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Rural Disabled Struggle for Independence

By Thomas D. Rowley

Independence is a hallmark of rural living, but for millions of rural Americans with disabilities, independence is often hard won.

There are a host of obstacles stacked up against their quest for independence: outdated attitudes toward the disabled; limited employment opportunities and the poverty that can result; and a lack of health care, social services, and transportation.

“Our lives, as people with disabilities, would be better served ... if we had adequate transportation available and accessible and affordable,” said Cherie Clark, a disability policy consultant, disability rights advocate, and rural advocate in Iowa who has cerebral palsy. “If we had health care that wasn’t linked to working. And if we could get whatever services that were needed in order to get us up in the morning and provide for our long-term care needs.”

Rural people with disabilities often live with the uncomfortable irony of being isolated yet dependent on others. Efforts are underway, however, to change that.

A New Paradigm

“Some people call it the new paradigm of disability—not just a medical condition to be cured, but as an interaction between individuals’ capacities and their immediate environment,” said Dr. Tom Seekins, director of the Research and Training Center on Rural Rehabilitation Services at the University of Montana (RTC). Included in that interaction is everything from jobs to social activities to assistance programs.

According to Seekins, participation in community life has become the gold standard and part and parcel of that participation is self-direction. Therefore, the cornerstone of the new paradigm, Seekins believes, is the recognition that people with disabilities are the best judges of their own needs and interests.

Linda Gonzalez, who directs the Association of Programs for Rural Independent Living (APRIL), takes the idea a step further.

“Independent living is a social movement,” said Gonzales, whose organization represents more than



Cherie Clark, a policy consultant in Iowa, advocates better services for the rural disabled.

200 rural centers for independent living. “People with disabilities are empowering themselves to take their rightful place alongside their non-disabled peers in society, the workplace, and the community.”

(continued on next page)



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To achieve that, experts agree, people with disabilities need better information and support systems with which to manage their own health and independence. Not surprisingly, both are more difficult to access in rural areas.

Programs that work with the disabled in rural areas are different from urban programs because they are often the only show in town, according to Gonzales.

She says that a rural location makes for other differences in working with the disabled—some helpful, some not. Among the pluses she cited are an ingenuity born of necessity and a sense of community that promotes working together.

Unfortunately, there are also some minuses.

“We’re working against decades of constructs and attitudes that keep people with disabilities from full participation in their community,” said Gonzalez. “Outdated systems that give preference to institutions rather than true integration and community-based services. [Rural communities face] high unemployment rates that keep people who want to work dependent and living on government subsidies. Living in rural America should be as much an option for people with disabilities as it is for the non-disabled.”

Addressing the challenges faced by folks in rural areas who live with disabilities will require taking on several key issues such as transportation, funding, and access to specialty care.

Transportation

Transportation, experts say, is a huge problem for people with disabilities in rural America, more so than in urban America. The greater distances, the relatively small numbers of people, and the lack of resources combine to severely restrict transportation options.

A look at the numbers from the University of Montana’s Research and Training Center explains why.

- Although some 20 percent of the U.S. population lives in rural areas, only about six percent of federal transportation funds are allocated to rural areas.
- People without a car in urban areas average about 955 publicly subsidized trips per year, 80 per month, 20 per week. People without a car in rural areas average only about 38 publicly subsidized trips per year, three per month, less than one per week.

TEA-21

With the reauthorization of TEA-21 (the federal Transportation Equity Act for the 21st Century) coming up, hopes are high for changes that might benefit the disabled.

Linda Gonzalez, Director of the Association of Programs for Rural Independent Living, said advocates are looking for help to overcome obstacles for the rural disabled. For starters, she’d like to see Congress send more public transportation funds to rural America and have the act live up to the “equity” in its name. She would also like an increase in funding for innovative programs, such as:

- Vehicle sharing among service providers— for example, using the senior van to also transport people with disabilities to medical appointments.

- Vouchers programs—enabling people with disabilities to “purchase” rides from a variety of transport providers, even private individuals.
- Personal and/or private enterprises—providing, for example, interest-free loans for people with disabilities to buy a car.

