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The Future of Disability and Rehabilitation in Rural Communities

Rural Futures Lab Foundation Paper No. 3

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RTC: Rural, Rural Institute
University of Montana
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The Future of Disability and Rehabilitation in Rural Communities: An Emerging Narrative

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The Research and Training Center on Disability in Rural Communities is an organization whose mission is to improve the employment and health status of rural Americans with disabilities, and enhance their ability to participate fully in community life. Our aim is to integrate disability into the mainstream agenda for rural America.

Rural Futures Lab Foundation Papers are intended to present current thinking on the economic drivers and opportunities that will shape the future of rural America. They provide the foundation upon which it will be possible to answer the question that drives the Lab's work – What has to happen today in order to achieve positive rural outcomes tomorrow?

Executive Summary

As a new narrative emerges for rural America so does a new paradigm of disability. An underlying philosophy of that new paradigm is that disability is a natural part of the human experience – not to be treated as separate or special, or as a commodity. This new paradigm of disability emphasizes participation in community life as the outcome of interactions between an individual and his or her environment. From this perspective, disability occurs when the environment presents barriers to participation. In the disability context, environment is understood as the communities in which we live. Accordingly, the research, policy, and action agenda for disability in rural communities is broad. In its totality, this agenda addresses the needs of people with any impairment and of any age, gender, racial or ethnic heritage As such, disability may serve as a litmus test of the quality of our communities. It challenges our understanding of the place human diversity plays within a community and the degree to which community ecology is designed to accommodate participation in economic and civic life. In the future, people with disabilities will play increasingly important roles in helping to design communities that can accommodate broad human variation.

Introduction

> Disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.
>
> (Rehabilitation Act, 2004 p. 1)

People live in rural America because they were born there and their families live there; or because they moved there for opportunity, for beauty, or to escape urban stress. Regardless of their reasons, some 56 million Americans live in rural areas. Nearly 20% of them live with a disability.

While rural America is their home, living there can place those who experience disability at a disadvantage. Compared to their urban counterparts, rural Americans with disabilities experience higher rates of poverty, higher unemployment, and poorer health. This population includes husbands and wives, neighbors and friends, and children and grandparents. Increasingly, they are also business owners, valued employees, and civic leaders. People with disability are part of every rural community.

Many people with disabilities feel the pinch of social isolation and discrimination. These challenges come in many forms, including an employer who says that a job might not be a good fit for a man with cerebral palsy because it's important that employees show up on time, or the steps leading into a small town public library confronted by a young man who uses a wheelchair. Similarly, it's not unusual to hear a person with a spinal cord injury or the parents of a child with serious impairments to report that the medical staff at a tertiary facility where they first received care told them that they would have to move from their rural or small town home to a large city in order to get the services and supports they will need.

People who experience disability and who live in a rural area aspire to fit seamlessly into the routines and rhythms of their community's life. They see a day in which the old infrastructure of rural communities (e.g., sidewalks, retail business buildings, schools, parks, government buildings and public places) will have been largely replaced with new infrastructure that is "universally" accessible. Similarly, societal attitudes will largely have come to accept people with disabilities as full members of the community, and they will serve as business owners, employees, and civic leaders. The health care system will have been transformed so that it equitably provides a continuum of services from primary prevention, through medical treatment, to health maintenance that maximizes participation in community life. Rural schools – public, private, or home schools – will have access to the most effective curricula that prepares all students for adult roles in civic life and work. In short, we look forward to the day when disability is accepted as a normal part of life and communities are organized in ways that promote the participation of all.

What is disability?

The common understanding of disability has evolved through three major stages in Western society: spiritual, medical, and ecological (Braddock & Parish, 2001). In ancient civilizations through the dark ages, disability was viewed as a visitation of the gods – usually as a curse but in some cases as an exalted gift. With the rise of science, disability became viewed as a physiological problem in need of medical treatment. For 600 years - beginning in 1357 with the founding of Bedlam hospital in London – medical treatment frequently involved placement in institutions where individuals were cut off from

their family and community. Importantly, under these conditions, people with disabilities had few opportunities to pursue their dreams or construct lives that represented their potential.

This medical model of disability focused attention on impairments experienced by individuals. Impairments included such conditions as intellectual impairment due to genetic variation (e.g., Down Syndrome), congenital birth defects (e.g., cerebral palsy), mobility impairments due to acquired injuries (e.g.spinal cord injuries), chronic health conditions (e.g., multiple sclerosis), psychiatric and cognitive impairments (e.g., brain injury), and sensory impairments (e.g., blindness). The medical view emphasized providing treatment that minimized impairment, so a person could function in an environment that was seen as stable and unchanging. Thus, a blind woman could learn new cooking skills, so she could continue to use her kitchen. Often enough, however, people with significant impairments, such as a spinal cord injury, might have been sent to a nursing home because the community had no accessible place for them to live (Seekins et al., in press).

