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Vincent Francisco

University of North Carolina

Craig Ravesloot Ph.D.

University of Montana - Research and Training Center on Disability in Rural Communities

University of Montana Rural Institute

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State of the Science Report

Overview of Rural Health

Vincent Francisco

University of North Carolina

Craig Ravesloot

RTC:Rural, The University of Montana

Ultimately, the challenge of health care reform is the challenge of building community (Shortell et al., 1996).

It makes little sense to discuss health without also discussing environment. Environments may be toxic physical environments due to pollution, noise and crime, or toxic social environments that promote health risk behavior like smoking and sedentary living. Alternatively, environments may be constructed to promote health behavior (e.g., physical activity) or reduce health risks (e.g., indoor smoking policy). In either case, the population's health status is shaped by their environment.

Rural people are less healthy than urban people (Institute of Medicine, 2005). Rural environments have fewer healthcare resources to address health problems and to promote health of rural populations. However, the cause of this disparity goes well beyond access to healthcare, the focus of most rural health researchers and advocates (Bailey, 2010).

The World Health Organization (WHO) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1948). Further, WHO defined and operationalized health promotion during the Ottawa Convention in 1986. From those proceedings:

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being (World Health Organization, 1986).

The University of Montana Rural Institute

RTC

RURAL

Research and Training Center on
Disability in Rural Communities

RTC:Rural
52 Corbin Hall
The University of Montana
Missoula, MT 59812
Toll Free: 888.268.2743
Fax: 406.243.2349
TTY: 406.243.4200
rtc rural@ruralinstitute.umt.edu
rtc.ruralinstitute.umt.edu
Alternative formats available

These documents indicate the global community has understood the far reaching inputs and impacts of health status for the world's population for well over 25 if not over 60 years. Further, the role of social and physical environments that promote good health status have been described in detail suggesting the current trend in the US toward community-based interventions is woefully behind other countries with regard to population health. For example, the US ranks 28th in life expectancy despite spending more money per capita on healthcare than any other nation (National Research Council, 2011). Given these figures it is no surprise that very little of the \$2.6 trillion annually allocated to healthcare is spent on health promotion (Centers for Medicare & Medicaid Services, 2012).

It is true that medical researchers have made tremendous contributions in treating diseases. Yet, as better treatments emerge, they present us with the ethical question of how to make such treatments available to meet the standards of a just society. That challenge is particularly pronounced for those populations with economic challenges and those populations living in sparsely populated, remote rural areas. Still, even when medical service providers patch together a system to deliver medical care, we are no closer to achieving better population health. Instead, we need policies that improve “the [rural healthcare] system as it affects rural interests” (Mueller, 2010).

While improving access to and the delivery of medical services is a worthy goal, finding ways to promote and maintain health remains a challenge. In this case, focusing on health encompasses medicine but expands our view to include more than delivering treatment, which increases our options for action. Further, focusing on health has particular advantages for addressing rural issues which are brought together through an ecological model of health.

Using such a model shines a light on the numerous pathways to promoting and

maintaining the health of entire populations. The purpose of this paper is to examine rural health and disability looking through the ecological lens to examine the relationship between rural environments and the health of rural people with disabilities. This paper encompasses 1) rural health ecology; 2) a multi-level ecological model for addressing the health needs of rural people with disabilities; 3) rural health and disability topics, working from the rural health ecological model; 4) two case examples: a program that demonstrated community level interventions for rural populations, and a program that adapted and implemented a health promotion program for rural people with disabilities; and 5) recommendations to improve the health of rural people with disabilities.

The Ecology of Rural Health

Health outcomes are best understood within an ecological, multi-level model. Ecological models have raised awareness of the many determinants of health, including individual factors, environmental factors, and social determinants of health (Howard, Nieuwenhuijsen, & Saleeby, 2008; The World Health Organization, 1986). With less physical and social infrastructure (e.g., public transportation) rural individuals must be resilient to meet challenges to their health status. Figure 1 presents an ecological model of rural health that shows how features of the environment interact with features of the individual to produce health outcomes. Individual vulnerabilities in a harsh environment produce the worst health. The best health outcomes are observed when robust or resilient individuals are in abundant environments. Unfortunately, since most rural environments are not abundant, it is incumbent upon rural residents to manage preventable health problems. It follows that health status for these individuals is potentially more dependent on individual level characteristics than it would be for their urban counterparts. Even so, we are mistaken if we believe these health outcomes are independent of environmental factors. An ecological model of health suggests the

