-bodied counterparts, persons with disabilities are less likely to receive information on smoking cessation programs, and Somerset et al. (2001) found that persons with multiple sclerosis are less likely to receive information on exercise and fitness.

When health care providers do not understand behavioural or personality issues of particular clients, barriers to health information can occur. This concern, which arose in one focus group, is more common with clients with behavioural issues and psychiatric disabilities. In this situation, health care providers can take guidance from the support worker, who understands the psychology of the client and how to work with them, e.g., with some clients, communication needs to be markedly firm and direct in order to be effective.

Recommendations

While it is not clear in the literature why health care professionals might fail to provide health information to persons with disabilities (e.g., due to hurried consultations or perceptions that certain health information is not relevant to persons with disabilities), it is recommended that health care providers take the time to provide health information (Armour et al., 2007), and examine their own beliefs for assumptions and biases that might lead them to consider certain types of information to be irrelevant to persons with disabilities (Brown, 2005). The availability of print, audio and visual health information materials in formats that are accessible to persons with disabilities should also be examined, and deficiencies addressed (Steinberg et al., 2006; Brown; Ubido et al., 2002).

As the focus groups revealed considerable communication barriers between support workers and health care providers, it may be beneficial for the Region to work more closely with support workers, perhaps through regular meetings and in-services on topics like conflict resolution and non-violent crisis intervention.

Finally, print materials should be developed in consultation with existing guidelines, such as those produced by Owens (2006); for example, written materials should use plain English, avoiding medical jargon and acronyms, and should use large print, easy to read font and sufficient white space between blocks of text; graphics should be used to support text; and paper with a low sheen should be used to reduce glare. Because persons with dexterity impairments have difficulty turning pages and folding out long sections of brochures, single-page leaflets are preferred; when multiple pages are necessary, a heavier paper makes it easier to turn the pages. Focus group participants noted that print information, when read out to visually impaired persons, should be read word-for-word and not paraphrased. They also encouraged health care providers to contact organizations such as Deaf & Hard of Hearing Society and the Canadian National Institute for the Blind for advice on communicating effectively with persons with communication disabilities.

Aids and Devices and Support for the Activities of Daily Living

The health and wellness of persons with disabilities is influenced by the accessibility of aids and devices as well as human support to accomplish the activities of daily living (Bingham and

Beatty, 2003; Sheerer et al., 2003). According to the 2001 Participation and Activity Limitation Survey (Fawcett et al., 2004), 39% of Canadian adults with disabilities have unmet needs for devices and aids to assist with the activities of daily living. Two-thirds (66%) cite cost as the main barrier, with half of those reporting that the item(s) they need are not covered by health insurance; nearly 20% cite not knowing where to obtain the needed item(s) as the main barrier. Canadian children are even less likely to access needed aids and devices; while 68% of children aged 5-14 with disabilities require some type of aid or device, 47% do not have their needs fully met.

Fawcett et al. (2004) also reported that children with very severe disabilities are the most likely to have unmet needs for aids and devices (69% compared to 19% of children with mild disabilities). Children with speech-related disabilities requiring a computer to communicate and children with learning disabilities requiring voice activated or synthesis software are least likely to have access to this type of specialized equipment (63%). Moreover, about three in five children require but do not have assistive devices in the home, such as ramps and street-level entrances, elevators or lift devices, widened hallways or doorways, or automatic or easy to open doors. Cost, lack of resources available locally, and not knowing where to obtain needed aids and devices are the most commonly reported barriers.

In contrast to the above information, persons with disabilities and their support workers in the focus groups generally did not have difficulty accessing aids to daily living, although issues of restricted access to recreational activities was identified. The lack of difficulty accessing aids may be because the participants in the focus groups were well connected with agencies. Some support workers suggested that some health care providers are misinformed about the Persons with Developmental Disabilities (PDD) program in Alberta and do not understand what supports are and are not available to clients in the community. In some cases, clients may be discharged into the community although the care they require may be beyond the limit of the community care workers, e.g., injections for antipsychotic medication or diabetes.

With respect to human support, 70% of Canadian adults with disabilities require help with daily activities of living (such as meal preparation and household chores); of those, 35% report that they have their needs somewhat or fully unmet (this figure increases to 46% among persons with very severe disabilities; Fawcett et al., 2004). Six percent require specialized nursing or medical treatment but of those, 29% do not have their needs fully met. Of persons requiring more support, half (52%) cite cost as the main barrier, 27% indicate that informal support is not available, and 24% do not know where to obtain the help they need. Two-thirds of parents of children with disabilities report unmet support needs and of those, 73% cite cost as the main barrier and 37% do not know where to obtain the help they need (Fawcett et al., 2004).

Retaining support care staff to care for disabled clients is a growing concern. Community agencies, a critical part of the team supporting persons with disabilities who live outside institutions, struggle to keep the staff they have and hire new staff to fill vacancies. And as one person with a disability said, "Without them [support workers], we're nothing."

One support worker said, "Front line workers in our community earn \$8 to \$15 an hour. People can go to Tim Horton's and make \$15."

Focus group for persons with disabilities

Recommendations

Issues of cost and lack of information about where to obtain aids, devices and supports for daily living clearly need to be addressed. In addition to examining health insurance policies for the provision of aids, devices and human support, it is recommended that efforts be made to better communicate to persons with disabilities the available means of acquiring the items/supports they need, as well as information about community agencies providing aids, devices and support at low or no cost (Fawcett et al., 2004). It is also important that health care providers be educated on the limitations of community care for persons with disabilities.