More recently, the disability rights movement (e.g., DeJong, 1983; Pope & Tarlov, 1991; Wolfensberger, 1972) articulated a "new paradigm" of disability. In this "ecological" model, disability is viewed as an outcome of the interaction between an individual and his or her environment (World Health Organization, 2001). Here, the environment typically means the communities in which we live. This view – a social rather than a medical model of disability – supported the de-institutionalization movements of the 1960s and 1970s, led to the development of laws prohibiting discrimination and requiring accessible environments (e.g., Americans with Disabilities Act of 1990), and led to the development of systems of community-based supports. This new paradigm views the environment as malleable and that it can be arranged to accommodate individuals with functional limitations due to impairments. Now, the blind woman's kitchen would be modified to facilitate her cooking, and her home may be designed to be "visitable" (Seekins, Traci, Cummigs, Oreskovich, & Ravesloot, 2008: Smith, Rayer, & Smith, 2008) so that her friend who uses a wheelchair could visit her from his fully accessible home around the corner by rolling down sidewalks with curb cuts. As such, this new paradigm of disability has expanded the views of how to address disability; emphasizing the need for both individual and community level solutions.

Demography of disability. The ecological model creates a tension between disability as a characteristic of an individual or as a consequence of environmental arrangements. One area of tension involves counting people with disabilities (Altman, 2001; Zola, 1993; Fujiura & Rutkowski-Kmitta, 2001).[1] It is simply easier to estimate the prevalence of impairment by counting the number of individuals who report specific conditions (e.g., spinal cord paralysis) or functional limitations (e.g., unable to work due to a health conditions) than to estimate the incidence of disability by counting instances in which an individual's participation in an event is limited by their environment. Table 1 presents Census 2000 estimates of the population of people with disabilities (i.e., reporting functional limitations) living in the 2,052 non-metropolitan counties; four million of those lived in counties without a town of at least 10,000. About 30.1 percent of rural families and 28.5 percent of urban families reported at least one member with a disability (U.S. Census, 2005).

[1] Depending on the survey questions asked, many people who use wheelchairs do no report that they have a disability. For example, if a survey question asks if the respondent is prevented from working because of a health condition lasting more than six months, a respondent who attributes his or her lack of employment to discrimination might answer "no."

Table 1 Population of People with Disabilities Living in Rural (Nonmetropolitan) United States[2]

	Number of counties	Total population	Civilian, non-institutionalized persons, 5 yrs & older Total number	**Number with disability**	Percent of total population with **disability**	Percent of disabled population
United States	3,141	281,421,906	257,167,527	49,746,248	19.30%	100%
County Classification (OMB, November 2004)						
Metropolitan	1,089	232,579,940	212,657,595	40,091,987	18.90%	80.6%
Non-Metro	**2,052**	**48,841,966**	**44,509,932**	**9,654,261**	**21.70%**	**19.4%**
Micropolitan	692	29,477,802	26,843,971	5,625,928	21.00%	11.3%
Non-core	1,360	19,364,164	17,665,961	4,028,333	22.80%	8.1%

Disability, poverty, and wealth. Poverty and disability overlap. Roughly two-thirds of working-age adults with consistent income poverty in the United States have at least one disability (Fremstad, 2009). The American Community Survey (2008) reports that 25.3 percent of adults with a disability between 21 and 64 years of age have incomes below the poverty line compared to just 9.6 percent of those who do not report a disability (American Community Survey, 2008). Stapleton, O'Day, Livermore, and Imparato (2005) argue that current policies create a poverty trap by assuming that those with impairments are not capable of working and must be supported by society directly. Further, the policies often preclude people from working in order to receive minimal public benefits.

The Importance of Disability as a Rural Issue

"John Wesley Powell – the first promoter of regional watershed collaboration – lost an arm in the civil war. Yet, he led the first expedition down the Colorado River from a chair he rigged so he could row the boat."

(Alexandra Enders, 2010)

Various estimates consistently point to a higher disability rate in rural areas (e.g., Glascow, Johnson, & Morton, 2004; National Center for Health Statistics, 1986). This is due, in part, to higher rates of injuries (e.g., Baker, 1992), limited emergency response (Branas et al.., 2005), and less access to preventive and primary medical care (e.g., Lishner et al., 1996).

People with disabilities constitute a sizable proportion of the rural population – more than one in five. Rural residents with disabilities experience many of the same challenges as their urban

[2] The census used categories of functional limitations. For example, questions that asked if the individual had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to perform certain activities such as learning, remembering, or concentrating (mental disability); (b) dressing, bathing, or getting around inside the home (self-care disability); (c) going outside the home alone to shop or visit a doctor's office (going outside the home disability); and (d) working at a job or business (employment disability).

counterparts experience but the form and degree varies. As a group, they have a diverse range of needs and expectations that present challenges and unique opportunities for rural communities. These people must travel further to get the same level of services as their urban counter parts or accept less quality of care in their communities.

At the same time, people with disabilities represent human capital - assets for rural communities that are often overlooked and underutilized. For example, people with disabilities in rural areas are more likely than the general population and their urban counterparts to be self-employed (Bureau of Labor Statistics, 2010). They also serve as elected leaders (see sidebar) and community volunteers (Seekins, Shuttleworth, & Kasnitz, 2004). Thoughtful community arrangements can facilitate their participation and contribution to community development.

