Medicaid Home and Community-Based Services for Persons with Developmental Disabilities in Wyoming

Final Report

Observations from a site visit of
May 1 – May 5, 2000

Submitted to:
Health Care Financing Administration

Submitted by:
The Lewin Group

Prepared by:
K. Charlie Lakin
Research and Training Center on Community Living
Institute on Community Integration,
University of Minnesota

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INTRODUCTION

This report summarizes findings and observations of a site visit to Wyoming to view and discuss with key state officials, service providers, program participants and others the implementation, outcomes and challenges of the state's Medicaid Home and Community-Based Services ("waiver") program.

Authorization of the Medicaid Home and Community Based Services "waiver" program (HCBS) was contained in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), passed on August 13, 1981. It granted the Secretary of U.S. Department of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The HCBS program was designed to provide home and community-based services for people who are aged, blind, disabled, or who have mental retardation or a related condition (MR/RC), who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid certified, institutional facility. HCBS regulations were published initially in March 1985. Since then a number of new rules and interpretations have been developed, including revised regulations published in July 1994, although these have not changed the fundamental premise of the program, which is to use home and community-based services and supports to reduce the need for institutional services.

The non-institutional services that can be provided in an HCBS program include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can establish in its application will lead to decreased need for and costs of Medicaid funded long-term care. States are not allowed to use HCBS reimbursements to pay for room and board, but all states offering HCBS to persons with MR/RC do provide residential support services under the categories of personal care, habilitation, homemaker or other similar service types. But HCBS recipients must use their own money, usually from cash assistance provided by other Social Security Act programs to fund room and board costs. In June 1999 about two-thirds (68.6%) of HCBS recipients in the 43 states reporting such data, received services in settings other than the home of natural or adoptive family members (Prouty & Lakin, 2000).

Given both its flexibility and its potential for promoting the individualization of services, the HCBS program is recognized in all states as a significant resource in the provision of community services to persons with MR/RC. Beginning in the early 1990s, administrative requirements that prevailed in the HCBS program's first decade that required that state applications to provide HCBS show reductions in projected ICF-MR residents and expenditures roughly equal to the projected increases in HCBS participants and expenditures were considerably relaxed, and were then deleted in the 1994 revised regulations. As a result, there has been since 1992 dramatic growth in the number of HCBS participants. On June 30, 1999, states provided HCBS to more than 4 times as many people with MR/RC (261,930) as in June 1992 (62,429) and to more than twice as many HCBS recipients as to people residing in the Intermediate Care Facilities – Mental Retardation (ICFs-MR) for which HCBS is the non-institutional alternative (117,900).

CASE STUDY OVERVIEW

Purpose

All states have been expanding their services to individuals with MR/RC and families through community services programs. States use a variety of mechanisms to fund these services, including their generic Medicaid program (e.g., home health and personal care), and MR/RC targeted Medicaid Home and Community-Based Services (Section 1915[c] waivers), state-financed programs, and in some states small community ICFs-MR. By far the most significant and rapidly growing program for persons with MR/RC has been the Medicaid HCBS program. While it is committed to non-institutional services, the Health Care Financing Administration has relatively little systematically gathered information about how states have organized and delivered HCBS or about the effectiveness of services in contributing to the health and well-being of those who received them.

HCFA contracted with the Lewin Group to design and implement a study of the impact of Medicaid Home and Community Based Services (HCBS) programs on quality of life, quality of care, utilization and cost. The Lewin Group subcontracted with the Urban Institute, Mathematica Policy Research, Inc., the University of Minnesota and the MEDSTAT Group to

assist in aspects of the study. One project of this study was site visits to 6 states to describe the financing, delivery and outcomes of Medicaid HCBS for people with MR/RC and site visits to another six states to describe similar features of HCBS programs for older and younger people with physical disabilities.

The University of Minnesota conducted the state site visits related to HCBS administration and services delivery for people with MR/RC. Site visits were conducted between February 2000 and August 2000. During these visits, site visitors conducted in-person interviews with state and substate region government officials who were associated with different aspects of the HCBS program, administrators of service agencies, case managers, direct care staff, advocates, and service recipients and their family members.

The case studies examined key program features, including (a) the context of the program, (b) the philosophy and goals, (c) coordination with the State Medicaid agency, (d) administration, (e) eligibility criteria, (f) financing, reimbursement and contracting for services, (g) quality assurance and monitoring, and (h) challenges for the future. This report is a summary of the case study of Wyoming's Medicaid HCBS program. The Wyoming site visit was conducted May 1 to May 5, 2000 by K. Charlie Lakin (report author) and Amy Hewitt of the University of Minnesota.

Methodology

State Selection

States were selected for participation in this study based on a variety of features intended to sample HCBS programs so that both the relatively well-developed program as well as programs that were still developing would be represented. With the assistance of the Technical Advisory Group factors were identified to order states for sampling purposes including: the number of HCBS recipients as a proportion of all long-term care recipients with MR/RC, HCBS recipients per 100,000 of state population, HCBS expenditures as a percentage of all Medicaid long-term care expenditures for people with MR/RC, the proportion of all ICF-MR and HCBS recipients served in congregate housing, and the location of the state. Based on these factors and index ranking was created and states were statistically ordered in a

continuum from which they were selected. The states involved in this study held ranking of 1, 4, 9, 33, 44 and 51 on these indexes, reflecting the desired distribution from "well-developed" to "developing" that was desired for the study.