rural environment has a substantial impact on health outcomes via multiple pathways. For example, much of the rural health literature focuses on direct effects of geography on health outcomes by way of factors like healthcare access. Similarly, rural residents are at greater risk for injury due to inherent dangers in rural occupations (e.g., farming, logging, and fishing) and distances traveled (i.e., greater risk of motor vehicle accidents; National Rural Health Association, 2012). Beyond these direct effects, emerging evidence suggests the pathways between the rural landscape and health are often indirect (Bailey, 2010). Indirect pathways are expressed at the individual level via socio demographic and health risk and health protective factors.

Individual Level Health Effects

Poverty. Rural residents are poorer than their urban counterparts (Bailey, 2010). Like healthcare, economic opportunities are distributed across the landscape and in many areas are simply less available than in urban areas. Health status for both rural and urban dwellers is directly related to socioeconomic status (SES). In fact, several studies conducted in Western developed countries have demonstrated there is little variation in health status between urban and rural groups when controlling for the variability due to socioeconomic status (Auchincloss & Hadden, 2002; Bailey, 2010; House, Lepkowski, Williams et al., 2000).

Minority status. Highly related to SES is membership in racial and ethnic minority groups (e.g., Black, Hispanic, Native American). These groups are poorer and have worse health than members of the majority culture. With 17% of rural residents representing minority groups, a portion of the health burden observed among rural residents is accounted for by the nexus of race and SES (National Rural Health Association, 2012).

Health Risk and Protective Behaviors. Health risk behavior differences between urban and rural residents are well documented

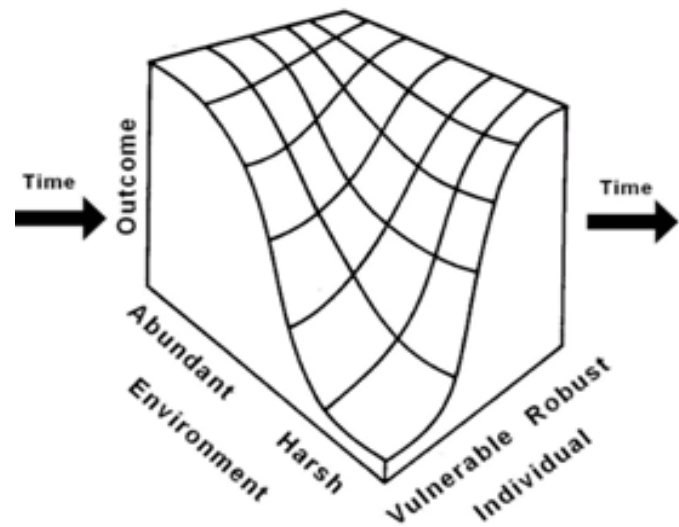


Figure 1 :Ecological Model of Rural Health

(Bailey, 2010; Institute of Medicine, 2005). For example, rural residents are more likely to smoke, be obese, and be sedentary (Institute of Medicine, 2005; Ramsey & Glenn, 2002). Hence, in addition to the risks due to SES and poor access to healthcare services, rural residents are more likely to put their health at risk via lifestyle choices. However, even these “personal behavior choices” are not independent of the social environment, which heavily influences individuals.

Rural Health Access

Obtaining safe, effective, timely healthcare in rural areas has many challenges (Institute of Medicine, 2005) including access to quality primary, specialty, and hospital care (Stamm, Lambert, Piland, & Speck, 2007). For example, half of the Idaho population lives at least 66 miles from the closest tertiary hospital (Stamm et al., 2003). Emergency response times for rural incidents are nearly double those of urban (13.6 minutes vs. 7 minutes) with transport times more than double in rural areas (17.2 vs. 8.2 minutes). When response times go beyond 30 minutes, the risk of death increases 7-fold (Grossman et al., 1997). Many rural counties are designated either as healthcare professional shortage areas or as medically under served, further complicating the problems posed by distance (Gaston et al., 2000). Unfortunately, even when care is reached, the practitioner’s scope of practice is often stretched beyond that of the urban

counterpart (Weeks, Yano, & Rubenstein, 2002).

