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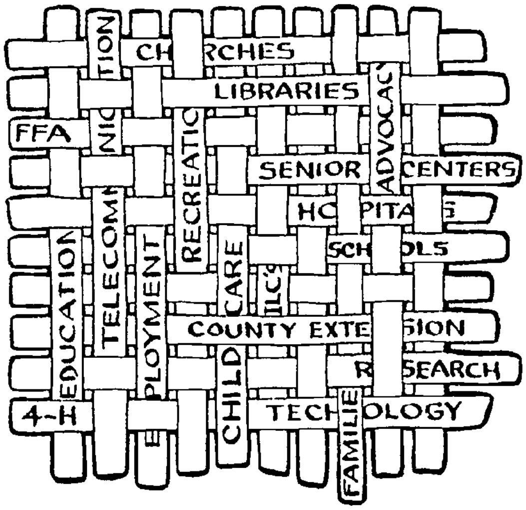
ABSTRACT

This proceedings contains presentations, workshop summaries, program profiles, and other highlights of a conference on rural disability issues. The major conference theme was the normalcy of having a disability. A plenary discussion developed a list of 17 rural community disability priorities. Keynote speeches were: (1) "Rural Economies and Disability" (Dennis O'Donnell); (2) "Building Strong Inclusive Community through Servant Leadership" (Bob Jahner); and (3) "Community Development and Advocacy" (Jim DeJong). Workshops focused on strategies to use naturally occurring rural assets. Nine workshops are summarized, covering integration of health care with rural service delivery, child care and community inclusion for young children, vocational rehabilitation, aging in rural areas, issues in rural independent living, developing local support groups for rural independent living, parenting education to prevent child abuse and preserve families, community development and advocacy, and community and human development in the rural context. Five facilitators synthesized a blueprint for action that focuses on making personal connections between the disabled and nondisabled in the community and building support from diverse community groups. A final section summarizes a preconference forum "Choosing Inclusion: Consumer-Driven Supported Employment." Forum workshops covered diversified funding strategies, training and technical assistance for supported employment, and cross-cultural services for American Indians with disabilities. Six programs receiving awards for "best practices in rural independent living" are profiled. (SV)

Proceedings

COMMON THREADS '93

Equitable Solutions ... because disability is a natural part of human experience.



A National Conference on Rural Disability Issues
Montana University Affiliated Rural Institue on Disabilities
The University of Montana, Missoula, Montana
September 10-13, 1993

COMMON THREADS '93

Proceedings of the 1993 Common Threads Conference

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Sponsored by the
Montana University Affiliated Rural Institute on Disabilities
The University of Montana, Missoula, Montana

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Rural Institue on Disabilities

The Montana University Affiliated Rural Institute on Disabilities (Rural Institute) is an interdisciplinary, university-sponsored organization that promotes the full participation in rural life of individuals of all ages with disabilities by developing and disseminating innovations in teaching, research, community services and policy advocacy.

In 1978, the federal Administration on Developmental Disabilities (ADD) acknowledged the need for a University Affiliated Program in Montana. ADD granted funding and the Rural Institute began operation on the University of Montana campus in 1979. The Research and Training Center on Rural Rehabilitation Services (RTC:Rural) was established within the Rural Institute in 1987, with funds from the U.S. Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). Throughout its history, the Rural Institute has clarified its mission, steadily increased the number of its programs and expanded the scope of its activities to a national scale.

The Rural Institute conducts service, training, technical assistance, research and information dissemination activities which:

- help people with disabilities in rural areas access quality social and educational services and health care,
- increase the quantity and quality of disability service professionals and providers in rural settings,
- discover and develop state-of-the-art approaches to meet the challenges of living with a disability in rural areas, and
- provide information about rural issues to the public and professionals.

The ultimate aim of the Rural Institute on Disabilities is to improve the independence, productivity and community integration of rural Americans with disabilities.

Table of Contents

■ Common Threads '93 ■
Equitable solutions ... because disability is a natural part of human experience.

Common Threads Plenary Discussion

Common Threads Keynote Speeches

6

Common Threads Workshops

6 A

Common Threads Action Session

■ Choosing Inclusion ■
Consumer-Driven Supported Employment Forum

Choosing Inclusion Keynote Speech

Choosing Inclusion Forum Workshops

■ 1993 Best Practices ■ In Rural Independent Living Awards

Acronyms

ADA	Americans with Disabilities Act of 1990
ADD	Administration on Developmental Disabilities
APSE	Association for Persons in Supported Employment
ARC	Association for Retarded Citizens
BNG	Breaking New Ground
CFI	Center for Independence
CHOISE	Community-Hosted Options in Supported Employment
EMC	Eastern Montana College
HASL	Handicap Awareness and Support League
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
ILC	Independent Living Center
IRWE	Impairment-Related Work Expense
ITP	Individual Transition Plans
JTPA	Job Training Partnership Act
MAF	Medical Assistance Facility
MSED-I	Montana Supported Employment Development Project
MSED-II	Montana Supported Employment Demonstration Project
MonTECH	Montana's Assistive Technology-Related Assistance Program for People with Disabilities

NIDRR	U.S. Department of Education, National Institute on Disability and Rehabilitation Research
O-PACT	Opportunities for Parents and Children Together
ORI	Opportunity Resources Inc. of Missoula
PASS	Plan to Achieve Self-Sufficiency
RFP	Request for Proposal
RTC:Rural	Research and Training Center on Rural Rehabilitation Services
SET NET	Interactive Satellite Link System from Virginia Commonwealth University
SIL	Services for Independent Living
VR	Vocational Rehabilitation

Introduction

In most countries that provide social services to their citizens, the systems spring from the philosophy that everyone needs help at some point with something. Because everyone has received, does receive or will receive some kind of state-sponsored care, no stigma adheres to the process. Only in the United States does the need for assistance carry with it a negative connotation.

Perhaps because of our often quarrelsome history of so-called rugged individualism and the desire to be free of anyone telling us what to do, those of us who find ourselves needing services tend to be encouraged by the system to think of ourselves as unsuccessful or, at the very least, different — certainly not normal. Our system also encourages fragmentation of both effort and purpose by creating individual programs for individual disabilities, by building separate bureaucracies for work-related needs, home-related needs, educational needs. And with each of these programs and bureaucracies comes a separate pot of money which, since each pot is never deep enough for its purpose, is viewed by other programs and bureaucracies with an eye to figuring out a way to dip into it, thus saving money in one's own pot.

While such internecine struggles may benefit individual agencies, both consumers and society lose by the process — consumers because we are not acknowledged as whole people but as parts, and society because we foot the bill and get less in return than we should expect for our money.

At the Rural Institute on Disabilities, based at The University of Montana, we have chosen to emphasize our commonalities and to celebrate those similarities by sharing our successes and failures, problems and solutions, at an annual conference called Common Threads. The theme for this year's conference, our third — for which you now hold the proceedings in your hands, was "Equitable Solutions ... because disability is a natural part of the human experience." These words were taken from language in the 1992 amendments to the Rehabilitation Act, language which for the first time acknowledges in law that having a disability is normal.

At the societal level, this is revolutionary stuff! If having a disability is normal, then we are all — disabled and non-disabled — in this together. If we are all in this together, however, we must begin to wonder why we allow ourselves to be separated from each other. Why do we allow the existence of such things as specialized housing boards and specialized transportation systems?

What we know already is that modifications designed to make life accessible to people with disabilities also improve the quality of life for people without disabilities. Curb cuts designed to aid wheelchair users, for instance, make life better for parents pushing strollers and for kids riding bicycles. According to the President's Committee on Employment of People with Disabilities, when given a choice between steps and a ramp, 80 percent of people without physical disabilities choose to use the ramp.

Because receiving an appropriate education used to be difficult, often impossible, for children with disabilities, the Individual Education Plan (IEP) was devised. However, if all parents were given the option of choosing to have an IEP in place for their child without having to accept a disability label for the child along with it, it would be the rare parent who wouldn't leap at the chance. With luck and timing, maybe someday it will happen.

Additionally, if we are all in this together, we have the right to receive care but the responsibility to give care as well. One of the enduring images taken away by participants at the Common Threads '93 conference will be Jim DeJong's description of filling sandbags last summer from his wheelchair by the levee to use in his community's battle to hold back the floodwaters inundating the Midwest. That's what being a participant in life is; it's more than being a taker. We need to make ourselves more visible in just such ways.

A second problem we face in the disability community is society's reluctance, and our own, to face squarely the reality that disability is a **poverty** issue. Most of the issues related to disability are directly related to poverty: accessible housing, reliable transportation, well-trained personal care assistants who stick around, technology that opens the world to us. The social service system in the United States is set up to "fix" individuals, but we can't solve poverty by working on individuals. We have to think bigger.

At the institute's Research and Training Center on Rural Rehabilitation Services we have been working to link disability issues, economic development issues, health-access issues and employment issues in a way that makes their commonalities more easily evident. One of the ways we disperse our findings and gain new insight is at the Common Threads gatherings.

This year we brought in economist Dennis O'Donnell to discuss the impact of disabilities on rural economies. Bob Jahner spoke about his philosophy of "servant leadership" and its role in building inclusive communities. Jim DeJong inspired us to become more visible and successful advocates. Jay McLaughlin made us understand that consumer-driven employment strategies lead to consumer-driven lives. Each of their keynote addresses is included in these proceedings, as are summaries of what went on in the various small-group sessions covering health, children, vocational rehabilitation, aging, independent living, assistive technology, community and economic development and more.

No one gets to come to Common Threads and be a spectator — we can't afford to waste resources that way. Everyone who attends contributes his or her expertise and perspective and takes away ideas to try (or to avoid trying) back home. If you were there, these proceedings will jog your memory. If you weren't, you missed a great time and we hope you come next year!

Common Threads Plenary Discussion

RURAL COMMUNITY DISABILITY PRIORITIES

Plenary Discussion, September 11, 1993

Round-table discussion groups proposed the following priorities. Those mentioned most frequently are listed first:

- **Employment**
- **Housing** should be available, accessible and affordable. Mortgage money should be available and affordable. People with disabilities need to infiltrate the housing industry.
- "Good ol' boy" networks make **participation in community decision-making** difficult. Identify **key gatekeepers**. People with disabilities need to be more involved in **community decision-making and advocacy** activities. Sit on those boards of directors! Integrate the rural community through **coalition-building**. However, remember that the energy needed for **survival** often prohibits community involvement.
- **Attitudinal barriers** need to be overcome by disability awareness activities.
- **Fragmented service delivery** — agencies need to see "the big picture" and work toward **specific common goals** through **interagency cooperation**. Establish a single point of intake.
- People with disabilities need **personal assistance services** and access to **health care**.
- Rural areas lack basic services. **Fill in the service gaps**. **Create a demand for culturally sensitive, consumer-driven services**.
- Human services **need to be considered as an economic force**. Share resources with **economic development** and special interest groups.
- **Volunteerism**: people with disabilities are a community resource.
- **Transportation**, especially for health care services, should be available and accessible.
  Longer-term vehicle loans for accessible vans ease current cash flow problems.
  Contract for services with community members.
  Pool school buses and agency vans.
  Mandate that all state vehicles be accessible.

- Recruitment, training and retention of professionals.
- Video link-ups and other communication technology.
- Recreational activities.
- Funding is unstable and too competitive.
- Professional attitudes encourage dependency.
- Isolation — independent rural attitudes make it difficult to ask for help.
- Funding for, and awareness of the need for, community accessibility modifications.

Common Threads Keynote Speeches

RURAL ECONOMIES AND DISABILITY

Dennis O'Donnell
Mansfield Professor of Modern Asian Affairs
The Maureen and Mike Mansfield Center
The University of Montana, Missoula, Montana

Interdependency

The rural economy is viewed as peripheral, secondary, out of sight and out of mind in the larger economy, much as people with disabilities as workers and citizens are viewed in the rural community. Both the rural economy and people with disabilities are part of the human experience. Both the rural economy and the disability community in rural areas can benefit from a recognition that they are here to stay, are mutually interdependent, and that potential exists for improvement if mutual interests are recognized. These common threads need explicit definition and the pattern of interaction requires a weave that generates a positive sum in order for the disability community to prosper in the turbulent times facing rural America.

A recognition of the link between economic development and the options available to people with disabilities in the rural context go beyond a simple realization that some people with disabilities need jobs and that a healthy economy is preferable to a weak one. The recognition must go the very core of stability for the support system for people with disabilities in all aspects of their lives, from employment to long-term health care and rehabilitation to living conditions and the quality of life. People with disabilities are stakeholders in the efficiency, diversity, stability and broad statement of interests characterizing the communities they live in.

The Rural Economy

The rural economy today is what remains of a once dominant sector after the transition of the United States into a post-industrial power fighting on terms no longer structurally defined in its favor in an increasingly complex international economy. This means that the rural economy will no longer have the luxury of being a preserve of historical values subsidized by an urban society emergent from rural beginnings. The modern urban society is looking toward a competitive world wide struggle in which U.S. rural values and output are very small factors in survival and a collective rural memory is absent.

Today's economy has been characterized by Richard J. Barnet of the Institute for Policy Studies as one in which "The problem is starkly simple: an astonishingly large and increasing number of human beings are not needed or wanted to make the goods or to provide the services that the paying customers of the world can afford. Since most people in the world depend on having a job just to eat, the unemployed, the unemployable, the underemployed and the 'subemployed' — a term used to describe those work part-time but need to work full-time, or who earn wages that are too low to support a minimum standard of living, have neither the money nor the state of mind to keep the global mass-consumption system humming." The rural economy has a disproportionate share of these marginal workers and, by a significant margin, the rural worker with a disability is the least advantaged of all. In Gary Burtless' world we see "a future of lousy jobs" in which the problem is systemic, with the lousy jobs being the end product of economic isolation and noncompetitive levels of savings and investment in the rural sector over the past decades. This is not to say that, for example, agriculture is not productive; it is to say that it does not create jobs. This means that the economic base underpinning all aspects of disability support systems are weakening with the decline of rural America.

Guarantees and Realities

Recent developments that may seem to hold out hope for people with disabilities in an economic sense — for example, the American Disabilities Act — have a moral imperative but may have disappointing results, especially in rural settings. Of primary import in this context is the effect on costs of ADA compliance and the ability to simply not hire in situations in which cost avoidance comes primarily through substitution of capital for labor. Secondly, given scale economies in urban areas relative to rural areas, compliance costs may disproportionately affect investment and job growth in the rural sector. These same phenomena have led to disappointing results in attaining the economic goals of civil rights and EEO legislation. The goals are no less noble for being hard to achieve, but strategies must be developed to cope with adaptations to the cost implications and the economic realities of those factors not within the scope of the legislation. Specifically, ADA provides no jobs nor a guarantee of economic growth.