Site Visit Goals

The Wyoming site visit, like the other HCBS site visits, was designed to be a "process evaluation." Its primary focus was on the organizational aspects of delivering HCBS services and how key informants throughout Wyoming viewed the effectiveness of the organizational structures created in achieving the objectives established for the program. Site visitors probed for the perceptions of different stakeholders about what was working well in the Wyoming HCBS program and what might be improved and how. In all descriptions of the purpose of this study site visitors always made it clear that they had no regulatory role in the Medicaid HCBS program and that they questions asked were asked only to better understand the program. It was also explained to stakeholders that a second "outcome evaluation" stage of the study would focus directly on the effects of HCBS on the lives of a large sample of service recipients and on their satisfaction with the services received.

The site visit to Wyoming attended to broad HCBS program design and implementation, including:

1. What principles, goals and objectives guide the state's use of the Medicaid HCBS program, how were those principles, goals and objectives defined, and what is the nature, status and effects of the overall state effort to achieve them?
2. What are the origins, design, internal organization, financing and program relationships of the public and private agencies delivery HCBS? How and what is the extent of their cooperation, coordination and coinvolvement with each other and with the state in pursuing the principles, goals and objectives established by the state for the HCBS program?
3. What is the nature and effectiveness of efforts within the state to define, monitor and improve the quality of services and consumer protections and how well do these

achieve the minimum standards established by Congress and the specific principles, goals and objectives established by the state?

4. What are the primary accomplishments and challenges facing the state and its HCBS providing agencies and individuals in achieving state goals and objectives and the expectations of service recipients; and what planning, staff recruitment and development, service delivery and service quality management practices are needed to enhance and maintain efforts to realize them?

Case Study Approach

A primary approach of this study was to interview representatives of major stakeholders and "implementers" of Wyoming's HCBS program to describe the nature, quality, and outcomes of relationships among state and regional agencies, the agencies that provide and receive HCBS. Interviews were supplemented by a wide range of documents. In case studies it is typical to hear both consensus and differences in impressions about different aspects of programs, policies and agencies. The goal of the case study approach is to synthesize and summarize information from different sources to better understand the program and how policies, practices, and interpersonal factors have affected its development and challenges for the future. A range of information sources contributed to this summary.

Interviews. The primary methods of obtaining information in this case study was a series of interviews built around the general research goals identified above. Interview schedules were drafted by the project team. These were reviewed by members of the Technical Advisory Group and HCFA staff and were subsequently revised. The interview schedules were structured so that multi-level, multi-respondent, corroborating interviews were generated in each of the research areas. For example, the interviews with state officials asked about the state's objectives for HCBS. The interview schedule for service providers gathered corresponding information on how the state's objectives were communicated, understood, and supported through policy, training, technical assistance and in other methods at the local levels.

Document review. In addition to interviews there was extensive use of document and data review in this case study. We gathered and examined the following types of documents: 1) the Wyoming adult and children's HCBS applications; 2) the state HCBS technical assistance

manuals; 3) the procedures and protocols used in annual agency reviews and the reports of findings of these reviews by the Wyoming Developmental Disabilities Division and by CARF survey teams; 4) written and video training materials related to administrative matters such as eligibility determination, billing procedures; and resource allocation; 5) research and evaluation reports developed by the Division and contractors on consumer satisfaction, service recipient characteristics and needs, service outcomes and other topics; 6) documents related to individual service provider agency qualifications, mission, goals and performance; 7) documents describing the state context in which the HCBS program operates (e.g., the *Weston* Settlement Agreement, and documents related to the development of the State Planning Council on Developmental Disabilities long range plan); and 9) other state or provider agency materials and correspondence shown as relevant to HCBS.

Collaboration with the Division on Developmental Disabilities Division

We had extremely positive and helpful support from Jon Fortune, Adult Services Manager, in preparing for this site visit. During the visit, the gifts of time, enthusiasm and commitment of Mr. Fortune; Division Administrator, Robert Clabby; Program Manager, Wayne Johnson; Children's Waiver Manager, Kathleen Petersen; Eligibility and Special Waiver Specialist, Jerry Allen; Area Resource Specialist, Leo Urbanek; and many other state and community agency administrators, staff and service recipients was truly remarkable and deeply appreciated.

Review of the Draft Report

The initial draft of this report was provided to select key Wyoming state informants. They reviewed a draft of the report and provided corrections, criticisms, and questions to the site visit leader. Clarifications were accomplished through follow-up correspondence and telephone interviews. Appropriate corrections to the draft report were made.

Selection of Sites and Interviews

The selection of individuals and sites that were visited was carried out by the site visit coordinator key contact, Jon Fortune in consultation with the University of Minnesota site visit team. As in other states, this visit was designed to include key staff members of the state's

administrative apparatus for HCBS, including 1) key staff members of the Wyoming Developmental Disabilities Division, including Administrator, Program Manager, Adult and Children's "Waiver" Managers and Directors of the Department of Health (the Medicaid single state agency) and its Office of Medicaid administrator and Program Coordination Liaison, and the Area Resource Manager; 2) the state Protection and Advocacy System (PAS) Director, the Planning Council on Developmental Disabilities (DD Council) Director and most members of the Council; 3) Area Resource Specialists responsible for regions of the state visited; 4) service providers, organization administrators and staff, including individual case managers and respite and "host family" providers, who were contracted by the state as HCBS providers; and 5) HCBS recipients and their family members.

At the time of our visit, HCBS-financed services were being provided in all of Wyoming's 9 service areas. Thanks to generous support of the State and the use of a state airplane we were able to visit 6 of these areas. Individual "sites" were sampled to include: 1) sites representing Wyoming's traditional "Regional Service Providers;" 2) sites in which non-traditional respite, host-family and other supports are provided by small independent providers; 3) sites which provide special expertise and serve as a statewide resource; and 4) sites that reflect both urban (for Wyoming) and rural catchment areas.