Civic Leadership

Natalie Alden is a married mother of two. She lives in a northwestern Colorado city of less than 10,000. She has a high-level spinal cord injury that results in quadriplegia. She works full time and volunteers with many community organizations. She also serves on the board of directors of a local human services program. She ran successfully as a Republican for city council. Once elected, she took on the duties that included being the council representative to the wastewater department, the police department, the Chamber of Commerce, the legacy committee, and the airport advisory committee. At the time of her interview, she was contemplating a campaign for the state House of Representatives.

(From Seekins, Shuttleworth, & Kasnitz, 2004)

Finally, people with disabilities may be a significant source of human and social capital and employees in rural communities but they are often assumed to be a drag on the economy or a contribution only through the transfer payments they receive. In one major report addressing the problem of rural areas providing capable workers, people with disabilities were mentioned only in relation to their receipt of SSDI and the assumption that they are unable to work (Executive Office of the President, 2010, p. 7). The assumption persists, despite efforts such as the national program, Ticket to Work, with the express policy goal of helping Social Security Disability Income recipients return to work (Social Security Online, 2010). This situation highlights both a misunderstanding of disability and an opportunity to integrate people with disabilities into community life.

Disability as a litmus test. The way our society treats people with disability is a litmus test of its quality. Most of us will experience disability during a significant portion of our life, and it is in our personal interest to promote communities that accommodate those who experience disability. Unlike the traditional rehabilitation model that focuses on remediating impairment, the ecological model assumes that the environment is infinitely malleable and can be organized to accommodate individuals with various impairments. Under this framework, there are new opportunities for partnerships between people with disabilities, those who may become disabled, disability advocates, and community development researchers and practitioners.

Disability dilemma. These current views of disability present a dilemma between goals of equality and integration and a need for accommodations for impairments. On the one hand, a just society has an obligation to provide opportunity for all its citizens (e.g., Rawls, 1975), and people with disabilities want to be integrated into and participate fully in community life (N.O.D./Harris Community Participation Study, 2000). On the other, to achieve equity, society may be required to provide extra or

unique supports – to design communities in ways that would not be done otherwise. For example, in developing healthy, livable communities, planners need to design curb cuts, audible traffic signals, and other accommodations. Recognizing and accepting the range of human diversity is one solution to the dilemma. Universal design – the intentional production of spaces and products that accommodate people with and without disabilities – is another (e.g., Priesser & Osteroff, 2001)/

Many feel that such accommodations could add costs to products and services. Some people may both fear and resent the additional costs associated with accommodating people with disabilities – even though research has shown that many of these changes cost nothing and that fewer than 3 percent of them cost more than $1,000 (U.S. Department of Justice, 2010). Nonetheless, in small towns and rural communities, the infrastructure is often old, and there are few resources to rejuvenate public or private places. This situation challenges our moral sense as well as our ability to arrange resources for the future.

Disability Policy

The new paradigm of disability – the ecological view - permeates a great deal of current disability policy, scholarship, research, and action. This reflects the "new paradigm" and has been surprisingly durable (Ravesloot, 2010). Disability politics flow from three elements of independent living: consumer control, community integration, and environmental causes.

Disability as a Social Movement

The demand for consumer control is a reaction against control by others – i.e., physicians, parents, etc. – and an assertion of the right to self-determination (DeJong, 1983). While most disability organizations assert the right for consumer control, it was first articulated by the independent living movement. Even the term "consumer," now current among many disability groups to refer to people with disabilities, derives from this perspective.

Second, community integration first emerged as part of the deinstitutionalization movement. At the time, it referred primarily to the effort to move out of institutions and back into community life. Over time, it has grown to reflect a much broader view that "disability is part of the natural course of human experience" (Rehabilitation Act, 2004 p. 1) and that people with disability should be integrated into all aspects of community life. It is the disability rights movement's equivalent of the fight against racial segregation referred to as "separate but equal." It directly implies that all service and supports should be aimed at sustaining individuals living independently in community settings.

Finally, the idea that a great deal of the variance in disability outcome can be attributed to the environment serves as a focal point for interventions to accommodate individuals with diverse functional abilities. This creates a conflict in the demand for resources between the medical view and those who hold the ecological view. For example, the annual Muscular Dystrophy telethon has raised hundreds of millions of dollars for medical research seeking a cure, but critics point out that the program has done nothing to help adults living with MD – no new curb cuts, no new accessible playground equipment, and no new brailed signs. Are resources best invested in seeking cures or to support community living of those with disabilities (e.g., Johnson, 1992)?

Disability policies and their rural dimensions. The cornerstone of disability policy is the Americans with Disabilities Act of 1990. This is viewed as the civil rights act for people with disabilities. It defines disability broadly, prohibits discrimination in employment, and requires public and private entities to make reasonable accommodations to remove barriers to participation by people with impairments. Arguably, it is one of the largest “environmental” interventions in the nation’s history. The employment provisions of the original ADA were only directed at businesses with more than 15 employees. As most employers in small towns and rural areas are small businesses with fewer than 15 employees, those provisions of the ADA do not apply widely in rural areas.

Table 2 lists other major policies sampled across the human life span. The relevance of each policy to rural resident is noted. In the future, disability issues are likely to be integrated into other legislation and program regulations rather than stand on their own. For example, the Transportation Act includes many provisions for accessible public transportation. Similarly, HP 2010 and 2020, the nation’s blueprint for health, integrates disability into many of its objectives by targeting populations at risk. More local initiatives are also likely to emerge, such as initiatives adopted in many cities that promote “visitability” in housing construction (Maisel, 2006).