On the health care side of the equation facing people with disabilities in rural America, the weak rural economy is again the backdrop for the outcome of the sweeping health care reform package sure to come out of the Clinton administration. The goals provide signs of hope, with guaranteed coverage providing financial access for rural people with disabilities to health care chief among the benefits defined so far. However, despite overcoming the financial risks facing people with disabilities, the more self-employed, smaller business community and the smaller population in the rural areas, the reform legislation will not guarantee that providers of health and vocational care will reside in the rural community. The overall economic health of the rural community and the ability of the rural community to be a cost-effective provider of health care will have the most significant effects on whether health care for rural people, and people with disabilities in particular, actually occurs in the rural community where people now live. Given the size of the health care sector of the economy, the health of rural economies may be linked in part to rural residents' ability to keep health care providers and services a vital part of their local communities.

Strategic Commitment

Recent research in which I participated suggests a point of view that may be useful in thinking about the dilemma of people with disabilities in rural communities with fragile economies. In Planning Small Town America we discovered that taking the community as given and planning from the practical realities of place and existing commitments led to insights and potential efficiencies that were not possible through more typical "best case" or "utopian" planning. We recognized that often infrastructure of small towns was underused. Sometimes infrastructure was underused because it was built in anticipation of growth that failed to materialize or because of local economic decline. High costs were then due in part to excess capacity and in part to the fact that new location decisions around the town outside the service areas of the infrastructure were not efficient for the best interests of the global community. For example, impact fees that were designed to pay costs drove people out of the community into fringe areas and prevented the alleviation of the underuse problem and the potential unit-cost reduction of community services. Compartmentalized thinking about individual services such as fire and water and sewer needs led to a failure to keep the overall cost of public services to an achievable minimum. The implications were that this compartmentalization had a negative influence on economic development and jobs and also yielded inefficiency and higher taxes in small towns. We developed "committed lands analysis" to analyze these effects. The approach emphasizes developing infrastructure efficiency on a system-wide basis in a community, and making sure that planning supports this integrated approach so that options are created from cost savings and synergy rather than from growth or factors outside the communities' control.

A look at the broad range of disability services provided in rural America indicates a significant pattern of compartmentalized services along functional lines with varying degrees of internal interaction and weak linkages to economic development efforts in those same communities. In the economic development aspect of the problem we find the following: The independent living centers need a robust economy but are not part of the system that creates one. Vocational Rehabilitation uses job placement as an end goal of therapy but is not part of the planning system creating jobs. All the public services related to people with disabilities need a strong tax base but are not found as part of the economic development efforts to strengthen the tax base. On the efficiency side of the question, disability services in rural communities are often high cost due to lack of integration with other, complementary services and/or due to a pattern of excess capacity and low use in some subsectors of the service system. Compartmentalization often arises from the rural application of standard urban patterns of specialization, in which scale economies are available and inefficiency may come from overburdening the system — not from excess capacity, as we find in the rural setting.

The factors listed above suggest that people with disabilities in rural areas and the system supporting them are making the best of a situation they do not play a role in controlling or in setting the agenda for.

Taking stock would not, however, suggest that people with disabilities or their support systems take on the job of fixing the secular decline of the rural economy or of fixing the health care and Vocational Rehabilitation system as a way of alleviating the situation. Strategic thinking would recognize that solutions in this "new world order" are not found in grand schemes. Taking this as given, one might take some aspect of the phrase "think globally, act locally" and adapt it to the problems facing people with disabilities in rural areas. Committed Lands thinking does just this by acknowledging that the starting point takes the world as a given and out of local control, looks first at local efficiency as a principle goal and deals with local problems system-wide rather than piecemeal.

Economic Development Starts at Home

Many rural communities and virtually every economic development body has at one time or another in recent times sought the elusive quick fix of new business or government location as the antidote to declining economic fortunes or as the answer to the need for revitalization. Some notable successes have been achieved, but many places have either failed at great expense or gained a marginal business location at great cost in terms of expensive inducements and/or giveaways that ultimately have negative social and tax-base effects that are often underestimated at the time. People with disabilities and social services are frequently not helped, and sometimes damaged, by the diversion of services and tax dollars toward new location incentives. The basic philosophy of seeking outside fixes to local economic deficiencies is not unsound, just high risk and potentially very expensive. In any case, one might find the decision by a quality business to locate in a community has more to do with the quality and efficiency of the community and its labor force, infrastructure, health and vocational rehabilitation system, and the derivative quality of life and community spirit, than it does with tax breaks or development incentives. Recognizing this suggests that economic development can begin locally through the effort to improve the quality and efficiency of the community in an experimental and locally integrative fashion. This is the primary way to induce new location, and even if this fails to draw new business, you have a better, more efficient community to live and work in and, thus, significant benefits from your efforts.

The experimental approach implies working on creating new, locally based approaches to generating indigenous growth. The emphasis on location from the outside or export-oriented growth belies the fact that growth ultimately comes from innovation, specialization and cost reduction. Obviously, for the world as a whole, new locations or export-led growth are not possible at this time. This lesson can apply to sub-units such as a rural community. If the existing structure of the community is generating stagnant growth, the needs of people with disabilities may become linked to new structures. The development of non-profits, use of tax-increment districts and consolidation of public services with the goal of reduced costs from an application of the principles of appropriate technology may be examples of ways to generate indigenous growth through a reorganization of local resources.

Rural people with disabilities can find a place in a newly restructured system that uses excess capacity, lowers cost and creates an innovative local attitude toward change.

The emphasis on cost reduction as a growth stimulus can be illustrated very clearly when the example of the Medical Assistance Facility (MAF) is examined. This experimental approach to rural health care illustrates many features of the approach implied above.

The MAF is a limited-service hospital located in communities with populations of less than 1,000 in "frontier" areas (defined as counties with less than six people per square mile). The MAF provides in-patient care that is primary rather than specialized for periods not to exceed 96 hours. The MAF uses the administrative and diagnostic analysis capacity of larger hospitals through communication links, thus allowing lower costs and an expanded role for non-physicians and innovative staffing arrangements. In all of the demonstration sites in rural Montana the MAF is linked to a nursing home, further consolidating primary care and long-term care. The Health Care Financing Administration has arranged a waiver system so that Medicare reimbursement can occur on a cost basis.

In the context of our discussion, the MAF is symbolic of what can be done to solve many problems of people with disabilities, rural communities and the need for economic development in one effort. The concept can provide health care and could be extended to include vocational and rehabilitation components at reduced costs. The concept retains economic activity in the rural area and allows for people to remain in the community both to serve and be served by this health care provider. The concept matches the need for services with the ability of the community to support the supply of health care services at an appropriate level of expertise and cost. The Office of the Inspector General finds that no loss of quality is suffered by the community. In this example, the innovative MAF concept turns health care needs in the rural community into a vehicle for retaining, at efficient cost, economic activity within the community. It is clear that people with disabilities would have a stake in this type of economic development activity.

Committed People

People with disabilities and the service system that provides for their special needs must get involved in the economic development process explicitly and in a way that is part of consensus-building for the rural community. The innovation and change suggested by a model of indigenous growth described here is threatening and disruptive in a stagnant rural community. Such an effort led by people with disabilities and the system supporting their special needs may be even more threatening. The perception exists that this group is traditionally very expensive to serve and thus burdensome to a stagnant or poor community. Disarming this perception requires broad-based effort to build consensus around shared interests of all parties in the community-building effort. To the extent that people with disabilities and their advocates can demonstrate that meeting their needs and employment goals can lead to lower costs, new economic structures and a more internally stable and attractive community, much can be done to change perceptions.

In his recent book Breaking the Impasse: Consensual Approaches to Resolving Disputes, Lawrence Susskind, MIT professor of Urban and Environmental Planning, speaks to the process of consensus building in ways that are instructive to a community of people who are initially disenfranchised and located in an isolated environment. Susskind identifies six key characteristics of consensus building that need to be woven into the process of getting commitment from people to join together in common goals. First, consensus building is a supplement to representative democracy. Second, it operates informally. Third, it must represent all parties with an interest in the outcome. Fourth, it is assisted conversation, often using facilitators. Fifth, the system is ad hoc; the parties invent the rules. Finally, it is consensus-seeking, ending without a vote when the parties agree they have done everything they can to address the concerns of each of the stakeholding groups present.

Conclusion

Once achieved, a consensus forms a broad-based group of committed people working toward mutually interactive goals. To the extent that people with disabilities and their advocates are part of such a process fostering local economic development in rural communities, they will find their needs integral to new economic structures in the community. They no longer will be cast in the role of an added cost but as part of the system in which growth potential comes from commitments they have made to community efficiency and local diversification of the economic system. The existence of committed people, including people with disabilities and their constituents, is a form of community infrastructure just as important as the schools, the roads or the water system. This public asset is part of the common thread that makes the community fabric hold together and support the quality of life for everyone in a small rural community. Communities such as this concept envisions can survive and rekindle the rural values we see vanishing. One of those values was inclusion, in which people with disabilities were integral parts of the community.

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BUILDING STRONG INCLUSIVE COMMUNITY THROUGH SERVANT LEADERSHIP

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This paper traces and reviews the developmental language of this age of supported employment, the Americans with Disabilities Act (ADA) of 1990 and the 1992 Rehabilitation Act Amendments. It is a derivation of a previously prepared retreat and was given to groups of people who are committed to leadership in the vocation of rehabilitation. The retreat was designed to assist members of vocational rehabilitation (VR) agencies, private non-profits and associations examine their own developmental experience in community settings and relate those experiences to our common profession of vocational rehabilitation. Servant leadership is one articulation of the unique challenges, values and responsibilities of public service in a democratic society.

The Servant Leader

The servant leader is distinguished by the skill of entering into relationships with individuals or communities to:

- inspire vision;
- enlist commitment to a mission; and
- serve the larger vision.

> In our African language we say "a person is a person through other persons." I would not know how to be a human at all except I learned this from other human beings. We are made for a delicate network of relationships of interdependence. We are meant to complement each other. All kinds of things go horribly wrong when we break that fundamental law of our being.
>
> **Bishop Desmond TuTu**

> True integration will be achieved by true neighbors who are willingly obedient to unenforceable obligations.
>
> **Martin Luther King**

The Power of Language and Modeling the Model of Health

This paper seeks to address the challenges of professionals whose work is to facilitate the process by which people who have experienced traumatic loss find their way into community. These pages contain assumptions meant for our consideration as we explore our experience with growth and community. We are required to act as leaders by virtue of our profession. In our work our most important asset is our awareness of the wealth of developmental experience we carry in memory from our own growth in the communities that have included or excluded us.

Any discussion of community must begin with the power of language. Language is a shared symbolic system that we use to extend unarticulated personal experience into the realm of interpersonal relationship and into public expression. It is our first "power" tool. Powerful words can affect a person's health for better or worse. Some contend that words can heal or cure. Our language and how it initially described that configuration of values called vocation is critical in this difficult profession of intervention. The words of our first communities, schools, playgrounds, churches and intimate relationships are the language upon which the servant leader seeks to find common ground with people of diverse experience and background.

The common-ground language created by the leader establishes a new capacity in communities for compassionate experience. Compassionate experience occurs when individuals have had the same feelings and emotions arise from a shared experience. It is the most basic building block for the formation of relationships and for political expression. Commonality of experience serves as linkage between individuals and discrete communities. When two people have no conscious awareness of either common ground or compassionate experience, there is no basis for human relationship. Common language is the first building block of inclusive community.

PART I: The Nature of Natural Supports: Discerning Relationship

A Model of Health Leadership Declaration:

> We believe in inclusiveness. Inclusiveness is the ability to include people who are strangers to us in community activities. Including people who are strangers is more valued than excluding them. Inclusiveness is a value, a vision and a commitment. It is not necessarily a spontaneous feeling.

Integral to servant leadership is the leader's skill and capacity to enter into relationships with individuals and communities. To succeed in leadership one must have the capacity to discern the developmental process of community and to discern the range of relationships that occur in it. It is a premise of this paper that the process of community is exclusive as well as inclusive. Which of those two tendencies predominates depends a great deal on the values declared by the leadership and subscribed to through the community's living model of health.

To create a framework for discussing the "process" of community we will propose a developmental model that recognizes two levels of community: the nurturance community and the vocational community.

Nurturance Community: This community is composed of relationships that are initially and primarily one-to-one, and very often set in youth or crisis. We live in a nurturance community all of our lives and this community is not bound by place or time. A central role of the nurturance community is the development of a capacity for intrinsic authority within the individual and the preparation of that individual for the expression of authority in vocational community. The relationships of nurturance community are part of a lifelong process and they are usually described in terms of friendship, family and, frequently in this last decade, support group. This community is the source of personal authority (empowerment). Transition, grief and gain are processed in this community. Without a nurturance community, a person is incapable of personal authority (empowerment) or participation in vocational community.

Vocational Community: This community consists of a network of relationships associated with one's public expression of inclination, gift and work. This level of community is productive and expressive. It links and articulates the diverse compassionate experiences of nurturance community into public consensus. A role of vocational community is to be the vehicle by which the individual moves the internal authority of the nurturance community into public expression. Vocational communities are the basis for strong, participatory democracy.

PART II: The Nurturance Community:
The Authorization of the Individual for Relationship

A Model of Health Leadership Declaration:

> We believe in the intrinsic authority of the individual. Empowerment is an attempt to explain the movement of authority from an extrinsic source to an intrinsic seat. The exercise of power from an intrinsic authority is more valued than the exercise of power from an extrinsic source.

If "inclusive community" is a choice and commitment rather than a fact of nature, those in leadership must decide if they will use the power of vocational community to subordinate the entire community under a predetermined model of health or to harvest the natural authority of a community to facilitate the articulation of a consensus model of health. The servant leader's skill accomplishes the latter through the inspiration of the public's intrinsic authority.

Authority, whether it resides within us or is conferred upon us from an external source, is our grounds for acting. It is our grounds for exercising power, but it is not, in itself, power. When you authorize a person to do something, you lay down a locus of control in which a person or a group of people can: 1. make decisions without conferring, 2. experience the consequences of the decision and 3. respond without fear of retribution.

In a time when it is popular to promote the dignity of risk, we need to keep in mind that the "dignity" side of dignity of risk is possible only when the risks of a situation are not viewed by the author of the action as overwhelming. Dignity is possible when a person's capacity to trust all possible outcomes is stronger than the natural anxiety of a strange situation. This seems to be the case for both the relationships of nurturance community as well as the more abstract situations in vocational community.

The relationships of the nurturance community lay the ground for risk-taking, which in turn is the basis for all vocational expression. The nurturance relationships establish a sense of safety and trust. They are distinguished by a lack of conditionality (though never entirely unconditional). Our mistakes or failures in the conditional power communities of vocation are forgiven in nurturance community. The consequences of vocational mistakes may be painful, but we are assured by our nurturance community that they will not be fatal in a psychological or physical sense. These relationships are our laboratory for forming identity, experimenting with relating to other people and expressing identity and value. They are our safety net of performance. Dignity of risk is possible only when the nurturance community is in place for an individual. Without nurturance community, performance failure in vocational community takes on life-or-death proportions. Even in adult life, we sustain a nurturance network which is the safety net for adult transitions.

Issues of safety are as valid for the larger community as they are for the vulnerable individual. One of the challenges of leadership is to inspire trust and safety in the community being served. The leader must know how and when to nurture the inspiration of community vision, while being available to assume vocational roles of power and conditionality in the implementation of the vision. Being able to discern the different roles allows the leader to avoid betrayal of either role. The basic trust factor defines the capacity of a person's community for inclusiveness. Fear plays in the opposite direction. As individuals, our own nurturance community has contributed over time to our potential for trust, authority, relationship and, ultimately, inclusiveness.