To achieve better transportation for rural people with disabilities, Gonzalez realizes the need to work with other transportation-dependent constituents—the elderly, students, working moms, etc. In return, she hopes those groups will remember the disabled when pushing for transportation improvements.

- Nearly 37 million rural residents—40 percent of all rural residents—live in the 1,200 counties that have no public transportation at all

In addition, rural people with disabilities face numerous constraints their urban counterparts do not.

- Rides for people with disabilities in rural areas usually must be arranged 24 hours in advance.
- Many rural streets are unpaved and lack sidewalks.
- Rural public transportation options are few and are limited where they do exist. Given that few rural areas run public bus systems, public transportation may be a taxi that is not easily wheelchair accessible, or a van that is not equipped for handicapped riders.

No one understands the transportation challenges better than Clark.

“In a place like Iowa transportation becomes critical,” she said. “If people don’t have access to transportation, they can’t get health and wellness information. They can’t get the services they need. They can’t go to the local mall when they’re having a health fair and have their blood pressure checked. These are symptomatic problems nationwide, but they are especially profound in rural America.”

Funding

Experts note that people with disabilities are far and away the poorest group of Americans. Difficulty in getting and keeping a job

Defining “Disabled”?

Some 20 percent of people in the United States have a disability; about half have a “severe” disability. According to 1990 Census data, between 11 and 15 million people who live in rural America are disabled. In other words, with only 20 percent of the nation’s total population, rural America is home to 23 percent of the disabled population.

Although the numbers are old, they are still fairly accurate, according to Dr. Tom Seekins, director of the Research and Training Center on Rural Rehabilitation Services. They can vary, however, depending on the definition of disability.

- Under the federal Social Security Disability Insurance Program, disability is narrowly defined as “unable to engage

in substantial gainful employment.”

- The Americans with Disabilities Act of 1990 has a broader definition and considers a person disabled if he or she a) has physical or mental impairment that substantially limits one or more major life activities; b) has a record of such impairment; or c) is regarded as having such an impairment.
- The Bureau of the Census defines a person with a severe disability as someone who is unable to perform one or more activities, has one or more specific impairments, uses a wheelchair, or is a long-term user of crutches, canes, or a walker.

plays a significant role in their poverty, as does the fact that many people with disabilities have limited education as a result of their disabilities.

“People with disabilities have a very high unemployment rate and an even higher underemployment rate,” said Clark. “Part of that is built into the system. While we’re getting better at understanding that people with disabilities can be both healthy and disabled and work, the way the system has been structured there’s been a disincentive to work. If you

go to work you lose your health insurance, your benefits and your home, if you’re in a low-rent project.”

The economic downturn has only made things worse for rural Americans with disabilities.

“In the boom years of the 1990s, many people with disabilities went to work,” Clark said. “Now, in tough times, the first people laid off are usually the last people hired—that includes a high number of people with disabilities.”

Clark continued, “Health insurance costs also play a role. People are getting let go not because of merit, but because of the health insurance system. People with disabilities are let go as a way to cut health insurance premiums paid by employers.”

And health insurance is critical since, according to figures from the RTC, people with disabilities account for 47 percent of all medical expenditures in the United States.

Access to Specialty Care

Rural areas have always had trouble ensuring even basic access to

health care services. For folks with disabilities, the challenges are compounded. Many rural areas consider themselves lucky just to have access to primary care. Access to specialist physicians, rehabilitation and occupational therapists and other specialists are critically important to those with disabilities. Unfortunately, they are not largely available in rural areas.

“It’s very difficult to find specialists who understand disabilities well,” said Clark. “At the opposite end, we have family practice docs that tend to be scared to treat us, because they don’t have a clue that we’re normal people who get colds and flus in addition to our specialty care needs.”

Promoting Independent Living

Despite all those challenges, there are some efforts around the country that help provide a multi-pronged, holistic approach necessary for independent living. Experts in the disability field note that the key is collaborating across the health and human service sectors.

Living Well with Disability

This program, developed by researchers at the Universities of Montana and Kansas with support from the Centers for Disease Control and Prevention, is an eight-week

Centers for Independent Living

Centers for Independent Living—the member programs of APRIL—are, in the words of one observer, “resource centers run by the disabled for the disabled.”

