

Rural Residents with Disabilities Confront Substantial Barriers to Obtaining Primary Care

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Objective. To learn about the health care experiences of rural residents with disabilities.

Study Setting. Rural areas in Massachusetts and Virginia.

Study Design. Local centers for independent living recruited 35 adults with sensory, physical, or psychiatric disabilities to participate in four focus group interviews.

Data Collection Methods. Verbatim transcripts of interviews were reviewed to identify major themes.

Principal Findings. Interviewees described the many well-recognized impediments to health care in rural America; disability appears to exacerbate these barriers. Interviewees reported substantial difficulties finding physicians who understand their disabilities and sometimes feel that they must teach their local doctors about their underlying conditions. Interviewees described needing to travel periodically to large medical centers to get necessary specialty care. Many are poor and are either uninsured or have Medicaid coverage, complicating their searches for willing primary care physicians. Because many cannot drive, they face great difficulties getting to their local doctor and especially making long trips to urban centers. Available public transportation often is inaccessible and unreliable. Physicians' offices are sometimes located in old buildings that do not have accessible entrances or equipment. Based on their personal experiences, interviewees perceive that rural areas are generally less sensitive to disability access issues than urban areas.

Conclusions. Meeting the health care needs of rural residents with disabilities will require interventions beyond health care, involving transportation and access issues more broadly.

Key Words. Disability, rural, accessibility, barriers

Rural residents often confront significant barriers when seeking health care, including limited numbers of primary care and specialist physicians nearby, the absence of sophisticated inpatient and diagnostic services, lack of public transportation, and inadequate or absent health insurance coverage,

compounded by widespread poverty, low rates of employment-related health insurance, and fragile socioeconomic infrastructures (Ricketts 1999, 2005; Auchincloss and Hadden 2002; Gamm et al. 2002; Hart et al. 2002; Moscovice and Stensland 2002; Slifkin 2002; Arcury, Gesler et al. 2005; Goins et al. 2005; Larson and Hill 2005). Given the nature of these well-documented impediments, certain subpopulations or rural residents, such as elderly individuals (Goins et al. 2005) and ethnic minorities (Glover et al. 2004; Probst et al. 2004), may face considerable hurdles when seeking health care services. We wondered about the experiences of a subpopulation that might be especially disadvantaged by physical, economic, and health care delivery system barriers: working-age, community dwelling rural residents with disabilities.

In general, persons with disabilities report lower satisfaction with their health care than do others (Rosenbach 1995; Rosenbach, Acamache, and Khandker 1995; Iezzoni, Davis et al. 2002, 2003, 2004; Jha et al. 2002). Many reasons might explain such findings, including the greater need for complex health services, inadequate communication with clinicians, problematic attitudes of health care professionals and office staff toward disabling conditions, written health information in inaccessible formats, physically inaccessible care settings, and difficulties obtaining reliable transportation to health care facilities. In addition, compared with nondisabled populations, persons with disabilities on average face considerable socioeconomic disadvantages, such as higher rates of poverty and unemployment, lower educational attainment, and comparable to slightly higher rates of missing or inadequate health insurance (Hanson et al. 2003; Harris Interactive 2004; Kaiser Family Foundation 2004; Iezzoni and O'Day 2006). These problems compromise the health care experiences of persons with disabilities even in communities with extensive resources (Reis et al. 2004; Iezzoni and O'Day 2006). Sparse health care options in some rural communities could exacerbate such difficulties.

A limited literature suggests that rural residents with disabilities do have more problems with their health care than do nondisabled individuals (Lishner et al. 1996). However, relatively little in-depth information exists about how working-age, community dwelling rural residents with disabilities perceive their health care experiences. "Understanding the *perspective* of the

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individual . . . is a key component to forming a complete picture of rural health care access” (Goins et al. 2005, p. 207). Learning these individual perceptions is critical to crafting patient-centered solutions—reforms that consider persons’ values, preferences, and expectations (Institute of Medicine 2001; Berwick 2002). To begin exploring this issue, we conducted four focus groups in 2000–2001 with working-age adults with diverse disabilities living in two rural areas.

