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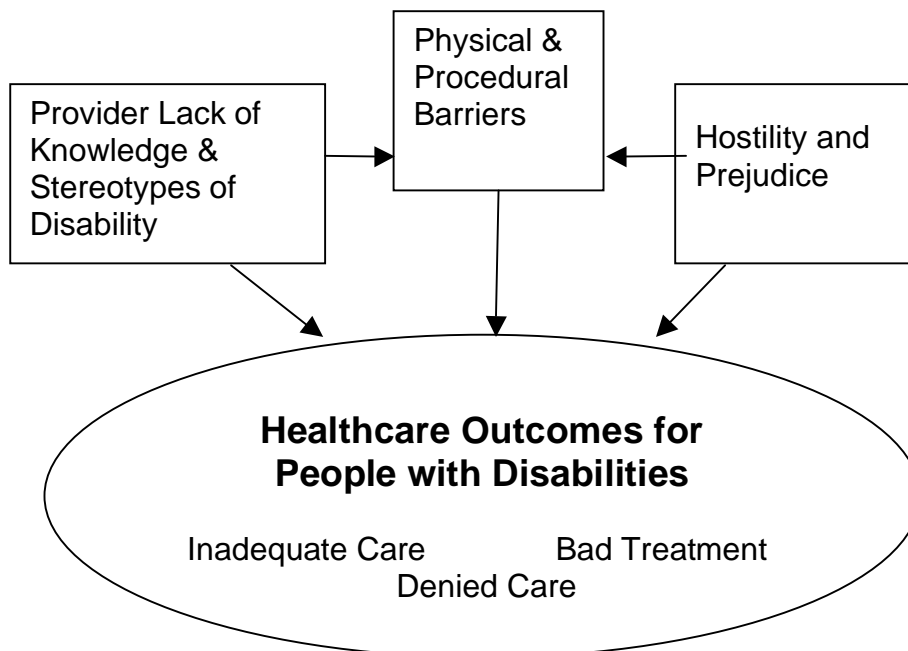
Disability Healthcare Access Brief*

Statement of Problem

Obtaining and maintaining health insurance coverage and quality healthcare is a critical issue for everyone in the United States, but people with disabilities face additional barriers to receiving adequate healthcare. These barriers can range from physically inaccessible healthcare provider locations, to exam and diagnostic equipment that cannot be adjusted for a range of patient function, to a failure to modify office policies or practices to accommodate the communication and accommodation needs of patients with various disabilities.

While federal laws, such as the Americans with Disabilities Act of 1990, as well as many state laws, prohibit discrimination on the basis of disability and clearly apply to the offices of healthcare providers, enforcement efforts to date have failed to bring about needed systemic change in healthcare access for people for disabilities.

The ongoing gap between legal theory and on-the-ground practice results in people with disabilities being far more likely to receive a range of poor responses when seeking healthcare, from outright denial of care to inadequate care to bad treatment, and the problem behind these responses can be rooted in the existence of physical or procedural barriers, the holding of stereotypes and ignorance about people with disabilities, and actual hostility and prejudice. The following illustration can serve as a simple way to frame how the range of potential individual and systemic healthcare responses interacts with the different kinds of factors that can result in making healthcare inaccessible for a person with a disability.



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It may be helpful to keep the above illustration in mind as you read the following reported healthcare statistics and stories from people with disabilities. Consider how and why the existing healthcare system in each particular documented story failed the person seeking care, and the kinds of factors that contributed to that failure. It is also important to remember that in reality, the contributing factors and outcomes specified in the illustration do not comprise watertight compartments. For example, someone with a hearing disability who seeks care for a specific health issue could be turned away at the door, given a cursory physical exam that does not detect the problem, or treated with disrespect and shouted at if a provider incorrectly assumes that Deaf patients must bring their own interpreters. It is certainly arguable that there are aspects of denial of care, inadequate care and bad treatment in all three of these scenarios.

Similarly, false assumptions and stereotypes about those who have a disability often lie behind the systemic physical and procedural barriers that are rife in the healthcare delivery system. For example, the false assumption that “people with disabilities probably live in nursing homes and get all their care in hospitals” has resulted in examination and diagnostic equipment that can only be used by patients who can stand or self-transfer to chairs and tables. The stereotype that “people with disabilities are not employed, are all on welfare, and do not have private insurance”¹ leads managed care organizations and provider offices and clinics that do not take Medicaid to believe that they have no patients with disabilities and need not adopt intake procedures and office policies for someone with a communication disability or a mental disability.