Technology. Health information technology (HIT) is becoming an important part of the rural healthcare environment. When medical practices adopt HIT, including electronic medical records (EMR), healthcare quality improves. Unfortunately, as of 2006, adoption remained low with only 36 percent of critical access and 41 percent of rural hospitals reporting adoption of an EMR. In fact, adoption of EMR is 1.5 times greater in urban than rural areas (McCullough, Casey, & Moscovice, 2009).

Telehealth is an efficient modality for getting specialized medical and health information to rural providers, but even today it is not widely used by rural providers (Institute of Medicine, 2005). Problems related to rural infrastructure, staff training, and reimbursement are often cited as reasons for low adoption. At the same time, a study of telemedicine funding found 362 projects in the US of which two-thirds were in urban areas (Institute of Medicine, 2005). This seems backward given the need, but may reflect the desires of many rural communities. Telehealth may negatively impact the health of rural populations when it supplants local community resources capable of promoting health status of local residents. Instead, strategies that integrate telehealth into community health planning are needed so the best possible healthcare system is available locally.

Public Health Approaches to Resolving Rural Health Issues

In light of the health issues noted above, public health promotion strategies developed in response to complex social and behavioral phenomena in communities offer a promising approach to resolution. Treatment alone cannot resolve these health issues in the broader population, and many of the issues encompass more than the focused treatment of health delivery systems. A common thread for these strategies includes behavioral,

biological, and environmental components that can be modified through the collective effort of community members who are directly or indirectly affected by these problems (Miller, Reed, & Francisco, in press). This collective effort can be facilitated or held back by structural issues such as the extent to which agencies include the broader community in decision-making (Reed, Miller, & Francisco, in press), the availability of community health information relating to the problems experienced by the target population (Smedley & Syme, 2000), and prior history and success with collective action (Zimmerman, 2000). Minkler, Wallerstein, and Wilson (2008, p. 293) developed a heuristic that organizes most-effective strategies into strength and need based approaches, and into consensus and conflict organizing approaches. While it is not known how effective these community-based approaches are, relative to the need, it is clear that building strengths and addressing needs are important. Problem identification, consensus building, community assessment, and conflict organizing are also important. Ultimately, to affect broader conditions that create the context for health problems, we need to work on issues such as empowerment of marginalized individuals and groups, social capital, and collective action. These approaches need to be relevant to complex communities whether they are large or small, but a number of these issues are even more pronounced and impactful in rural areas.

Synergy of Efforts and Syndemics

Efforts to resolve health issues can affect multiple outcomes, even though the primary goal of the collective action might be very narrow. An area of focus in public health is the intersection of multiple epidemics, or syndemics (Milstein, Horner, & Hirsch, 2010). Some evidence suggests that syndemics may be useful framework in health outcomes that more directly result from human behavior such as drug and alcohol use among teens, teen pregnancy, and assaultive violence. The overlap of risk factors for these conditions is significant, and reducing risks (or enhancing protection) is believed to improve a variety of

situations at the same time. This is (in part) what is behind the development of asset-based efforts (Benson, Leffert, Scales, & Blythe, 2012).

Hindering an understanding of these efforts is a paucity of data systems in rural and low population urban areas. Several national efforts have been launched (e.g., Epi Work Groups) to deal with this issue, but it remains the case nationwide that little data is available for decision making around health issues for the general population, and even less for those with physical disabilities. This lack of data for health decision making at the population level is the result of several situations including poor sampling strategies and no infrastructure locally or at the state level for basic understanding of needs and capacities. The majority of health delivery and health improvement systems are not organized to facilitate health promotion, or primary and secondary prevention (IOM, 2002a).

Also hindering these efforts is the lack of adequate conceptualization of solutions that span the life of the persons experiencing the problem. This can be partially improved through the use of more current approaches in public health. Recent re-conceptualizations of socio-ecologic behavioral models (e.g., Bronfenbrenner, 1979) for public health outcomes (McLeroy et al., 1988; Stokols, 1996; McLeroy et al., 2008) can help provide an overall framework for solutions that span the range of contexts in which we experience health, and the range of possible solutions across the life span. The current emphasis on broader community improvement is the focus of the new Public Health, but the history of Public Health is to provide direct service in rural (and low population urban) areas. The ability to use these broader socio-ecologic approaches has direct implications for people with disabilities. If we don't emphasize (or focus directly on) the disability, but improve the context for success more broadly, we could have improvements that span multiple generations. The emphasis here is on systems

improvement rather than just individual programs.