According to Lenore Schwager, Executive Director of the Finger Lakes Center for Independent Living in Ithaca, New York, the centers began in California in the early 1970s. People with disabilities wanted control of their lives, she said. So they started the centers.

Funding for the centers comes from both federal and state governments. Most are non-profit 501c3 organizations, and all provide four core services

(most, free of charge) to people with disabilities:

- Peer support—contact with other people with disabilities who can share information and provide emotional and inspirational support;
- Training in independent living skills—help with everything from budgeting to learning to cook in a wheelchair;
- Information and referral—assistance getting information and access to services and providers; and
- Advocacy at both individual and policy levels.

Most of the services are free of charge. Sometimes the centers run afoul of other service providers whose financial interests may be best served by dependence rather than independence.

Tom Osborn, who directs the North Central Independent Living Center in Black Eagle, Montana, said that the goal of independent living sometimes conflicts with a hospital’s or a nursing home’s need for keeping people with disabilities institutionalized.

“That gets difficult,” he said.

workshop that uses goal setting and problem solving as the framework for developing healthy lifestyles. Underlying the workshop is the notion that people are more likely to practice healthy living when they have meaningful activities they want to do. Therefore, Living Well begins with *why* someone wants to be well. Subsequent sessions concentrate on developing tools and skills for healthy living, including healthy reactions and communication, managing depression, information seeking, physical activity, nutrition, and advocacy.

According to the RTC, the Living Well workshop “differs from many medically-based health promotion interventions because improved health is an objective to a goal, rather than the goal itself.”

Data from the RTC show that some 218 Living Well Workshops in 17 states have served 1,585 people, and the program has resulted in an annual total increase of 19,020 symptom-free days for participants and a cost savings from services not needed of \$1.5 to \$2.5 million. In addition, Living Well participants report improvements in their outlook and positive changes in daily activity, such as new recreational pursuits or returning to school. According to the RTC, many participants learn they can pursue meaningful goals despite their limitations and develop a sense of belonging as they are accepted and encouraged by their peers.

According to Seekins, Living Well with a Disability has proven so successful that he and others are trying to figure how to expand it throughout the U.S.

Family to Family

Still another program offers help to the families of people with disabilities, specifically children with disabilities or special needs.

“If your child has special needs, so do you,” said Sue Offutt, Director of North Dakota’s Family to Family Network.

The Family to Family Network provides support to the parents of children with disabilities by linking them with parents in similar situations. The network—modeled after a national program called “Parent to Parent”, which was started by the parent of a disabled child—is based on the philosophy that the best support for parents of children with special needs comes from other parents of children with special needs.

“We the professional can give them information, but if we haven’t walked the walk we can’t know what it’s like and give them the emotional support they need,” said Offutt.

Within the network, parents get emotional support, a chance to share experiences, and support in accessing resources. The service is free, confidential and easy to access. Indeed, most of the interaction between parents occurs over the phone or by email.

“Participation ranges from one phone call to a lifetime friendship,” Offutt said.

In addition to linking families, the program also acts as a resource to families; educators; policy makers; health care, human service and child care providers; and others.

Offutt identified several difficulties faced by families of children with disabilities:

- Many rural families are hundreds of miles away from care providers and must quit their jobs in order to move closer to care.
- Getting health insurance to cover the medications, surgeries, and treatments for a child with special needs can be a huge battle.
- Faced with tight budgets, schools cannot provide all of the services a parent might want for their child.

As a result of these and other difficulties, stress is a fact of life for families with special needs kids. According to Offutt, however, research shows that the program is giving families strategies to cope, reducing their stress, and providing them hope for the future.

Pam Burkes, the mother of two special needs children, is living proof of the need for support and the effectiveness of it. Brady, age nine, has attention deficit hyperactivity disorder. Brandon, age 11, has central auditory processing disorder. Consequently, the needs of the Burkes family are broad. Burkes, a mental health professional, had looked everywhere for help and was stuck, she said. Then she found the Family to Family Network.

“Family to Family was a groundbreaking place for us,” said Burkes, who found people in the network who shared her troubles and helped her find solutions. “Right now, I see good things happening. I think that we’re on the right road.”