PART III: The Loss of Community:
When Traumatic Experience Makes You a Stranger in a Familiar Land

A Model of Health Leadership Declaration:

> Personal loss and gain are inseparable tools in the formation of personal identity. People experience losses every day — some large and some small. A person's acknowledgement of loss and gain with community is essential to successful transitions from birth through death. The model does not encourage the acceptance of loss (disability) as much as it encourages the conscious and communal acknowledgment of loss so that a person can form the next stage of identity. Acceptance comes when an acceptable vision of the future is formed around the acknowledged loss. Acceptance is accommodated vocation.

Whenever we as individuals experience something to which no one else can relate, we become strangers. After a point, our strangeness estranges us from our familiar community. The experience of disability can be so estranging that the only possibility for the re-formation of community is with other people with disabilities who have compassionate experience. The total loss of community (alienation) for an individual is psychological death, not long to be followed by physical death.

Whether it be a fact of nature or a cultural tendency, the leader must contend with society's tendency to exclude all those people whose behavior or appearance takes on characteristics that are unfamiliar to the mainstream nurturance and vocational community. People who experience trauma are isolated for periods of time from daily life. Extended isolation can result in progressive marginalization leading to a terminal point of alienation. Leadership in this era is recognizing the critical role of vocational community in incubating the experience of inclusiveness. Inclusiveness is a mainstream outcome. Consumers who have experienced the marginalization are forming their own nurturance communities out of which they can exercise the authority of their unique experience to re-enter mainstream vocational communities. The vehicle for re-integration is the association or support group. These "triage communities" form around the experiences of catastrophe to help the survivors form compassionate communities. These communities create the nurturance level of community out of which an authority can be articulated by the members. This articulated authority becomes expressed in the vocational community as political expression. Our model of health expresses a commitment to fostering the authority and power of these associations committed to the reintegration of their members.

PART IV: The Inspirational Leader: The Responsibility of Authority and Power and the Leadership Declaration

The Model of Health Leadership Declaration:

> The servant leader declares vocation openly to the public as an articulation of commitment to specific values. To the degree the authority of the declaration finds a response from the community at large, there is potential for personal, organizational and social change toward the values articulated in the declaration. The servant leader's role is to facilitate the formulation of the mission statement in the common language of the vocational and compassionate communities subscribing to the declaration.

The mission statement is explicit language declaring the responsibility of behavior to authority. A mission statement is a commitment that can be measured in terms of behavior. The slow work of this form of leadership requires the careful incorporation of the individual's experiences and authority into the larger group. This is achieved primarily by creating the opportunity for people to tell the stories of their lives in relationship to the leadership declaration. When this work occurs, the individual forms a relationship with the larger group and invests his or her authority into that group. Each person's authority enhances and alters the vision of the group. With this public relationship comes the inevitable commitment to respond to the demands of the values. In facilitating the declaration of responsibility, the leader brings into reality the mission statement. The authority of the vocational community, as a public entity, and all of the private individuals within are invested in the mission statement. The essential importance of this form of leadership is that the commitments of responsibility are mutual. **The participants in the movement arrive at their personal sense of responsibility based on stories told publicly in their own words, and then rendered into consensus by taking into account a larger set of community concerns.**

This model presumes the expression of vocation as a primary process and the expression of need to be secondary. Without a focused sense of vocation, we can not clearly define need. The needs of a group of people who commit themselves to inclusive community will be very much different from the needs of a group committed to exclusivity. The leadership assists in creating the model from which the sense of need is derived. The leadership declaration serves the purpose of expressing commitment to the authority of a value system. It serves as a focus for anyone whose sense of vocation or vision is similar, but not necessarily as articulated. Coming into relationship with a leader, and through that relationship being able to articulate more clearly one's own vocation, it then becomes possible to define need. The independent living and supported employment movements declared inclusion, integration and consumer-centered services as the central "calling" or vocation of rehabilitation. Since hearing those declarations, vocational communities across the nation in the form of agencies, corporations, support groups, etc. have responded to the authority of those words by formulating mission statements around those central values. This leadership's articulation will assist people in their own articulation of experience. When the individual's experience is incorporated into the articulation of the larger community, we achieve consensus. When the consensus is rendered into explicit commitments to respond, we have consensus and responsibility. This is the strongest expression of the democratic model of government.

PART V: Serving the Larger Vision: The Administration of Rehabilitation

The hospitality of listening
The coaches of language and expression
The administrators of responsive system

The Model of Health Leadership Declaration:

> When we as individuals declare our personal authority and then express our needs relative to that authority, we are engaged in the expression of our private lives. When the public sector seeks the assistance of the community members, the hospitality rules of the community must prevail to assure the private dignity of the community members. When the individual community member wishes to participate in the public resource, within the context of private dignity assured all people under our Constitution, that person becomes responsible for expressing vocation and need.

An organization's level of commitment to servant leadership can be measured in terms of hospitality. In the "servant" dimension of the servant leader definition, the leader serves the larger vision by becoming subordinate to the authority of the community. Vocation (vision) and mission are dynamic. Leadership recognizes that the action of community means the continuous articulation of value and the subsequent performance of responsibilities. Rehabilitation issues span the border of nurturance and vocational community. In order for consumers to drive the programs, the rules of hospitality of both communities must be taken into account when developing the service agency's strategic planning process. The first challenge of administration (ad Ministrar; to serve) is the creation of hospitality space appropriate to the community. The protocol of the vocational world is usually very explicit. The protocol of the nurturance community is usually contained in what we call "manners" or "rules of hospitality." When a leader makes a leadership declaration that affects the authority of the nurturance community, the servant leader enters into relationship with that community under the hospitality rules of that community. The leader is then stating a willingness to subordinate to the community's manners for the purpose of creating a future.

A democratic community's values are articulated and institutionalized through statute, regulation and rules. The role of supervision is accountability of behavior to law. The role of administration is distinguished from supervision in that it serves to allow members of the community to move compassionate experience to articulation, consensus and, if necessary, law and accountability. The public service system exists to facilitate the community's responsibility to continually express the authority of its own experience in law and rule.

The irony of the public system is that it can be as enlightened only as the public that hands it its instructions. If strong and inclusive community is indeed the value of our profession, the task is to declare that value in a compelling manner, and to live in a model inclusive community so that our friends and neighbors are inspired to move the consensus of inclusiveness to an ever-broader level of public mandate.

GLOSSARY

I found myself using terminology with some license and felt it only fair to the reader that I offer a comparison of my usage with the standard we all run to: the dictionary. I have written the formal definitions in bold and then below my version of the word's meaning as it is used in this document.

Bob Jahner

Alienation:

A withdrawing or separation of a person or his/her affections from an object or position of former attachment ... isolation or exile from the values of one's society.
The separation of an individual from the community process; a terminal state of exile from nurturance and vocational community.

Authority:

A conclusive statement or set of statements; a decision taken as a precedent.
Capacity of the individual to act in a conclusive, committed fashion to a set of values. "Authorization" is permission to act responsibly out of internal authority without fear of retribution in the form of artificial consequences.

Articulate:

To utter distinctly; to give clear and effective utterance (utter: to send forth as sound).

To apply symbol or language to states of feeling and emotion for purpose of relationship.

Community:

A unified body of individuals; a people of common interests living in a particular area.

A process by which the private person:

1. develops personal, conscious identity; and
2. responsibly expresses that identity as vocation in the context of public authority.

Intervention:

Coming between by way of hindrance, interfering by using force in another's internal affairs.

The use of power from extrinsic authority to separate a person from his or her intrinsic authority.

Power:

Possession of control, authority or influence over others; the ability to act or produce an effect.

Conscious access to tools to express internal authority in vocational community. (Tool: any effective symbolic or concrete instrument available for conscious manipulation.)

Responsibility:

Liable to be called on to answer as the primary cause, motive or agent.

A commitment to act over time in a predictable manner in response to an articulated value system.

Story:

To narrate an account; pictures adorning windows of medieval building.

A vivid narration of events spoken in the primary language of the community conveyed with either implicit or explicit purpose.

Trust:

Assured reliance on the character, ability, strength or truth of someone or something; to be confident.

The ability to act without conscious consideration.

Value:

A fair return or equivalent for something exchanged. To estimate or assign worth.

That on which we consistently confer worth through behavior and expression.

Vocation:

A summons or strong inclination to a particular state or course of action.

The expression of authority in community.

COMMUNITY DEVELOPMENT AND ADVOCACY

Jim DeJong
Project Director, The Great Plains ADA Project, University of Missouri at Columbia

On July 26, 1990, President George Bush signed the Americans with Disabilities Act and stated that we would change the landscape of America through the implementation of this historic legislation. America — urban, suburban or rural — has been slow to respond. Although there has been some change, it has been inconsistent and incomplete.

In 1992, Congress reauthorized the Rehabilitation Act. This amended law contains a phrase of paramount importance: "Disability is a natural part of human experience." I contend that the mainstream of American society doesn't yet comprehend this simple, yet profound, statement.

The content and purpose of both laws require a new way of thinking, a realignment of thought for society. The new premise or paradigm is that you can't get to inclusion through exclusion.

To create viable change we must understand that laws and mandates alone will not do the job. We must understand what triggers people to learn and to change their habits and beliefs. Other minority movements have demonstrated this.

First, we must recognize that we live in a diverse society of urban and rural people of many races, with widely varying ethnic backgrounds and economic stations. Religion influences us, sometimes for the better, sometimes not. Historically, these influences often have been divisive, encouraging the rejection of others who may be "different."

Relationships are the single most important component of change. Social interaction creates the opportunity for relationships and, therefore, for change. People of all backgrounds learn and change through the commonality of their experience. If we want to change society and its institutions, we must form relationships within the institutions, within society. We must bring our knowledge and experiences to the communities — our communities — by being involved in their processes. Attend those forum meetings, school board meetings and legislative caucuses. Go to the places in town where people hang out: the cafes of decision-making, the taverns of dialogue and the town squares of debate. To gain support for our issues of access and opportunity, we must first contribute our energy and solutions to ensuring that our communities survive.

This summer, the Flood of '93 brought this point home to us in Missouri. Water is like a good time: it's necessary, but too much of it can be debilitating. As we watched our rivers — the source of our growth — swell and spill over their banks onto farmland and homes, sweeping away lives, we knew we had to get involved.

A St. Louis television news program showed a young man tying up freshly filled sandbags. The bags were then loaded on pallets to build up dikes against the rushing waters threatening his community. The station mentioned that, due to spina bifida, the young man happened to use a wheelchair. Meanwhile, in Hannibal, the historic home of Mark Twain, the Missouri Disability Rights Coalition had gathered to celebrate the anniversary of the ADA. Instead they turned to their community, donating the food and drink for the celebration to people who had just lost their homes to the rising waters. In Columbia, people from the disability community donated food, clothes, blankets, linens and money. In Rocheport, Huntsdale and Hartsburg, others joined the army of volunteers fighting the rising waters. I joined the effort in Hartsburg and at first was met with curiosity — what I could do to help? Many hours and sandbags later, I left with the expressions of gratitude of my co-workers. Clearly, we change attitudes through our actions — better yet, our **interactions** — with our communities. The lessons we learn from disasters need to be applied to everyday life.

When we come to the table of exchange, we must bring our learning, our experiences and our values to create a better place for all. We must expand the community's consciousness to include all of humanity. Get out of the offices and into the streets of our communities, into the local places of interaction and decision-making. Community means interdependence; we need to bring our menu to the table. This conference is called "Common Threads," but perhaps it should be called "Common Breads." As we eat and drink with our fellow citizens, we can change their perceptions.

At the first Common Threads conference I spoke of "POWER" in our community to create change:

P Pride in our profession and in the people we are working to help. Remember, we enter this field, not for the financial rewards, but to make America a better place for all its citizens.

O Outreach to under-represented groups and to potential allies, such as senior citizens.

W Wisdom to understand the society we wish to integrate through participatory, democratic action.

E Energy to attend town meetings and political activities so our presence and views are consistently felt and heard.

R Respect for each another and the unique and individual talents we bring to our political movement. There is more than one good way to influence the political arena.

Today I would add "E = Education" to the description. Our schools are at a critical crossroad. We need to be a part of the solution to the serious, often deadly, conflicts occurring in our schools. It is easier to change a young, growing mind than to have to shift a paradigm of thought later in life. I know there is enough talent in this room and across the country to bring a culture of inclusion and accessibility to our classrooms and communities — **we need to just do it.**

To change the landscape of America, as President Bush predicted, we must interact with America by changing the hearts and souls of our communities. Only then will we have accessibility, acceptance and opportunity. Thank you.

Common Threads Workshops

INTEGRATING HEALTH WITH RURAL SERVICE DELIVERY

Tom Seekins
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Craig Ravesloot
Project Director, Rural Secondary Conditions Prevention and Management Project
Rural Institute on Disabilities, The University of Montana, Missoula, Montana
Mike Mayer
Director, Summit Independent Living Center, Missoula, Montana

Public Health and Disability by Tom Seekins

There are two major sectors in rural health care efforts: 1. **Medical service providers**, whose concerns are improved access to acute and obstetrical care, insurance coverage, rural hospital survival and recruitment/retention of medical personnel. Interest in disability issues is embryonic; and 2. **National, state, and local public health services providers**, with a historical concern for disability issues, especially maternal/child health. Public health now includes the disability prevention movement.

Our longevity and quality of life are largely attributable to public health measures. Public health and independent living philosophies are similar in that both are community-based, stress individual responsibility (consumer control), promote social change (advocacy), link poverty with lowered quality of life and are interested in epidemiology.

The National Council on Disability started the secondary disability prevention movement in the United States. The U.S. Centers for Disease Control originated the study of secondary conditions resulting from existing disabilities.

Public health officials are interested in disability and secondary conditions because the data indicates a need. (See Disability in America: Toward a National Agenda for Prevention, by Pope and Tarlov.) For example:

Disability is the largest public health problem in the United States. Forty-four million U.S. citizens have a chronic illness or permanent impairment. Of these, 11-15 million live in rural areas.

Disability and chronic illness cost $169-176 billion annually, attributable to:

- **Direct costs** (hospital payments, workers' compensation benefits, long-term care, community service providers, etc.) = 51 %
- **Lost productivity** (two-thirds of people with chronic illnesses or disability are unemployed) = 39 %

- Secondary income loss (such as a parent leaving employment to care for a child with a disability) = 11%

If we assume that disabilities are evenly distributed in the U.S., approximately 150,000 Montanans have a chronic illness or permanent impairment. This adds up to $500 million in annual costs:

- Direct: $255 million
- Lost Productivity: $195 million
- Secondary Income Loss: $150 million

On the average, each of us can expect to experience 12.8 years of disability in our lifetimes (men, 11.6 years, and women, 14.1 years).