Public health has moved toward a greater emphasis on systems change and community engagement with the advent of reports such as the *Future of the Public's Health in the 21st Century* (IOM, 2002a), and the even more seminal *Who will keep the Public Healthy in the 21st Century* (IOM, 2002b). These reports called for more systems and participatory approaches to public health improvement. Public Health hoped to improve data systems and feedback mechanisms from systems thinking and systems dynamics fields (Midgley, 2006), and also hoped to improve the built environment and implications for behavior and health through systems modeling and lessons learned (Milstein, Homer, & Hirsch, 2010). A variety of evidence and opportunities are emerging from participatory approaches including action planning for systems improvement (Fawcett et al., 2000), action research (Argyris, 1989), Participatory Action Research (George, Daniel, & Green, 2006), Community Based Participatory Research (Minkler & Wallerstein, 2003), Empowerment Evaluation (Fetterman & Wandersman, 2005) and other community approaches.

Systems Improvement for Health Outcomes

Community-based organizations, governmental agencies, and community partnerships oftentimes attempt to affect youth health and development, community development, and public health outcomes for either population-based health or more proximal individual health improvement; they confront the daunting task of building largely voluntary organizations (including informal groups) to tackle some of society's most complex problems that cannot be addressed within any one organization. The determinants of health outcomes at the individual and broader community are multiple and interconnected and include contributing factors from genetics, the social environment, the physical environment, behavior, and healthcare.

Solutions can come from more comprehensive and strategic, community-based efforts that reflect an understanding of the concerns, behaviors, assets, and environment of local people, yet support for engaging in these efforts and understanding these challenges is often inadequate. Promising conditions for success may include the following:

- 1) a targeted vision and mission;
- 2) charismatic and distributed leadership;
- 3) a strategic action plan that articulates environmental (e.g., social and physical) changes to be sought;
- 4) documentation of efforts to facilitate community and systems change, and performance feedback on progress toward that goal;
- 5) proactive and responsive technical assistance; and
- 6) an intermediate and more distant outcomes that matter to grant makers and stakeholders (Fawcett, Francisco, Paine-Andrews et al., 2000; Roussos & Fawcett, 2000).

Unfortunately, such conditions for supporting the work of community partnerships and systems of healthcare are rare. In particular, there is limited support for bringing about intermediate outcomes (i.e., systems change) and for understanding whether local efforts to bring about such change are associated with improvement in more distant outcomes. Documenting the efforts and accomplishments of community initiatives is vital for any attempt to address community health issues such as relieving disparities in health outcomes, but it is often done only for reporting and reimbursement purposes, rather than for building community capacity to understand and solve problems (Fawcett, Paine-Andrews et al., 1996; Fawcett, Francisco, Hyra et al., 2000).

Documentation of systems change (e.g., new or modified programs, policies, and practices) can enable community decision makers to see the unfolding of intermediate outcomes and to make mid-course corrections in long-term efforts (Fawcett, Paine et al., 1993; Francisco

et al., 1993), can provide information for grant makers and for status reports, and can provide the ability to track the results of mobilization efforts to improve health in the community. Supplemental information, such as the location in the community where change is taking place and who is involved, can enhance its function in making adjustments in the work. As with other behaviors, documentation is more likely when it is made easier and more rewarding. Making the information readily available will increase its utility to community members. By enhancing ease of access through an on-line system, we can remove one of the greatest barriers to entering and using data along community and systems change (Schultz et al., 2000).

In complex adaptive systems, where attribution of cause and effect is difficult, an analysis of the contribution of the initiatives can benefit from documenting how community and systems change (an intermediate outcome) move distant outcomes (e.g., access). Linking systems changes brought about by a local community initiative to health improvements (e.g. for diabetes, HIV/AIDS) provides information to the organization that can help direct its efforts. Using this method, community leadership can better understand the contribution of strategies they are using to address particular health goals and whether they are targeting the sectors of the community that can help make a difference. Communities will be able to examine whether their pattern of systems change is associated with improvements in health (Fawcett, Lewis et al., 1997).