Disability as a rural commodity. Historically, many institutions were situated in rural areas of the United States – “out of sight, out of mind.” These facilities provided valued jobs and economic activity for those communities. Powerful constituencies developed around these institutions to protect the economic interests of the community and employees at the expense of residents’ freedom. This transformed institutional residents from patients into a commodity that produced profit. While larger institutions are gone or substantially diminished, the nursing home industry holds a similar position in the eyes of the disability rights movement today. This is particularly important to rural areas because a disproportionately higher number of nursing homes are located in rural areas and they “house” a disproportionate share of the population. These facilitates play an important role in many small town economies. While their advocates argue that they fill a need because there are inadequate resources to support people living in the community, disability advocates argue that their presence is an obstacle to developing those supports.

The future of providing supports to people with disabilities living in rural communities will likely move from those services being institutionally based to being community based and from being medically directed toward being consumer controlled. Hence, current institutions will need to shift their business model away from providing only institutional care toward providing training and supports for delivering community services. This shift could lead to new opportunities for providing community supports that increase rural economic activity. For example, an emerging market involves providing supports so that people may continue to live at home regardless of functional loss. This may include constructing or remodeling homes to be accessible (Smith et al., 2008), providing assistive technologies (Sherer, 1996), personal assistance (LaPlante, Harrington, & Kang, 2002), and even distance services and smart-home technology (Chan, M., Estève, D., Escriba, C. & Campo, E. (2008).

Table 2 - Disability Laws and Policies across the Life Span

Age Range	Examples of Federal or State Legislation and Policy Issues	Examples of Documented Rural Issues
0 – 5	99-457 Early Intervention Act – provides for in-home and pre-school support services provided by states.	Lack of access to medical and allied health specialists; distance to early intervention programs; policies that limit family care-giving; professional reimbursement issues; social isolation.
6 - 18	P.L. 101-476 Individuals with Disabilities Education Act – provides for a free public education provided by states in integrated settings.	Low-incidence populations make it difficult for rural schools to provide specialized supports such as interpreters for the deaf; system difficulty in recruiting specialists to rural locations; inadequate systems of transitions planning from school to adult life. Mainstreaming – integration into regular classes – has been controversial in rural areas.
16-65	Rehabilitation Act – provides for a national system of vocational rehabilitation services to promote the employment of people with disabilities; provides for a national network of centers for independent living.	Evidence suggests that rural areas offer fewer employment opportunities; distance from a vocational rehabilitation office has been shown to be negatively associated with receipt of employment services and supports; discrepancy in access to Centers for Independent Living with 40% of the nation's counties (mostly rural) unserved; lack of accessible rural public transportation options; lack of sufficient employment opportunities and supports; discrepancy in internet access
18 +	CLASS Act - Proposes a system of personal assistance services to facilitate independent living and employment of individuals with significant impairments.	Inappropriate nursing home placements due to lack of affordable, accessible housing; difficulty in providing personal assistance services.
All ages	P.L. 109-59 - Sections 5310, 5311, and 5317 SAFETEA-LU (Safe Accountable, Flexible, Efficient Transportation Equity Act: A Legacy For Users) – Provides for accessible transportation in rural areas.	The lack of accessible transportation is consistently reported as one of the major problems experienced by people with disabilities living in rural areas and those who serve them.
All ages	Healthy People 2010 – The nation's blueprint for a healthy population includes a chapter on health for people with disabilities, as well as numerous objectives scattered throughout other chapters.	Rural residents experience higher rates of chronic conditions and disability than their urban counterparts. Rural residents with disabilities also lack access to health services.
All ages	World Health Organization's International Classification of Disability, Health, and Function – creates the internationally recognized model of disability that sets the requirement for measurement for use in standardizing classification and evaluation.	Adopts the ecological model of disability; points to the added justification for infrastructure redevelopment in small towns and rural communities; highlights community participation as the outcome of meaning; emphasizes the role people with disabilities can play as assets to their communities.

Approaches to social change. Advocacy has played a central role in achieving many gains in the disability rights movement. Urban independent living centers champion an aggressive, social action approach to advocacy in which demands are made for systems to change. This can be done because urban systems are not tightly linked, and a change in one system may have little or no effect on others.

Even more, urban advocates can remain largely anonymous so that their advocacy efforts don't have negative personal consequences. In small towns and rural communities, however, systems are more tightly linked and individuals are readily identifiable. A demand for change in one system might threaten the existence of others. Further, relationships in small communities must be managed for the long run. Accordingly, rural disability advocates prefer cooperative – community development – approaches to advocating for change.

In the future, rural advocates may use more electronic communication (e.g., text messaging) to educate the public and to organize efforts for change. These communication strategies can be directed to a specific audience and may preserve anonymity in rural areas as messages for change are delivered to the community. This may increase both the amount and quality of rural advocacy, leading to greater change within communities that increase opportunities for community members with disabilities.