Most disability is preventable by social or economic methods. The World Health Organization's Nagi Model states that quality of life is a product of biology, environment and lifestyle behavior. Functional limitation may occur when pathology interacts with any of these attributes. **Disability is contingent on a person's location or activity**. An individual who uses a wheelchair has no disability in a meeting where all participants are seated.

From an economic perspective, functional limitation is preventable by accessible homes and communities, assistive technology, disability rights legislation and income. Independent living advocacy activities mesh with public health goals.

From a social perspective, behavior change can prevent some disabilities. For example, gunshot wounds and tobacco use are major causes of death and disability in the U.S. Therefore, public health agencies advocate for gun-control legislation and produce anti-smoking campaigns.

Public health has data, strength and interest in disability issues. It needs more involvement from the disability community. The federal government's goal is a capacity-building project in each state for injury prevention, prevention of birth defects and prevention of secondary conditions. The model can prevent pathology, provide early intervention for children with disabilities and promote supportive environments to reduce functional limitations for people with disabilities.

Secondary Conditions by Craig Ravesloot

Even with full environmental accessibility, there still will be significant functional limitation for some people with disabilities. Our work uses personal intervention to help people be healthy enough to overcome environmental obstacles.

Our project has had a five-year journey. First we defined "secondary conditions." Consumer focus groups listed 40 medical/psychosocial problems, including pain, depression, contractures, weight gain/loss and others, that had caused limitations in addition to their primary disabilities. We developed a survey describing each condition and asked 1,500 people with physical disabilities to rate, on a scale of 0-3, how significantly each condition limited their activity. The 600 responses showed that the average respondent experienced 14 secondary conditions annually!

We started with the notion that primary disabilities have certain associated conditions. For example, we expected spinal cord injury to be associated with urinary tract infections, pressure sores, hypertension and access problems. However, we found that this wasn't true. We made a model of 22 secondary conditions that correlated highly and asked, "What causes this?" Lacking an accurate name, we simply labelled it a "syndrome."

"Health" — what is it? There are many psychosocial answers: "It's the absence of disease; a sense of well-being; the ability to fulfill occupational roles; physical, social and emotional wellness." We found two models in the health promotion literature.

The "sense of coherence" was developed by Aaron Antonovsky in 1987. It states that we live neither in a state of absolute health nor of absolute disease, but along a **continuum**; we can move either way along that continuum. Three beliefs are crucial to health:

1. Life is understandable.
2. Life is manageable.
3. Life is meaningful. (The person controls his/her major activities.)

Martin Seligman developed "learned optimism." He found that people see causes of events in a characteristically optimistic or pessimistic way — their **attribution style**. For example, the optimist who is hired thinks, "I'm best qualified for this job." The pessimist thinks, "They felt sorry for me," or "There probably weren't many applicants." The optimist who isn't hired thinks, "They screwed up when they didn't hire me," or "I had a bad day and didn't interview well." The pessimist thinks, "I'm incompetent," or, "With my disability, I won't work again."

These models relate to secondary conditions and reducing functional limitations. For example, we've traditionally taught people to avoid getting pressure sores by recognizing the signs, positioning correctly and using appropriate equipment. We thought that, if taught, a person would automatically comply. Now we believe that a person's sense of coherence and attribution style set the occasion for his or her response. We may be able to identify people susceptible to secondary conditions, based on their knowledge, sense of coherence and attribution style. Pessimism highly correlates with a high incidence of secondary conditions; optimism correlates with a low incidence.

We wanted to teach people a more positive attribution style and new behavioral strategies. Rehabilitation hospitals don't teach everything consumers need to know about living with a disability, so we are developing a two-month-long, community-based workshop to teach secondary condition risk-reduction. Participants alternate in teacher/student roles, while discovering their strengths and weaknesses.

Our topics include:

- Goal-setting. This helps each person identify important goals and encourages motivation.
- Problem-solving. People who function well in the community are good problem-solvers. Participants identify sources of stress and learn management techniques.
- Attribution style, to teach optimism
- Depression and loss, dealing with changing roles (male/female, breadwinner/homemaker, etc.) and learning interpersonal and family communication skills.

Improvements in these four areas set the occasion for learning secondary-conditions prevention skills:

- Nutrition;
- Behavioral strategies to avoid conditions (i.e. urinary tract infections, pressure sores) that might interfere with achieving goals; and
- Maintenance and community advocacy.

Materials encompassing these goals and skills were developed for use by independent living and public health staff.

The Role of Summit Independent Living Center and Montana Independent Living Project by Mike Mayer

We were contracted to gather consumers to define "secondary conditions" and to develop self-help methods. The self-help strategy complements independent living practices of individual control and peer support.

We wrote a community resource manual for the groups which listed home health agencies, occupational therapists, etc. We helped people develop goals, such as weight loss, and a staff member conducted individual follow-up. A Robert Wood Johnson grant allowed us to continue the workshop model of secondary-conditions prevention and health promotion. First, we educated local YMCA staff on disability issues. Participants with disabilities identified their personal fitness goals, then were integrated into existing YMCA programs. We've had some success, but need to continue our work.

We've developed a rehabilitation-transition program, in cooperation with Community Rehabilitation Center of Missoula, that may help participants avoid developing some secondary conditions. Our three satellite offices in western Montana help people transitioning from rehabilitation find housing, equipment and personal attendant services. Inpatients at Community Medical Center can attend a disability-adjustment group which provides peer support and prepares them for community living. We're integrating nutrition counseling, household and economic management, occupational therapy and other services into our independent living curriculum.

Medicaid optional services are under attack and we're fighting to keep them so people can stay in their communities. Our state is looking at health care reform and a single payer vs. multiple-payer system. As independent living centers begin systems advocacy, programs such as the secondary conditions and health promotion project can provide important individual help.

Discussion: "How does the secondary conditions project address cultural, gender and class differences?"

Tom Seekins: Montana isn't a very diverse state. Native Americans are our largest minority population. There are more than 300 recognized Indian tribes in the U.S. They see disability very differently and often deal with it within their own communities rather than seeking independent living services.

Julie Clay surveyed the reservations and reported that rates of secondary conditions were slightly higher, especially for conditions such as diabetes. One Montana reservation has 49 members with spinal cord injury; another reservation in the same area has none — why is there such a discrepancy?

Craig Ravesloot: Montana Indian Health Service officials are interested in adapting our materials for reservation use. We may provide technical assistance for workshops and then evaluate their effectiveness. Montana has 10 recognized tribes; each will have to adapt the material to its own needs — a good way to operate with minority populations.

CHILD CARE PLUS+: COMMUNITY INCLUSION FOR YOUNG CHILDREN

Kathy Miller Green
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The goal of our program, Educational Home Model Outreach (EHM), is to integrate young children with disabilities into existing child care facilities. This benefits all children and could reduce the need for special education teachers.

Our staff — Sandra Morris, Sarah Mulligan Gordon and me — offer training and technical assistance that enable child-care providers to care for children with medical, physical or developmental disabilities. We offer a one-year training program in localities where groups of child-care providers express interest in integrating children with disabilities into their programs.

There are experiences that no child should be denied. I recall my own childhood; I wouldn't give up the memory of tasting dirt or cattle feed for anything. Every child needs to learn by trying things out.

When adults say, "All they did was play all day," I say, "Great!" Play is a child's job. The workday differs for kids of various ages. For infants, a diaper bag is a briefcase and the day's task is to get things into their mouths. Two-year-olds have more work to do: learn language; grab blocks, toys and food; use a fork and learn how aggression can achieve goals. A 5-year-old's briefcase is a backpack and the job is using markers and paints. Let kids be kids, and don't forget your own childhood.

Integrated child care can improve the educational experiences of all kids. Sandy, a 3-year-old with cerebral palsy, cried because her out-of-class exercise program meant missing show-and-tell. The other kids wondered what happened to her while she was gone. When the class's jazzercise routine was modified for Sandy, she didn't have to leave class for her exercise and the other kids became involved in helping Sandy with her disability. They brought a bolster to put under her feet and then realized that a lunchbox would also work. They enjoyed developing their own solutions. The kids and the care providers learned that kids with disabilities develop like everyone else, and that integration benefits everyone.

There are many kinds of integration, and integration serves many needs. Rachael was a medically fragile child and was expected to have a short lifespan. Her mom, who spent 24 hours a day with her, needed a break. She said, "I'm tired of waiting for my baby to die." Integrated child care enabled the mom to have some time off to take an exercise class. When Rachael died, some kids said, "Rachael must have done something really bad," but a classmate's artwork told another story: the drawing showed Rachael floating over the driver's seat of a bus taking the kids in the class for a ride.

Diana was a 5-year-old with multiple disabilities and we worried that integration would be difficult. Those fears were swept away when Diana greeted us with, "Call me 'Daisy'!" "Daisy" made crowns for the other kids in the class. Her mom had never expected Daisy to have friends, but when Daisy was invited to a classmate's birthday party, Daisy's mom was delighted. Maybe there would also be a time when she would be making Daisy a prom dress!

Child-care providers aren't taking advantage of the expertise of early intervention specialists in diagnosing disabilities; it's also hard to find child care for children with disabilities. Integrated programs will be developed only if early intervention specialists work with care providers to develop them. With that goal in mind, EHM trains child-care providers in many areas of integrated child care, using an approach tailored to family day-care homes and child-care centers. Training includes workshops, individual consultation and technical assistance which address the specific concerns and characteristics of each participating program and provider.

GETTING THE JOB DONE

Dan Burke
Technical and Training Specialist
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Joe Mathews
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Montana Department of Social and Rehabilitative Services, Helena, Montana

Vocational Rehabilitation dates to a 1920 act established to help disabled World War I veterans; each U.S. state and territory now operates a VR agency. Although VR's goal has always been employment of people with disabilities, the 1992 Rehabilitation Act amendments re-emphasize "**employment, employment, employment.**" The amendments update both language and philosophy.

As a result of the amended Rehabilitation Act, there will be increased access to rehabilitation/employment services for people who have the "most severe" disabilities. Strong language designates the consumer as a customer, partner, decider and requester of specific support.

Vocational Rehabilitation is very simple: it helps people get jobs. The terms "client," "consumer" and "customer" are dissatisfying; perhaps the term "constituent" should be substituted. Constituents are **supposed** to have input. Government programs have historically trained people to be dependent, to say, "So, what am I eligible for?" Consumers have had little voice in the paternalistic VR process.

Congress asked the disability community "to come together with one voice, to shape and modify the Act," and 53 groups responded. The Rehab Act now shares a great deal of language with the Americans with Disabilities Act and the Individuals with Disabilities Education Act (IDEA).

VR is a program, not simply a funding source; there's a lot of confusion about this. Unlike special education and Social Security, VR is not an entitlement program ; access to services is based on meeting eligibility criteria and on the availability of resources. Those people with the "most severe" disabilities have priority. The service all applicants are entitled to is the Individual Written Rehabilitation Plan, which now also requires written consumer input.

How will the system determine whose disabilities are the "most severe?" It will be interesting to see how it works out, because each disability group believes its own constituency is the most deserving. Currently, each state makes its own determination. Each annually reviews its demand for services (Montana VR counselors each serve between 150 and 200 people annually) and the resources available. If resources aren't adequate to meet the demand, VR goes to the "order of selection," in which disabilities are weighted by severity.

The renewed emphasis on competitive employment may also eliminate sheltered employment and "homemaker closures," which allow people to receive VR training in order to remain in their own homes, rather than preparing for outside employment. For example, in Montana, elderly people with acquired visual impairments have received VR training that has enabled them live independently at home. The Secretary of Education will hold hearings on these and other questions as regulations are written for the Act.

The establishment of "presumptive disability" is a positive change in the law. If a person is entitled to Social Security Disability Income or Supplemental Security Income, then VR can begin establishing whether an "impediment to employment" also exists. The Rehab Act allows VR to use existing diagnostic test results (i.e. tests done for an Individual Education Plan and/or medical tests) rather than requiring time-consuming, expensive retesting.

The IDEA already requires Individual Transition Plans (ITP) for post-high school transition. VR likes to talk to kids early in their junior year; unfortunately, in rural states there aren't enough staff to attend each ITP meeting, so eligible students slip through the cracks. Also, deficits which make a student eligible for an IEP and special education don't necessarily translate to VR. For example, it's difficult to assess whether a learning disability impedes a person's ability to work. We need to "beat down VR's door" and demand its involvement; without school/VR collaboration, students can graduate having had too much emphasis on academics and too little vocational experience.

Montana VR is interpreting the amended Act and trying to apply it consistently across the state. Eligibility must be determined within 60 days of application and is based on the degree to which a person's mental or physical disability impedes employment. It must be shown that VR services are necessary in order for the person to become employable. In the past, the consumer had to prove that he or she had a "reasonable expectation of employability" — now there's an assumption that a person is employable.

Anyone denied services may appeal. An applicant should first discuss the problem with a VR counselor. If this is dissatisfying, he or she can contact the state's Client Assistance Program for advice, advocacy and/or representation. If there's still no resolution, the CAP representative or consumer should speak with the counselor's supervisor. If this procedure fails to resolve the problem, the law allows for a fair hearing.

Eighty to 90 percent of Montana's VR appeals are solved at the counselor or supervisory level. Other states have had litigation, but Montana's VR system has encouraged creative solutions — "If it's not illegal and fills the bill, do it."

The reauthorization of the Rehabilitation Act requires that a well-defined state advisory council design and submit a three-year strategic plan. Unlike many states, Montana already had such a council in place, but the amended Act gives the council more power and responsibility. Montana's council has identified 17 objectives that will give Montana a state-of-the-art VR program.

The most important rule for VR counselors is simply: "Listen." People rehabilitate themselves; the counselor's job is to facilitate that. Complaints about VR result from failure to establish a good counselor/consumer relationship.

The three facets of rural rehabilitation are: relationships, solutions and the "Code of the West." Rural areas lack hard resources; the relationships among people are the VR system's major assets. Relationships enable solutions. There are no rural Lone Rangers — we all rely on our neighbors for survival.

AGING IN RURAL AREAS: SHARING SOLUTIONS

Philip Wittekiend
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We can integrate seniors with disabilities into the community and increase their quality of life if we recognize our shared needs, cultivate natural community-based resources and build coalitions.

Informal Networks by Philip Wittekiend

Please, recognize the value of informal community networks based on common interests. Sometimes it's too big a leap to ask someone to "help" people with disabilities, and too limiting to ask simply for support. A person may be reluctant to commit the time, or may be uncomfortable with people who have disabilities. Instead of recruiting advocates, look for opportunities to encourage activities based on personal interests. An angler or craftsperson would be more likely to spend time with another person who enjoys fishing or craftwork — and who has a disability. People need to get to know one another before they can be expected to make a commitment to spend time together.

I've spoken to various Missoula fraternal service organizations about aging and disabilities. Most members are already very involved in community service, including services for people with disabilities. Obviously, members also enjoy the camaraderie of their group. I say to them, "I know someone who would enjoy doing what you do — would you consider inviting this individual to join you?" Usually they haven't thought of service in such informal terms and are willing to invite the individual.

