

Defining Programmatic Access to Healthcare for People with Disabilities

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A growing number of publications document that people with disabilities experience barriers in the delivery of appropriate primary and preventive health care (Kirschner, Breslin, and Iezzoni, 2007; Panko Reis, Breslin, Iezzoni, Kirschner, 2004; Parish and Huh, 2006; Scheer, Kroll, Neri, & Beatty, 2003; Neri and Kroll, 2003; Drainoni, et. al., 2006). These barriers are present for those with public as well as private insurance coverage. The barriers can be classified into three (sometimes overlapping) categories: financial, structural, and programmatic. In the financial category are problems related to coverage limitations for medications, durable medical equipment, mental health treatment, referrals to specialists, and treatment for chronic conditions. In the structural barrier category are problems related to the architectural characteristics of medical offices (e.g., parking and entrance locations, doorway width, stairs and ramps, and bathroom accessibility). The barriers to access that can be considered programmatic include aspects of how physician offices operate, the accessibility of the equipment utilized for medical examinations, the medical responses of doctors and nurses to patients with disabilities, and the absence of physician and allied health professional expertise regarding the provision of primary care to someone with a disability.

The financial and structural access problems are elaborated in a number of studies (Neri and Kroll, 2003; Drainoni et. al., 2006; Iezzoni, McCarthy, Davis, & Siebens, 2000). Physicians, policy makers, and the public appear to have some grasp of what financial and structural access mean, even if the implementation of solutions lags. However, Drainoni, et. al. (2006) find that while there are financial and structural access problems, a large proportion of the barriers reported to them by people with disabilities involve the processes used to deliver healthcare (p. 111). These issues of *programmatic* access appear to be less well-recognized or understood. The discussion below strives to define programmatic access and outline how medical practice procedures can be organized to provide programmatic access to healthcare for people with disabilities.

A Definition of Programmatic Access

Programmatic access to healthcare means that the *policies and practices* that are part of the delivery of healthcare do not hinder the ability of patients with disabilities to receive the same quality of care as other persons. Where usual healthcare practice may impose barriers, modifications in policy or procedure may be necessary to assure access. Policies and procedures that comprise programmatic access involve: methods of communicating with patients for the provision of individual medical information and general health information; appointment scheduling procedures and time slots; patient treatment by the medical staff; awareness of and methods for selecting and purchasing accessible equipment; staff training and knowledge (e.g., for operation of accessible equipment, assistance with transfer and dressing, conduct of the exam); standards for referral for tests or other treatment; system-wide coordination and flexibility to enable access; and disability cultural competence. Each of these areas is presented in more detail in Table 1.

**Table 1: Components of Programmatic Access to Healthcare
For People with Disabilities**

| Policies for Communication & Access to Information | |
|---|---|
| Policy or Procedure | Rationale or Method |
| Provisions for intake forms to be completed by persons with visual impairments with the same confidentiality afforded other patients | Use of large print forms, electronic or online web-based forms, or in-person staff assistance in a private location |
| Provision for the presence of sign language interpreters to enable full communication with deaf patients who use sign language | Professionalism and confidentiality require that the healthcare provider take responsibility for the communication |
| Provisions for making auditory information (e.g., automated phone menus or messages) available via alternative means | Written communication or secure web-based methods are possible substitutes |
| Provisions for communicating with deaf patients by telephone. | Use of the telephone relay service (TRS), a TDD, or use of secure electronic means |
| Policies for Scheduling and Waiting | |
| Policy or Procedure | Rationale or Method |
| Policies that allow scheduling additional time for the duration of appointments for patients with disabilities who may require it | Patients may require more time than the standard because of complexities associated with the interaction of a non-disability-related medical condition with the existing impairment or disability. More time may be needed to conduct the examination or for communication through an interpreter or because of other communication issues. |
| Policies to enable patients who may not be able to tolerate waiting in a reception area to be seen immediately upon arrival | Patients with cognitive, intellectual or some psychiatric disabilities may be unable to wait in a crowded reception area without becoming agitated or anxious. |
| Policies to allow flexibility in appointment times for patients who use paratransit | Patients may arrive late at appointments because of delays or other problems with paratransit scheduling and reliability. |
| Policies to enable compliance with the federal law that guarantees access to medical offices for people with disabilities who use service animals | Patients with service animals expect the animal to accompany them into the waiting and examination rooms, and this is a protected right under the Americans with Disabilities Act. A policy enables medical offices to be prepared to respond appropriately to the needs of all patients. |