Disparities and Discrepancies

Ample evidence shows that individuals with disabilities living in rural areas face unique challenges in acquiring services and supports (Arnold & Seekins, 1998; Arnold, Seekins, & Nelson, 1997; Gamm, Hutchinson, Bellamy et al., 2002; HHS, 2002; Seekins, 2002a, 2002b). For example, people with disabilities living in rural areas continue to experience unemployment rates higher than their urban counterparts (U.S. Census, 2000). Those with severe disabilities living in rural areas are particularly disadvantaged (Lustig et al., 2004). Indeed, Kaye (2010) found that the 2007-2009 economic recessions had a disproportionate effect on people with disabilities, especially those with mobility impairments, younger workers with disabilities, and people who experience difficulties performing routine daily tasks. The national network of vocational rehabilitation (VR) is designed to help people with disabilities acquire employment but Jackson (1994) reported that the farther one lived from a VR office program, the less likely an eligible person was to receive employment assistance. Similarly, VR counselors serving rural areas report a lack of resources for assisting people with disabilities to find employment (Arnold, Seekins, & Nelson, 1997; Arnold & Seekins, 1998).

Similarly, Lishner et al., (1996) reported that people with disabilities living in rural areas lack access to appropriate medical, health, and related services. They also found that without the access to providers knowledgeable about disabilities, people with disabilities frequently turn to paraprofessionals and alternative models of care. Casey et al., (2001) found that rural residents, in general, receive fewer preventive medicine services than their urban counterparts but Wenhui and colleagues (2006) reported that rural women with disabilities received varying levels of preventive services.

Innes et al. (2000) found that residents of most metropolitan counties have access to a Center for Independent Living serving their community but that residents of 40% of non-metropolitan counties were unserved by any CIL. The Rural Transit Assistance Program found that while individuals with disabilities make up nearly a third of those classified as transportation dependent, nearly 40% of the population lives in counties with no public transportation at all. Enders and colleagues (1999; 2006) found that while telecommunications were being promoted as a solution to rural service problems, those living in rural areas had the least access at the highest cost. Moreover, people with disabilities living in rural areas have the lowest level of telecommunication use of any subgroup assessed.

Cutting through these discrepancies, there is a documented gap in access to broadband internet in rural America that affects people with disabilities significantly (e.g., Copps, M.J. 2009). Indeed, people

with disabilities living in rural areas have the least access and lowest rates of internet use of any subgroup in the United States (Enders, 2006). To the extent that our society is trending to the use of the internet for a wide range of services – from health care to education and advocacy - people with disabilities will be left even further behind.

Key Issues from the Disability Perspective

Gaps are particularly evident in rural education, employment, health, and infrastructure. In addition, three emerging populations – youth, the elderly, and veterans – will pose new challenges for rural communities. We highlight four areas of particular concern for all groups: education; employment and economic participation; health and disability; and community development and independent living. In addition, we introduce the concerns about the growing rural population of elderly and veterans. The relevance of these areas to the lives of people with disabilities has been enduring and will likely continue to garner attention in the future.

Education

For children with disabilities, education begins shortly after birth with early intervention programs, a national program established by P.L. 99457. Family support specialists work with families to learn skills that promote child development, to develop a life plan to identify needed services, and to coordinate benefits and providers. In rural and small towns, there is often a lack of needed professionals (e.g., pediatricians, physical therapists, occupational therapists, speech therapists, etc.) and even paraprofessional providers (e.g., respite providers and habilitation aides). Oftentimes, a Family Support Specialist must travel from a central region office or satellite program.

The Individuals with Disabilities Education Act established the right of all children to have a free and appropriate public education. This includes the development of an individual education plan (IEP) by an interdisciplinary panel serving the child. Most recently, this program has been implemented with full integration of students in mainstream classes. Of course, for many small rural schools, there are few if any specialists representing various disciplines. Rather, services are provided by regional special education cooperatives. In this arrangement, providers may visit a school and work with students on a scheduled basis but are more likely to work with the teacher or an aide to implement the plan.

However, the transition from education to adult life and employment is of particular concern in disability and rehabilitation. There are two elements of transition: building self-esteem and planning transitions to post-secondary education or work. Achieving personal adjustment and self-esteem for a child with a disability is facilitated by the availability of peers and age appropriate role models. In rural areas, there are few peers or role models.

In the future, these gaps in access to professional providers and appropriate peers will be addressed increasingly through information technology. Tele-medicine has already been demonstrated in providing in-home services (Connell, Sanders, Markie-Dadds, 1997), but it is not yet in wide-spread use because of reimbursement issues. On the other hand, for those looking to build self-esteem, FaceBook, YouTube, and Twitter provide alternative social networking avenues. Providing these services in an acceptable format or guiding the use of freely available networks, however, may be a challenge.

Finally, a major goal of transitions programs is to promote success in post-secondary education or work. Macke (personal communication, 2010) suggests that school systems may not be preparing students for the emerging rural economic structure: a more contingent economy based on temporary employment, contracted labor, and self-employment. From the disability perspective, this suggests that one innovative approach to addressing this important issue will involve modifying secondary school curricula to teach students how to string together a series of contracted jobs to create a career, how to negotiate contracts for work, how to save for tax payments, and how to manage a benefit program.