Professionals working in aging and disability services also need informal opportunities to get acquainted. Until you invest time and energy in each other's networks and get acquainted, you can't cultivate your shared resources. Administrators — free your staff! Let them leave the agency to participate in community activities and events and build their informal networks. Disability service providers need to seek out aging organizations and bring those people into the disability network.

Coalition-Building by Bob Bartholomew

There are three good examples of Montana coalition-building between senior centers in Bozeman, Helena and Polson and their respective senior disability communities. State and federal dollars are scarcer than they once were, so there is far less incentive for each network to remain isolated and more opportunity and motivation to share resources. Senior centers may someday evolve into community centers.

The three senior centers I mentioned received two-year grants to establish coalitions with their local disability networks. Each community had its own unique resources on which to build. Polson benefitted from its existing aging network, its disability services, its tribal programs and a history of successful integration. Bozeman had a beautiful new senior center. Helena had already successfully integrated workshops, day programs, Head Start and other activities into its senior center.

Coalitions are not always successful. Most senior-center participants are 75 to 80 years old. When these people were younger, those with disabilities were routinely institutionalized. This perception of people with disabilities may leave senior-center participants unreceptive to integrating their facility. Fear may play a part, as elderly senior-center participants are reminded of the possibility of their own future disability.

We need alternatives to institutional care. First we moved from big institutions to smaller institutions; now the goal is the home environment. Canby, Oregon, has a good model of assistive living. Assistive living is a least-restrictive, user-friendly environment based on a social, rather than medical, model. Montana has a shortage of affordable housing, which complicates the option of elderly people remaining at home. Even if a person is physically able to live at home, he or she may not be able to afford it.

The single-point access model is another alternative to solving the bureaucratic maze. The key is access to three or four resources at one entrance point, allowing a person to easily receive information and assistance on different levels of care and case management. Frequently we provide more services than individuals need or want; individuals must go through Medicaid for everything. The real issues are access and the need for a better model.

ISSUES IN RURAL INDEPENDENT LIVING

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Consumerism and Benevolent Institutions by Brad Bernier

Independent living centers (ILCs) can improve their effectiveness by stressing the value and ability of each individual, and by involving clients in ILC administration. ILCs and their clients must be politically active, demand enforcement of the Rehabilitation Act and choose action over endless organizing.

Our complex, impersonal, materialistic society denies many people their basic civil and human rights; compassion must supplant profit. Stereotypes of dependence severely limit people with disabilities — **everyone** is dependent on others to some extent. ILCs should emphasize **inter**dependence over independence.

An ILC has a unique obligation to be operated by the people it serves. It can improve clients' lives by:

- Collecting and analyzing community-wide data that show what clients need and how to improve services.
- Serving as an information clearinghouse for clients.
- Shaping public policy.
- Ensuring Rehabilitation Act compliance by getting involved in city planning. Don't wait for businesses to comply voluntarily. Review and approve or reject applications for construction permits. Focus on architectural barriers and on access to programs and assistive technology.
- Making telecommunications technology available to those who need it most, not just the fortunate few. Inaccessible technology widens the gap between rural and urban, rich and poor, educated and non-educated.
- Allowing directors and staff ample time for research and training to meet the changing needs of clients.
- Encouraging people with disabilities to participate in the ILC's daily operation, and to work with staff and administration through internships at universities and vocational-technical centers.

- Owning their office space instead of renting or leasing. Rely more on mobile service delivery instead of supporting expensive branch offices.

Access is the major issue for people with disabilities — access to health care, housing, transportation, education and employment. Inaccessibility is oppression. For example, access to health care is often tied to wealth, but most people with disabilities are unemployed or impoverished. In addition, the insurance system allows large health maintenance organizations and corporations to limit access to health care. Our health care and rehabilitation institutions, both medical and psychiatric, increase the cost of having a disability without acknowledging the basic truth: Health care is a human right, not a privilege or a matter of eligibility.

Employers, traditionally autonomous, deny access to groups they view as less economically productive. Oppressed people have a responsibility to ask why they are excluded and to question their society's structure. The purpose of an ILC is not to make a profit, but to enhance the individual and challenge society's assumption that self-worth and independence are tied to wealth.

"Independence," "empowerment," and "self-help" are often reduced to catch phrases used by others to avoid providing the support people with disabilities and their families need. American "rugged individualism," the notion that people can somehow live without depending on others, is a myth. Interdependence is closer to the truth for most people. Society doesn't expect a 3-year-old or a 74-year-old to live independently. Why then demand independence from everyone who is 32 or 22 or 48 years old? Research and training are tainted by such unfair assumptions; researchers need honest communication with their subjects to expose the truth behind the myths.

Emphasis must shift from agency and organization to the individual. Labelling clients "consumers," internal squabbling and emphasizing the cost of programs leaves people with disabilities at the mercy of the system.

Discussion

Many people with disabilities hesitate to take charge of their lives or get involved in political issues. Among possible explanations are the following:

- Many people feel powerless because they rely on helpers, such as doctors and family members, to make decisions for them. ILCs encourage people to make their own decisions. "At some point in life, everyone becomes responsible."

- Depression may cause apathy. Peer counseling, sincere personal relationships and the confidence that comes with empowerment may alleviate depression.

- Consumers are used to groveling and fear retaliation if they dare to speak out.

- Consumers come to ILCs for service, not to take charge.

- Few Americans participate in politics; people with disabilities are no different.

Rules for Better ILC Service:

- Encourage cooperation by stressing the things clients have in common rather than their differences.
- Avoid extreme positions that alienate potential allies.
- Encourage clients to advocate for themselves and others.
- Overcome community apathy with community involvement.
- Help clients overcome embarrassment about their disabilities.
- Appraise clients of their basic human rights.
- Require ILC accreditation.
- Maintain current information and technology.
- Communicate with other rehabilitation programs.
- Encourage consumer participation on IL councils.
- Promote a wide range of options for consumers.

The Top Independent Living Needs Are:

- Interdependence
- Combatting apathy
- Personal and political involvement
- Accessible services
- Elimination of shame and embarrassment
- Consumer-controlled ILCs
- Qualified ILCs
- Information clearinghouse & referral services
- Funding
- Transportation
- Coordinated human services
- Rural representation on IL Councils.
- Options
- Independent living training in schools
- Fees for service at ILCs
- Housing

ASSISTIVE TOOLS FOR RURAL INDEPENDENT LIVING: DEVELOPING LOCAL CIRCLES OF SUPPORT

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People with disabilities can improve the quality of their lives and live more independently if they develop circles of support. Circles of support include using local tradespeople (mechanics, electricians, carpenters, etc.) to maintain assistive equipment rather than depending on distant medical-equipment technicians.

Why must wheelchairs go back to the factory to be repaired while bicycles do not? They needn't — wheelchairs can be repaired locally, too, and the bicycle shop owner is a likely candidate for the job.

When something goes wrong with an assistive device, it's important to figure out the exact problem. The nature of the problem determines which tradesperson you ask to do the work. The bike shop or auto mechanic can repair a broken drive chain or other mechanical problem. A welder can repair broken or cracked metal parts. To fix power wheelchair controls, check the electronic repair shop or an auto repair shop. Heavy equipment shops or aircraft mechanics can repair malfunctioning hydraulic lifts and hoists.

Assistive devices are just tools; even seemingly complex devices are made up of simple components that local technicians can repair. Developing those local resources into a circle of support can make it possible for people with disabilities to survive in rural communities that lack conventional repair facilities.

Also, consumers can often design or prescribe the assistive tools they need better than occupational or physical therapists. In my 37 years of living with a disability, I've learned that we are the best designers of the tools that work for us. Early in my odyssey, therapists told me my arms would never be strong enough to transfer without assistance. I had an idea: why not make small versions of leg braces to fit my arms? The therapists liked the idea and had a set built. The braces worked; eventually, I built up sufficient strength to transfer without them.

When you need a new piece of equipment, it's best to try out as many variations as possible on your own. When you've narrowed down the choices, ask a professional — an occupational therapist, physical therapist or medical doctor — to help make the final selection and prescribe your choice. Make sure your needs and concerns are part of the selection process. I'm the one who knows if my butt hurts, so I should choose my wheelchair and its accessories.

There are some roadblocks to developing effective circles of support and to creating innovative new equipment. Insurance companies, which will pay for repairs done by authorized equipment dealers, often won't pay for the same repairs done by an equally competent local tradesperson. You might not be reimbursed for repairs unless you ship your chair off to the dealer — I've never been able to wait that long.

Fear of product-liability lawsuits slows the introduction of new products by established companies, and high insurance premiums prevent new companies from entering the market. Don't be deterred by these obstacles. We need to be instrumental in designing the tools we need, and we've got to keep talking about our vision.

People who are newly disabled often feel at the mercy of professionals. Other people with disabilities are a valuable source of information; there's a gold mine of experience around.

Until recently, assistive technology was available only through disability professionals, which has created dependency. Occupational therapists and physical therapists are valuable resources, but professionals must not thwart our moves toward independence.

LEAVE NO CHILD BEHIND

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If our society truly wants children to grow in their most nurturing environment, family service providers must give more than lip service to the idea of family-centered services. It can happen, if providers believe that all families have strengths and capabilities, and if providers trust parents' ability to learn and change.

The Rural Institute on Disabilities has developed and implemented an all-inclusive program in Missoula called "Opportunities for Parents and Children Together" (O-PACT) for families of infants and toddlers. The program has served more than 100 parents and children (ages 0-3), and has successfully helped families in jeopardy of losing custody of their children to remain intact.

Traditionally, parenting skills classes use lectures, worksheets, reading assignments and discussion groups — and many parents drop out. Those remaining are already comfortable with their skills, but enjoy being with other parents. Parents drop out for a variety of reasons: some are unable to read the materials; some are confused by professional jargon; others feel awkward or unable to apply class discussions to their own situations.

All families have some things in common, but each has its own desires, concerns and priorities — each has the right to choices and options. Most of O-PACT's parents participate in an effort to keep Montana's Department of Family Services from removing their children from the home. O-PACT offers these parents incentives, parent-to-parent support, intergenerational interaction, peer mentoring, support and resource coordination, bartering, informal supports, parenting instruction, peer interaction and activities for the children and professional intervention for both the child and the family.

There is no prescribed curriculum. Parents choose and explore services from the above options list. Parents also may choose individual consultation with staff, and/or small or large group interaction. Typically, parents participate in more activities as time passes.

About half of O-PACT's parents are struggling with parenthood; the rest come to meet with other parents or to have their children interact with other children. They watch, learn from and support each other. Instead of instructing, staff members structure events and situations for parents to experience.

The program is offered at six easily accessible sites (many in churches), with rooms arranged to ensure that interactions are comfortable and informal. The program presents ongoing, long-term behavior modeling. For example, a parent is less likely to lose her temper when her 15-month-old throws food after seeing that this behavior is absolutely normal at that age and learning that there are ways to arrange the environment so that the parent is comfortable.

The program also presents experiences that are easily replicable at home. More than half of the program's toys, for instance, are homemade. All Playdough, paint and glue is made on-site by the parents. Making materials becomes part of the interaction among families, and between children and parents.

O-PACT focuses on very young children for three reasons:

1. Children are the most vulnerable to physical/emotional abuse and neglect from birth to age 3.

2. The effects of abuse and neglect during this period are most likely to lead to severe disturbances as the child ages.

3. Long-term positive change is more likely when parents and children have a shorter history of maladaptive interaction to overcome.

The goal is family preservation and the consumer is the family as an entity. Families' desires and ideas determine what staff provide. The families needn't justify themselves. Staff must win their trust — without relying on files or asking probing personal questions.

The emphasis on modeling often helps a parent who can't read. Also, parents can readily identify their own interaction problems when they see themselves on videotape. Staff practice environmental engineering to facilitate their objectives when working with families. For example, young children "aren't wired" to share toys until about the age of 5 (society is pushing them to do this at ever-earlier ages), so staff provide multiples of each toy when they work with groups of children. Staff avoid store-bought toys and provide objects (blocks, scarves, etc.) that can be used in different ways by various age groups.

Parents like to feel they are giving, as well as receiving from a program. Often they informally barter with each other, trading babysitting chores or making chocolate chip cookies in return for lawn mowing.

O-PACT also works with pregnant and parenting teens, who programs have traditionally treated either as children or as adults. An adolescent girl is generally in an identity crisis — still bonded to her parents while trying to establish a parental bond with her own child. Agencies need to gain a better understanding of teen parents. One shouldn't be angry with a teenager for being a poor parent; the literature says teens who are still detaching from their parents will have difficulty forming parental attachments to their own children.

O-PACT, which has been in place for more than three years, is an economical, replicable model for communities wishing to help families at risk of disintegrating. It works for the families. In fact, families who once participated only under the threat of losing their children have begun referring other families to the program — that's success!

The benefits are many. Parents and children develop self-esteem; they have access to professionals who can diagnose and monitor any developmental problems; parents become confident of their parenting skills; and families remain intact. Society may benefit even more. Fewer out-of-home placements, for example, mean that money previously used for foster care or institutionalization can be spent elsewhere. Independently functioning families can mobilize their own resources, freeing the service delivery system to work with other families. In the long run, parents who learn how to interact effectively with their children will produce the good parents of the future.

COMMUNITY DEVELOPMENT AND ADVOCACY

Jim DeJong
Project Director, The Great Plains ADA Project
University of Missouri at Columbia

It's a time for all of us to feel good, pat ourselves on the back, and puff out our chests. We recognize our success, and a good time has been had by all. We want to share it. We've navigated the barriers of selected communities to create networks of individuals, agencies and resources. We've brought the issues of access to the attention of bank presidents, merchants, and local political leaders — the decision-makers — of those communities. "Let's implement the ADA, it's the law."

I recognize the talent, intense courage and profound persistence present here. Conference participants serve on local transportation boards, city councils, school and housing boards. Your influence affects city, county, state and national government.

What strategies facilitate this change? Mock legislative training is effective; individuals are assigned roles and enact the legislative process from lobbying to the introduction of a bill. In real life, only 5 percent of senators read past the first page of proposed legislation — public officials are only as smart as you make them be.

We need to build accepting communities. Go into a town and scout it out. Find out who the decision-makers are and where they hang out — then eavesdrop! Broaden our constituency to include the elderly, homeless, incarcerated and unemployed. Absorb these people, and then request their involvement. Recognize the systems that are working in a community and be aware of turf protection. Stop thinking like social service workers and get out into the real world; take consensus from the outside and bring it back inside. **If you don't say anything, no one does anything.**

Unemployment of individuals with disabilities is one of the major issues that must be addressed. Two-thirds of individuals with disabilities are employed, but only one-third are working full-time. Mentors can be helpful in increasing the employment of individuals with disabilities. Eliminate prejudices and barriers by emphasizing that we share "common bread." It's all a matter of dollars and cents; access makes good economic sense. it's just good business.

There are many questions. Do we have an organized voice? Do the eastern and western, rural and urban, old and young leaders have consensus regarding the issues and goals to be addressed? Have effective strategies been identified? Health care is hot, housing is critical, transportation is a dilemma and education/employment will be the battle. Are individuals working to build "accepting" architectural, as well as programmatic, communities?