Burkes and her family have begun helping others in the network, becoming one of 155 mentor families around the state.

Vocational Rehabilitation for Native Americans

A project in Montana provides another innovative model for serving the disabled. While helping people with disabilities and supporting them in their desire to stay at home is a long tradition among Native Americans, the independent living concept and movement is relatively new to most reservations according to Wilfred (Max) Bear, director of the Fort Peck Assiniboine Sioux Vocational Rehabilitation Program.

The program serves people on the 2.1 million acre Fort Peck Reservation in northeastern Montana. Its mission is to provide culturally appropriate services to tribal members who have mental or physical disabilities but who are employable.

That means doing “whatever moves them toward employment,” Bear said, which includes everything from needs assessment to financial assistance to vehicle repairs to Native American healing practices. The services are provided both at the program office in Poplar (population about 2,000) and at remote sites on the reservation—all at no cost. (By contrast, the Centers for Independent Living serve all people with disabilities regardless of their employability. Thus, the two types of programs are different but can work together, as do the Fort Peck rehab program and the North Central Independent Living Center in Black Eagle in serving

people with disabilities on the reservation.)

Finding employment for program consumers is no easy feat, however, on a reservation where the unemployment rate among Native Americans is some 65 percent, poverty is rampant, and many people do not even have regular phone service.

“They’ve already got a strike against them for being Native American,” Bear said. “The disability just compounds that frustration.”

Still, from a pool of 82 consumers, Bear said, the program has already placed 19 in jobs this year, 12 last year, and 15 the year before.

Those results notwithstanding, the future of the program is uncertain. Bear’s federally funded program is in the fourth year of a five-year grant. Soon, Bear said, he’ll be writing another proposal for continued funding. He doesn’t take the money for granted.

According to Bear, only one percent of all federal vocational rehabilitation funds go to tribal programs, and only two Centers for Independent Living are on Indian land. Native Americans are, he said, the largest unserved/underserved populations of individuals with disabilities in rural areas.

“When the cuts start coming down, it’s usually Native Americans that face them first,” said Bear, speaking of the current state and federal fiscal environment.

Ticket to Work

Finally, a new program being launched across the country offers still more support for people with

disabilities. Although the program is not rural-specific, it has the potential to help in all areas.

The Ticket to Work and Self-Sufficiency Program was signed into law by President Clinton in December of 1999. This nationwide initiative aims to help people get the training and support they need to go to work. One of the program’s major benefits for disabled people is that they may continue to receive health care benefits.

It works like this: The Social Security Administration (SSA) will mail tickets (vouchers) to some nine million eligible beneficiaries who may use them to obtain employment, vocational rehabilitation, and other support services from a public or private service provider. The provider and beneficiary will then work together to design an Individual Work Plan outlining the services to be provided that will enable the beneficiary to reach his or her employment goal. The program is voluntary. No one has to participate.

The SSA began the program in early 2002 by mailing tickets to eligible beneficiaries in 13 states. Later that year, 20 more states and the District of Columbia were added. In late 2003, the remaining 17 states and five territories will have access to the program.

According to Cherie Clark, Ticket to Work could prove beneficial, especially because it allows disabled people to continue receiving health benefits. Still, the program is new, so it is too early to tell whether it will succeed in promoting independence, particularly in rural areas.

“Ask me in five years,” she said.

Around the Country

by Erica Hauck

Arizona

Building Homes and Employment

The White Mountain Apache Housing Authority in Arizona is using its Apache Dawn program to simultaneously address two of the reservation's most pressing problems: soaring unemployment and a serious shortage of affordable housing.

The White Mountain Apache Tribe, with a population of 14,000, has an unemployment rate near 65 percent and more than 1,400 families on the Housing Authority's waiting list to obtain adequate, affordable housing. To address these needs, the Authority has undertaken the Apache Dawn program to build more than 300 single-family homes on the reservation using tribal businesses and tribal workers for construction.