A vision of a successful systems improvement initiative that promotes primary and secondary prevention among people with disabilities in rural areas includes three broad elements. One of these elements might be for organizations and families in communities to work together to make a difference through the development of systems of care for intensive health needs of specific youth. Another might be for the development of networks to facilitate learning with (and building capacity among)

those involved in the delivery of health services for persons with physical disabilities, and to facilitate systems change more broadly to create a context of success in health improvement and living healthy lives. A third might be to enhance the work of strategic partners engaged in social change at the local and state levels to support and promote success.

Rural Health and Disability

Rural residents with disabilities reported many of the same types of difficulties accessing health care as described by nondisabled rural residents in the literature, but often with a special twist reflecting particular sensory or physical impairments and persons' long experiences with the health care system (Iezzoni, Killeen & O'Day, 2006).

Rural Individuals with Disabilities

Having a potentially disabling impairment (e.g., paralysis) does not preclude having good health (Krahn, Putnam, Drum, & Powers, 2006; Lollar, 2008). Epidemiological data clearly indicates that the proportion of people with disabilities that experience poor health status is simply greater for people with impairments than for the general population. For example, people with mobility limitations report a higher prevalence for eight of the top 10 health conditions ranked by incidence when compared to people without limitations (Rasch, Magder, Hochberg, Magaziner, & Altman, 2008). One useful framework for understanding this difference has been the "secondary condition" framework (Marge, 1988). Secondary conditions are medical, social emotional, family, or community problems that a person with a primary disabling condition likely experiences (U.S. Department of Health and Human Services, 1991). In this framework, poorer health status of people with disabilities is a function of their increased risk for secondary conditions.

Rural residents with disabilities report experiencing 14 secondary conditions

annually that limit their participation in daily activities (Seekins, 1991). Some of these are medical conditions like pressure ulcers or urinary tract infections. Others are mental health conditions like depression and anxiety, while still others like chronic pain and fatigue often represent a combination of physical and mental health conditions. Evidence suggests that rural residents with disabilities have higher rates of depression, pain, and the overall burden of secondary conditions (Seekins, 1991). The burden of secondary conditions evident among rural people with disabilities is associated with poorer quality of life. For example, 75.1% of 208 rural Medicaid beneficiaries with disabilities randomly selected in two states reported ongoing pain, and the severity of their pain was positively associated with depression (Ravesloot, 2004). In a separate study, people with disabilities reported an average of 9.4 days when pain made usual activities difficult, 9.8 days when their physical health was not good, and 8.5 days when their mental health was not good (Ravesloot, Seekins, & White, 2005). These results suggest that maintaining health is a significant challenge for people with disabilities.

An important aspect of the secondary condition framework is malleability and prevention (Ravesloot, Seekins, & Walsh, 1997). Individuals with disabilities can modify the risk and course of secondary conditions with behavior that promotes general health (Pope & Tarlov, 1991; Ravesloot et al., 2005; Ravesloot et al., 2007). Hence, while people with disabilities may have a narrower margin of health (i.e., increased risk for secondary conditions; Pope & Tarlov, 1991), they are able to improve their health status. However, disabled people not only have the same health risk and protective factors as the general population (e.g., smoking, lack of physical activity, diet). They are also prone to social isolation, low education, and unemployment, further complicating health improvement (U.S. Department of Health and Human Services, 1999).

Despite these social determinants of health disadvantages, people with disabilities are capable of changing their health risk profile and improving their health status. For example, evaluation of the *Living Well with a Disability (LWD)* program demonstrated that urban and rural program participants who experience a wide range of disabling conditions reported less limitation due to secondary conditions, improvements in health related quality of life, and reductions in healthcare costs following the intervention (Pope & Tarlov, 1991; Ravesloot et al., 2005; Ravesloot et al., 2007). Similarly, health improvement has been reported in impairment specific health promotion intervention studies including arthritis,¹ post-polio,² multiple sclerosis,³ stroke,⁴ spinal cord injury,⁵ and developmental disabilities.⁶

The Rural Environment and Disability

Not surprisingly, rural healthcare access problems are exacerbated by disability issues (Iezzoni, Killeen, & O'Day, 2006). Because many people with disabilities do not drive, distance barriers are intensified such that specialty care available only in large urban areas is functionally unavailable to many rural residents with disabilities. Echoing broader rural healthcare concerns, rural people with disabilities report problems finding knowledgeable providers who will accept Medicaid reimbursement. Additionally, because rural care providers often work in older facilities, basic access to healthcare facilities for people with mobility impairments is often lacking (Iezzoni et al., 2006). These problems are monumental for people with disabilities who, as noted above, require more medical services to maintain their health status and quality of life.