Community workers know what the needs are. They witness the pain and suffering that lack of access inflicts on individuals with disabilities. We need access to legal services; we need to rock the boat. Can we accept a new vision? Do we have the creativity to embellish this vision, to eliminate the failures no longer tolerable in our systems and society? Do individuals with disabilities, young and old, understand their history as a people? When I spoke at the 1991 Common Threads, I spoke of the components of POWER. The P stands for pride. How do we restore pride to an individual and people that have personal histories of oppression and denial? The O is for outreach. Who does, and who receives, outreach? Who disseminates the information, the issues and the direction? W is for wisdom. Where are the mentors? Are they safely living out their lives, telling stories of the "old" days and the barriers overcome? Have they achieved enough personal security to effectively mentor? E is for energy. Individuals with disabilities have to recognize their individual energy. Does anyone have the energy to explore anything when he or she is scrambling to access the transportation necessary to get there? R is for respect. Can we accept and respect new voices and new visions, or will we perpetuate the old civil rights strategies that exhaust us in yet another fruitless battle? This is 1993 — we must begin to use our individual creative power and energy.

COMMUNITY AND HUMAN DEVELOPMENT IN THE RURAL CONTEXT: KNITTING THE COMMON THREAD FOR EVERYONE

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We will discuss issues such as the need for disability organizations to actively participate in economic and community development, strategies for gaining access to community resources and the importance of effectively conveying the message that disability organizations and the people they serve are themselves community resources.

Organizations serving people with disabilities must participate more fully in community and economic development. Assessing the community's needs enables an organization to take an active role in development. An Indiana organization helps with community projects such as park beautification and setting up a recycling project. This organization is no longer perceived as one that serves only people with disabilities, but as a valuable resource to the whole community. Once the community sees an organization differently, it will see the people served in the organization differently as well.

Organizations that volunteer to improve their community demonstrate that they and the people they serve are valuable resources. Service providers often don't stress this message strongly enough. They ask for help instead of showing what people with disabilities can give. Both service organizations and the people they serve must have a strong understanding of what they can do for themselves and what resources they can offer, not just what others can do for them or give to them.

A community's own economic pressures may reinforce negative perceptions of people with disabilities. For example, public schools are required under ADA, IDEA and the Rehabilitation Act, to provide various services to children with disabilities. However, because schools are underfunded (like everyone else), a school may not comply until faced with the threat of litigation. When the school does comply, the individual student may already have been singled out as an economic burden. This illustrates the challenges disability organizations may face in communicating a positive message to the community.

It's not just the message that you send, but how you send it. Frequently, members of the disability community are content to act as gadflies — demanding parking spaces, curb cuts and so on. Teaching people the manners, dress and, most important, the language needed to better access the economic development community would be valuable.

There are strategies for negotiating and gaining influence. Learn the skills of negotiation. Effective negotiation includes:

1. determining means appropriate to the scale of the problem,
2. setting priorities on how and with whom to negotiate,
3. identifying and articulating the issue you wish to address,
4. knowing the person with whom you are negotiating,
5. understanding the other side's issues, and
6. spending time with those with whom you disagree. If you interact only with those with whom you're comfortable, you will only be comfortable, not effective.

Influencing the system to change means organizations and individuals must spend time **with** the system. An individual cannot expect to make a demand once and see immediate results. The more often a message is repeated, the more likely it is to be listened to and taken seriously. Have an agenda and track your progress, but, at the same time, be aware of other issues.

Getting the word out about your organization through public service announcements and other advertising methods is also key. The community needs to know your organization exists before it can pay attention.

Common Threads: Blueprint for Action

Facilitator: Steve Dalin, Human Development Center, Rural Institute on Disabilities

Increase the visibility of individuals with disabilities and of the services you offer. Learn the language of your community and get involved — we all have things to offer. Emphasize the things people have in common rather than their differences. Historically, we've had low expectations for people with disabilities.

An Oregon church made accessibility modifications in response to the attendance of people with physical and sensory disabilities. The need to become accessible had been personalized, and the non-disabled members of the congregation were gratified to see the impact of the modifications on the lives of their fellow parishioners. "Build it and they will come" also functions in reverse: "Be there, and they will build it."

We don't have to be the experts; we just have to know how to find the experts. Innovate, and remember what works!

In an economically depressed North Dakota town, a disabilities service provider won a grant from an agricultural research firm to package birdseed. The provider did a feasibility study, showed it to a birdseed company in the eastern United States and brought company representatives to town. The company decided to relocate to North Dakota and has guaranteed that some of its jobs will go to jobseekers with disabilities. This effort will benefit the whole community.

Facilitator: **Mike Jakupcak, Rural Institute on Disabilities**

Consider, and learn from, our history. Incorporate those ideas which are still valid (such as a single point of access and a single application for services) into today's context. Learn from other cultures.

Access doesn't apply just to disability; it means more options for everyone. Market curb cuts and other modifications as an enrichment for the entire community.

Look for experts in sheep's clothing — maybe Lions, Elks, plumbers or your neighbors will be the experts you've needed all along. Find the person behind the role or title.

An Idaho adult/child development center served a child with multiple disabilities. Another early intervention program was mandated to integrate children with disabilities into its services and began to develop head-hunting behavior. It discovered that this child was eligible for its services and wanted to evaluate and serve the child, although the development center felt this wasn't in the child's best interest. The problem was resolved when the professionals involved shared information about the child's needs and the services available.

Facilitator: Rick Offner, The University of Montana

Consider forming sister-city relationships between independent living centers in different communities.

Identify the key players in your community. Join existing economic development groups.

Talk to young people about disability issues and involve them in city council and other meetings.

Diversity isn't just a cultural issue; include people with disabilities in diversity activities. Integrate people with disabilities into existing activities.

In a Montana community, T-ball is a popular team sport for 4-year-olds, but children with disabilities had never been included in the program. Fifteen children with disabilities were recruited but, unfortunately, the program directors wanted to assign them all to one team. Under pressure, the authorities agreed that each child should play on the team in his or her home-school area. Inclusion worked well and more children with disabilities are expected to participate next year. Each child came to be known as an individual and not just as a representative of a disability group.

Transportation is a perennial rural problem. Work out a research strategy:

1. Ask, "Is transportation a problem in our community"?
2. If it is, determine how people currently travel in the community.
3. Collect information: get reports from your transportation district and city council meetings, talk to transportation providers and consumers, look at what other communities are doing.
4. Design an action.
5. Describe the problem.
6. Form a focus group for brainstorming solutions.
7. Report to your community.

Facilitator: Kate Jackson, Rural Institute on Disabilities

New Mexico enjoys an active tourist trade. Although one community had a paratransit system for elderly people and did periodic studies of its fixed transit-route system, it failed to develop an accessible system for citizens with disabilities. The disability community decided to push for an accessible fixed-route system. They recruited support from diverse groups, including environmentalists and businesses catering to tourists. Advocates for an accessible system attracted attention by attending city council meetings in large numbers and by choosing a spokesperson knowledgeable about the ADA. How would the system be paid for? Advocates convinced the city to hold a special referendum to increase the sales tax. The referendum was approved and the increase passed. This community now has the only accessible fixed-route bus system in New Mexico. There was an additional benefit: curb cuts have been installed at all bus stops!

Strategy for inclusion:

1. Find a need that cuts across many segments of the community and transcends "disability." Transportation and accessibility are two good examples.
2. Identify the decision-makers in your community. Build grassroots support.
3. Know the history of your issue and gather facts to support your case.
4. Develop a strategy that identifies your goal and the direction you should take to get there.
5. Identify your community's resources.
6. Prepare for success or failure. What will you do afterward in the event of success? In the event of failure?

Facilitator: Duane Gimbel, MonTECH

How do we bring people together? By going to the people, joining community organizations, fostering interagency cooperation and sharing resources. Network, rather than fragment. Offer yourself as a resource — this eliminates your contact's reasons for not cooperating.

Don't be disability-specific, but work for universal accessibility. Provide technical expertise and focus on the positive reasons for improving accessibility.

A Montana historic public building was due for an accessibility makeover, but the authorities objected that modifications would violate the building's architectural and historic integrity. For each objection, the assistive technology adviser managed to come up a variety of solutions. Sometimes, however, technical assistance comes via litigation.

Wrapping Up the Common Threads by Tom Seekins

Frequently I bring my own agenda to conferences, although the agenda tends to unravel as things happen. Back at work I struggle to make up my workload and it's difficult to act on my conference experiences. Common Threads has talked about independent living, community development, transportation, accessibility, values and strategies. What **will you** do when you get home? What is **your** commitment to change? We're planning to call participants to assess the conference's impact at six- and nine-month intervals.

Today is the day the Israeli-Palestinian peace agreement was signed; let today be the day **you** started to make your dreams come true.

Choosing Inclusion:
Consumer-Driven Supported Employment

Introduction

The Montana Supported Employment Development Program branch of the Rural Institute on Disabilities spent a day before the main body of the Common Threads conference discussing the progress made and pitfalls discovered in extending the idea of supported employment to a variety of groups in Montana.

Montana is one of only two states to receive first- and second-round systems-change supported employment grants from the U.S. Department of Education's Rehabilitation Services Administration. The first grant, now known as MSED-I, pushed for supported employment of people with developmental disabilities or who have been a part of the mental health system, and successfully moved more than 450 people into integrated employment. One young man, Nic Marsello, who has mental retardation and was placed through the program by Opportunity Resources Inc. (ORI) of Missoula, received a national award last spring for his success as a custodian at The University of Montana.

The second grant, MSED-II, which has just begun its third and final year, has extended supported employment opportunities to people who have learning disabilities, who are American Indians with disabilities or who are survivors of traumatic brain injury. Five subcontractors are conducting six supported employment projects across the state, focusing on the use of natural supports in rural remote areas, and each brought their insights to share at the forum.

Jay McLaughlin opened the conference with an account of his own journey from traumatic brain injury survivor back to athlete and sported employment specialist. His story, which he tells with dry yet gentle humor, provided a good jumping off place for the four workshops that followed.

Each of the workshop presentations targeted a particular aspect of supported employment under MSED-II. The first explored ways to attain more diversified funding, and advised long-term strategic planning and a variety of innovative approaches to fund raising. The second focused on cultural and practical issues providers are likely to face when serving members of Indian tribes, each of whom has its own tribal beliefs and practices and may not even have a word for "disability" in the language. The difficulties of providing training and technical assistance to people in remote rural areas without a statewide telecommunication system was the topic of a third workshop, while the fourth discussed the changes and challenges that the philosophy of consumer-driven services has brought to supported employment. Jay's keynote address and the findings of each workshop are summarized in the following pages.

Choosing Inclusion: Keynote Speech

THE GOAL:
CONSUMER-INITIATED SUPPORTED EMPLOYMENT

Jay McLaughlin
Employment Specialist
Rehabilitation Research and Training Center on Supported Employment
Virginia Commonwealth University, Richmond, Virginia

Editors note: Jay McLaughlin's experiences as a survivor of traumatic brain injury have given him insights into consumer-driven supported employment — insights that have been valuable in his work as an employment specialist at Virginia Commonwealth University's Rehabilitation Research and Training Center.

On April 1, 1988, I was moving up in a rapidly expanding company, married and signing on the dotted line to buy a home. On April 5, while training for the bicycle leg of my third triathalon, I was hit from behind by a car traveling at 65 miles per hour.

When my helmet hit the pavement it broke into three pieces. That helmet is the only reason I'm alive to talk about the accident. If I hadn't had it on, it would have been my head in pieces. Even so, I was in a coma for five days.

My own experience as a consumer trying driving the service system around me has been extremely valuable as I have worked as a job coach and employment specialist. But getting there took time.

I grew up in the Washington, D.C., area in a medium-large Irish Catholic, middle class family. I began college in 1979 at Virginia Commonwealth University in Richmond., Va., about 100 miles from my home, but I dropped out in my sophomore year when I figured out that I was more interested in athletics than in educational pursuits, and went to work.

I started out very low and small in a fast-moving company, and as they grew they kept moving me up, and eventually I had a pretty good job. It was a parking service in downtown Richmond. I had a nice office and everything looked great.

Then came the accident. I didn't have any identification on me and they took me to the Medical College of Virginia, which I think is the best brain injury center perhaps in the world — without a doubt on the East Coast — and they took good care of me.

I was in a coma for five days and I shattered my right arm and my left leg. Those five days in a coma were the easiest five days of my recovery. It got more difficult after that. I remember the nurse constantly saying while I was in the hospital, "There's better times coming. There's better times coming," but what she didn't say was, "There's worse times coming, too."

I was in the hospital for two months. When I left for what turned out to be six months of rehabilitation work at an out-patient facility, I was still in a wheelchair.

When I got out of the wheelchair, I remember my constant frustration with the crutches and I came to a decision: I'd been training for a triathalon when this happened and I made it my goal to be in a triathalon again. A triathalon is a race where you swim and then you bike and then you run. Anyway, it was a good dream and I'd think about it as I crutched around the block.

When I finally got the cast off my leg and could swim again, I went back to the Tuckahoe YMCA, where I'd trained for triathalons before the accident and where I had lots of friends.

It was important to me to be working again, something I hadn't been able to do since the accident. When I asked the YMCA director for a job, pointing out that I was still not very cognitively together, he gave me a lot of light janitorial things to do, emptying wastebaskets and so on.

I knew that the Y would help me out. I felt comfortable there. I felt confident. I didn't have to break through a lot of barriers. If I'd been placed in someplace alien to me, it would have been much more difficult. I suppose you could call that my first successful experience with consumer-initiated supported employment.

My second goal — from which no one could have dissuaded me if they'd tried — was to return to my old job. Because I wanted to do it, everyone — my job coach, my employers and my family — tried to help me make it happen, but after months of trying to fit into my old skin, I found my marriage going downhill and my thoughts turning to suicide.

I was diagnosed with severe clinical depression and spent two weeks in an adult psychiatric ward. That's not an uncommon experience for traumatic brain injury survivors. When I was discharged, I decided I couldn't go back to my old job. Even my termination was consumer-initiated.

I went back to the YMCA, but this time I worked in the after-school program for kids. I knew it was only temporary, just until school was out and that I'd have to figure out something long term, but this gave me time to think and I really enjoyed being around kids. I was getting to know my own strengths and weaknesses by this time and, looking back, I can see that trying to fit into my old job didn't work because it was simply a bad job match.

I competed in a triathalon one year and seven days after the accident, but my marriage was coming to an end, along with the child care job at the YMCA, and I looked around for the next thing.

A lot of my cognitive abilities were coming back, but being able to organize things wasn't one of them. I knew I wanted to work in a place where the organization was already set up, and I knew I wanted to work in something that had to do with athletics and the outdoors, so I went out into the country and found a sporting goods store and asked for a job. I told the owner, "I'll give you a strong back and a weak mind," and he said that what he did when he hired people was give them a 30-day trial period. So I took it, and two weeks later he hired me permanently. I stayed there for two and a half years.

Meanwhile, I was getting to know some other head-injury survivors and someone asked me to come and talk about my experiences at a disability conference in Philadelphia. Dr. Paul Wehrman heard me speak there and offered me a job as an employment specialist at Virginia Commonwealth University's Rehabilitation Research and Training Center.