The Authority contracts with local tribal businesses for most of the construction on the homes. This has helped stimulate the local economy while lowering its per-unit price by 30 percent. Nearly 85 percent of the lumber for construction comes from a tribal timber company, and all the necessary cement and gravel from the Tribal Public Works Division. As a result, the Authority estimates the project has provided 150 new jobs for tribal members.

The homes are available, at the cost of construction, to tribal members on a lease-purchase basis. The leases are renewable every five years, and after ten years, the occupants have the option to purchase the home. In order to assist the residents and promote homeownership, the

Housing Authority provides education and counseling on budgeting, obtaining and paying off credit, and the responsibilities of owning a home.

Funding for the \$25 million project came from an innovative combination of HUD Section 184 guaranteed loans, Indian Housing Block Grant funds, and tribally-issued tax-exempt bonds.

"We are trying to infuse the \$25 million into the tribal economy and keep it on the reservation. It's a win-win situation all around," said Aneva Yazzie, a management consultant working closely with the Housing Authority on the project.

For more information, contact Aneva Yazzie, Management Consultant for the White Mountain Apache Housing Authority, at 928-338-4831.

Alabama

Getting Kids and Moms to the Doctor

Thanks to Alabama's Kid One program, thousands of poor children and expectant mothers, many of whom had foregone medical treatment for weeks or months because they lacked transportation, are now going to the doctor.

Kid One was born from a tragic experience. While working as a firefighter in Hoover, Alabama, Russell Jackson witnessed the accidental death of a young boy. This led Jackson to volunteer in community efforts for children, especially in poor, rural areas. He began working

in an isolated mining camp, where he drove a boy with a severe speech impediment to and from doctors' appointments. Social workers asked if he could drive other sick children as well. Recognizing the severity of the problem, Jackson cashed in his retirement savings, bought a van, and established Kid One.

What began as a one-man operation has grown into a \$1.3 million a year organization consisting of 12 drivers. The program serves urban and rural clients in 23 counties in Alabama and operates out of a central office in Birmingham. Drivers keep the Kid One cars at their own homes and receive information from the central office about the driving schedules in their counties. Funding for the majority of the program's expenses comes from private donations, including Mercedes-Benz US International in Vance, Alabama, which contributes about two vehicles each year to Kid One.

To date, Kid One has provided more than 57,000 trips to more than 4,000 children, but Jackson still sees a need for expansion.

"We are their only solution," he said. "And we're still turning away children left and right."

That said, a recent \$500,000 grant awarded from the Federal Transit Administration should help. The money will be used to purchase vehicles and extend services into the southern counties of Alabama, where rural poverty levels are among the highest in the nation.

For more information, visit Kid One's website at www.kidone.org, or contact

Russell Jackson, Founder and CEO, at 205-978-1001.

Mississippi

A Sanctuary for Hospice Patients

Drawing on the support and generosity of the residents of northern Mississippi, a group of nurses and doctors in Tupelo is working to establish the region's first in-patient hospice home for terminally ill patients. By August 2003, the group had already raised \$1.35 million from private sources in the area and received a \$918,000 grant from HUD to care for terminally ill homeless patients. Construction on the Sanctuary Hospice House began in April.

Sanctuary Hospice House President Nancy Collins realized the need for in-patient care for dying patients in the rural areas around Tupelo after working as a hospice nurse for one of the area's hospice agencies. Although she says the hospice agencies are already providing excellent in-home services, many patients have no caregiver in the home, and the nearest residential hospice facility is more than two hours away. A missionary trip to Mexico City, where she visited a privately funded residential hospice house for extremely poor patients, further dedicated her to the cause, prompting her to collaborate with others in the area who were working towards the same goal. Collins said she realized, "If they can do it in Mexico City, we can do it in Northern Mississippi."

The home, which is located on donated land, will consist of 16 private rooms for patients and their families, common family areas, an accessible kitchen, a chapel and outdoor gardens. In accordance with the HUD grant, four of the rooms will be reserved for homeless patients.

The Sanctuary House anticipates about 50-60 percent of its expenses will be reimbursed by Medicaid, Medicare or private insurance, while the rest will be paid from private donations and money raised from the annual fundraiser—a holiday shopping festival at which some 100 private vendors rent booths to sell their goods. No patient will be turned away based upon ability to pay.