1 Crotty et al., 2009; Lorig, Lubeck, Kraines, Seleznick, & Holman, 1985

2 Agre, 1995; Stanghelle & Festvag, 1997

3 Motl & McAuley, 2009; Motl et al., 2010; Stuifbergen, 1997

4 Battersby et al., 2009; Chen & Rimmer, 2011

5 Elliott & Kennedy, 2004; Ipsen, Ravesloot, Seekins, & Seninger, 2006; Ljungberg, Kroll, Libin, & Gordon, 2011; Perry, Nicholas, & Middleton, 2010; Zemper et al., 2003

6 Marks, Sisirak, & Heller, 2010

Beyond the direct effects of healthcare access on health, access to opportunities for community participation vis à vis employment, education, and community engagement may play a role in the health of people with disabilities. The International Classification of Functioning, Disability and Health (World Health Organization, 2001) suggests participation may have reciprocal effects on body functions and impairment status. Additionally, there is some evidence that concepts like “sense of coherence,” which is anchored in a sense of meaningfulness,⁷ is related to the health status of people with disabilities⁸ by their sense of control and coping ability,⁹ occupational outcomes,¹⁰ and quality of life.¹¹ These findings suggest a potential mechanism for the poorer health status of rural people with disabilities based on features of rural environments that limit participation (i.e., fewer opportunities for community participation).

Case Example #1:

Study of Promoting Systems

Improvement for Children and Youth with Special Health Care Needs

Innovative Approaches (IA), an initiative of the North Carolina Division of Public Health, was designed to improve the health of children and youth with special health care needs (CYSHCN) through local systems of care that are family centered, coordinated, and sustainable. The initiative, rather than a program, was created with the intent to build local teams to identify gaps and duplication in the system of services provided to CYSHNC and their families and to provide a coordinated/family centered approach to care that improves the health and well-

7 Antonovsky, 1987

8 Johansson, Ytterberg, Hillert, Holmqvist, & von Koch, 2008; Ravesloot, Seekins, & Young, 1998; Ravesloot, 1995; Ristner, Anderson, Johansson, Johansson, & Ponzer, 2000

9 Lustig, Rosenthal, Strauser, & Haynes, 2000; Lustig, 2005; Kaiser, Mattsson, Marklund, & Wimo, 2006

10 Kaiser et al., 2006

11 Germano, Misajon, & Cummins, 2001

being of CYSHCN. The approach developed was anticipated to be an adjunct to existing programs and services. Anticipated outcomes included increased satisfaction among the youth and families involved in the initiative (when compared to previous approaches and to other approaches) and improved outcomes for youth with special health care needs.

The primary goals of this initiative were

- 1) to foster and support community strategies to create effective systems of care for families of CYSHCN,
- 2) to identify these promising practices, and then
- 3) to help disseminate these practices to other communities.

Within the context of Innovative Approaches, the aim was to facilitate the development of improved logic models and action plans for service delivery and systems improvement as a means to improve the context for implementation, and to focus the systems of care on achieving the health outcomes most valued by them. In addition to improving the health delivery systems directly, an emphasis was placed on two other important areas. One area was the involvement of parents and families in the decision making around the specific systems improvement objectives, and the embedment of families in the decision making processes of service agencies. Another area included the facilitation of systems improvement in the broader context. Not only do families in rural areas have issues of getting access to care, they also have issues in basic quality of life that affect health outcomes.

An important focus was to provide technical assistance and training on skills related to local project development, leadership, and collaboration that would improve the sustainability and capacity of the local implementation teams. Initial “getting to know you” activities with the grantees and local implementations teams provided an overall assessment of capacities and experience relevant to the implementation of the effort.

The assessment activities helped to develop an overview of experience and capacity to implement the initiative, the initial project logic models to guide implementation, and a sense of the available data and data systems and the additional data needed to support the initiatives as they unfolded. Developing an approach with the State DPH and the local implementation teams to identify and address systems changes across relevant channels of influence was important. Action planning can be very generative of creating a healthier environment overall, and was essential to the long term sustainability and institutionalization of the effort. Finally, developing an integrated and collaborative evaluation approach that had regular sense-making activities (monthly, quarterly and annually, as appropriate to the data and needs) was critical to the success of the initiative. The evaluation included the documentation of service delivery, systems change, resources generated, critical events, lessons learned, and health outcomes achieved.