While staff retention is a significant issue for many areas of the public and private sectors, there may be opportunities for the health care system and organizations hiring support workers to learn from each other about successfully recruiting and retaining staff, including support workers for persons with disabilities.

Summary

Barriers identified in this section include inaccessible equipment, lack of time during health consultations for rapport-building and for comprehensive care, ill-suited/ineffective practices and procedures, restricted access of support workers, and inappropriate discharge practices. Transportation, health information and access to aids/devices and supports for daily living also present significant barriers to health care. Both the literature review and community consultation revealed solid insight into the implications of these barriers, as well as possible solutions.

In the next section, we examine barriers stemming from the interactions among persons with disabilities, their caregivers, and members of the health care team.

4.2 Process Barriers and Recommendations

Process barriers refer to characteristics of interactions between health care providers and persons with disabilities that may impede access to adequate and appropriate health care. Process barriers discussed in this section concern the knowledge, experience and attitudes of health care providers; the extent to which the disability is the focus of the health care encounter; communication; and coordination of care.

Knowledge and Experience

With the shift to a community model of care, general practitioners / family physicians are more likely than in the past to provide care to persons with disabilities, and it is not uncommon for health care providers in the community and hospital setting to lack specialized knowledge in the full range of complex disabling conditions (Smeltzer et al., 2007; Kroll et al., 2006; Reichard et al., 2004). In the focus groups, persons with disabilities and support workers appreciated when health care providers enabled persons with disabilities full ability (e.g., feeding self, toileting self and ambulating self) rather than doing things for them that were not necessary.

“They [health care workers] don’t know the capabilities of people with disabilities.”

*Focus group for
persons with disabilities*

A lack of disability-specific knowledge and experience is known to play a role in the provision of inadequate and inappropriate health care to persons with disabilities (Iezzoni, 2006); knowledge and experience deficits are associated with missed symptoms, misdiagnoses, inappropriate prescribing of medications, and delayed treatment (Betz et al., 2004). A concern expressed in one focus group was that referrals to the Deaf and Hard of Hearing Society are often made only as a last resort because doctors are looking at implants as the first option instead of sign language. This results in important learning windows for the person being missed.

Knowledge and experience deficits have been found to increase the likelihood of 'diagnostic overshadowing,' in which symptoms of health conditions go unrecognized, undiagnosed and untreated because they are masked by the disability (Palsbo and Kroll, 2007; Read, 2005). Research provides examples of depression being downplayed as a 'normal' consequence of having a disability and therefore going undiagnosed and untreated; examples have also been found of symptoms of mental illness being erroneously attributed to learning and developmental disabilities, rather than to unrelated and treatable mental health conditions (Connolly et al., 2006; Ouellette-Kuntz et al., 2005). Concern has also been raised about the ability of general practitioners to be sufficiently up-to-date on disability-related advances in treatments and medications (O'Day et al., 2005) and to be fully knowledgeable about disability-related community-based services and supports (Smeltzer et al., 2007).

Persons with disabilities often end up teaching health care providers how to adapt to their disabilities. For example, home care workers visiting the home of a visually impaired person were reminded not to move furniture and other items in the home, which would make it difficult for the person to get around safely.

Focus group for persons with disabilities

Lack of knowledge and experience has further been associated with lower rates of Pap tests and pelvic exams and failure to provide women with disabilities with information on sexual health and pregnancy (Clark and O'Toole, 2007; Richman, 2007; Smeltzer et al., 2007; Gavin et al., 2006; Parish and Saville, 2006; Wei et al., 2006; Ramirez et al., 2005; Schopp et al., 2002; Ubido et al., 2002). Of disabled women surveyed in Ontario, 10% of those who had never had a Pap test had reportedly been told by their physician that they did not require the test because they were sexually inactive (Cooper and Yoshida). Whether their physicians were not aware of the need for preventive screening among sexually inactive women, or whether they had other reasons for not conducting the exam, is unknown. In addition, Alborz et al. (2005) suggest that women with disabilities tend not to be invited to participate in community outreach screening programs because they are perceived as not needing this service. Inexperience may further cause health care providers to assume, often erroneously, that their patients with disabilities are not sexually active or interested in becoming parents, resulting in their failure to provide adequate and appropriate health information on these topics. Research conducted by Mele et al. (2005) for example found that women with disabilities are seldom asked by their physicians about whether they have a regular and adequate source of gynecological care.

In addition to actual deficiencies in knowledge and experience, it is not uncommon for persons with disabilities to report that they perceive their health care providers to be uninformed about their disability; Kroll et al. (2003) for example found that 70% of their American sample of persons with cerebral palsy, multiple sclerosis and spinal cord injuries was dissatisfied with the level of knowledge practitioners appeared to have about their specific disability. Perceiving health care providers as unknowledgeable or inexperienced can lead persons with disabilities to feel misunderstood and poorly cared for, which in turn can lead to decreased service utilization (Palsbo and Kroll, 2007; O'Day et al., 2005).