Despite support from the region, as well as endorsements from such organizations as the American Medical Association and the Hospice Association of America, Collins and the other advocates of the Sanctuary Hospice Home have run into several obstacles, the most substantial being a law stipulating that in order to receive Medicare reimbursement, the hospice agency must provide at least 80 percent of its services to patients living in their own homes. Sanctuary Hospice House's goal, however, is to provide in-patient care to the terminally ill in surrounding rural areas who are not able to remain in their homes. A bill, drafted by Sanctuary House supporters and the AMA, is currently pending in Congress to loosen the requirement for nonprofit hospice homes in rural areas.

Beyond helping the terminally ill and their families in Northern

Mississippi, Collins also envisions the Sanctuary Hospice House as a model for other rural communities where in-patient hospice care is scarce. The bill, if passed, will help ease the path of other groups who want to open similar facilities in rural areas.

"If communities want to take care of their terminally ill neighbors, we want to show them how to do it," Collins said. "Our work won't be just for us – it's for the whole country."

For more information, visit www.sanctuaryhospicehouse.com, or contact Nancy Collins, President, at 662-341-0921.

North Carolina

An Innovative Way to Keep a Hospital Open

A few years ago, the residents of Swain County, North Carolina, feared they would lose the only hospital in their county due to financial troubles. An innovative community effort, however, not only kept the doors open, but also increased profitability, improved access to health care among residents, and expanded the medical services available in the county.

In 1997, facing potential financial collapse and closure, Swain County Hospital merged with Harris Regional Hospital in a neighboring county to form WestCare Health System to provide collaborative medical services on a regional basis and make medical care more cost effective. In 2000, the hospital became a Critical Access Hospital, a

designation that has allowed for more efficient service provision and greater Medicare reimbursement.

In addition, various governmental and health organizations in Swain County have worked together to provide an integrative approach to provide multiple health services in one location that improves accessibility, quality and scope of health care.

“The only way to survive and treat our patients was to work together,” said Swain County Hospital Administrator Ronnie Sloan.

The county health department, which previously had clinic services scattered around three different locations throughout the county due to spacing limitations, will soon have one central clinic housed in a new building attached to the hospital. The 12,000 square foot medical building, partially financed through \$1.2 million from the Duke Endowment and the Kate B. Reynolds Foundation, will be connected to the main hospital building through both the main lobby and the emergency room.

Also located in the new building will be the Swain County Medical Clinic, a group of five family practitioners and one internist. Two new pediatricians and several specialists who rotate between Swain County Hospital and Harris Regional will also have offices in the new building.

In addition, in order to integrate all health-related services into one location, the offices of the county Department of Health and Human Services, Department of Social Services and Health Department will all move to a building located on the hospital campus. The end result will

be one centralized “portal” through which all of the health care needs of county residents can be met.

The improvements in service have increased confidence in the hospital among county residents. While administrators had estimated about 400 visits to the ER per month, during July, August and September of this year, they averaged about 700. According to Sloan, “People who were passing by our hospital to receive treatment in other counties are now stopping.”

For more information, contact Ronnie Sloan, Swain County Hospital Administrator, at 828-488-2155.

New Mexico

A One-Stop Shop for Family Health

The Family Support Centers in Hidalgo and Grant counties in the southwestern corner of New Mexico are a “one-stop shop” for connecting families to various health-related services.

The Centers are a program of Hidalgo Medical Services, a federally qualified community health center currently providing primary care services at four sites in the two counties. The Centers engage in a wide variety of activities, such as facilitating referrals to the appropriate agencies for services; conducting educational workshops on issues such as prenatal care; providing tobacco cessation programs; helping families apply for programs such as Medicaid and food stamps; and administering a diabetes

education program. All services are provided by “Promotoras” (lay health workers).

Funding comes from a variety of sources, including the community health centers’ general funds, a CDC grant, tobacco settlement monies, and other private foundations.

According to Family Support Coordinator Nikki Zeuner, the residents of the area face considerable barriers to accessing the appropriate services. About half of the residents are Hispanic, and the counties have poverty rates well above the national average.