Accomplishments from Client Engagement

Coordinators in the four counties that participated in this initiative involved parents and families, rather than solely service providers, in setting the goals and objectives for what was needed to allow them to be successful and healthy. Many of the service providers and government agencies felt that the establishment of a medical home model, the adoption of electronic medical records, and the establishment of a mechanism for improved communications among providers would resolve most of the issues related to youth with special health care needs and their families. The families had a different perspective. Their issues included transportation, respite care, assistance with keeping track of appointments with service providers, assistance in navigating the health care delivery systems, and general knowledge of what might be available to assist in these areas. These issues transcended rural and urban populations, even within the same county. At the state level, issues included the

need for improved funding coordination for services, improved capacity building support for governmental agencies and service providers to support diverse families with many language and cultural needs beyond their experiences in the US, and improved data systems to understand the level of need and whether their investments were making a difference.

After nearly three years of implementation of this systems improvement approach, the community partnerships were able to bring about 123 systems changes. These systems changes were broadly categorized as new or modified programs, policies, and practices. Some were very small in scope, and others were wide-reaching policy changes that were difficult to establish. All four counties established referral and support agency databases that were more accessible to the families. They succeeded in disseminating awareness-building events and materials through the medical providers and other service providers, as well as establishing awareness events at county fairs, health fairs, and common events within their school systems. Communication improved specifically between the schools and parents of youth with special health care needs.

Transportation remains one of the top priorities, especially in the most rural county, but one county succeeded in establishing an on-call bus system using vans from transportation companies and churches that had significant down time. Another county managed to improve the relationship between parents and the school district by getting the school district to allow other parents who were serving in the role of lay client advocates to be present during IEP meetings. In yet another county, parents who were inspired by the needs discussed in a town hall meeting developed a new company to provide respite services, parent and youth advocacy, and transportation services. This company is being run by and for families with children who have special health care needs, and shows every sign of continued success. In

addition, all six pediatrician offices in one county adopted the Medical Home model and an electronic medical records system that is shared between them and the area hospital. In all, systems changes were accomplished in eight sectors of the community including the schools, medical providers, transportation, governmental agencies, and social service agencies.

Case Example #2:

Disability and Health Promotion in Rural, South Carolina

The gap between research and practice is a central limitation in rural health promotion practice. Researchers develop most health promotion interventions in efficacy studies that use narrowly defined methods to control for threats to internal validity. Intervention effectiveness studies that address threats to external validity, a common knowledge translation problem, are far less common. Rural environments pose specific challenges to knowledge translation and the external validity of evidence-based health promotion interventions. For example, treatment fidelity may be affected by distance to training resources and identification of qualified personnel. Reach and adoption of programs may suffer from recruitment problems due to small target populations.

We employed research methods in the KT process to solicit input from community stakeholders (e.g., consumers, human service agency staff) to adapt and evaluate the *Living Well with a Disability* program in rural South Carolina. Partnering with disAbility Resource Center in Charleston, SC the research team facilitated this PAR strategy in a rural SC community. The goal was to develop a structured approach to adapting an evidence-based health promotion program to fit the local rural context and to evaluate the effectiveness of those adaptations.

Over the course of two years, the project unfolded in four overlapping phases. The first phase was an introductory phase. The CIL

staff began to meet with community leaders to introduce the CIL staff to members of the disability community who were clients of the local Disabilities Services Board (DSB) and received services and support in a day treatment center. Through this introductory process, it became clear that the DSB had the consumers who were most motivated to adapt and implement the *LWD* program in this small community.

The second phase included getting to know one another. An essential feature of this phase was introducing community members to independent living (IL) philosophy through presentations and actions. The actions were occasioned by hiring two of the DSB clients to serve as community liaisons for the project. These two gentlemen set meetings with other community members to describe the *LWD* program and to invite them to a community meeting.