Leading Statistics and Stories

- 28% of insured people with disabilities reported needing particular therapies, equipment or medications that were not covered by their health plans, compared to 7 percent of those without disabilities.²

A Deaf individual who could not get coverage for American Sign Language classes because his insurer did not consider such classes to be “rehabilitative” questions this gate-keeping concept as it is was applied to him, since “for someone who has lost their hearing, [learning ASL] is what rehabilitation means.”³

Medicaid payment limitations for equipment and supplies lead to insufficiency and health-compromising practices as follows: “It’s . . . hard to get G-tubes, drainage bags, nebulizers, catheters, leg bags, etc. When you’re limited to a small number of these, you have to reuse products which are contaminated.”

One parent reports annual out-of-pocket expenses of approximately \$15,000 for the healthcare needs of her child with a disability, because their family’s insurance covered only specific brands of supplies, such as diapers to which her child is allergic.

- 19 percent of people with disabilities reported that they did not receive medical care needed in the previous year, compared to 6% of nondisabled persons.⁴

One of the plaintiffs who participated in a lawsuit brought in 2000 against the largest nonprofit health maintenance organization in the country was usually “examined” in his wheelchair for his check-ups rather than given needed lift or transfer assistance. He developed a pressure sore that remain undetected, became infected, and eventually required surgery.⁵

Some emergency room healthcare providers seem to believe that patients with mental retardation do not feel pain and therefore do not need anesthesia. In those rare instances in which someone with a developmental disability does not experience pain, this cannot be an excuse to forego needed medical treatment. The mother of a child with autism relates that "Once, my son had a piece of metal in his eye. We could see it there, but he didn't feel it [due to the autism], so the doctor wanted us to go [home]."

There is great fear of getting needed healthcare because health personnel can minimize the critical need for information and often do not take the time to communicate with people with disabilities. One Deaf individual describes the experience of undergoing surgery as follows: "I needed a tonsillectomy. I went to the hospital and I was scared. I was sedated and anesthetized, and I woke up afterwards, scared and crying. I didn't know what to expect or what was going on with the swelling. There was no interpreter there."

- When over 3,500 athletes with intellectual disabilities were given health screenings at the 2003 Special Olympics, 35% had obvious signs of tooth decay (without X-rays or probing in their molar teeth), and 12% of athletes reported tooth or mouth pain, compared to 2% of all U.S. employed adults who reported that their last visit to the dentist was for a toothache.⁶

A mother describes her experiences trying to obtain dental services for her son with developmental disabilities by saying that we "can't really get full care. It's hard to find people with the patience to work with him, because he has to be given general anesthesia. When he was a child, he had to get caps put on his teeth, and this was a two-hour process. . . . Dentists don't want to deal with the hassle."

A dentist's office staff refused to assist a blind couple to fill out written consent forms while simultaneously informing them that treatment would be denied unless the forms were completed.⁷

- 33% of athletes aged 8-17 at the last Summer and Winter Special Olympic World Games had never received an eye exam.⁸

Many people with developmental disabilities such as Down Syndrome often need a specialist to conduct basic vision and hearing tests, but insurance companies can refuse to refer members with such disabilities to an out-of-network specialist, insisting instead that they must attend an in-network provider who lacks expertise or any familiarity in working with people with the relevant disability.

- Among women with physical disabilities, nearly 1/3 report being denied services at a doctor's office solely because of their disabilities,⁹ and 56% of women with disabilities who have given birth in hospitals reported that the hospital had failed to prepare for needed disability-specific accommodations.¹⁰

A doctor suggested to the sister of one his patients, a woman in her 50s with developmental disabilities, that the patient's visits be reduced from every few months to once a year, and when asked why responded "She's lived a good life – once a year is fine."