| Procedures for Conducting the Examination | |
|---|--|
| Policy or Procedure | Rationale or Method |
| Training of nurses and medical staff to safely assist or lift patients from wheelchairs to examination tables or other equipment, and return them safely after the exam. Training to appropriately help a patient who may need assistance with dressing both before and at the conclusion of the exam | Training will reduce the likelihood of injury to the patient or to the medical personnel providing assistance, and ensure that a comprehensive examination can be conducted |
| Ability to identify the need for equipment to assure an exam or procedure can be fully conducted; knowledge about purchasing accessible equipment, repairing or replacing it | Special equipment (e.g., for lifting, weighing, or examining a patient) may make thorough exams possible and better for both patient and provider. |
| Training of doctors, nurses, and other medical staff in the operation of accessible equipment | Medical office staff must know how to operate the accessible equipment, such as adjustable height exam tables and mammography machines and weight scales, so they can be regularly and easily utilized. |
| Training of doctors, nurses, and other office staff for disability cultural competence-- knowledge regarding how to treat a patient with a disability with dignity and respect, and knowledge of how disability may affect the provision of medical treatment for primary and other care. | Stereotypes regarding whether people with disabilities experience pain or are capable of making medical decisions have resulted in deficient treatment. Providers may fail to speak directly to the patient, may not provide for privacy, or may make incorrect assumptions. |
| Plan for emergency evacuation of patients includes evacuation procedures for people with disabilities | Evacuation plans should cover procedures for people who may need assistance in exiting the facility under extraordinary conditions. |
| Procedures for Follow-up or Referral | |
| Policy or Procedure | Rationale or Method |
| Current and potential patients, including people with disabilities, should only be referred to another provider for established medical reasons or specialized expertise. | Referral results in a delay of treatment and subjects patients to additional time and expense and also reduces patient choice of provider. |
| Knowledge and/or attention to the accessibility of laboratories, testing facilities, specialists, or other healthcare delivery venues to which patients are referred | Patients may be unable to comply with medical recommendations if referred to a location for testing, special treatment or a specialist that is not accessible or is not prepared to provide the recommended service |
| Healthcare System-wide Issues | |
| Ability to provide healthcare through flexibility or creativity to overcome barriers resulting from system-wide policies or practices | Where services may need to be delivered in an atypical venue (e.g., teeth cleaning under general anesthesia), system-wide policies and/or coordination is required to ensure access |

References

Drainoni, Mari-Lynn; Lee-Hood, Elizabeth; Tobia, Carol; Bachman, Sara S.; Andrew, Jennifer; Maisels, Lisa (2006). Cross-disability experiences of barriers of health-care access, *Journal of Disability Policy Studies*, 17(2): 101-115.297(10): 1121-1125.

Iezzoni, Lisa I.; McCarthy, Ellen P.; Dvais, Roger B.; and Siebens, Hilary, (2000). Mobility impairments and use of screening and preventive services, *American Journal of Public Health*, 90(6): 955-961.

Kirschner, Kristi L.; Breslin, Mary Lou; and Iezzoni, Lisa I. (2007). Structural impairments that limit access to health care for patients with disabilities, *JAMA*

Neri, M.T. and Kroll, T. (2003). Understanding the consequences of access barriers to health care: Experiences of adults with disabilities, *Disability and Rehabilitation*, 25(2): 85-96

Panko Reis, J.P.; Breslin, M.L.; Iezzoni, L.I.; and Kirschner, K.L. (2004). *It takes more than ramps to solve the crisis in healthcare for people with disabilities*, Rehabilitation Institute of Chicago, Chicago: Ill., September.

Parish, S.L. and Huh, J. (2006). Health care for women with disabilities: Population-based evidence of disparities, *Health and Social Work*, 32(1)7-15.

Scheer, J.; Kroll, T.; Neri, M.T.; and Beatty, P. (2003). Access barriers for persons with disabilities, *Journal of Disability Policy Studies*, 13(4): 221-230