METHODS

Focus Group Content

This project occurred within a larger study using focus group interviews to examine primary health care experiences of community dwelling, working-age adults with various disabling conditions (Iezzoni and O’Day 2003, 2006). Different sensory, physical, and mental health disabilities can affect these experiences in varying ways. Therefore, our goal was not explicitly to compare experiences across disability types or residential settings, but instead to hear directly from persons about what they confront in seeking and obtaining services and their views about the role of their disabling condition in these experiences.

Focus groups should optimally involve persons who share critical or defining characteristics of interest (Krueger 1994). Because our health topics included some sex-specific queries (e.g., access to and experiences with specific screening tests, such as breast and testicular examinations), as well gender-related sensitivities, we chose to hold separate focus groups for men and women to promote freer discussions. Specific types of disabling conditions can raise somewhat different issues relating to health care quality and access. Therefore, for the 13 focus groups we conducted in metropolitan Boston and Washington, DC, we sought persons who shared a specific disabling condition (e.g., all participants were deaf or all were hard of hearing, Iezzoni, O’Day et al. 2004; all who were blind or had low vision, O’Day, Killeen, and Iezzoni 2004; all who had psychiatric disabilities, O’Day et al. 2005). Small numbers of rural residents with specific conditions made that strategy impossible. The four rural focus groups involved 35 persons across sensory, physical, and psychiatric disabilities; many participants reported multiple disabilities (Table 1).

We drew from our quantitative research findings (Iezzoni et al. 2000, 2001, 2002; Weil et al. 2002) and literature reviews to design an interview guide addressing eight topics: overall health care quality; access to primary

Table 1: Characteristics of Interviewees by Focus Group

<i>Characteristic</i>	<i>Virginia</i>		<i>Massachusetts</i>	
	<i>Women</i>	<i>Men</i>	<i>Women</i>	<i>Men</i>
Number	9	5	11	10
Age range (years)	24–57	47–60	31–64	21–61
Number under age 45 years	7	0	3	4
White*	4	0	5	9
African American	4	5	4	1
Employed	3	1	2	1
Completed high school	8	3	10	6
College graduate	2	0	2	0
Income under \$20,000 [†]	8	5	9	9
Has primary care physician	6	2	11	9
Medicaid insurance [‡]	4	0	6	8
Medicare insurance	2	3	6	1
Uninsured	2	2	0	0

*Three persons did not self-identify race.

[†]Two women and one man in Massachusetts did not answer the income question.

[‡]Two persons had private insurance; one woman had both Medicare and Medicaid.

care, access to specialized services, communication, accessibility experiences within physicians’ offices, training physicians about disability accommodations, suggestions for designing accessible health care settings, and disseminating our results among persons with disabilities. By adding disability-specific questions, we used variants of this basic moderator’s guide for condition-specific focus groups in metropolitan Boston and Washington, DC. Thus, different disability-specific focus groups concentrated on topics especially relevant to the particular condition. For the rural focus groups, we used the basic guide (available from the authors).

Convening the Rural Focus Groups

We performed separate focus group interviews for men and women, convening two groups in Massachusetts and two in Virginia. We chose our rural locations based on our contacts with regional centers for independent living, private nonprofit agencies that provide community services to individuals with varying disabilities. According to two typologies of county population densities—the urban influence codes (UIC, codes 1–12) and the rural–urban continuum codes (RUCC, codes 1–9), with higher numbered codes indicating more rural regions (Economic Research Service 2005a, b)—Massachusetts

has no nonmetropolitan counties, except for Nantucket and Martha's Vineyard Islands. Massachusetts interviewees lived in a county assigned a UIC code of 2 and an RUCC code of 3, indicating a "small metropolitan" but with the lowest population density statewide outside of the Islands. Both typologies scored the two counties where Virginia interviewees lived as highly rural: UIC codes 9 and 12 and RUCC codes 7 and 9.