Evaluators interviewed approximately 42 key informants in Wyoming plus the entire DD Council. HCBS recipients and family members were interviewed on an individual basis or in pairs at their homes, places of work or at private settings arranged by agencies. Almost everyone approached agreed to be interviewed. All key informants were extremely accommodating of the site visit team's requests and schedules. The week was structured so that evaluators had the opportunity to see and meet with a variety of recipients and other key stakeholders.

All respondents were promised anonymity. All interviews began with an explanation of the purpose of the site visit and assurances that the evaluators had no regulatory or enforcement roles in HCBS. We also made it clear that we were not employees of HCFA. At several site visits, there was some confusion about the power of the site visitors to make changes or get certain services for certain people. After complete explanation of the role and purpose of the visit, these misunderstandings were cleared up.

Major Areas of Inquiry

The major areas of inquiry described in this case study correspond to the primary topics form the interview protocol. Major areas of inquiry that are reflected in the outline of the report include: as 1) the context of the program, 2) the philosophy and goals, 3) coordination with the State Medicaid agency, 4) administration, 5) eligibility criteria, 6) financing and reimbursement, and 7) quality assurance and monitoring. A final heading on "challenges in Wyoming" has also been added.

CONTEXT OF WYOMING'S HCBS PROGRAM

Services for Wyoming's citizens with mental retardation and related conditions (MR/RC) were literally transformed in the decade of the 1990's. Two major, interrelated factors were key components in that transformation: the skillful organization and management of rapidly expanding community service system and a shared commitment on the part of major stakeholder groups to work together to substantially elevate the quality and community orientation of Wyoming's services for persons with MR/RC. The platform on which the transformation was built was a community service system that until 1991 had managed to finance and provide support to hundreds of persons with MR/RC without the benefit of federal financial participation. But few in Wyoming would disagree that the catalyst for Wyoming's transformation was a class action suit filed in 1990.

The Weston Settlement

In 1989 the Wyoming Protection and Advocacy System, Inc. (PAS) conducted a review of institutional and community services for persons with MR/RC in Wyoming. The review led PAS to conclude that the entire Wyoming service system, including the Wyoming State Training School, was inadequate to meet the basic needs of persons with MR/RC. Based on these findings, Weston, etc. al. v. Wyoming State Training School was filed on January 3, 1990 on behalf of "all individuals with mental retardation, currently at WSTS, or who are currently, or may in the future be at risk of placement at the WSTS, including youth from birth to 21 years, adults and senior citizens" seeking "relief regarding conditions at the Wyoming State Training School ("WSTS") and the lack of services provided to people with mental retardation" (Annotated Settlement Agreement, 1994).

Agreeing "that it is in the best interests of people receiving services and to the parties to resolve this dispute without rancorous and expensive litigation… [that] only diverts resources from people receiving services" and recognizing the essential truth to the charges against the state and its provisions for persons with MR/RC, the state entered into a settlement agreement with the plaintiffs in March 1991. The subsequent Consent Decree and Order (July 1, 1991) laid out specific requirements for post-Weston service system for persons with MR/RC that would dramatically change service delivery in Wyoming.

As Wyoming state officials, advocates and service providers pursued the realization of specific principles and requirements in the Weston settlement the principle of avoiding rancor and the specific attention to establishing a new partnership at the "federal level" to achieve the goals of settlement become very important to the future of Wyoming's system of services for people with MR/RC. Governor Sullivan, in office at the time of Weston is given great credit for setting a tone of commitment and cooperation that has prevailed as Wyoming undertook the initiative to substantially reform its MR/RC services. But support in the state's highest office has been evident all through the decade. The state's current Governor Geringer was Chair of the Appropriations Committee at the time of Weston and was then and remains committed to the development of community services in Wyoming.

Participation in Medicaid Long-Term Care

In 1989, as the Wyoming PAS prepared its civil suit on behalf of the Weston plaintiffs, Wyoming was the only state in the U.S. that participated in neither Medicaid ICF-MR nor HCBS programs for persons with MR/RC. On June 30, 1989 of 689 total residential services recipients in Wyoming 411 (60%) were residing at WSTS. In response to WSTS suit state officials made a number of concessions that dramatically changed both the reliance of the state on WSTS as the primary place for providing services and the nearly exclusive reliance on state monies as the way of financing them. In response to the Weston agreement, Wyoming officials began to:

1. obtain ICF-MR certification and federal matching funds for WSTS;

2. develop community services for Weston class members determined to be inappropriately placed at WSTS;
3. improving access and quality of community services for people at risk of placement in WSTS; and
4. consider sources of financing for the developing system of community services.

As with their efforts to improve the quality of both the WSTS and community service, state officials committed to increasing substantially the resources for this reformed system both through increased state revenues and by leveraging federal Medicaid cost-share. Efforts to do so with community service were specifically limited to the HCBS program that is it was decided that Wyoming would not develop new or certify existing community group homes as ICFs-MR.

Between Fiscal Years 1990 and 1999 federal contributions to Wyoming's service system for ICF-MR (at WSTS) and HCBS went from $0 to a combined total of nearly $35,000,000. In FY 1999 the average federal contribution to per person expenditures for these Medicaid recipients was about $28,900. On June 30, 1999 Wyoming had a total of 1,203 combined ICF-MR and HCBS recipients. Only 10% (or 120) of these people lived at WSTS.