Employment and economic participation

> "Well, many of our fellow citizens with disabilities are unemployed, they want to work and they can work. And this is a tremendous pool of people."
>
> (President George H.W. Bush
> ADA Signing Ceremony - July 26,1990)

Despite significant investments in delivering employment support services, the unemployment rate for people with disabilities remains stubbornly high. Years of research and development that focused on individual and service delivery factors have produced surprisingly few effective approaches for promoting employment outcomes. However, research into employment for people with disabilities living in small towns and rural areas has helped frame two basic questions. First, what employment opportunities exist or can be created? Second, how can employment support services be provided to people scattered across the countryside?

Most employment support programs serving people with disabilities living in rural areas (e.g., vocational rehabilitation) have operated from the perspective of an industrial model in which they seek full time permanent employment with benefits from jobs created by others. This may no longer be a realistic approach. Many economists argue that the rural economy is undergoing a structural rather than cyclical change; moving toward a contingent economy in which part-time, contractual, and self-employment will increase in importance (e.g., Bureau of Labor Statistics, 2010). Employment strategies more consistent with the new economic reality in which so much of our rural industrial base has been outsourced include seeking temporary, part-time, or contractual work, or becoming self-employed (Seekins & Arnold, 1999). Vocational rehabilitation policies present obstacles for doing so, however.

Creating Jobs

In a pilot project, Catherine Ipsen, Karl Kraync and their colleague assessed the effects of a community economic development project led by people with disabilities and a small business investment program (Ipsen et al., 2006). CED leaders – recruited from among vocational rehabilitation clients – first used a strategy based on import substitution and value-added analysis to identify business opportunities within the community. An investment board (a partnership between community human service providers and economic development programs) reviewed business proposals and made micro-loans. The project led to the creation of 72 new local businesses and 115 new local jobs. (In 2005, the Utah State Legislative Auditor verified these benefits).

(From Ipsen et al., 2006)

An innovative approach to promoting rural employment for people with disabilities involves creating employment opportunities rather than waiting for them to be created by others. (See sidebar)

Another approach being tried in Utah involves promoting self-employment through partnerships between vocational rehabilitation providers and small business development centers (Ipsen, C., Arnold, N. L., Colling, K., 2005). In this arrangement, VR "screens clients" for interest in self-employment; those with interest are referred to a regional SBDC for assistance in developing a business. The client, VR, and the SBDC then facilitate access to capital for business start up. Such an approach fills an employment gap and can contribute to the economic development of an entire small community.

Yet another approach for rural employment might involve developing worker and owner cooperatives (e.g., Jossi, 1997; Markley & McNamara, 1995; Sperry, 2001). Recent emphasis on community self-help as a means to rural economic development, and the large untapped potential of unemployed rural workers with disabilities, invites the application of some innovative mechanism for linking these circumstances for the mutual benefit of all involved. The worker cooperative may be just such an innovative mechanism. Cooperative ventures in general have a long tradition in rural America. Research might explore the utility of such ventures in rural areas around specific business sectors such as agricultural productivity and value added processes.

Regardless of the strategy used, delivering employment support services poses challenges. Most VR services are provided out of regional or satellite offices with some itinerant counselors travelling to communities within a service area on a scheduled basis to meet with clients and potential employers. In the future, counselors are likely to use information technology to work with clients and employers. Surprisingly little research has addressed the questions involved in the approach, however. Ipsen and Rigles (2011) reported that the use of telecommunication eliminated transportation barriers and saved money, and time. Increasing client and counselor access to, and comfort with, various forms of telecom may be useful for rural VR service delivery.

Health and Disability

About 15 percent of the population has an impairment that leads to disability, but these people account for 47 percent of health care costs (Max, Rice, & Trupin, 1996). Disability exacerbates many rural health care barriers including basic access, specialty care, and transportation (Iezzoni, 2006). People with significant disabilities and rural residents have less access to many preventive health services than their urban counterparts (Beatty, Jones, & Dhort, 2001; Casey, Thiede, & Klinger, 2001). This can lead to lowered health-related quality of life (Buchannan et al., 2008) and may lead to increased mortality (Cosby et al., 2008).

Access to medical services – medical specialties in particular – presents problems for rural residents with disabilities and their families. Poverty, transportation, and physical access to rural clinics all present barriers commonly experienced by people with disabilities in rural areas (Iezzoni, 2006). This is consistent with rural health care research that finds having a usual source for health care is related both to regional economic health and mix of physician specialties. In the absence of consistent care, prevention of health problems takes on particular importance (Seekins, Clay & Ravesloot, 1994).

Unfortunately, access to health promotion services is severely limited and often non-existent for rural people with disabilities.

Until recently, medical rehabilitation and selected individual medical problems experienced on an out-patient basis (e.g., Urinary Tract Infections, skin ulcers, etc.) garnered most of the disability and health attention. This medically oriented approach applied acute care serially to acute problems. However, over the past 20 years, there has been an explosion of interest in health promotion, wellness, and prevention of health problems for people with disabilities. Indeed, researchers have reported health promotion strategies that reduce impairments and increase participation (Ravesloot et al, 2007; Stuifbergen et al., 2010; Seekins et al. (under review). Few of these programs integrate people with disabilities into the ongoing program offered to everyone, however. Most specifically target populations of people with disabilities and offer the programs in "segregated" arrangements.