Recommendations

While primary health care providers cannot be expected to garner medical expertise in all types of complex disabling conditions, it is recommended that they enhance their knowledge of the medical care needs of persons with disabilities seen in their practice (Lieu et al., 2007; Mann et al., 2007; Kroll et al., 2006; Iezzoni, 2006; O'Hearn, 2006; Brown, 2005; Reeves and Kokoruwe, 2005; O'Day et al., 2004; Fenton et al., 2003; Powrie, 2003). Physicians should become knowledgeable in how symptoms of health problems are expressed in persons with certain disabilities (weight gain in persons with Down's syndrome for example is often an early sign of hypothyroidism; Ruddick, 2005); should examine their understanding of and beliefs about disability and sexuality; and should promote the importance of preventive screening among all their clientele (Clark and O'Toole, 2007; Parish and Saville, 2006; Schopp et al., 2002; Veltman et al., 2001). It is also recommended that health care providers acknowledge their deficits in knowledge and/or experience to their patients, and be willing to consult patients, families and caregivers, as well as specialists, to expand their knowledge base (Palsbo and Kroll, 2007; Tuffrey-Wijne et al., 2007; Iezzoni, 2006; Alborz et al., 2005; O'Day et al., 2005).

Physicians who do not often provide care to persons with particular types of disabilities might consider keeping 'prompt cards' in the files of patients with those disabilities which can be used for quick reference, and that include information on health issues and secondary conditions known to be associated with the disability as well as information on available support services that can be passed on to patients (Alborz et al., 2005). In addition, to the extent that they are available, health care professionals should consult guidelines for the provision of care to persons with disabilities; guidelines currently exist for the provision of primary health care to persons with developmental disabilities in Canada ("Preventive Care Checklist for Adults with Developmental Disabilities;" see Sullivan et al., 2006).

Participants in the focus groups suggested improving the coordination of training for health care providers that is already being provided by government and community agencies.

Attitudinal Influences

Health care providers may convey an unwelcoming attitude toward persons with disabilities for a number of reasons, including attitudes of prejudice or discrimination (Parish and Saville, 2006; Read, 2005; Betz et al., 2004; Sullivan et al., 2004); feelings of discomfort around particular disabilities (O'Day et al., 2005), a lack of confidence in their ability to provide adequate and thorough care (Parish and Saville), resentment of additional (and perhaps uncompensated)

paperwork, report writing and coordination of care (Betz et al.), or increased workloads resulting from downsizing or closing of institutions (Ruddick, 2005).

Unwelcoming attitudes can be conveyed through the refusal of care⁶ (Read, 2005), but are more often conveyed through subtle (verbal and non-verbal) communication. Acting hurried, impatient or abrupt can convey the message that persons with disabilities are an 'inconvenience' (Steinberg et al., 2006; Mele et al., 2005). Speaking in a patronizing manner, 'infantilizing' speech, or speaking to a companion rather than directly to the patient can convey the message that persons with disabilities necessarily have cognitive impairments (Smeltzer et al., 2007; Kroll et al., 2006; Iezzoni et al., 2006; Edey and Robey, 2005). Persons with disabilities may further feel unwelcome when providers display obvious signs of discomfort with the disability (Mele et al.), and may feel poorly understood when providers convey the attitude that disabilities represent 'deficiencies' that should be 'corrected' (Edey and Robey, 2005; Marks and Heller, 2003) or convey the assumption that persons with disabilities lead comparatively unproductive and unfulfilling lives (Iezzoni, 2006).

Visually impaired participants in the focus groups expressed concerns about insensitive care in a few situations: being bathed with the curtains open and having health care personnel "sneak up" without identifying themselves or talking about the procedure they were about to do.

Focus group for persons with disabilities

An issue that was more prominent in the focus groups than the literature was related to "do not resuscitate" (DNR) orders being suggested or assumed in some situations with persons with disabilities. As one support worker said, "They don't ask people with disabilities if they want DNR. They assume it's a DNR...Or they'll ask the support worker in front of [the disabled person]." Some support workers said, in some cases, DNR was written on clients' charts without consultation with the public guardian. "This doesn't happen often but we've seen it more than we should see it. This is an assumption that's not healthy." In one case, the physician for a disabled client with a severe bowel infection called the guardian and suggested treatment "wasn't worth it." However, a second physician who took over the case treated the client successfully with antibiotics. In another case, the physician of a developmentally disabled client with pneumonia advised DNR. It was suggested that persons with disabilities need personal directives just as do the non-disabled population.

Recommendations

Negative attitudes and misperceptions about persons with disabilities can compromise rapport and trust-building, reduce patient satisfaction, and decrease service utilization (Jenkins, 2005; Sullivan et al., 2004). It is recommended that health care providers examine their personal attitudes toward and beliefs about persons with disabilities, become aware of how messages of acceptance are communicated or inhibited in their interactions with persons with disabilities (Alborz et al., 2005; Mele et al., 2005), and enhance their 'disability etiquette' skills, including sensitive, courteous and respectful interpersonal skills (Mele et al.). Education for health care providers around DNR orders and persons with disabilities would be beneficial.

⁶ There is little evidence of persons with disabilities being refused health care in this country, though 8% of persons with disabilities in Veltman et al's (2001) Toronto study reported having been refused medical treatment by a family doctor because of their disability.