To recruit participants, we worked with local centers for independent living, asking them to solicit working-age, community dwelling adults with disabilities and to host the focus groups at their facility. The independent living centers posted notices about the focus groups in their newsletters and on bulletin boards. We specifically asked the Massachusetts center director to reach out directly to disabled individuals he knew who lived some distance from town in the most isolated areas of the county; many participants traveled 20 or more miles to attend a focus group. Because no sign language users volunteered to participate, we conducted all focus groups using oral English.

The Committee on Clinical Investigations at Beth Israel Deaconess Medical Center approved this study, and participants gave written informed consent. One author moderated all groups, and the interviews lasted roughly 2 hours. Participants received \$75 afterwards and reimbursement of their transportation costs.

Analysis

A professional transcription service prepared verbatim transcripts from audiotapes of the interviews. After reviewing transcripts, we generated coding categories reflecting broad concepts. Using these categories, one author sorted the texts with *NVivo* software (QRS International, Melbourne, Australia) to facilitate analysis. Each investigator independently reviewed the sorted texts, noting major themes describing the interviewees' experiences with health care. We reached consensus during telephone discussions and e-mail correspondence.

RESULTS

Table 1 shows basic demographic characteristics of the 35 interviewees in each of the four groups. Many people had more than one disabling sensory, physical, or psychiatric condition. Conditions included blindness and low vision (including vision loss related to diabetes), hearing loss, traumatic brain injury, spinal cord injury, multiple sclerosis, cerebral palsy, stroke, muscular

dystrophy, postpolio syndrome, arthritis, back problems, limb amputation, heart conditions, extreme obesity, depression, and bipolar disorder. Two women in Virginia attended as parents of children with cerebral palsy; one woman in Massachusetts participated by telephone because she could not get accessible transportation to the center.

As an overarching observation, interviewees described the many well-recognized barriers to health care in rural America, only “more so.” Here we highlight issues beyond those affecting rural residents in general, where rural issues and barriers related to disability intersect. Concerns coalesced around six major topics: finding caring and competent primary care physicians, need for specialty care, poverty and reliance on Medicaid, physical access to health care settings, accessible transportation, need for advocacy and information resources. All interviewee names below are pseudonyms; we edited quotations to reduce length and redundancy.

Finding Caring and Competent Physicians

From years of living with disabling conditions and receiving extensive medical services, many interviewees know exactly what they want in their doctors. They therefore “doctor shop,” trying out different clinicians until they find the right match. Once they establish relationships with clinicians, they seek continuity: teaching new physicians about their complete medical histories and preferences for care takes time and effort. These needs put persons with disabilities at special risk in rural regions where physicians are relatively scarce, thus limiting choices, and often transient. Davey, in his late 30s, highlighted these complexities.

I have a hearing disability, glaucoma, major depression, and severe knee problems. . . . When I moved out to [this area] ten years ago, it took me about five years to find a primary care physician who I liked and trusted. I spent lots of time on the computer looking up doctors. I went to three or four and didn't like their attitudes toward me. . . . You sit down, explain your situation, what your handicaps are, what your concerns are, what you're looking for in a doctor, and see if they can help you. If they can't, then go out and look for someone else. . . . Now I have a wonderful physician. I always tell her, 'You're a gift from God. Don't ever leave me.' I don't know if I'll ever find another one like her.

Similar to Davey, other interviewees underscore the interpersonal dimension of relationships with physicians. Interviewees debated whether rural physicians exhibit more empathy and caring than physicians they visit in cities: different people had strongly held views on both sides. Several interviewees suggested that local “foreign doctors”—international medical graduates who

gravitate to rural regions with open practice opportunities—exemplify the patient-centered approach they desire. “Relationships with my foreign doctors seem to have taken off right away,” said one woman. “Folks from other places tend to be more socialistic about their approach to medicine. . . . The foreign doctors aren’t into money. They put the individual first.”