Wyoming has steadily increased the number and proportion of all Medicaid long-term care recipients whose services are financed through the HCBS program. In June 1999 Wyoming ranked 5th nationally in its number of HCBS recipients per 100,000 of state population. Its rate of MR/RC HCBS participation (231.7 recipients per 100,000) was more than double above the national average (96.1), but fell within the general range of other rural states in the same region (Montana, 105.2; North Dakota, 295.7; and South Dakota, 268.9).

Since 1992, the Health Care Financing Administration has substantially relaxed requirements that states demonstrate that HCBS growth be reflected in roughly equivalent reductions in actual and projected ICF-MR use. As a result between June 1992 and June 1999 states rapidly expanded their numbers of HCBS recipients with MR/RC (from 62,429 to 261,930). In other words, the HCBS program, which grew by an average of about 6,000 recipients per year in its first 10 years, grew by an average of nearly 29,000 recipients per year

in the 7 years between 1992 and 1999. Wyoming's program growth between 1992 and 1999 was substantial, but less than the national average rate. Wyoming's HCBS program grew from 318 recipients on June 30, 1992 to 1,112 recipients on June 30, 1999 (250%), while nationally HCBS recipients grew by 320%.

The types of places in which Wyoming's HCBS recipients live vary somewhat from the national tendencies (Prouty & Lakin, 2000). In June 1999, based on reports from 43 states, nationwide an estimated 38.7% of HCBS recipients lived in residential settings that were owned, rented or managed by the agency that provided residential supports to the HCBS recipients. This compared with 28.8% in Wyoming. Nationwide an estimated 31.4% of HCBS recipients lived with members of their own family, as compared with 36.2% in Wyoming. Wyoming ranked above the national average in the proportion of HCBS recipients living in homes that they themselves rented or owned in their own names (15.0% nationally, 29.3% in Wyoming). Wyoming's use of family or "host family" care in which people with MR/RC live in a home which is the primary home of the people who provide direct support to them (i.e., in the manner of traditional "foster care") was slightly less than the national average (5.7% in Wyoming, 9.6% nationally), although growing interest in "host family" models was noted during the site visit.

PHILOSOPHY AND GOALS

A decade after the Weston Consent Decree and Order of July 1, 1991 the most frequently noted and visible statement of principles of Wyoming's HCBS program are still those of the decree. They were:

- Services and supports shall be tailored to the distinct and unique characteristics of each class member.
- Life in the community is a basic human right, not a privilege to be earned.
- Each class member has a right to participate in normal every day life.
- Each class member can grow and develop.
- All class members and employees shall be treated with dignity.

- Class member autonomy shall only be subject to State intrusion to the absolute minimum extent necessary to receive the appropriate supports and services.
- A class member's rights shall be cherished, valued, and protected and actively promoted.
- Services shall be provided in a manner which meets the needs of class members regardless of their funding eligibility or participation in any particular government program.
- Class members, parents and guardians are expected to play an active and meaningful role in the development and implementation of appropriate supports and services in accordance with the class members' IPP.
- The system shall be strengthened by the intentional inclusion of partnerships at the federal, state, and area levels. Planning and implementation shall specify the unique role to be played by each.

The articulated mission of "Community Programs" of Wyoming's Developmental Disabilities Division (DDD), the agency responsible for administration on both community and institution services for persons with MR/RC, attends modestly to its role in realizing the Weston principles. It notes simply that "Our mission is to provide funding and guidance responsive to the needs of people with developmental disabilities to live, work and learn in Wyoming's communities."

ADMINISTRATIVE LOCATION OF HCBS

The Wyoming Department of Health is the Single State Agency for Medicaid. Within it the Office of Medicaid oversees Medicaid funded programs within the Department's 6 divisions, programs including the Division for Developmental Disabilities. The Department of Health and its Office of Medicaid maintain specific responsibilities related to the HCBS program, including oversight of compliance with federal regulations, liaison with the HCFA Regional Office in Denver, Medicaid eligibility determination (through agreement with the Department of Family Services), maintaining the Medicaid Management of Information System, surveillance for Medicaid fraud, abuse and improper fiscal management, and insurance, estate

and over-payment recovery. Although Department of Health and Office of Medicaid maintain an integrated role with DDD and other program divisions, including Aging, Mental Health, Community and Family Health, Substance Abuse, program managing divisions are allowed to operate quite autonomously. According to the state Director of Health this autonomy permits Divisions to advocate independently for budgets and manage programs from a position of disciplinary expertise.

Interviews with the state Director of the Department of Health and the Office of Medicaid Agent and staff, communicated high levels of confidence, cooperation and pride of accomplishment in Wyoming's HCBS program. Both officials independently noted the importance of the continuity of DDD key personnel over the past decade and the effects of their values, energy, skills, attention to details and sense of public stewardship on the shaping of the developmental disabilities service system, but also the effects of their example on other state and community programs as well. While the Office of Medicaid has truly delegated HCBS program management responsibility to DDD, it stays engaged in decisions, from policy to individual views itself as an advocate for persons who are Medicaid eligible who could benefit from HCBS, but who are determined by DDD, not to be categorically eligible for HCBS, often requesting specific documentation to justify denial of eligibility.

Although the Department and Office of Medicaid have scheduled retreats for "Olmstead planning," there is a strong sense among state officials that Wyoming's biggest challenges in developing non-institutional services are in services for persons with disability associated with aging, physical impairments and mental health problems. Wyoming's public advocates for persons with developmental disabilities and some community service providers on the other hand express some concern that there may be developing a tacit acceptance of institutional placement at WSTS as permanent for a significant number of people.