In my work there I've seen the importance of getting to know the whole person. If I only see a client at work, I can't be as helpful. That means I've gone to art galleries and ballgames and other non-employment-related activities with clients. Of course, I didn't get paid for that time because of the way reimbursement works, but it's really worthwhile. When you're working with clients, think of them as you there. What would you want?

I know that my recovery was made much easier than most people have it because of the settlement I got from the accident. It gave me a lot of economic freedom. In particular, it let me do a lot of different kinds of volunteer work, which I highly recommend to anyone else doing rehabilitation work. People are glad to have you and there's no judgement, much lower stress. It also gives you the opportunity to polish job skills and you also make contacts that help you later on.

Right now I'm moving on myself. Today (Sept. 10, 1993) is my last official day with the Rehabilitation Research and Training Center. I am now a full-time student working toward a degree in psychology at Virginia Commonwealth University.

What's my current goal? A consumer-initiated life — that's the ultimate goal.

Choosing Inclusion: Workshops

CONSUMER-DRIVEN SERVICES

Jay McLaughlin
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"The right to fail is inherent in consumer-driven services."

Supported employment is in a state of flux. As funding options expand and more "user-friendly" opportunities develop, the field is also reacting to litigation and liability issues, which narrow consumer choices.

The "typical" supported employee profile also has changed. Employees are now less likely to have orthopedic impairments or cerebral palsy and are more likely to have survived traumatic brain injuries. There is an increased need to include a consumer's family and friends in supported employment plans. We're redefining families as consumers, too. If a supported employee is nonverbal, for instance, family members often are the interpreters who can gauge whether the employee approves or disapproves of a plan or situation.

Most important, as the system changes to a consumer-driven philosophy, family members and service providers must allow people to take risks and possibly fail. It may be impossible to convince a person that his or her pre-injury job is no longer appropriate; only a trial run can determine whether the old job is still a good match. Consumers often start out with an extremely narrow goal and gradually become more flexible. The initial goal may be painting art reproductions of Old Masters, which evolves into wanting to work in an art supply store. The final goal may be simply working in a retail operation.

There's no disability that prevents employment, only a lack of motivation. Sometimes it's hard to keep personal prejudice out of job coaching, when the coach feels clients aren't really trying.

Is it necessary for every person receiving vocational rehabilitation services to be aiming at full-time employment? In some tribal cultures, for instance, such a goal may disrupt the family system. If people without disabilities aren't expected to work and instead are very involved with an avocation or homemaking, it may be discriminatory to disallow those options for people who do have disabilities.

In Montana and in other rural states, clients often must choose between good housing and an established support system in their rural hometown and employment in an urban area which lacks housing and support. When this happens, consumers need to challenge the status quo and use the VR appeal system more than they have in the past. Sometimes counselors and consumers should just go ahead with plans that seem most useful and logical even when such plans are untested. It's much easier to seek forgiveness than to seek permission.

What Consumer-Driven Progress Has Been Made?

- Consumers make up 85 percent of the VR Advisory Council.
- Individual Written Rehabilitation Plans are required annually and must include consumer input.
- Assistive technology is improving nonverbal clients' ability to communicate choices.
- The current planning system is person-centered.
- The 1992 amendments to the Rehabilitation Act mandate that consumer voices be heard.
- Consumers have the right to say they want to change jobs, and counselors often help facilitate problem-solving between workers and employers.
- Consumers initiate addition of services to the VR menu.
- Consumers invite people to attend their team meetings.
- Consumer satisfaction has been surveyed.

How Can Employment Services Be More Consumer-Driven?

- Reduce VR counselor caseloads so that counselors have more time to help clients plan.
- Train consumers about motivation, their rights and their responsibilities.
- Include more consumer-written questions on the consumer-satisfaction survey.
- Pay counselors to spend time in the community learning more about their clients as whole people.
- Research alternative ways for nonverbal clients to express their opinions.
- Invite more consumers to workshops.
- Have consumers hire their own follow-along service providers.

- Educate the community about attitudinal and physical barriers and create accurate perceptions of potential workers.
- Keep an open-door policy.
- Teach self-advocacy.
- Strengthen networks and connections.
- Create inclusive, supportive communities. Be available.

DIVERSIFIED FUNDING STRATEGIES

Bob Jahner
Community Rehabilitation Specialist, Vocational Rehabilitation Division
Montana Department of Social and Rehabilitative Services, Helena, Montana
Mike Kelly
Program Director, Flathead Industries, Kalispell, Montana

History of Montana Funding Issues By Bob Jahner

Funding means money. Maybe "money" is too concrete and scary to talk about because there's not much out there. Let's change our perception and talk about **diversified** funding — the kind you get through **campaigning**. First, a working definition of "natural supports": supported employees work in a context; the people they encounter in that context can be enhanced to serve as natural supports. Public funding changes the nature of relationships. **Natural supports are what's left after you subtract public intervention**. Since nature doesn't always work in our interest, public funding may be used to support a person in the community; in the '80s, it built comprehensive support systems.

Rural people wear lots of different hats. As a mid-level state manager and a federal systems-change grant coordinator, I see both federal and state perspectives.

Unlike a mother's love, money is **always** conditional; there will always be strings attached, complicated and frustrating as that may be. Funding is like a copy machine with a simple manual for the user and a complicated one for the repair technician. Human services professionals are the technicians who "wire in" resources so the consumer can easily function as the user.

Job coaches were often the first to realize that there are multiple sources of money, and multiple conditions and consequences to its use and misuse.

All funding is attached to some authority. Public-authority funding (federal or state) is governed by law and/or administrative rule, which usually has the force of law. Private entities control private funding and may allow us to do something a public authority wouldn't. The private entity still will impose certain conditions, such as submitting reports or participating in publicity campaigns. Public funding is more reliable.

Staff must be very serious about funding, as our personal blind spots could restrict funding for the whole state. When asked "Why not?" about funding, too often our answers reflect personal superstition, habit and practice: "We just don't **do** that." Or, at the administrative level, "Policy and procedure say we can't do that." At the public-authority level, it becomes "against the rule," and at the legislative level, "against the law." At these last two levels, funding cannot be changed without great difficulty.

In the '80s the federal government began funding time-limited systems-change projects. Supported employment projects did the time-limited activities well, but couldn't find anyone to provide long-term funding. About that time, I received a letter from a Sidney, Montana, mother seeking supported employment services for her daughter. Services weren't available and the family had to move to Miles City. I asked, "What have I done that's responsible for this situation?" and decided to visit the family. During my three-hour meeting with the family and their friends, I realized we would have to reconsider how to use small communities while still complying with funding source requirements. We put out a request for proposal (RFP) for the last year of the MSED-I systems change grant, which was awarded to Mike Kelly' program, Flathead Industries.

Funding Strategies by Mike Kelly

In 1987 few Montanans understood the concept of supported employment and it wasn't well received. Service providers shared the values that were the basis of the idea, but didn't know where the money to back it up would come from. Fortunately, the people in the places that provide funding also saw the value of supported employment. Many disability groups and providers wanted a piece of the funding, but we didn't know how long the money would last or how to sustain activity when the grant ended.

A survey of service providers found that 51 percent of their concerns involve providing consumer services; 49 percent involve fiscal responsibility. As Bob has said, boards of directors, staff, parents and other family members are susceptible to myth and superstition. There is a great reluctance to take action that may be perceived as "breaking the rules." Often we don't really have to break the rules; we just need to carefully research our position. Often we can show that it is possible to circumvent the system to get money for services without breaking rules or laws. When we find that what we need to do would break the rules, long-term strategic planning is crucial to changing rules and laws.

Rising costs and declining state funding make supported employment implementation difficult. Vocational rehabilitation has little ongoing funding and most is time-limited. When the VR supported-employment dollars run out, you must have other long-term funding in place. Flathead Industries has taken a number of approaches to this.

We used to set aside pots of money for each employment-related program we had — one pot for extended employment, another for on-the-job training, and so on — and each program had its own set of rules. Now we have implemented a job-coaching model for all employment services. Our five job coaches don't think much about funding rules because all of the money is in one pot. Caseloads are mixed; we have individuals with traumatic brain injury and others with learning or developmental disabilities. Each month, coaches submit their records to the administrative staff and we determine where each case should go. VR initially had difficulty with this system, but has learned to cope with us. For example, if I have work-adjustment money but no extended-employment money, I'll temporarily use work-adjustment funds to pay a person's extended employment expenses until more extended employment money comes in.

We went after and won an MSED-II grant to use natural supports and existing funding sources to support employment for people with traumatic brain injury or learning disabilities. Our service area is the Flathead Valley from Big Fork, Montana, north to Eureka and west to Libby, where the only previous employment-related service had been occasional VR assessments. We named our project "Community-Hosted Options in Supported Employment" (Project CHOISE). We have a caseload of five employees (three with traumatic brain injury and two with learning disabilities) who live in remote rural areas and were referred by a VR counselor. Volunteers provide job coach-type services. It's difficult to work in communities where services have never been available; we've done a lot of community networking, raising money and finding, training and supporting volunteers. We educate consumers and their co-workers about each other. Consumers introduce themselves and describe their own needs. Their co-workers do the same, and usually everyone figures out for themselves how to settle problems and meet everyone's needs.

The grant, however, is just beginning its final year and we will need public intervention to maintain our natural supports. We've approached potential long-term financial supports, such as the Lions Club, the Kiwanis and the Rotary Club, and asked them for $3,000 annually, per supported employee, for five years. They have pledged long-term funding for two or three supported employees, which gives us time to figure out how to fund services past that five-year period. The Legislature has also given us some money. The Flathead Association for Retarded Citizens (ARC) has pledged $15,000 to support another employee and the Pilot Club, a women's organization, is also contributing. We also use the PASS (Plan to Achieve Self-Sufficiency) program for funding.

We've hired a community development specialist for fund raising, public relations and product marketing who has developed several fund-raising activities. Each year, for instance, we produce the Big Mountain Climb with five corporate sponsors each donating $2,500. Big Mountain Ski Resort donates its facility for the day. Although individual climbers collect pledges for each foot of elevation they climb, our primary market is business-sponsored teams of eight climbers each. Each business pays its team's registration fee and, in return, Flathead provides team members with T-shirts featuring their sponsor's business logo. Climbers enjoy free food (donated by Tidyman's supermarket) and music on the mountaintop, then ride the chairlift down.

The first year we had 200 climbers. This year we had more than 900 climbers and cleared $66,000. Four of the five corporate sponsors have already pledged support for next year, when our goal is to clear $100,000.

Our No-show Christmas Gala also is popular — nobody wants another social obligation at Christmas, so we allow people to pay to avoid attending the event of their choice. Last year we made $9,000.

Hiring a professional fund raiser has paid off for us, and might pay off for you, too, but the most important idea I want you to take away from this session is to broaden your hunting grounds. Chances are it will broaden your community.

Working Group Discussion

Participants use various funding sources: Medicaid, legislative General Fund, donations, production-generated income (sheltered workshop earnings); Title 19 Medicaid Waiver; employer-provided training and supports; United Way; foundation grants; Developmental Disabilities Planning and Advisory Council grants (usually time-limited grants to move individuals from sheltered to supported employment); private pay; personal trust accounts; vendor relationships with VR; PASS and IRWE (Impairment-Related Work Expense) programs; Veterans Administration; Workers' Compensation; Carl Perkins grants; private insurance; private multi-sponsoring (provided by individuals, businesses and/or other organizations).

The Texas Commission for the Blind provides some limited compensation. Great Falls, Montana, community mental health agencies have entered into long-term sign-offs for supported employees with mental illness. Instead of a cash donation, businesses in some areas are asked to contribute a job placement.

A three-year Montana VR establishment grant pays for transitional employment of people with psychiatric disabilities.

The North Dakota University Affiliated Program secured a grant from the U.S. Department of Education to create integrated employment in that state.

The Alabama Job Training Partnership Act (JTPA) puts job coaches into high schools. These coaches accompany the graduating students into the job market and use the Individual Educational Plan as the job standard requirement, instead of the usual $7 per hour earnings standard. MSED-II is working with JTPA and VR on cooperative training.

Job Service offices have some time-limited money. Also Montana has four of the 12 Native American VR 130 grants in the United States. Civic groups, such as the American Legion and the Association for Retarded Citizens, may contribute to long-term support. An Idaho Developmental Disabilities Planning Council grant developed a resource guide called Community Connections; it's a good starting place to look for funding. If you don't have a similar guide for your community, develop one.

The Billings, Montana, mental health advocacy group watches for job openings and notifies the local supported employment service provider. The most successful job leads are those in which family members know someone at the potential job site; ask families to help look for placements and funding.

Are "natural supports" really just a way to put responsibility for providing services back on the family? A North Dakota study showed that most rural support services come from family, friends and community members. We expect families to absorb more responsibility as funding shrinks. Families are beginning to realize that service providers can't do everything — especially in the long-term. Natural supports aren't free; often, employers can provide or pay for some supports, such as transportation.

Don't be afraid to go to your state legislature for money. Montana's citizens with traumatic brain injury managed to get some money from the last Legislature. Other disability groups, such as the deaf community, could do the same thing.

TRAINING AND TECHNICAL ASSISTANCE SERVICES

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Editors note: Rita Schilling and Marie Ray coordinated the MSED-I demonstration sites and provided systems-change training and technical assistance.

Montana needs a concrete strategy to ensure that supported employment training and technical assistance continue when MSED-II ends next year. We're asking workshop participants: "What's available now? What do we need? How do we ensure that training and technical assistance will continue?"

What Training Is Available for Coaches?

Idaho's agency which funds supported employment for people with developmental disabilities writes training requirements into its contracts with service providers. Idaho's Developmental Disabilities Planning Council is developing a job coach curriculum for area technical schools.

The special education department at Eastern Montana College (EMC) provides training, but Montana's problem is complex: 1. Community service providers hire employees with varied backgrounds and levels of expertise; 2. Montana is large and many providers are far from EMC; and, 3. It's difficult to provide both new-employee and ongoing training. To bridge the gap between ivory tower and community, EMC has hired Dan Steer at the Montana Center on Disability to teach classes and to do community outreach.

Oregon's Vocational Rehabilitation Division lists qualified trainers in various fields, including supported employment. Potential trainers must apply to be added to the list, which is available to service providers.

Other resources are: state, regional and national conferences; in-house training; MSED-II staff; out-of-state technical assistance; job coach curricula taught at vocational-technical schools; regional vocational rehabilitation training; Association for Persons in Supported Employment (APSE); interagency coordination among non-profit providers (i.e. quarterly sessions with three or four non-profits, each training on areas of expertise); professional networking; parent organizations (such as Parents, Let's Unite for Kids); United Cerebral Palsy Association correspondence courses; and the University of Northern Colorado's Center for Technical Assistance and Training.

What is Needed?