Focus on Disability

It is not uncommon for persons with disabilities to report that health care providers focus inappropriately on their disability, particularly when the health visit is meant to address concerns unrelated to the disability (Kroll et al., 2006; Pain and Wiles, 2006; O'Day et al., 2005; Veltman et al., 2001). Research has found that illnesses and conditions unrelated to the disability are often overlooked, and some suggest that this may be due in part to an inappropriate focus on the disability during health visits (Wei et al., 2006; O'Day et al., 2005). In addition, focusing inappropriately on the disability can reduce the time available during the consultation to address preventive health care needs (Kroll et al., 2006; Sullivan et al., 2004); Cooper and Yoshida (2007) for example suggest that opportunities for cancer screening among women with cerebral palsy in their Canadian study may have been undermined by a focus on the disability during physician visits.

"We avoid the health care system as much as we can. Don't want to go since...only thing they want to address is our disability."

Focus group for persons with disabilities

While focus group participants provided several examples of over-focus on disability, this was not the case for all, as illustrated by the story told by one visually impaired woman. This woman fell on a patch of ice and was still on the ground when a passer-by stopped to help. She was "dragged to the hospital" by the helper, who insisted she needed care. The triage nurse at the hospital listened to the woman describe the situation and then explained to the helper that the woman was capable of making her own decisions.

Recommendations

When health conditions unrelated to the disability are ignored or minimized, or when additional symptoms are not investigated, persons with disabilities are at greater risk for poor health; they are also less likely to be satisfied with their health care, and may be reluctant to seek further care (O'Day et al., 2005; Mele et al., 2003). It is recommended that health care providers be encouraged through education sessions to avoid over-focusing on the disability.

Communication

Effective communication is a cornerstone of health care, and is often cited by persons with disabilities as the most important factor in quality health care (O'Day et al., 2005). When communication is impaired, physicians report difficulty understanding symptoms, making health assessments and diagnoses, and determining appropriate treatment plans (Iezzoni, 2006; Hoffman et al., 2005; Jenkins, 2005; Ouellette-Kuntz et al., 2005). Miscommunication can also impair the understanding of health information, medical instructions, prescribed medications, and medical and surgical interventions, and can lead to poor adherence to treatment recommendations (Sullivan et al., 2006; Folkins et al., 2005; Hoffman et al., 2005; Iezzoni et al., 2004; Steinberg et al., 2002). O'Hearn (2006) for example reports that Deaf persons misunderstand up to one-third of what is said in an un-interpreted medical encounter, and research conducted by Reeves and Kokoruwe (2005) found that 37% of Deaf persons communicating without a sign language interpreter gained no better understanding of their health condition from the medical encounter.

Poor communication can also contribute to feelings of frustration among persons with cognitive disabilities, which in turn may increase the likelihood that such individuals will demonstrate uncooperative or difficult behaviours during the medical consultation (Hoffman et al., 2005). Poor communication more generally has been identified as among the leading causes of dissatisfaction with health care among persons with disabilities, which in turn is associated with the under-utilization or avoidance of health care services (Iezzoni, 2006; O’Hearn, 2006; Sullivan et al., 2006; Reeves and Kokoruwe, 2005; Steinberg et al., 2002).

Recommendations

A number of characteristics typify successful communicative encounters between health care providers and persons with disabilities. Persons with disabilities report greater satisfaction when they feel their physician takes time to get to know them, recognizes their individuality, talks openly about the disability without allowing the disability to overshadow the reason for the consultation, explains complex procedures or medical interactions, and listens to (and believes) their description of symptoms (O’Day et al., 2005; Kroll et al., 2003). Successful communication with persons with cognitive disabilities is typified by the use of simple language, slow speech, symbols and diagrams, and a step-by-step method of explaining medical procedures (Brown, 2005; Read, 2005). Health care providers might incorporate these characteristic into their communications with persons with disabilities, and might also consider consulting persons with disabilities and their caregivers and families to identify preferred and effective modes of communication, and be careful not to assume that communication barriers signify a lack of intelligence or cognitive deficit (Iezzoni, 2006; Edey and Robey, 2005).

Sign Language Interpretation

The communicative barriers and needs of persons who are Deaf have received a great deal of attention in the literature, and merit special consideration. While the use of qualified sign language interpreters during medical encounters is preferred by persons who are Deaf (O’Hearn, 2006), and despite research evidence that the use of qualified sign language interpreters enhances patient satisfaction, adherence to treatment recommendations, and the use of preventive health services (O’Hearn; Reeves and Kokoruwe, 2005; Steinberg et al., 2002;), interpreters remain underutilized in health care environments (Lieu et al., 2007; Smeltzer et al., 2007; O’Hearn, 2006). Sign language interpreters are available through the Calgary Health Region’s Interpretation and Translation Services, although one participant in a focus group expressed frustration at not always being able to book an interpreter when required. She also felt that signage for sign language interpretation could be improved, as it was not as prominent as signage for spoken language interpretation.

The underutilization of interpreters is attributed in part to misconceptions held by health care professionals about the adequacy of alternative modes of communication. It is frequently assumed for example that lip reading and note-writing are adequate modes of communication, despite evidence to the contrary (Reeves and Kokoruwe, 2005; Iezzoni et al., 2004). A mere 30-40% of speech is visible on the lips, and speaking unclearly, too quickly, and using complex language can make lip reading ineffective (Sullivan et al., 2006; Reeves and Kokoruwe, 2005).