Developmental Disabilities Division

The actual administration of Wyoming's HCBS occurs within Developmental Disabilities Division (DDD) of the Department of Health. The Developmental Disabilities Division manages 6 programs. In addition to the Adult and Children's HCBS programs, the Division managers

the state's Early Intervention and Preschool Services Program, a targeted case management for HCBS-eligible people who are currently waiting for HCBS, a state-funded respite care program for about 100 children who are not eligible for or are on the waiting list for HCBS and the Wyoming State Training School.

The Administrator of the Division, Robert Clabby, who originally came to Wyoming as Superintendent of the WSTS at the time of the Weston suit was being filed, is viewed throughout the state as both a masterful and principled "political" as well as administrative leader. His leadership and that of his senior staff of adult and children's "Community Programs" is viewed throughout the state with high levels of trust, respect and personal regard for hard work, commitment, technical skills, shared responsibility and achievement. There are many people in Wyoming who identify many things left to be accomplished in developing and maintaining the best in services for people with MR/RC in Wyoming, but in a manner rare among states, DDD is seldom identified as either the primary impediment or solely responsible for the solution in achieving what different respondents believe needs to be accomplished.

General Organization

The Adult and Children's HCBS programs fall under the authority of the Administrator of the Developmental Disabilities Division (DDD) and Community Services Manager (Wayne Johnson). The Adult and Children's HCBS programs each have an independent manager and waiver specialists housed in the central office in Cheyenne. Working in support of all DDD Community Services programs, but principally the HCBS programs, is an Area Resource Manager and 9 Area Resource Specialists, each serving a region of the State.

The HCBS child and adult program managers have general responsibility for the implementation of the HCBS program according to federal regulations and Wyoming's approved application. They are responsible for eligibility, service development, data management, quality assurance and other functions required for program implementation. The Area Resource Specialists (ARS) have a range of street level functions related to overall eligibility determination, rate setting, and provider certification; participation on quality assurance teams and assistance to organizations in preparation for annual reviews; and recruitment,

development and support of new and existing service providers. In recent years ARSs report that their obligations have been shifting away from resource development and support and toward roles in eligibility determination and information gathering for rate setting.

Roles of the Developmental Disabilities Division on HCBS Management

In addition to what might be viewed as explicit responsibilities in HCBS management, the Developmental Disabilities Division in Wyoming has taken on a number of roles and identities that have played a significant role in shaping Wyoming's program. These are widened across the various aspects of the growth and development of HCBS in the state.

Maximize Federal Contributions

At the time of the Weston suit in 1989 Wyoming was not participating in either the Medicaid ICF-MR or HCBS long-term care programs. One of the guiding principles of the Weston settlement was that Wyoming would seek a new level of "partnership" (i.e., cost-sharing with the federal government.) In FY 1989 Wyoming was spending about 23.2 million dollars per year for long-term care, about 65% for persons with MR/RC at WSTS, and virtually all of the spending came from state funding. After a decade of partnership with federal Medicaid programs, in 1999, Wyoming reports that approximately 55.4 million dollars were spent on Medicaid long-term care programs for persons with MR/RC, (an 139% increase) while total state contributions for MR/RC service, because of the favorable federal cost-share rate of 64% federal and the aggressive refinancing of all previously state-financed long-term care services had increased substantially less.

At the time of the lawsuit, as one consequence of Wyoming using state resources exclusively for community services, funding for community services was limited. Agencies reported that $12,500 was available for adults needing both residential and day services in 1990. Comparable average funding in 1999 was about $44,000, but the state's total contribution to that increase would have been about $3,300. With the advent of Wyoming's HCBS program expectations placed on service providers with HCBS participation were substantially increased, but these have been made much more acceptable by the increased funding associated with them.

Manage Conservatively

For the most part Wyoming's HCBS administration can be characterized as quite conservative. It tends to assign substantial resources and to develop detailed procedures for administrative functions such as eligibility determination, quality assurance, plan of care development and billing. It created very specific instructions and associated manuals, newsletters, alerts, training tapes and websites associated with the implementation of these procedures. It has created computerized audits that compare services pre-authorized on Individual Plans of Care and the actual billings for service provided to assure integrity in reimbursements. The state contracts with independent Certified Public Accountants to do annual field reviews of documented correspondence between services authorized, service provided and amounts billed. It makes clear to providers that it believes fraud and abuse are real and serious possibilities and that every claim for payment faces some risk of review.

State administrators justify such extensive involvement on at 3 grounds. First, they feel the Medicaid law and regulations require it. Second, they feel that in a conservative state where public programs have ready critics, it is especially important to avoid fraud, abuse and any other source of actual or perceived mismanagement. Third, they believe that specific standards, procedures and training establish a framework in which everyone can understand and respond to known expectations so that there is reduced fear by providers being found out of compliance or accused by the state of inadequate business practice.

Public Information about Agency and System Performance

In addition to its numerous manuals on administrative procedures and expectations one of the most visible efforts in Wyoming is the public presentation of information on overall state program and specific agency performance. The specific findings of the annual reviews of the community service agencies are available to everyone in the state (and beyond) via the state DDD website and in print forms. The state DDD records and publicizes information that compares Wyoming with other states on a wide range of variables reported in national statistical programs, including MR/DD funding as a percentage of state personal income, percentage of

people receiving residential services living on settings of six or fewer residents, average per recipient expenditures for combined HCBS and ICF-MR programs.