The community meeting was held in the local library and included 26 community members. The CIL director led a discussion of the community's experiences in relating to both barriers and community supports for the disability community. Individuals shared stories. For example, a county councilman who has a son with disabilities shared experiences with problems and barriers his son encountered in the school system. The magistrate (a former high school principal) also spoke from an educator's perspective about students with disabilities in the school system. A few individuals related their experiences of living in a rural community where transportation, employment, lack of accommodations, and accessibility are common barriers. The CIL director asked for volunteers that would be willing to become part of a community advisory council; approximately half of the group indicated an interest in serving as an advisor.

Next, 10 consumers of the DSB attended a statewide independent living conference where they met IL leaders and attended sessions about independent living and the

Living Well program. The second phase concluded with local community members travelling to the CIL 90 minutes away to participate in a disability awareness dinner hosted by the DRC. Overall, this phase introduced DSB consumers and community members to independent living philosophy and services. The *LWD* program was used to highlight this content and was used as a vehicle to introduce these concepts to the community.

The third phase involved establishing a working group to make curriculum adaptations, to organize logistics for the training, and to implement the curriculum with consumers. Four community members from the DSB, CIL staff, and a local social worker met weekly to review the curriculum, make adaptations, implement, and review effectiveness. This phase included implementing the revised curriculum with DSB clients. A total of 16 adults from the DSB participated in the *LWD* implementation, which was co-facilitated by the DSB consumers hired to implement and adapt the curriculum.

The fourth and final phase involved facilitating self-assessment of program effectiveness and goals achieved during program implementation. A picnic to honor program participants was attended by DSB clients and staff (e.g., executive director, program specialist), CIL staff, and local service providers (VR counselor, case manager). This meeting highlighted both individual and systems changes within the DSB. Namely, individuals achieved personal goals like getting a driver's license and health related goals like getting more exercise. This progress was paralleled by changes within the DSB that increased client empowerment and program level health behavior (e.g., improved nutrition). The executive director made public commitments to increase options for independent living in the community for DSB clients.

Follow-up with the DRC indicated the program materials were used beyond the initial

program period and commitments made were honored. One DSB consumer moved into his own apartment and participated with other DRC staff and clients in the “Medicaid Matters” rally in Washington, DC, June 2010.

This case example highlights how inclusion and participation of consumers can enhance individual behavior and system behavior that promotes health of community members. One theme evident during follow-up was surprise among DSB staff and local service providers that DSB clients could set and work toward health and IL goals. Inclusion of DSB clients in the development of the program structure and materials was a key to the program’s success. These clients became leaders and advocates within the DSB community holding staff and other community members accountable for supporting goal pursuit among DSB members.

Conclusion

People with disabilities face substantial challenges to maintaining health status. With fewer economic and other social resources to draw on, they are at a distinct disadvantage for health behavior change and healthcare access despite their greater needs for support. Consequently, behavioral syndemics emerge that put these individuals at risk for significant secondary conditions that require even greater access to specialty medical care. Novel solutions to these complex health problems that affect all rural people can emerge through a community systems approach. Organizing across public and private health sectors to create opportunities for community participation including health promotion holds promise for addressing these substantial problems and for meeting the needs of people with disabilities.

In summary, we have examined the ecology of rural health and disability highlighting multilevel issues that impact the health of rural people with disabilities. Individuals are both responsible for their health and highly influenced by the environment in which they live. As long as community participation

in rural communities is limited by physical, economic, and social structures, the health of people with disabilities will be at risk. However, community interventions that level the playing field for all community members will encourage both individual and community level behavior that improves health for all people.

Recommendations

- 1) Include disability screening questions and county of residence on all health related national data collection efforts to allow analysis of health status between the general population, people with disabilities, and rural people with disabilities.
- 2) Conduct epidemiological research that examines the relationship between rural residence, community participation, and health outcomes for people with disabilities.
- 3) Train rural healthcare providers to provide Self-Management Support by networking with community health resources including health promotion and disease prevention activities.
- 4) Conduct demonstration projects of community level health planning that involve people with disabilities using participatory research methods.

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For additional information please contact:

Research and Training Center on Disability in Rural Communities; The University of Montana Rural Institute; 52 Corbin Hall, Missoula, MT 59812-7056; 888-268-2743 or 406-243-4562; 406-243-4200 (TTY); 406-243-2349 (Fax); rtcrural@ruralinstitute.umt.edu; <http://rtc.ruralinstitute.umt.edu>

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