Moreover, there are numerous instances in the health care encounter when the lips are not visible, such as when an exam is being conducted or a surgical mask is worn (Lieu et al., 2007; Iezzoni et al.; Ubido et al., 2002). The complexity of medical vocabulary, along with poor handwriting quality, makes note-writing an ineffective mode of communication as well (Lieu et al., 2007; Sullivan et al., 2006). This point was confirmed in the focus groups where participants expressed frustration over the assumption by some health care providers that note-writing was an adequate form of communication.

For many persons who are Deaf, American Sign Language (ASL) has been learned as a first language and English as a second language (Connolly et al., 2006; Barnett, 2002; Ubido et al., 2002). When health care providers become aware of the differences between ASL and English, they may be more likely to utilize sign language interpreters and may be better able to understand the communication style of persons using ASL. Specifically, health care providers should be aware that ASL and English do not use the same grammar and syntax; that facial expressions and body posture comprise part of the ASL vocabulary and punctuation, that non-verbal cues have different meanings (for example nodding may indicate comprehension rather than agreement), and not all English words have meaning in ASL (including for example bowel, smear and penicillin; Lieu et al., 2007; Barnett, 2002; Ubido et al., 2002). There are also differences in conversational structure, with important information normally being shared first in ASL and social 'catching up' occurring after important business has been attended to. Incongruence between this style and that of the medical interview, in which rapport-building normally precedes the medical discussion, can cause frustration for providers and patients alike. The patient may feel that the physician considers rapport-building more important than the health issue at hand; knowing this, the simple gesture of reserving social conversation for the conclusion of the medical encounter can facilitate the patient-physician interaction and lead to greater satisfaction with care (Barnett).

Recommendations

When health care providers understand the differences between ASL and English, they are less likely to attribute communication difficulties to cognitive deficits in persons who are Deaf. This is significant, given that perceptions of cognitive deficits can cause health care providers to treat persons who are Deaf as less able and willing to participate in their own care, and reduces patient satisfaction (Lieu et al., 2007; Iezzoni et al., 2004). It is recommended that health care providers routinely inquire about the Deaf patient's preferred mode of communication; doing so not only allows for interpreter services to be arranged, but conveys to the patient that their needs are respected and valued (Smeltzer et al., 2007; O'Hearn, 2006; Reeves and Kokoruwe, 2005; Steinberg et al., 2002). During the medical encounter, health care providers should periodically ask whether communication is effective and how it could be improved (O'Hearn, 2006; Steinberg et al., 2006; Iezzoni et al., 2004).

It was suggested in a focus group that the Calgary Health Region investigate providing sign language through video interpretation relay service, as is available in some American states. This would increase the availability of interpretation services.

Coordination of Care

Case management and service integration have long been regarded as important in meeting the complex health care needs of persons with disabilities (Kastner and Walsh, 2006). A well integrated and coordinated system of care can enhance service delivery and service utilization by reducing the fragmentation of services, reducing service gaps, and reducing bureaucracy and simplifying processes, thereby making it easier for persons with disabilities and their families to navigate the health care system and to obtain services (Gavin et al., 2006; Kastner and Walsh, 2006; Krahn et al., 2006a; King and Meyer, 2006; Wei et al., 2006; Kerr et al., 2003; Hayden et al., 2005; Dryden et al., 2004; Majnemer et al., 2002; Branigan et al., 2001).

A number of studies, however, have found persons with disabilities cite a lack of service coordination and integration as a major barrier to quality health care (Miller et al., 2007; Pain and Wiles, 2006; Palsbo and Kroll, 2007; Peter et al., 2007; Taggart et al., 2007; Gavin et al., 2006; Jenkins and Davies, 2006; Betz et al., 2004; Reichard et al., 2004); just 55% of persons with disabilities surveyed in Toronto, for example, indicated that they were satisfied with the coordination of specialist services (Branigan et al., 2001).

Although many participants in the focus groups were satisfied with coordination of care, a number of support workers expressed frustration over lack of service coordination and integration. For example, upon admittance to hospital, they provided the health care team with written information on the client's disability, health issues, medications and provided the actual medications. It has been the experience of some support workers that this information is not passed on between members of the health care team. As one support worker said, "There's a lack of information sharing. Nothing lasts. There's no tracking... We don't know how our clients are using the hospital."

Support workers said they often needed to think ahead about what health issues needed to be dealt with and what needed to be communicated to whom on the health care team, e.g., psychiatric patients were not always notified in advance by the pharmacy that their prescription refill is expiring, which can result in a delay in medication unless the support worker is able to "ask a special favour of the doctor." Yes, clients with psychiatric disabilities who received their medication by home delivery were notified in advance of refill expiration.

One participant in the focus group, who was on self-managed care and therefore coordinated and paid for much of her own care, was very satisfied with the system. She cautioned, however, that self-managed care might be less successful in a "dysfunctional family" situation.

Recommendations

The Council on Children with Disabilities (2005) recommends that care coordination be the designated responsibility of a key worker or care coordinator, rather than the responsibility of the primary care physician, as the latter may lack knowledge about the disability, community resources, and/or the coordination process. According to the Council, responsibilities of key

workers or care coordinators include developing a service plan that integrates the recommendations of multiple professionals and service systems; assisting the individual and/or family in accessing services and resources; facilitating communication among multiple professionals and services; and identifying and eliminating the duplication of services. Key worker programs implemented in the UK have been found effective in providing a single point of contact, providing advice and assistance, and facilitating access to and coordination of services from various agencies and professionals; in addition, key worker programs are shown to enhance relationships among persons with disabilities and their families and health care providers, improve morale and decrease social isolation, lessen the burden on family members and other informal care givers, and reduce the prevalence of unmet health care needs (Greco and Sloper, 2003).