The state HCBS program personnel have developed a remarkably active program of targeted research and evaluation of service outcomes ranging from general topics like HCBS recipients participation in supported employment, their quality of life and persons waiting for services. They also include specific evaluations of outcomes of one agency's program of support for people with dual diagnosis and another agencies development of "host family" settings. Other materials disseminated statewide about system performance include case studies of "success stories," results of consumer satisfaction surveys administered statewide by the Wyoming Institute on Disabilities, and occasional articles in the Division newsletter, "Division Broadcast."

Encourage Studying and Learning

Beyond the Wyoming DDD's active focus and substantial achievement in generating, analyzing and disseminating program relevant information it also makes a substantial commitment to an attitude of studying and learning in the state. This active learning community approach often provides a vehicle by which DDD staff collaborate with staff or provider agencies to study issues of importance to Wyoming, as well as, but beyond to the disability service world more generally. In 3-4 months subsequent to this site visit DDD staff and in-state were presenting research/evaluation data from Wyoming data sets and studies at national and international conferences in New York City, Washington DC and Seattle. In addition, during the period the Division was sponsoring a two-day provider conference. The investment in study time, travel and conference participation is viewed as a contribution to a number of important outcomes. It contributes to the level of knowledge in Wyoming, as participants learn from others at a conference. It contributes educating people about Wyoming, and as the Wyoming service system is recognized for its accomplishments, advocacy in Wyoming benefits. It contributes to people's interest in system performance and understanding of means and importance of measuring it. And finally it adds to breadth and enjoyment of work roles that can become

routine and "bureaucratic" and contributes to a sense of professionalism among those taking advantage of the opportunity

Collaborate with Advocates

Wyoming has four advocacy organization that play roles in the MR/RC service system; the PAS, the DD Council, the Arc and the Family Support Network. One of the notable aspects of Wyoming is the collegial relations and sense of common purpose among the state DDD and the principal advocacy groups. One state advocacy leader called the relationship "extraordinarily rare, if not unique" among the states with which she is familiar. This relationship has a foundation in the decision of Governor Sullivan and his administration to accept the basic contentions of the PAS in the *Weston* suit and to work together with advocacy groups and community service providers to institute major system reforms.

Advocates note that the relationship between DDD and advocates has not always been as positive as present, but that a cooperative spirit and sense of mutual respect has grown steadily in recent years. Advocacy group representatives note that over the past 3 years communication and information sharing has improved substantially and that the DDD appears to have valued more greatly the benefits to their responsibilities of working closely with the advocacy community. In addition to integrated activities the policy level, advocacy groups have representation on the DDD Advisory Council which directly advises the DDD Administrator on matters related policy and program implementation (e.g., the DOORS individual resource allocation model), specific initiatives (e.g., developing independent case management), or priorities (e.g., growing HCBS commitment to children). Clearly a major factor in the growing sense of collegiality among DDD and advocates is the growing pride, sense of accomplishment and satisfaction that Wyoming has developed a generally effective service and that all the stakeholder groups have had the opportunity to contribute substantially to its success.

Respect Established Agencies, But "Nurture" Choice

One Wyoming advocate observed that, "We [the advocacy community] lost on choice. We have choice written into everything, but we really don't have a lot of choice." While other stakeholders expressed concerns less polemically clearly the extent to which people have

sufficient options and independence to exercise the options they have is of concern to many people in Wyoming. An underlying factor in such concerns is the dominance of the larger Regional Service Providers (RSP). The RSP providers are dominant in large measure because until the early 1990s they were the only service agency serving large catchment areas. The community services available for people with MR/RC in those areas was due in large part to the resourcefulness of the RSPs. Although clarifying that she felt it was "not a systemic catastrophe," one state level advocate observed that choice is often limited by agency dominance: "Providers are so well-established. It is difficult to go up against established organizations unless something is really wrong." System-wide state DDD has decided that nothing is "really wrong" and has taken the approach of nurturing new options across Wyoming without challenging the dominance of the RSPs.

Clearly one of the areas in which provider strength is most evident is in the area of independent case management. Most case managers in Wyoming work for the agency that provides services to people with MR/RC. One DDD Area Resource Specialist acknowledged "agency case management sometimes affects people's decisions." A state advocacy group director noted that there were "instances of people being told that if you want our services you need to have our case manager" and that "there are real problems when you have your case manager based in an agency in which one is having problems."

Such issues have been evident throughout Wyoming's post-Weston development of HCBS-financed community services. As these discussions have been taking place, Wyoming has steadily developed a cadre of individual service providers and to a less extent small agencies into what state officials called a "blended system" in which larger Regional Service Providers and smaller alternative service providers can co-exist in offering options to people with MR/RC. The growth of alternative providers continues with general although sometimes hesitant support from Regional Service Providers. Advocates praise the goals of state DDD, but also note that work load of Area Resource Specialists who have primarily responsibility in this area are increasingly directed toward ICAP administration for the individual resource allocations. In the long run, however, both state officials, Area Resource Specialists, advocates and case managers share a general consensus that the individual resource allocations, low case

management "loads," growing numbers of individual and small group providers and ongoing information dissemination to case managers/service providers and consumers and families are all contributing to the nurturing of new options and greater choice in Wyoming, while respecting the valued role of RSPs as being a primary foundation of Wyoming's service system.