With the health care industry in crisis and congress taking desperate measures for systems change, the health of people with disabilities will take on even greater importance in the future. Interventions developed to improve the health of people with disabilities will increase urban-rural disparities if they are not appropriate and effectively applied in the rural context. It is imperative that rural researchers and practitioners be at the table to chart the course of health promotion for people with disabilities if future health promotion resources are to be equitably distributed.

Infrastructure for Independent Living

In the ecological framework, the environment is generally taken to mean the community. The outcome of the interaction between the individual and the environment may be measured by the degree of participation in community life. Unlike the traditional rehabilitation model that focuses on remediating impairment, this ecological model assumes that the environment is infinitely malleable and that it can be organized (treated) to accommodate individuals with various impairments. Centers for independent living (CILs) are the disability equivalent of community development agencies. Both aim to create sustainable community infrastructure, including housing, transportation, telecommunication, emergency preparedness, and social capital and civic leadership.

The lack of transportation is consistently ranked as one of the top problems facing people with disabilities living in rural areas and those who serve them (National Council on Disability, 2005). In the 1970s and 80s, disability and transportation advocates created basic

Transportation

In Sanders County (population of 11.034 in 2,790 square miles – Thompson Falls is the county seat with a population of 1,321), people with disabilities – through a disability advocacy organization - expressed a need for public transportation where there was none. But their efforts to organize local agencies had not succeeded. One of the local disability advocates approached his minister and asked for help in bringing the community together on the issue. The minister invited all the public agencies serving the county to his church to discuss local transportation. The disability advocacy group arranged for an expert in rural transportation to address the group. The group made a commitment to build a coordinated transportation project based on human service vehicles. Beginning with an old van owned by one of the senior centers, the group began providing transportation to the community. Working together over the next five years, the community was able to use resources targeting transportation for people with disabilities to create a rich and effective public transportation service that included a daily fixed route throughout the county and trips to Coeur D'Aleneand Missoula twice a week for medical appointments and shopping.

(A case study, 2011)

public transportation systems in many small communities by organizing existing human service agencies vehicles into "coordinated" systems (Kidder, 1989 – see sidebar). In the 1990s, research and disability advocates developed and demonstrated a voucher model for rural transportation (Gonzales, 2006).

In 1996, the Association of Programs for Rural Independent Living (APRIL) established a rural transportation agenda that included increased funding for general rural transportation program. They joined with other advocacy groups and achieved increased Federal funding for rural (5311) and accessible (5310/5317) programs. Moreover, the voucher model was specifically allowed in regulations that followed.

In the case of housing, disability advocates have worked hard to increase availability of affordable and accessible homes. This effort is particularly important to the effort to emancipate people living inappropriately in nursing homes back into the community (Seekins et al., under review b). In addition, disability advocates have worked hard to promote the concept of visitability in new home construction and renovations. Visitability is the simple idea that if all homes had a zero step entrance, people with mobility impairments could visit their friends and families (Concrete Change, 2008). Several cities and towns have adopted visitability ordinances (e.g., Maisel, 2006). In Montana, we estimated that nearly 20% of homes met the most basic requirements of being visitable in 2006.

Systems of Service

Because of its connection to health and human services, regional approaches to providing services and supports have been used to organize and deliver services to people with disabilities living in rural areas for quite some time. For example, the state system of vocational rehabilitation services typically organizes its offices to serve regions that reach large rural areas. In Montana, VR organizes its services into five regions. Each region has a central office and at least one satellite office. Clients can come into the offices, and the VR counselors travel out to meet clients in local communities.

Similarly, school districts serving small towns and rural areas have organized "special education cooperatives." Cooperatives provide professional services (e.g., physical therapy, speech therapy, sign language interpreters) to several schools that an individual small rural school could not afford to sustain.

In the areas of transportation, the State of Iowa has expanded the basic model of coordinated transportation using human service vehicles as a foundation and created regional transportation organization. In doing so, they have created one of the better rural public transportation systems in the nation.

A major concern is developing these systems of services is that they can become silos – segregating people with disabilities from the mainstream and from each other. As we march into the future together, we need to keep alert for opportunities to integrate systems in ways that fit seamlessly into our communities and in ways that everyone fits comfortably into the routines and rhythms of their community's life

Emerging Populations

The rural population of people who experience disability can be subdivided into categories of particular interest. There is a danger in doing this as historically policy bodies have used distinctions to pit one group against the other – leaving the squabble created as an excuse to do nothing. Nonetheless, careful consideration of difference can contribute to planning to insure that legitimate needs are addressed and that new opportunities are sized. Three emerging rural populations call for such focused attention.

Youth leadership. Leaders in the disability rights and independent living movement recognize that youth with disabilities are the future of the movement and have built a system for integrating them into leadership positions. (See Sidebar) At the national level, the Association of Programs for Rural Independent Living sponsors scholarships for youth to attend their annual conference and sponsors a peer-to-peer mentoring program. At the local level, CIL directors are delegating significant responsibilities to young staff with disabilities to lead state and local advocacy programs. These young leaders in the disability rights movement provide a reservoir of leadership skills and talents for their rural communities.