Successful implementation of key worker or care coordinator programs requires the development of effective methods of multiagency collaboration, including detailed action plans, commitment from senior managers at various agencies, joint planning, effective communication between agencies, and access to a designated budget, as well as the involvement of persons with disabilities and their families in the design and decision-making process (Greco and Sloper, 2003).

Summary

This section has identified various process-related barriers, including the knowledge, experience and attitudes of health care providers, inappropriate focus on the disability, communication barriers, and the lack of coordinated care. With increased sensitivity to, and knowledge and understanding of, the needs and circumstances of persons with disabilities, many of the barriers emerging from the interactions between health care providers and persons with disabilities can be overcome. We turn now to examine barriers to health care arising from the experience of having a disability, including difficulty identifying and communicating health issues and issues of agency and empowerment, including financial barriers to access to health care.

4.3 Individual Barriers and Recommendations

While the focus of this report has been on barriers to health care arising from the ways in which health care environments, practices and procedures are organized, and from characteristics of health care providers and their interactions with persons with disabilities, the literature also identifies barriers to health care that arise from the experience of having a disability, and to which health care systems may respond as they strive to become 'disability competent.' In this section we discuss the challenges persons with disabilities may experience in identifying and communicating health issues, and discuss factors which may contribute to persons with disabilities feeling disempowered to maintain their health and wellness and to pursue health care. Financial barriers to health care are also discussed.

Identifying and Communicating Health Issues

Effective health care requires that individuals be able to identify symptoms of ill health and to provide an accurate and comprehensive description of symptoms, concerns, and preferences for treatment. It is not uncommon, however, for health conditions to go unrecognized by persons with intellectual disabilities (and hence, to remain untreated; Sullivan et al., 2006). Persons with intellectual disabilities may not be fully aware of changes in their physical health, or may be less able to detect abnormal symptoms, if they have poor bodily awareness and depressed pain responses, and may have difficulty communicating their health concerns to others (Clark and O'Toole, 2007; Kastner and Walsh, 2006; Alborz et al., 2005; Brown, 2005; O'Day et al., 2005; Ruddick et al., 2005; Betz et al., 2004).

Persons who have difficulty identifying and communicating health issues are also likely to be persons who depend on others, such as family members, for support with the activities of daily life. It often falls, then, on the caregiver to recognize and identify symptoms of distress, to determine that medical attention is required, to negotiate the health care transaction and to facilitate communication with health care providers (Alborz et al., 2005; Betz et al., 2004). There are several challenges associated with this reliance on caregivers; it may be difficult for a caregiver to identify symptoms of conditions requiring medical attention if deterioration is gradual (Alborz et al.). Also, if caregivers trivialize symptoms and/or consider interventions unhelpful (e.g., not pursuing sight testing for a person who does not read; Alborz et al.; Betz et al.), particularly when additional barriers to accessing health care exist, such as transportation or behavioural challenges that make it difficult for the individual with the disability to participate in health care consultations (Alborz et al.).

Support workers are crucial supports for people with psychiatric disabilities. In one focus group, three of the participants said they take their support workers with them to appointments "just in case." The support workers help them understand what the psychiatrist is saying and help them read the doctors' writing.

Focus group for persons with disabilities

Recommendations

A possible solution is to ensure that persons who may have difficulty identifying and communicating symptoms of poor health have routine medical check-ups and regular preventive health screening opportunities (Alborz et al., 2005; Sullivan et al., 2006). Along with routine health care, systems should be in place to ensure that referrals for follow-up care and treatment are acted upon (Alborz et al.). When appropriate, persons with disabilities should be encouraged to bring their support workers to assist with identifying and communicating health issues.

Advice heard in the focus groups about how to be a self-advocate included: Know your diagnosis and the related medical terminology. Be prepared. Write notes in advance. Speak up. Express your needs. Be creative about problem solving.

Focus group for persons with disabilities

Empowerment and Agency

Having a disability can influence feelings of empowerment or agency to create or maintain a healthy lifestyle, and to pursue primary and preventive health care services. Disempowerment may

Self advocacy requires that someone is listening on the other end.

Focus group for persons with disabilities

be associated with adopting an external locus of control and with feelings of disenfranchisement associated with being dependent upon others for day-to-day needs (Read, 2005), as well as a lack of assertiveness skills and health care system literacy.

Persons with disabilities may, to varying degrees, feel they lack agency to create and maintain healthier lifestyles. Persons with psychiatric disabilities participating in O'Day et al's (2005) focus group research reported feeling overwhelmed by the prospect of changing unhealthy behaviours, such as quitting smoking. They also reported having difficulty managing the weight gain attributed to their medications, and felt that shopping for and preparing healthier foods would be an overwhelming task. Individuals with anxiety disorder and depression have been found to avoid preventive screening tests, including Pap tests and mammograms, due to the fear and anxiety associated with the examinations (Parish and Saville, 2006; Wei et al., 2006; Jenkins, 2005; O'Day et al.; Sullivan et al., 2004). According to Nosek et al (2006), persons with physical disabilities often cite weakness, fatigue and pain associated with their disability as an impediment to exercise. Women with physical disabilities interviewed by Mele et al (2005) were aware of the importance of self-screening for breast cancer, but tended not to self-examine because of spasms, pain, weakness and immobility associated with their disability. Finally, poor self-esteem and feelings of victimization have been cited by persons with disabilities as reasons for not pursuing needed substance abuse treatment (Krahn et al., 2006b).