Interviewees also desire technical competence to address their complex conditions, and here many believe rural physicians fall short. One woman in Massachusetts described care locally as “just a band-aid operation. It may be years before you get the proper referral, the proper diagnosis, and the proper tests to make the diagnosis.” Some interviewees think local physicians do not follow new medical developments and are uninformed about disabilities. “A lot of doctors here, I don’t know how much they do know,” observed one woman. “It’s really the people [with disabilities] who know more than anyone else. They have to tell the doctors what’s wrong and how they might be treated.” Several interviewees raised concerns about the currency of older physicians who “come here to retire and go out on yachts. I do have some good doctors here, but the majority of them, no.”

The transience of doctors raised special concerns. “Once you get adjusted to one doctor and the doctor gets to know you, then you’ve got another doctor,” said one woman. Another woman believes that doctors do not find the “quality of life here that they need. [Our area] doesn’t have a whole lot to offer unless you’re retiring or you’re a native. It’s not enough to keep doctors here. They’re here one day and gone tomorrow.”

Continuing Need for Specialists and Sophisticated Services

Almost all interviewees appear to need ongoing specialty care that requires them to travel periodically to nearby towns or large urban centers. Both rural areas lie within 3-hour drives of internationally renowned medical facilities, and some interviewees describe something akin to pilgrimages to medical Meccas to get super-specialized care. “Every year, I go to NIH [National Institutes of Health] in Bethesda, Maryland,” said Steve. “They give you a thorough examination, head to toe—everything. But around here, it’s just blood pressure, weight, ask how you feel, and send you on out. That’s a waste of my time.”

Many interviewees suggested that their rural physicians know their limits, both of skills and clinical facilities, and readily refer persons requiring specialized care. Sometimes a chain of referrals ensues, as for Rick, whose primary care physician detected a worrisome diminution in his already low

vision. Within just over 24 hours, Rick had seen two ophthalmologists, each in progressively larger cities, ending up having eye surgery at an urban academic medical center with a third referral. Although some interviewees described finding local specialists (e.g., neurologists) who provide acceptable care, others report having no options within their communities. Maria, in her early 50s, has an unusual disease, diagnosed in childhood, that caused multiple amputations and ultimately wheelchair use.

I live by myself, I'm very independent, nothing stops me, I just keep going. . . . [When she has a health crisis], the hospital doctors look at me: 'Oh, no! We can't take you!' They don't even want to see me. They see me coming, and they put me in an ambulance and send me to Boston. There's nothing in [my area] for care.

Poverty and Heavy Reliance on Medicaid

Because of poverty and disability, many interviewees had Medicaid coverage. This severely limited their choice of clinicians, as Davey found in his search: "First off, you must find a doctor who'll take Mass Health [Massachusetts Medicaid]. A lot of them don't take it. Dentists won't take it either." An already small pool of local clinicians becomes even smaller.

Medicaid does offer an important advantage: coverage of transportation to medical appointments. However, this may not extend to lengthy trips to urban specialists required by some persons with disabilities such as Toni, who felt that local doctors brushed off her health needs. "I will die of anything on my way to Boston before I go back to them!" Toni asserted. "When I told Mass Health that I have doctors in Boston they said, 'Can you get them in [your area]?' I said, 'Yes, but I won't.' 'Well, don't come to us about getting transportation to Boston.'"

Numerous persons spoke of overwhelming poverty, being unable to afford prescription medications or assistive technologies, such as power wheelchairs, uncovered by their insurance. Because of disability, many cannot work even part-time to boost their incomes. Some cut their medication doses; others do without. These concerns can consume their lives, as for Rick:

I used to be a truck driver, and I can't see to drive a truck anymore. Thank God I can see enough to do a little farm work. . . . But not having a full-time job, it's hard for me to get medical care. Working on a farm, you don't have the best medical insurance. It's rough. I think people don't realize what it's like to have to struggle because you don't have medical assistance coming your way. But I'll say this much: people with disabilities can't give up. We get booted in the butt, we get shoved aside, but we've still got to keep trying.