- Women who are unable to stand 10 minutes or climb 10 stairs are far less likely to have received a Pap smear in the last 3 years (63.3% compared to 81.4%), and also less likely to have received a mammogram in the last 2 years (45.3% compared to 63.5%).¹¹

A woman with mental retardation who had difficulty undergoing gynecological exams reported that her doctor downplayed the importance of such exams, ostensibly because the doctor assumed she was not sexually active.

- An observational study of over 100,000 women with stage I to stage IIIA breast cancer revealed that the 2800 women with disabilities who were in the study were less likely than the other women to receive radiotherapy following breast-conserving surgery (74.8% vs. 81.9%).¹²

A patient with mental retardation was diagnosed with advanced breast cancer that required surgery, "but her physician implied that due to her already low quality of life (owing to her disability), she did not merit the intervention, and her guardian did not want to make the decision to go forward without the physician's support." Surgery was delayed and the woman reportedly died within a year.

Statement of Response

A study based on over 2,500 responses from U.S. medical and dental school deans and residency program directors, medical and dental students, and advocacy and patient care groups, is encouraging in its finding that almost 75% of the students indicated interest in treating people with intellectual disabilities as part of their career. However, over 50% of the medical and dental students and deans acknowledged that medical and dental graduates were "not competent": to treat people with intellectual disabilities. Some of the major reasons given for this discrepancy between stated desire and actual fact are "lack of curriculum time" "lack of faculty expertise," and "lack of any clinical training" on the subject.¹³

Unfortunately the best of intentions do not make offering a bedpan to a patient in an office that lacks an accessible bathroom, or offering a woman using a wheelchair a gynecological exam on the floor because the office lacks a height-adjustable exam table, clinically or professionally appropriate. It is neither legal nor ethical to condition healthcare and health information for people with disabilities on their bringing lifting attendants, sign-language interpreters, and/or a personal advocate who will remind the provider of pertinent healthcare needs and potential treatment interactions to every medical appointment and provider office. These incidents occur, and will continue to occur, as long as the only impetus for change is the good intentions of individual healthcare providers, backed up only by laws that are inconsistently enforced and depend upon patient willingness to file lawsuits against their individual healthcare providers.¹⁴

Both the American public and state governments are beginning to understand that the issue of under- and uninsured health insurance in this country cannot be addressed without sweeping changes and some movement towards a universal healthcare system. Similarly, the disability access issues faced by people with disabilities cannot be solved without systemic reform of the healthcare delivery system. Meeting the health needs of people with disabilities, whether it involves the provision of basic healthcare and health maintenance for those with various disabilities or meeting the specific clinical needs of those with multiple disabilities and chronic conditions, is a matter of quality and equity as much as legal compliance. Just as those who

are poor, who are young, who are of different ethnicities, who are women, who are elderly, and various combinations of these factors, can experience a multitude of barriers to receiving excellent healthcare, those with disabilities experience the same and additional barriers – compounded by what is often an urgent or chronic need to maintain frequent consistent use with the healthcare system.¹⁵

Full inclusion of the healthcare issues faced by people with disabilities within the overall impetus for healthcare reform will require a willingness to develop a medical model in which functional maintenance shares equal billing with “cure,” finance priorities that do not emphasize short-term acute care over long-term prevention and health maintenance, and healthcare delivery systems that recognize the full “universal” range of human functioning and body-types. More immediately, there are a variety of specific ways to improve disability healthcare access. These include having states and health plans monitor, offer technical assistance on achieving, and enforcing existing accessibility standards; designing and requiring disability school curriculum and professional development for healthcare providers; and incentivizing research into healthcare delivery systems and clinical standards for people with disability. Unless systemic healthcare reform includes ways to ensure the equal access needs of people with disabilities, the “universal” in universal healthcare reform will be mere lip service to an ideal that we will have failed to achieve.

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¹ In a national survey of 1,505 non-elderly adults with disabilities conducted by the Henry J. Kaiser Family Foundation in 2003, 30% were covered only by Medicaid, 15% had only Medicare coverage, 19% had only private insurance, and 5% reported having no insurance. 14% relied on a combination of Medicaid and Medicare, 14% relied on a combination of Medicare and private insurance, and 3% reported reliance on some other source of insurance. See K. W. Hanson, P. Neuman, D. Dutwin, and J. D. Kasper. “Uncovering the Health Challenges Facing People with Disabilities: The Role of Health Insurance.” *Health Affairs* (2003): W3.552 – W3.565 (web exclusive). Health insurance coverage among women with disabilities aged 18-64 are comparable with 31.9% covered only by public insurance, 60.7% covered by private insurance (40% on their own policy and 20.7% as a dependent on another’s policy), and 7.4% uninsured. See *Research Findings #18: Stability and Change in Health Insurance Status: New Estimates from the 1996 MEP (2001)*. Agency for Healthcare Research and Quality, Rockville, MD. Available at http://www.meps.ahrq.gov/data_files/publications/rf17/rf17.shtml.