The financial cost of achieving health and wellness was a major discussion point in the focus groups. The experience of disempowerment has increased for some persons with disabilities due to rising costs in various areas of the economy. For example, increases in the price of gasoline has led to reduced recreational activities for many persons with disabilities because support workers who used to drive them to activities are now refusing because reimbursement for travel has not kept up with the cost of fuel. In one agency, instead of driving clients every day, support workers now drive them only once or twice a week. Nutrition is another area in which health is compromised due to financial cost. The following were examples reported by persons with disabilities in the focus groups: choosing to spend money on recreation rather than food, purchasing nutritional shakes rather than healthy food because the shakes were paid for by Assured Income for the Severely Handicapped (AISH) and having difficulty buying appropriate food for a diabetic diet on the small monthly supplement (\$40) received from AISH for a special diet. And finally, support workers for psychiatric patients said they discovered that some of their clients are not paying the \$2 on-site fee they were charged by some pharmacies for filling prescriptions and missing medication doses as a result, which could lead to a mental health crisis and emergency care. The agency supporting these clients was able to develop relationships with a number of pharmacies to get them to charge the agency if the client refuses to pay the fee, rather than have the client go without medication.

In addition to feelings of disempowerment stemming from physical and cognitive limitations, persons with disabilities may be inhibited in the pursuit of health and wellness by a lack of knowledge. For example, of women with disabilities surveyed in Ontario, one-in-five (19%) believed that they did not require routine Pap tests because they were sexually inactive (Cooper

and Yoshida, 2007), and Schopp et al (2002) report that women with disabilities may not seek mammography because they are not aware of the risk of breast cancer associated with nulliparity. In addition to physical barriers to exercise, Nosek et al (2006) report that persons with physical disabilities sometimes refrain from exercise because they do not have enough information about the potential positive and negative effects of exercise on their disability-related symptoms.

Recommendations

There are a number of opportunities for health care providers to facilitate feelings of empowerment and agency and to enhance the health literacy of persons with disabilities. Specifically, health care providers can work with persons with disabilities to ensure they have adequate support for accomplishing the tasks of daily living, including shopping and food preparation, support for participation in fitness activities, and conducting breast self-examinations. As well, health care providers can work with persons with disabilities and community agencies to help address additional life circumstances, such as poverty and social isolation, as well as low self-esteem and self-efficacy, which in turn can enhance feelings of empowerment and personal agency (O'Day et al., 2005; Nosek et al., 2006).

Persons with disabilities who experience fear or anxiety associated with preventive screening tests could be encouraged to have a trusted support person present during the examination. Physicians can be sure to effectively explain the procedure and obtain consent before beginning such exams as Pap tests and pelvic exams (Sullivan et al., 2004); counselling prior to the exam. This can further facilitate understanding of the procedure and help alleviate fears (Parish and Saville, 2006).

Health care providers can also identify and respond to gaps in knowledge concerning nutrition and exercise and preventive health care (O'Day et al., 2005; Cooper and Yoshida, 2007). A number of education intervention materials are available to promote health and wellness among persons with disabilities, including "Physical Activities & Healthy Lifestyles Project: A PowerPoint Training Tool⁷," "Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities⁸," and "Living Well with a Disability⁹." The Canadian Health Network provides online information as well.¹⁰

Health care providers can encourage persons with disabilities to become more assertive in having their health care needs met by encouraging them to increase their health literacy, including knowledge of their health status, their disability, self-care and wellness, and their knowledge of the health care system, and ways of becoming more assertive, perhaps through further education opportunities (Krahn et al., 2006a ; Kroll et al., 2006; Steinberg et al., 2006;

⁷ <http://www.ilcanada.ca/article/physical-activity-300.asp>

⁸ <http://www.uic.edu/orgs/rrtcamr/hpcurriculum.htm>

⁹ <http://www.livingwellweb.com/lwpage1.htm>

¹⁰ <http://www.canadian-health-network.ca/servlet/ContentServer?cid=1045848110489&pagename=CHN-RCS%2FPage%2FGTPPageTemplate&c=Page&lang=En>

Alborz et al., 2005; O'Day et al., 2005). The "Primary Preventive Services Resource Kit" is an example of an education initiative meant to improve the knowledge of persons with physical disabilities. The Kit provides information on primary preventive services and how to obtain them, case stories with anecdotes of successful primary care self-advocacy, report cards which help persons with disabilities choose disability-competent and accessible health care providers, and tips for appointment planning and scheduling (Kroll et al.). Similarly, Lennox et al (2004, cited in Krahn et al., 2006b) have developed an advocacy skills kit entitled "Ask," which is intended to help promote effective communication between persons with intellectual disabilities and their health care providers and to facilitate the development of advocacy skills.