Physical Access to Health Care Settings

Many interviewees commented on barriers to physical access at health care sites, including the absence of accessible entrances and equipment, such as automatically adjustable examining tables and mammography machines. Some reported that local physicians' offices fail to provide wheelchair accessible entrances. Even when office buildings ostensibly offer accessible entrances (e.g., by posting wheelchair access logos with arrows pointing around the building), persons may get through the doorway but immediately encounter steps, with no elevator or wheelchair lift device. Based on their personal experiences, interviewees suggested that their rural communities do not take physical access as seriously as do cities. "Most of us have been other places where things are better," said one man. "Half the places here don't even have walkways for the handicapped or ramps for wheelchairs."

Old structures and inadequate resources pose impediments to improving physical access. For instance, in the Virginia region, the aging county office building where people apply for Medicaid has no elevator; the Medicaid office is on the second floor. Medicaid staff meet applicants who cannot climb stairs on the first floor and conduct their interviews in public waiting rooms. "There's no confidentiality whatsoever," said one woman. "None. I've heard entire interviews sitting in the waiting room."

Barriers to Local and Long Distance Travel

Interviewees repeatedly raised concerns about the lack of reliable accessible transportation, both for reaching local health care facilities and for traveling long distances to urban centers. Because of sensory or physical disabilities, many individuals cannot drive. Public transportation is relatively nonexistent. Although local public transit vehicles are generally required to have lifts or accessible entrances, in reality they do not. Intercity bus lines also are often inaccessible. Local paratransit systems (specialized door-to-door transportation services for persons who are elderly or disabled) fail woefully. Even if persons manage to get reservations on paratransit services, they must book pick-up hours early, to ensure they arrive on time for appointments. To reach distant academic centers, persons seek accessible public transportation, but face such hurdles, as did Lois:

I can't get on a bus; I'm in a wheelchair. There are no buses that come down here with a lift. . . . For me to get into Boston, I have to get a company that will transport me. But they don't always show up. I've missed two appointments because of transportation problems, and these appointments are not easy to make. . . . When

you make an appointment, you better be there—you don't mess with the big doctors. Even these little doctors down here get mad at you.

People who do find transportation for long distances may face problems identifying accessible restrooms along the way. Some individuals with disabilities have difficulties sitting for long drives. Coordinating with other services also presents problems. "The ride had to come get me at eight o'clock," described one woman, "but my nurse's aid doesn't come to my house until eight-thirty."

Need for Advocacy and Information Resources

As suggested above, many interviewees feel that they must find their own health information—local providers have limited knowledge of disability. People are also unsure what social service resources are available. Some seek information via the Internet, but others admit they cannot afford computers or are not Internet savvy. Another impediment involves low education: "We have a lot of literacy problems here in [our town]." Not surprisingly given our recruitment source, several interviewees extolled the education, assistance, and advocacy of their local independent living center. Not only did the independent living centers help individuals find services they needed, but also these organizations advocated more broadly for disability access throughout the regions. "I've been here five years and I just learned about the independent living center maybe six, seven months ago," said Rick. "These are the kind of places we need to help get things that we want in these communities."

DISCUSSION

Rural residents with disabilities reported many of the same types of difficulties accessing health care as described by nondisabled rural residents in the literature, but often with a special twist reflecting particular sensory or physical impairments and persons' long experiences with the health care system. Based on their personal observations, interviewees perceived that rural regions are less sensitive than urban areas to disability issues generally, beyond health care. For instance, several interviewees raised concerns about absent curb cuts in sidewalks, limited accessible housing, and inadequate resources to renovate existing housing and public buildings to improve access.