“Sometimes people have fuzzy ideas about what programs they are eligible for,” Zeuner said.

The Centers work to provide them with as much information as possible about existing programs and put them in touch with the appropriate agencies.

In addition to client services, the Centers also engage in community development activities. In each community in which a center is located, the Family Support program conducts needs assessments, utilizing town hall meetings, focus groups and interviews with residents, in order to determine what local citizens consider the most important needs in their communities. The program also works to build collaboration between all health and human service agencies in the area to find ways to pool resources, increase accessibility and “fill in the gaps” in existing services. Agencies must collaborate to provide the most comprehensive services possible.

The program is also actively involved with the nonprofit Wellness Coalition, a group of representatives from Hidalgo, Grant, Luna and Catron counties that discusses area health issues and creates plans for future programs and services. The Coalition maintains a regional approach and recently obtained 501(c)3 status to apply for federal grants.

“If we pool our populations and pool our resources, we have a better chance of getting the larger grants,” Zeuner said.

For more information, contact Nikki Zeuner, Family Support Services Coordinator, at 505-534-0248.



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Something newsworthy going on in your part of rural America? Send a one-paragraph summary to the editor at: editor@raconline.org.

Research Roundup

by Thomas D. Rowley

The Informal Economy and Microenterprise in the United States

E. T. Malm, The Aspen Institute, *Field Forum*, Issue 14, March 2003

This report by the Aspen Institute's Microenterprise Fund for Innovation, Effectiveness, Learning, and Dissemination (FIELD) defines and describes the informal economy in the United States, identifies the experiences of and key issues for microenterprise practitioners, and lays out additional research to be conducted.

While it is difficult to measure, the data that exist show that the informal economy in the United States is "surprisingly large"—ranging from 15 to 25 percent of GNP.

Because of this difficulty and because informal work takes various forms, the easiest way to define it is to identify its characteristics: it is legal but unregulated, uses cash as the most common medium of exchange, has mostly unreported income or wages, and includes both the self-employed and those employed by others.

Participants in the informal economy include men and women, poor and non-poor, immigrants, and people with lower levels of education. Most are concentrated in certain industries and occupations such as non-precision manufacturing, electronic assembly, furniture manufacturing, auto repair, food production and processing, textiles and apparel, hospitality and tourism, domestic service, and construction.

Many informal workers are engaged in microenterprises. Indeed, says the report, the nature of being a microenterprise lends itself to operating in the informal economy. The report, therefore, looks at the use of microenterprise programs to reach out and assist informal microentrepreneurs and cites several challenges:

- Higher risk—because of their nature, many informal enterprises are difficult to evaluate for credit worthiness and may in fact be higher risk than formal enterprises.
- Higher need—many informal entrepreneurs need help with everything from banking and budgeting to tax flow analysis.
- Lower trust—there is a fear among entrepreneurs of exposing themselves to "the system".
- Lack of legal documentation—without proper documents, programs can be hard-pressed to provide assistance to informal entrepreneurs.

According to the report, "A big challenge may be identifying the types of products and services that might make better sense for these entrepreneurs, or finding ways to work on larger constraints to their more public participation in the formal economy."

Available at http://www.fieldus.org/publications/Field_Forum14.pdf.

The Mobility Needs of Older Americans: Implications for Transportation Reauthorization

Sandra Rosenbloom, Transportation Reform Series, Brookings Institution Center on Urban and Metropolitan Policy, July 2003

By 2030, the number of older Americans will more than double from today's 35 million. Yet, this unprecedented demographic shift and its impact on transportation needs has received little attention in public policy discussions. This policy brief discusses how an aging society adds to a range of transportation problems as "all but the most fortunate seniors will confront an array of medical and other constraints on their mobility even as they continue to seek an active community life." It also discusses special approaches and solutions necessary to meet the mobility needs of over 70 million seniors in the coming decades.

While the report does not focus on rural issues per se, rural elders—increasing in number—face even more transportation challenges than their urban counterparts. The report, therefore, should be of interest to rural readers.

According to the report, most older people lead active lives and depend on the convenience and flexibility of private cars. Because of this, the elderly "exacerbate several societal problems, even as they may disproportionately suffer from those problems." Among them: environmental pollution and energy consumption, metropolitan decentralization, congestion, and safety.