Persons with disabilities may become more empowered when they are able to make informed decisions in choosing health care providers (O'Day et al., 2005) and should be encouraged to investigate provider characteristics, availability, and disability competence, and how providers coordinate care for persons with disabilities, the physical accessibility of their offices, and the availability of assistance during a health examination (Palsbo and Kroll, 2007). Persons with disabilities should also be encouraged to make a list of questions and topics they wish to have covered before seeing their physician. Before seeing a new physician they might make a list of questions to ensure their needs for assistance and accessibility will be met, such as: "Can someone in a wheelchair get through your doors? Can someone in a wheelchair get up on your exam table? Do they have any means to accommodate a person in a wheelchair, say, a non-weight-bearing paraplegic" (Kroll et al., 2006).

Participation in support groups can further enhance empowerment by facilitating information-sharing, cultivating feelings of independence and autonomy, and providing a source of advocacy. In addition, support groups can provide opportunities for sharing and developing strategies for overcoming health care barriers, and for obtaining support for daily living (O'Day et al., 2005). Some agencies offer education for persons with disabilities in areas that will help them develop skills to become more empowered, e.g., the Canadian National Institute for the Blind runs a speakers club for visually impaired persons, which helps encourage the development of self-advocacy by developing communication skills.

The Internet also holds promise as a source of information on health and accessible health care providers (Kroll et al., 2006), and as a source of peer counselling, advocacy (submitting complaints/making suggestions/networking), and independent living skills-development (O'Day et al., 2004; Ritchie and Blanck, 2003). While Zeng (2003) notes "greater access to health information over the Internet will open a door to people with disabilities by offering them the exciting possibilities for independence and community participation by overcoming environmental barriers" (743), to be effective, websites must be accessible by persons with physical and cognitive disabilities. Reviewing the accessibility of health information websites using the "World Wide Web Consortium Web Content Accessibility Guidelines 1.0" and the U.S. Access Board's "Electronic and Information Technology Accessibility Standards," Zeng found government websites, followed by those of educational institutions, to be most accessible to persons with disabilities. Websites that are most accessible to persons with disabilities are

those that use 14 point Arial typeface, use multiple spacing rather than single spacing, have a simple and consistent page layout, have high contrast between foreground and background, avoid the use of fast moving and inappropriate graphics, provide a text caption with each graphic to explain the purpose of the graphic, use consistent menu selections and navigation buttons, minimize scrolling by placing critical information and navigation options at the top of the page, and provide keyboard as well as mouse navigation (Smeltzer et al., 2004).

Finally, persons with disabilities should be encouraged to become active participants in their own health care planning and decision making, but also in the planning and implementation of disability-competent health care services:

Although persons who are blind or have low vision know how to live, work, and travel daily throughout their homes and communities, health care providers rarely ask their advice about how to organize health care settings, communication approaches, and routine clinical practices to maximize their quality of care and experiences as patients (O'Day et al., 2004: 193).

Iezzoni (2006) suggests persons with disabilities should be invited to participate in interventions meant to reduce barriers to health care:

...to the extent possible, include persons with various disabilities in design decisions... Many people with disabilities are intensely practical and resourceful – they have had to find creative solutions to perform their daily activities and lead productive lives. They could make invaluable and reality based partners in thinking about ways to improve the safety and quality of health care that they and others will receive (406).

Participation in health care planning can enhance feelings of empowerment and agency, increase trust in the health care system, enhance feelings of satisfaction with health care services (Ngu and Flores, 2006), and lead to greater real and perceived access to health care (Jurkowski et al., 2002). The Calgary Health Region has helped to facilitate participation in health care planning by involving persons with disabilities and their support community in the focus groups conducted as part of this research.

The financial barriers discussed in this section cannot be addressed by the Calgary Health Region alone and must be addressed by participation in collaborative efforts to address the broader social determinants of health.

Summary

This section has identified challenges persons with disabilities may experience in identifying and communicating their health needs as well as challenges stemming from disempowerment or a lack of agency. A number of recommendations have emerged, many of which centre on the values of self-education, self-assertiveness and self-advocacy.

5.0 SUMMARY AND CONCLUSIONS

This paper has sought to sensitize health care providers to the potential multiplicity of health issues for persons with disabilities. More importantly, this paper has provided insight into the many environmental, process, and individual barriers experienced by persons with disabilities in the pursuit of quality health care. Interestingly, many of the barriers identified may be addressed, reduced or eliminated through minor modifications of health care practices and procedures. For example, simple modifications to physical environments, such as the addition of appropriate signage, can greatly enhance access for persons with disabilities. Common practices and procedures can be reviewed for ways in which they create challenges for persons with disabilities, and once identified, can be made more suitable. While overcoming some barriers may require the dedication of additional funds, for example for the purchase of appropriate medical equipment and provision of transportation subsidies, the vast majority of recommendations emerging from the literature review and community consultation require greater knowledge and understanding of, and sensitivity to, the lived experiences of persons with disabilities.

These findings suggest then that a great number of barriers to access to health care may be reduced or eliminated through concerted efforts on behalf of the health care team to fully understand, appreciate and become sensitive to the experiences of persons with disabilities.

The Calgary Health Region has an opportunity to become an influential role model in providing inclusive service for persons with disabilities. The literature review summarized here and the focus groups involving persons with disabilities and their support workers is an important first step. The next step will be for the Region to consider the recommendations put forth and develop an action plan that will reduce barriers and improve experiences in the health care system for all people with disabilities.

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