² National Organization on Disability. “2000 N.O.D./Harris Survey of Americans with Disabilities.” Washington, D.C. 2000.

³ This and the following anecdotes, except where otherwise noted, are excerpted from those reported through a series of focus groups that were held with persons with disabilities, family members and caregivers in Massachusetts in 2000. See M. D. Drainoni, E. Lee-Hood, C. Tobias, S. S. Bachman, J. Andrew, and L. Maisels, “Cross-Disability Experiences of Barriers to Health-Care Access.” *Journal of Disability Policy Studies* 17, no. 2 (2006): 101-115.

⁴ *Id.* Those who did not receive treatment attributed the failure to reasons that included a lack of insurance coverage (35%), high costs (31%), problems getting to provider offices or clinics and inadequate transportation (11%), and difficulties or disagreements with doctors (8%).

⁵ J. M. Glionna. "Suit Faults Kaiser's Care for Disabled; Courts: Advocates Say Provider Fails to Give Equal and Adequate Treatment to the Handicapped. Chain Says it Complies with Disabilities Act." *Los Angeles Times (Record edition)*, 27 July 2000, p. 3.

⁶ Special Olympics. "The Health and Health Care of People with Intellectual Disabilities." Washington, D.C. 2005. Summary of research and entire report available at http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Research/Health_Research/Health+and+Health+Care.htm.

⁷ J. P. Reis, M. L. Breslin, L. I. Iezzoni, K. L. Kirschner. *It Takes More Than Ramps to Solve the Crisis of healthcare for People with Disabilities*. Chicago, Rehabilitation Institute of Chicago, 2004, p. 18.

⁸ Special Olympics. Health screen data highlighted at <http://www.specialolympics.org/Special+Olympics+Public+Website/English/Initiatives/Research/default.htm>.

⁹ M. A. Nosek and C. A. Howland. "Breast and Cervical Cancer Screening Among Women with Physical Disabilities." *Archives of Physical Medicine and Rehabilitation*, 78 (suppl) (1997): S39-S44.

¹⁰ M. A. Nosek, C. Howland, D. H. Rintala, M. E. Young, and G. F. Chanpong. "National Study of Women with Physical Disabilities: Final Report." *Sexuality and Disability* 19, no. 1 (2001): 5-39.

¹¹ L. I. Iezzoni, E. P. McCarthy, R. B. Davis, and H. Siebens. "Mobility Impairments and Use of Screening and Preventative Services." *Am J Public Health* 90 (2000): 955-961.

¹² E. P. McCarthy, L. H. Ngo, R. G. Roetzheim, T. N. Chirikos, D. Li, R. Drews, L. I. Iezzoni. "Disparities in Breast Cancer Treatment and Survival for Women with Disabilities." *Ann Intern Med*. 145 (2006): 637-645.

¹³ *Supra* note 5 at 4-5.

¹⁴ 89.3% of the almost 880.5 million outpatient office visits that took place in the United States in 2001 took place in private practices, rather than clinics, outpatient facilities, health maintenance organizations, or other larger health centers. D. K. Cherry, C. W. Burt, and D. A. Woodwell. "National Ambulatory Medical Care Survey: 2001 summary." *Advance Data from Vital and Health Statistics* 337 (2003), p. 17.

¹⁵ Those who self-identified as black, having more severe disabilities, and lower incomes in a 2002-2003 survey of people with disabilities in L.A. County were also more likely to report healthcare access difficulties. Centers for Disease Control and Prevention. "Environmental Barriers to Health Care Among Persons with Disabilities – Los Angeles County, California, 2002-2003." *MMWR Morb Mortal Wkly Rep*. 55(2006): 1300-1303.