A job coach needs:

- Optimism — and lots of community connections. Often our lives are limited to work and home. Get out into your community and meet people!
- A map of the bureaucratic trail leading to services (such as Social Security benefits) and an understanding of incentives and disincentives.
- Job analysis skills and knowledge of jobs available in the community.
- The definition of "consumer-driven services," so the **consumer's** priorities come first.
- Knowledge of protection and advocacy procedures and resources.
- Accessibility/accommodation-assessment techniques, and awareness of available assistive technology.
- Training in Personal Futures Planning and in evaluating Quality of Life Indicators.
- Consideration for values held by consumers, families, employers and the community.
- Disability-specific information and skill in parent, employer, supervisor and co-worker education techniques.
- Effective communication skills and job development strategies.
- Training in effecting school-to-work transitions.
- Skill in fading out direct training.
- Stress and anger management techniques.
- Open, frequent intra- and inter-agency communication to connect the job coach with other relevant agencies.

When Should Training Be Provided?

Idaho models its training on the Certified Nursing Assistant curriculum. The Rehabilitation Act specifies that Vocational Rehabilitation counselors and contracted employees must be qualified.

Montana has various annual conferences: Montana Association for Rehabilitation, Developmental Disabilities Division, Montana Head Injury Association, Common Threads, etc. Do conferences provide adequate training? Consistent basic training is necessary for new job coaches, followed by ongoing training. The average professional lifespan of a job coach in Helena, Montana, is six months; good basic training (audiotapes, videotapes and/or teleconferences) is crucial to cope with turnover. Match your training schedule to your turnover rate.

In Idaho, job coach retention is a major goal. Job coaches often feel isolated from other agency employees. Involving the coach in other aspects of service provision helps reduce isolation. Idaho's job coach organization provides mentors who share knowledge, gripes and successes. In a rural area, a regional organization might work well. Electronic mail allows immediate sharing of problems and solutions — Apple and IBM might donate computers for a job coach network.

Credentialed job coaches must periodically be re-credentialed. Perhaps an associate degree program in job coaching would raise professionalism and cut turnover. Montana's mental health job coaches are at entry level; the best coaches move into case manager openings. Upgrading job coaches to case manager level would help, but requires more state funding. Oregon's job coach salaries are also equivalent to those of entry-level direct care staff.

Consumers, especially those with traumatic brain injuries, can train job coaches. Coaches can watch videotapes of consumers discussing their needs; periodic follow-up tapes review what is, and isn't, working — an educational, therapeutic, cheap and convenient method.

How Do We Provide Long-Term Training?

> "Plan for what you need; don't take cost into consideration."

Kansas has brain injury and developmental disability Medicaid waivers that pay for long-term training. Rural parents, other family members or friends can be job coaches; their training is billable under the waivers. The Kansas State Independent Living Plan provides for employment training, including long-term services, because employment isn't a separate issue — it's part of life. Waivers are great; they prevent institutionalization and legislatures like them!

Montana has a Medicaid waiver for people with developmental disabilities and a pilot project for people with traumatic brain injuries. These will save money while providing more services — a better idea that's also cheaper. Montana's a poor state that really needs to analyze its spending for effectiveness.

Eastern Montana College's tenure track for supported employment training requires coordination between the eastern (EMC) and western (Rural Institute on Disabilities) halves of the state. Job coaches need a current "best practices" curriculum taught by former successful job coaches. Field internships complement

81

classroom instruction and give service providers a dividend — they can try out aspiring job coaches. The university system also could coordinate Montana's Association for Persons in Supported Employment chapter.

Kansas offers continuing education credits for participation in statewide social work meetings; it's a good incentive because social workers need coursework to maintain licensure. The same strategy could help maintain job coach certification, while also allowing coaches to enjoy some professional camaraderie.

Action for Eastern Montana is preparing an area training-resource directory that will be useful, but state and regional directories are also needed. Look at external resources: the Green Thumb and the Job Training Partnership Act (JTPA) agencies provide training (although using JTPA money for non-JTPA training may be problematic).

Contracting out job coach training to temporary-employment agencies might work — if there were a way to pay for it.

Training in remote areas is particularly difficult. Many rural professionals (i.e. teachers) act as job coaches without formal training. Often coaches either don't hear about training opportunities or can't get away to attend. An interactive satellite link system (SET NET, from Virginia Commonwealth University) or non-interactive satellite network can facilitate rural training. Staff exchanges with other agencies work well. When the Vocational Rehabilitation counselor and the job coach trade duties, each gains a greater understanding of the other's function and of the common goal.

> "Last week a rural job coach asked me for training, but we just couldn't arrange it. It would have meant three days off the job for him: one to travel here, one for training, one to travel back. This person is the only job coach in town — he can't be away for three days!"
>
> Dan Burke

AMERICAN INDIANS WITH DISABILITIES: CROSS-CULTURAL EMPLOYMENT SERVICES

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While there's no cookbook, or even one good recipe, for successfully providing vocational rehabilitation or supported employment services on Indian reservations, three basic guidelines are crucial to avoiding failure:

- Zealously guard your personal credibility.
- Be prepared to stick around for the long haul.
- Understand that in the American Indian culture, the wants and needs of the family come before those of the individual.

Each tribe, and each member of a tribe, will require an individual approach. For example, in Montana, there are seven reservations and 11 tribes. There is no shared language, philosophy or perspective among them — life is entirely different from one reservation to another.

The Northern Cheyenne Reservation in southeastern Montana is home to 4,500 people who live clustered around five small towns. Very few non-Indians live on the reservation and there is no feeling that Indians are a minority group. Every aspect of reservation life is controlled by the tribal government. The duties of the director of the supported employment project run "from coach to crying towel," because every person has different needs.

The Flathead Reservation in northwestern Montana, on the other hand, includes 10,000 non-Indians, with the 6,800 tribal members in the minority. Reservation politics revolve around which entity (the county, the tribe, the town, the state or the federal government) controls each specific issue. As far as supported employment goes, consumer-driven services have been in place for some time — the needs and desires of families have always been more important to American Indians than aptitude test results. Families, even if they disapprove, will also allow family members to choose employment or rehabilitation services.

The entire philosophy of disabilities is different on the reservation than in the outside world. For example, the Northern Cheyenne have no word for "disability"; the nearest equivalent word translates into English as "that person is different." It's a completely different value system from that of white America, which values the individual over the group. Because the Northern Cheyenne place more value on the group, the reservation service provider must serve the family's needs before the individual's. When the family is strong, so is the individual.

Another difference in the value system is that some things are more important to American Indians than work. The Euro-Christian concept is that even if you have only one functioning finger, you should be working. It's not enough just to look at employment; you have to look at the place and at the extended family. An American Indian may not finish a vocational rehabilitation program right away because of family needs — that may make him or her a lousy potential employee in the eyes of non-Indians.

Lack of trust is a major problem for non-Indians who try to provide services on reservations. There's a tremendous amount of mistrust, based on centuries of abuse and the theft of native language, culture and land. It's natural for non-Indian service providers to wonder why people don't take advantage of services, but each time a new program comes to the reservation, it's like the second coming of Columbus. The mistrust stems from experiences such as the boarding school system which took children off the reservation for years at a time.

If you make one mistake, your credibility is gone. There are so many needs that tribes must set their priorities — without credibility, your program won't be a priority. If you have a good reputation, you have to hold on to it because people talk to people. They talk to their families. If one person walks out, many will — and they won't come back.

There are also many divisions within each tribe to which outsiders must be sensitive. The politics are exactly like those of third-world countries; these are shattered cultures trying to be administered by an impatient outside culture. The cross-cultural road is very hard to walk — a culture that can measure time in nanoseconds can't cope with a culture whose shortest measure of time is a day.

Just getting a service started can be a real problem. Having been burned numerous times before, American Indians often take a wait-and-see attitude before committing themselves to a program or idea. Maybe after a couple of years, when tribal members get to know the provider, something will happen. Since few grants sponsor programs for more than three years, services offered under such conditions are almost doomed to failure — and each new failure adds to the mistrust that already exists.

Reservation service providers must offer equal opportunities. Inequality inspires jealousy among people, causing further problems for the provider. It's usually best to start at the top; talk to the tribal council when offering new services.

Work Session Discussion

The following ideas were among those suggested to enhance or adopt more culturally sensitive supported employment services for American Indians:

- Serve the entire family. If there is conflict in the family, don't even try to resolve it. Wait until the family resolves it before going on.
- Don't think of American Indians as a minority group. Show respect for each person as a human being.
- Understand that non-Indians will always be outsiders.
- Be patient and take the long view. Be prepared to hang in there longer than any grant will.
- Make no assumptions. The tribal culture is complex and the white culture is complex and when they're mixed together, it's beyond complex. American Indians live in two worlds and experience constant conflict.
- In American Indian culture, actions have far more meaning than words. If you promise something you can't deliver, your credibility will disintegrate.
- There is no way you will know everything, or even enough, so **ask for** help.
- Employment is not the only goal, or even the most important goal, to American Indians, so look beyond it. The term "employment" may not even mean the same thing to Indians and non-Indians. Make sure both parties understand what is meant when the term is used.

1993 BEST PRACTICES IN RURAL INDEPENDENT LIVING

1993 BEST PRACTICES

This year the Best Practices in Rural Independent Living Project selected six innovative programs to receive awards for their outstanding efforts in implementing the ADA in rural areas. In its third and final year of funding from the National Institute on Disability and Rehabilitation Research, the Best Practices in Rural Independent Living Project identified as its priority issue, implementation strategies for the Americans with Disabilities Act by programs serving rural settings. The project initially mailed program announcements and application packets to independent living centers, National Organization of Disability Community Partners and disability advocacy organizations throughout the United States. Project staff then conducted 14 site visits to learn about their strategies for implementing the ADA and conducting ADA-related training in rural communities. Information about all 14 of these programs, as well as on programs from the past two years, will be included in the Rural Options Database.

Center for Independence

The Center for Independence (CFI) serves a 13-county region on Colorado's western slope. CFI reaches out to every segment of the community by gathering the resources of consumers, businesses and public agencies to implement ADA legislation in rural Colorado. CFI educates the community about the Americans with Disabilities Act by sponsoring workshops and presentations. CFI has a full-time staff position for ADA implementation which is currently being filled by a VISTA volunteer.

CFI also provides ADA training and consultation to consumers, businesses and public officials to help them comply with the ADA. The public library and 56 of the 61 regional polling precincts are now accessible because of CFI's advocacy and consultation. CFI is also working with city officials to increase accessibility on a large number of streets by designing a bike path with curb cuts wide enough for wheelchairs.

For more information, contact the Center for Independence, 835 Colorado Avenue, Grand Junction, Colorado 81501; 303/241-0315.

Breaking New Ground

Breaking New Ground (BNG) is a U.S. Department of Agriculture National AgriAbility Project directed towards rural communities, county/city government leaders, agricultural businesses, rural professionals and

Cooperative Extension Service personnel. BNG networks within these systems to assist rural communities with the education and training needed to implement the ADA. The agency has provided more than 50 ADA accessibility assessments within rural communities; provided an ADA checklist and ADA resource packet to more than 200 Extension agents; and presented ADA accessibility training to more than 500 rural professionals. BNG has developed a number of ADA resources which are available on request: 1. a video on compliance guidelines for county Extension offices and 4-H fairgrounds; 2. a video that provides an overview of the ADA and describes practical, low-cost solutions for small businesses; 3. resource packets and accessibility checklists specifically targeted for rural and agricultural businesses, county Extension agencies and 4-H fairgrounds; 4. a leader's guide for rural professionals on how to organize meetings on the ADA; 5. an educational publication for rural businesses; and 6. a newsletter for farmers and ranchers with physical disabilities.

Although churches are exempt from ADA, Breaking New Ground has developed an accessibility checklist and other materials for churches concerned about meeting the needs of people with physical disabilities.

For more information, contact Breaking New Ground, 1146 Agricultural Engineering Building,, Purdue University, West Lafayette, Indiana 47907; 317/494-1221.

IMPACT, Inc.

IMPACT is a non-profit organization founded in 1985 by people with disabilities in Madison, Illinois, and its surrounding counties. IMPACT educates rural communities about the needs of their citizens with disabilities and provides training on proper ADA evaluation procedures.

IMPACT assists municipalities, businesses, schools and other organizations in southwestern Illinois with ADA compliance. The organization evaluates employment practices, existing facilities, construction plans and program accessibility and recommends the needed changes, including compliance dates. After assessing buildings, parks and programs for accessibility, IMPACT will develop and disseminate a self-evaluation and transition plan. For instance, IMPACT contracted with the city of Alton to provide ADA consulting services for inspecting all of their building permits and to oversee their curb cut program. IMPACT has also given 50 presentations at city and county meetings and has provided 35 Title II ADA consultations for local governments.

IMPACT has received a state grant to provide smaller rural communities with ADA consulting services. The organization assists public and private organizations with locating funding sources and applying for funding to facilitate ADA compliance.

For more information, contact IMPACT, Inc., 2735 East Broadway, Alton, Illinois 62002; 618/462-1411.

Services for Independent Living

Services of Independent Living (SIL) is an independent living center serving 25 rural counties in mid-Missouri. SIL provides ADA education and training by developing and facilitating a network of community-based and consumer-directed coalitions. One consumer-led system resulted in SIL facilitating peer support for people with disabilities.

SIL assists coalitions in networking with other community resources, statewide ADA resources and each other. Each of the chapters is responsible for assisting its local governments, schools and businesses with ADA assessments and implementation plans. In addition, SIL conducts ADA surveys and provides compliance recommendations for public and private organizations.

For more information, contact Services for Independent Living, 1301 Vandiver Drive, Suite Q, Columbia, Missouri 65202; 314/874-1646.

Handicap Awareness and Support League, Inc.

The Handicap Awareness and Support League (HASL) is an independent living center which serves a five-county region in Oregon. HASL currently has an access committee and an ADA-certified staff member for providing training to public officials and business owners.

HASL works with local governments in evaluating government-owned buildings, sidewalks, parking areas and parks for compliance with the ADA. HASL has assisted local public officials to apply for and receive Community Development Block Grants from the state to bring public buildings into ADA compliance. HASL also helps businesses conduct evaluations and write recommendations. HASL not only conducts ADA surveys but provides a follow-up report which identifies the barriers, proposes solutions and sets up a proposed timeline for correction.

In celebration of National Barrier Awareness Day, HASL sponsored a scavenger hunt in which public officials, community leaders and business people used wheelchairs. The purpose was to allow these individuals to experience accessibility barriers firsthand.

For more information, contact HASL, 290 Northeast C Street, Grants Pass, Oregon 97526; 503/479-HASL (4275).

Prairie Freedom Center for Independent Living

The Prairie Freedom Center for Independent Living is an independent living center responsible for ADA implementation within a five-county region in eastern South Dakota. The center organizes meetings with interested consumers, disability organizations and civic groups and educates them on ADA specifications. These established community teams help the center set up informational meetings and other advocacy tasks within their communities. The center contacts city and county governments to discuss ADA requirements and reviews their ADA implementation plans. The Prairie Freedom Center also conducts ADA facility review for businesses and other service providers.

The center staff works directly with building and inspection offices as an available resource for consultation and referral on ADA requirements.

For more information, contact Prairie Freedom Center for Independent Living, 301 South Garfield, Sioux Falls, South Dakota 57104; 605/339-6558.

The University of Montana