Our study was not designed to compare barriers with health care for rural and urban residents with disabilities. Nonetheless, in focus groups we

conducted in Boston and greater Washington, DC, we also heard from persons with disabilities about insufficient knowledge of clinicians regarding certain disabling conditions, problems identifying appropriate primary care and specialist physicians, difficulties with continuity of care (especially when persons change insurance), inadequate physical access, local transportation problems, and inaccessible information (Iezzoni 2003; O'Day, Killeen, and Iezzoni 2004; Iezzoni, O'Day et al. 2004; O'Day et al. 2005; Iezzoni and O'Day 2006)—findings consistent with the clinical and access needs of many persons with disabilities regardless of where they live (Burns et al. 1990; Andriacchi 1997). Other studies, primarily involving largely urban populations, corroborate these barriers to care confronting persons with disabilities (Beatty and Dhont 2001; DeJong et al. 2002; O'Day et al. 2002; Hanson et al. 2003; Harris Interactive 2004). Relatively little has yet been done to address these problems except in small targeted programs, again primarily in cities (Master et al. 1996; Blanchard and Hosek 2003; Eichner and Blumenthal 2003; Reis et al. 2004).

Thus, persons with disabilities often face substantial barriers when seeking health care in both urban and rural settings. One could easily conjecture, however, that reducing these impediments in rural regions will prove more difficult than in cities. Rural regions display higher absolute rates of disability than urban areas, although adjusting for poverty, low education, and other markers of social disadvantage narrows these gaps (Auchincloss and Hadden 2002). Rural communities often suffer from clinician shortages, the absence of specialists, and fragile financial footing of existing providers (e.g., lacking economies of scale because of small, highly dispersed patient panels, high fixed overhead rates per patient). The number of rural areas designated as “health professional shortage areas” has grown over the last 20 years (Ricketts 2005), primarily driven by recruitment difficulties (Pathman et al. 2004). Providers may have inadequate resources to train new staff, renovate facilities, and upgrade equipment to better accommodate patients with disabilities. Many rural hospitals, especially small facilities, lack professional and financial resources to care effectively for persons with complex disabilities (Moscovice and Stensland 2002). Medicare beneficiaries are more likely to bypass their local rural hospital to enter urban teaching hospitals as their level of functional disability increases (with the exception of “bedridden” persons; Tai, Porell, and Adams 2004). “Local health care systems, with their small numbers of providers and sparse resources, are tenuously balanced to meet the needs of their residents while providing adequate income and quality of life to their providers” (Hart et al. 2002, p. 212).

Other factors endemic to rural living make accessing health care more difficult. Rural areas have more limited public transportation systems owing to sparse populations and long distances. Low populations and long distances also make paratransit services extremely expensive to operate. Nonetheless, one study found that the relatively small percentage of rural residents who do depend on public transportation were older, in poorer physical and mental health, and had lower rates of private health insurance than others, suggesting their relatively high need for health care services (Arcury, Preisser et al. 2005). Rural areas often lack environmental features required by nondrivers with disabilities, such as sidewalks, curb cuts, and street crossings with accessible traffic signals (i.e., visual and auditory cues about when it is safe to cross). Therefore, even if rural residents live close enough to walk or roll in a wheelchair to their health care facility, getting there safely may prove difficult.

As suggested by the interviewees, disabled rural residents with Medicaid may face special challenges. A survey of rural Minnesota residents on Medicaid found that persons reporting that health problems or impairments limit their daily activities experienced higher rates of unmet health needs than other Medicaid recipients, even after controlling for demographic characteristics (Long, Coughlin, and Kendall 2002). One-third of respondents reporting unmet needs blamed problems with the availability of providers. The researchers believe that levels of unmet need in rural Medicaid recipients are “more than double the rate that has been reported by the overall rural population” (Long, Coughlin, and Kendall 2002, p. 443). Hurley, Crawford, and Praeger (2002, p. 165) argue that Medicaid policies carry “the potential for a significant urban bias, depending on the degree of urbanization of a state.” Thus, the Medicaid experiences of rural residents with disabilities are likely to vary across states, with the risk that Medicaid might bolster urban or regional centers at the expense of limiting support of rural providers.