As for legislative and policy solutions to these problems, the author calls for planning explicitly for the mobility needs of the elderly, targeting public transit services and facilities directly for them, supporting alternative transport options, and improving the highway and street infrastructure. The rationale for doing so goes beyond concern for the elderly: “Solving the needs of such a large and growing segment of the population is integral to answering several of the transportation challenges facing society.”

Available at http://www.brookings.edu/es/urban/publications/20030807_Rosenbloom.pdf.

Assisted Living in Rural America: Results from a National Survey

C. Hawes, C. Phillips, S. Holan, and M. Sherman, Southwest Rural Health Research Center, Texas A&M University, August 2003

Assisted living has emerged as the fastest growing form of senior housing and a new model for providing long-term care that is more responsive to consumer preference. Its availability in rural areas, where alternatives are few, is important.

This paper describes the assisted living industry in urban and rural areas. Its findings include:

- Assisted living is largely a private-pay form of long-term care.
- Assisted living facilities (ALFs) are less prevalent in rural areas

than urban—about 25 percent of all ALFs are located in rural areas.

- Rural ALFs are, on average, smaller than those found in urban areas. As a result, rural areas are relatively underserved in terms of ALF beds, with only 15 percent of the nation’s total.
- Rural ALFs differ from urban ones in several key ways: They are less likely to embody the features associated with the philosophy of assisted living, to offer high privacy and high services, and to offer apartments and private accommodations.
- Finally, even though rural ALFs cost less, on average, (\$17,000 per year) the price is not affordable for most rural elders.

“Taken together,” says the report, “these findings suggest assisted living, as currently structured, will make only a marginal contribution to meeting the needs of frail elders living in rural areas.” To expand the supply and better meet needs in rural areas, policymakers “must explicitly focus financing and licensing policies on these objectives.”

Available at <http://www.srph.tamushsc.edu/centers/srhrc/ruralalfpdf.pdf>.

A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country

U.S. Commission on Civil Rights, July 2003

This report, based on a review of the budgets of the six federal agencies

with the largest expenditures on Native American programs and on an extensive literature review, finds that funding for programs to support and protect Native Americans has fallen short of what is needed. This results in higher rates of poverty, poor educational achievement, substandard housing, and higher rates of disease and illness. Native Americans’ conditions, according to the report, receive little attention and constitute a “quiet crisis.” This report is the Commission’s attempt to give voice to that crisis.

Among the findings of the report:

- While federal funding for Native American programs has increased significantly over the last 10 years, the increase has not been enough to compensate for a decline in spending power, nor to “overcome a long and sad history of neglect and discrimination.”
- A large deficit in funding for programs and a backlog of unmet needs exists, which must be corrected.
- Native Americans living on tribal lands do not have access to the same services and programs available to other Americans, even though the government is obligated to provide them.

The report looks at the Departments of Interior, Health and Human Services, Housing and Urban Development, Justice, Education, and Agriculture. It finds that while some agencies are “more proficient at managing funds and

addressing the needs of Native Americans than others, the government's failure is systemic." The report identifies several areas of jurisdictional overlap, inadequate collaboration, and lack of articulation that result in inefficiency, service delay, and wasted resources.

To address the problems, the Commission offers 11 recommendations to yield a thorough and precise calculation of unmet needs in Indian Country, increase efficiency and effectiveness of services, bring funding up to adequate levels, and advance the Indian nations toward independence and self-governance.

Available at <http://www.usccr.gov/pubs/na0703/na0731.pdf>.

GET CONNECTED

For more information on the people, data and sources described in this issue's cover story, you can check the following web sites:

Research and Training Center on Rural Rehabilitation Services, The University of Montana Rural Institute.

<http://rtc.ruralinstitute.umt.edu/>

The Association of Programs for Rural Independent Living

<http://www.april-rural.org/>

Living Well with a Disability Program

<http://www.livingwellweb.com/>

Family to Family Network

<http://www.med.und.nodak.edu/depts/rural/family/>

Ticket to Work

<http://www.yourtickettowork.com/>



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