Youth Development

Montana Youth Leadership Forum (MYLF) develops leadership capacity among high school sophomores, juniors, and seniors with disabilities from across this vast State. The program provides networking opportunities and training in self-advocacy. Successful men and women with disabilities serve as role models in helping youth realize their abilities and obligations to contribute to society. This educational and motivational forum involves an intense schedule. Throughout the training, small "working groups" explore personal leadership and career plans. The key to the MYLF is leadership by example. Adults with disabilities who have traveled the same path these young people are facing serve as faculty and staff.

(http://www.montanaylf.org)

Elderly. Proportionately, more elderly people live in rural areas than in cities and those in rural areas experience higher rates of impairments and disability (Jones, Parker, Ahearn, Mishra, & Variyam, 2009). The sheer number of the older population is growing. As people age, the population ages, the incidence of impairment increases. While some believe that rural communities are the best place to grow old, the evidence suggests otherwise (Church, 2010). The same issues that confront people with disabilities as they grow old – income insecurity, access to medical care, lack of accessible houses and public facilities – will confront older rural residents as they acquire impairments. In many cases, because their environments are not well designed, elderly individuals will experience disability. Making the investments to create accessible infrastructure now will minimize the prevalence of disability later.

Veterans. Many military veterans are returning from service with disabilities that compromise their health and ability to return to work. There are approximately 2.8 million Veterans receiving Veteran Administration disability compensation, of which 257,100 are rated 100 percent disabled. Approximately 40 percent of current military recruits come from rural areas, nearly twice the proportion of the total population living in rural areas. Despite the proportion of veterans from rural areas, Weeks et al. (2008) found surprisingly little published literature on the population.

Many veterans experience significant disability from injuries and chronic conditions. Veterans returning from combat to active duty return to a supportive environment. Those who served in the Reserves or the Guard simply return home. While their initial medical care and rehabilitation is often the best that can be provided in the world, veterans' pathways to services and supports after hospital discharge are less well-organized. This leaves many veterans at risk for an array of secondary conditions to their disability that further limits their ability to work. Many of these conditions could be managed and prevented effectively through community-based health promotion. But there are limited mechanisms for providing such supports outside of centralized veterans' programs. New approaches are needed to provide services and supports to veterans where they are living.

Conclusion

People with disabilities – children, youth, adults, elderly, or veterans – are a big part of rural America's future. Over the last 50 years, the disability trajectory has been moving further from special or segregated status toward more community integration. This has involved a significant effort to improve services and supports, and to fashion constructed spaces to be accommodating.

While people with disabilities benefit directly from such investments in community infrastructure, they can also contribute to community development. People with disabilities can help build rural communities of the future. Overall, to see these new realities emerge in the future of rural America, people with disabilities need a seat at the table, and their concerns need to be integrated into the broader agenda. Still many questions remain about how these aims might best be achieved, the risks for people with disabilities, and the costs associated with such efforts.

Questions: As disability is seen increasingly as a natural part of life, there is the risk that legitimate, individual needs might be overlooked. Moreover, in an era where many see waste in common effort, can society – will society – maintain its compact to provide supports that are needed for full participation in the life of rural communities by people with disabilities? What is the value to rural communities of integrating people with disabilities into all of community life? Do people with disabilities have a right to live in rural communities? At what cost and to whom? How can we measure that value and those costs? What arrangement can both benefit people with disabilities and contribute to the vitality of rural communities? If people with disabilities have unique needs, why shouldn't they be expected to move to a city where services are more readily available and they may be more accepted? How much can a small community be expected to take on?

What is the reality of alternative, local approaches? For example, in the area of health, how much can self-help, personal responsibility, and health promotion make up for the gap in medical services? How much can the new electronic communications contribute to health care? What combinations will form an effective health system for people with disabilities? Will the creation of systems for promoting and maintaining the health of rural residents with disabilities improve the overall system – the litmus test - or come at the expense of others? Will strategies developed in resource lean, rural environments be transferable to urban environments that have yet to resolve these same issues?

In the area of economic development and employment, can people with disabilities be recognized as entrepreneurs and small business owners without jeopardizing their business interests?

Next generation: As with other areas of concern, the next generation of generation of rural Americans is emerging at this moment. Many will have disabilities. Will their peers – exposed to them for a life time – be more or less likely to treat them as equals? How is our education system contributing to that vision? Can we look at a young woman who uses a wheelchair and see a future mayor?

Five pathways to the future: There are many paths to the future and we should take as many as possible. Some pathways might include:

1. Identifying, documenting, packaging and disseminating good examples of how rural communities have worked to address the concerns of people with disabilities and ended up benefitting the entire community and all its residents.

2. Exploring policies and strategies that break down segregated disability systems, and facilitate the integration of systems of support for people with disabilities. This might include convening forums of leaders of systems targeting populations to explore the gains that might be realized through consolidation and integration.

3. Similarly, working with those same systems to explore how they might address concerns of emerging populations of people with disabilities (e.g., veterans, elderly) without creating new, separate systems.

4. Developing protocol for incorporating people with disabilities into community and regional planning to insure their issues are considered and their talents and insights used.

5. Developing monitoring systems to track key indicators of community inclusion and to provide feedback about community process.

One dream is to build rural communities on the strength of their personal connections that embrace individuals in all their diversity. This will involve recognizing that while livable communities call for well-designed infrastructure, human connections and relationships are the cornerstone of livable communities.

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