Our study shares important limitations of other focus group research. Our two regions do not represent rural areas nationwide. According to the UIC and RUCC typologies, the Virginia site is highly rural, whereas the Massachusetts interviewees lived in a small metropolitan county. Many Massachusetts interviewees nonetheless viewed themselves as geographically isolated; we could not quantify the extent to which individuals did live in locales with low population density and limited health care services (Larson and Fleishman 2003). In addition, the 35 interviewees do not represent the full spectrum of community dwelling, working-age adults with disabling conditions. In particular, we did not include any sign language users or other persons with severe hearing loss. Twelve participants had Medicare insurance;

certain Medicare rules and regulations could skew the pool of disabled persons able to attend focus groups. For instance, requirements that persons remain “home bound” to receive home care services would likely preclude Medicare beneficiaries needing these services from volunteering for focus groups (Iezzoni 2003); restrictions on Medicare payment for mobility devices, especially power wheelchairs, might limit the ability of some beneficiaries to physically attend meetings outside their homes (Wolff, Agree, and Kasper 2005).

We recruited participants through centers for independent living to identify individuals who could articulate their experiences, positive and negative. These persons may hold an “advocacy” position not shared by other rural residents with disabilities. A focus group study of elderly rural residents in West Virginia suggested that aspects of “rural culture”—including conservative attitudes, sense of self-sufficiency, and reluctance to see international medical graduates—may lead residents to avoid seeking care (Goins et al. 2005). In contrast, many of our interviewees were strongly assertive and did not appear shy about making their needs known. Our moderator’s guide focused primarily on outpatient medical services, but the interviewees raised critical concerns about other topics, notably the absence of dental care. Similarly, we did not address problems relating to long-term care or disabled children, although the two mothers of children with cerebral palsy in our focus groups expressed concerns similar to those of the adults.

Despite these limitations, the interviewees raised concerns about the types of barriers to rural health care that are well recognized in the literature. Numerous efforts have attempted to remedy these difficulties, including regionalizing specialized care, establishing mobile outreach teams, using non-physician clinicians and other health professionals, training nonprofessional caregivers, introducing telemedicine and remote consultations, networking rural physicians with urban specialists, bolstering case management, and supporting community education programs to teach rural residents about health topics (Lishner et al. 1996). Such strategies may especially help persons with disabilities. Nonetheless, substantial lapses in care remain, with studies suggesting lower rates of prevention and screening services among rural residents (Zhang, Tao, and Irwin 2000; Gamm et al. 2002) as well as potential concerns about the quality and sophistication of some rural providers (Brasure, Stensland, and Wellever 2000).

At our nation’s founding, rural regions offered better quality lives for persons with disabilities than did emerging urban centers. In 1781, Thomas Jefferson (1984, p. 259) claimed that persons without “strength to labor” were

“boarded in the houses of good farmers, to whom a stipulated sum is annually paid” from tithes collected within local parishes. Only in “larger towns” might one see persons with disabilities begging in the street. Then as now, women were the primary informal caregivers: today, rural informal caregivers spend more time than their urban counterparts caring for persons with disabilities and chronic illness in their homes and communities (Horwitz and Rosenthal 1994).

Nowadays, however, many persons with disabilities want to live independently, maximizing their health and well being through diverse means, such as accessible housing and communities, paid personal assistance services, assistive technologies, and good quality health care. Researchers should continue to seek their views of both impediments to services and health care needs, although breaking down barriers to health care for rural residents must focus on “factors that are mutable” and “services that can be shown to improve outcomes” (Slifkin 2002, p. 238–239). Thoughtful solutions will require balancing notions of reasonable access, enabling factors (e.g., accessible transportation, health insurance), and the self-identified needs of persons with disabilities. Seeking the perspectives of persons themselves will be essential to achieving patient-centered reforms (Institute of Medicine 2001; Berwick 2002). “Understanding these perceptions is important to ensure that policy initiatives and community outreach efforts effectively address the most pressing needs expressed by [individuals] themselves” (Goins et al. 2005, p. 207). Future research must help craft this challenging balance and enlist the help of persons with disabilities in finding workable solutions.

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