Work for Fairness in Access and Funding

Two efforts in Wyoming reflect a commitment to assuring equitable access to services and appropriate levels of support under HCBS. The first of these is the system that has been implemented in Wyoming to set individual resource allocation based on objective assessment of specific characteristics and circumstances of each HCBS-eligible individual. The "DOORS" model will be described in greater detail subsequently, but it has been viewed as a significant mechanism to allocate funding based on individual needs assessed in an objective and standardized way. A second effort of importance in seeking "fairness" has been Wyoming's successful effort (at least temporarily) to eliminate the waiting list for HCBS. Significant waiting lists exist for HCBS-financed community service in most states. Wyoming has in recent years had ratios of persons waiting for services to persons receiving services that are among the lowest in the nation. Wyoming expects to enter the fall of 2000 with no waiting list for services. A second major factor in Wyoming's success has been the state's overall strong commitment to service development and funding. Only 4 states had higher numbers of HCBS recipients per 100,000 state residents than Wyoming (232) and only 3 states had higher ratios of MR/RC funding as a proportion of state personal income (Braddock, et. al, 2000; Prouty & Lakin, 2000). Another key factor in eliminating a waiting list has been the cost-controls that are built into Wyoming's individual funding allocation structure. Controlling the total costs of services for persons receiving services is viewed as a key component of providing access to all. A number of advocates noted some concern that Wyoming's ability to provide access to all eligible persons derives from relatively restrictive definitions of who is eligible for services. While these advocates understand the relationship between Wyoming's tight eligibility definitions and its ability to serve all the people who meet the definition, not all are convinced that they contribute the state's goal of fairness.

SERVICES AND SERVICE PROVIDERS

One the most salient characteristics of Wyoming and a feature that affects its service delivery system is it rural nature. Only Alaska of all U.S. states is more sparsely populated. With only about 500,000 people occupying nearly 100,000 square miles Wyoming's population was noted by one state official to be less densely populated than colonial America at the time of the Declaration of Independence. Only 3 cities in Wyoming exceed 20,000 residents and none is larger than 50,000. The rural nature of Wyoming presents many challenges in service delivery and has had a substantial impact on the evolution of the state's service delivery system. One of the notable influences of Wyoming's sparsely populated nature is its regionalization of service delivery with single predominant non-profit organization serving contiguous regions. There are 9 Regional Service Providers (RSP) in Wyoming and although these are often characterized as large, in reality they are quite small by the standards of most states in their average of about 100-125 service recipients.

Prior to Wyoming's use of Medicaid to finance long-term care the Wyoming Legislature passed the Community Human Services Act, "to establish, maintain and promote the development of a comprehensive range of services in communities of the state to provide prevention of, and treatment for individuals affected by mental illness, substance abuse, or developmental disabilities…" The Act created community boards to comprehensively plan, monitor and evaluate the services provided within their regions of jurisdiction.

Even after the Community Human Services Act, in the decade before the *Weston* suit, although community services were slowly developed, the great bulk of public funds went to the WSTS, with much more limited state investment in regional community services. To develop community services the RSPs made do on limited state funds and developed local funding, charitable support and volunteer participation. As such these organizations tend to be and recognize themselves to be established, valued and trusted institutions of the communities in which they operate.

Although the primary service delivery organizations in Wyoming predated the *Weston* suit, the current Wyoming state service system now finances almost all of the services they provide as well as agency administration. As the primary instruments of implementation of the

Weston suit requirements and the Wyoming HCBS program, the operations and to a large extent the missions and goals of the regional service providers have evolved to reflect the principles, goals and requirements of the settlement and HCBS program. As Wyoming DDD has worked with the RSP to develop services, program practices and administrative/business procedures congruent with state expectations, it has also worked to develop independent providers to offer the choices and options as required by Medicaid, but also as viewed by the state as an essential component to its goal of increasing consumer and family choice.

HCBS Services Available in Wyoming

Wyoming offers a fairly standard package of HCBS to persons with MR/RC. These services include for adults: case management, personal care services (including those provided to adults by family members meeting state standards), respite cares (including in-home and out-of-home), habilitation (including residential habilitation, in-home support, [habilitation] for people living in the family home, day habilitation, prevocational services, supported employment), environmental modifications, specialized medical equipment and supplies and specialized consultation/therapy services in a number of specialties (including respiratory therapy, psychological therapy, dietician and specialized diet services, skilled nursing, physical therapy, occupational therapy and speech, hearing and language therapy. For children the same basic services are available, although families may also receive homemaker services.

Interviews with consumers, family members, case managers and advocates suggest that the range of service options is sufficient to provide individuals the support, experiences and specialized services that they need. When there are criticisms of services it is not for lack of a type of service, but the quality and creativity in their implementation. Statewide surveys of adult and family HCBS recipients confirm the same general observations. There is consistent satisfaction with general types of services available with expressions of unmet needs being one's that could be addressed within existing service categories.

Case Management ("Individually-Selected Service Coordination")

Case management or "Individually-Selected Service Coordination" (ISC) as it is called in Wyoming, is an area of notable commitment, accomplishment and some degree of

controversy. It is interesting for a number of reasons. First, people receiving HCBS in Wyoming are required to select their own private case manager from a list of approved ISCs. Second, Wyoming's relatively high payment for ISCs and relative low cost of living in Wyoming permits Wyoming to have the lowest "caseloads" for HCBS case managers in the country. Third, although ISCs must be individually selected by consumers, in most instances they are employees of the same organizations that provide services to HCBS recipients. The extent to which ISCs in such circumstances can truly act independently on behalf of a consumer is of concern to advocates and to Wyoming's small, but impressive cadre of non-affiliated independent service coordinators. Questions about whether ISCs can feel free and enjoy support to encourage the development of options that are not available from their employers or the choice of alternatives when the employing agency's services do not seem best for an individual is the most commonly raised "controversy" in Wyoming. Relatedly, observations and commitment to suggest that case managers often mirror levels of knowledge, motivation and commitment to providing innovative, person-centered services of the agencies they work for, making agency-employed ISCs most effective when they work for the more progressive agencies and least so when the work for the most traditional.

Potential of Case Management

Wyoming makes a substantial investment in case management to keep the ratios of HCBS recipients to ISCs as low as needed to provide the level of support needed. Wyoming's average ratio of service recipients for case manager (in the range of 20-25 on average) appears to be the lowest of all states (Cooper & Smith, 1998), although such estimates are complicated. The reality is, however, that by paying case managers a substantial flat fee for providing support coordination to an individual ($200 per month for children, $150 per month for adults), Wyoming makes it possible for dedicated people to make an adequate living performing the service coordination role, while serving a small enough group of people to enjoy a significant role in their personal and service lives.

Requirements of Case Management

All HCBS recipients have an Individually-Selected Service Coordinator (ISC) who they must choose for themselves from a listing of qualified individuals. ISCs are selected by potential HCBS recipients at the time of application for HCBS. ISCs initiate the eligibility assessment process and subsequent assessments as required to individual Level of Care determinations. Working with the service recipients and other team members the ISC guides Plan of Care development and revisions. The ISC is responsible for assisting the individual to obtain the services authorized in the Plan of Care including non-HCBS medical, educational and other needed services, and to obtain HCBS services from a certified provider of the individual's choosing. ISCs are responsible for ongoing monitoring of the services delivery and the quality and "client" satisfaction of the services included on the individual's plan of care. An individual may change case managers up to twice each year. The ISCs are required by Wyoming HCBS regulations to meet the federal standards for Qualified Mental Retardation Professional (QMRP), although no formal state license is issued. QMRPs by definition have baccalaureate, master's or doctorate degrees in related health, social services of educational areas and one year of relevant experience or a two year degree in a related area and two years of actual experience.

In Wyoming ISCs have substantial potential to influence and contribute to people's lives. In Wyoming each individual is provided an individualized funding allocation and with the assistance of the ISC is promised choice in planning how those resources are used, including choice in the providers of services authorized in the Plan of Care. Low caseloads, individual resource allocations and assured choice provide the basic conditions for case managers being in a role of importance in helping people exercise considerable freedom. Still, as noted, many in Wyoming question whether the promise of independence in service coordination is comprised by having a substantial majority of "independent" service coordinators employed by the dominant residential and/or day program providers. At the time of the termination of the *Weston* Settlement the establishment and definitions of "independent service coordination" was a significant issue, with the PAS advocating independence from service providing entities of all case managers. In the end "independence" in service coordinators was defined that an

individual could independently choose a service provider and that service coordinator *could be* independent of a service providing entity, but that there was no expectation of such.

A CEO of a large Regional Service Provider noted, "I am supportive of internal case management because of the ongoing communication, but I understand the other side. It's easy to overestimate what a case manager can do especially when it's hard to expect much agency competition in an area as sparsely populated as Wyoming." Others viewing case management also doubt that the primary problems in service delivery rest in the case management structure. Some advocates note the limited knowledge and low expectations on the part of guardians and case managers about what would be possible if resources were used in more creative ways. There is considerable interest in efforts to promote education on innovation for consumers, families and case managers so that more will be expected of service providers who in the words of one agency director have "not much competition [or] need to keep moving."

Targeted Case Management. Wyoming also has a small, unique Targeted Case Management Program specifically for people with MR/RC who are eligible for and waiting for HCBS of Medicaid institutional services. Targeted Case Management recipients meet the same eligibility criteria as HCBS recipients and targeted case management providers meet the same standards as ISCs, indeed, are usually the same people. The primary difference in the roles between TCM and ISC regards a) the TCM's lack of access to the HCBS supports and the need to rely on Medicaid state plan and other "generic community resources," b) the voluntary nature of TCM in contrast to the requirement of ISCs for HCBS recipients, and c) the exclusion of all forms of direct support in the TCMs role, including transportation or personal assistance in using a community resource of service.

Summary. Organizationally independent case managers are increasing in number and visibility in Wyoming. Still an estimated 80% of service recipients still receive case management from employees of the larger established regional programs that serve 82% of all adult service recipients. Obviously Wyoming officials face significant challenges in addressing the perception or reality of less independence in service selection that it might want. They have sought and succeeded in working for change in supportive collaboration with all elements of the service system. The larger Regional Service Providers feel strongly that their service coordinators can

act sufficiently independently to serve their clientele well. Perhaps equally important in most parts of the state there are relatively few options to the traditional regional agencies for residential and vocational supports, particularly for adults. Among service recipients there is relatively little, easily accessible information about alternatives to traditional residential and day services. As such the issue of whether independent service coordinators are sufficiently independent may not be the most important issue.

Service Providers

As noted service delivery in Wyoming is dominated by 9 major Regional Service Providers (RSP) supplemented with the services of a growing number of small and individual providers.

Major Regional Service Providers

HCBS and other state DD community services in Wyoming are provided primarily through 9 non-profit Regional Service Providers (RSP). Overall these 9 organizations serve over 1,200 individuals, including an estimated 900 adult HCBS recipients. Regional service providers cover broad catchment areas ranging from one to 5 counties. Each of them existed prior to the existence of the HCBS program and 7 of the 9 pre-dated Wyoming's Community Human Services Act of 1979 which was passed to "establish, maintain, and promote the development of a comprehensive range of services in communities of the state" and created broad catchment areas for human services planning, service delivery and evaluation. The RSPs became the primary mechanisms for meeting the expectations of the Act for persons with MR/RC.

Because of their long-standing role in serving their communities and broad catchment areas, their accomplishments in community program development and fund-raising prior to the availability of federal cost-sharing and their visibility, integration and connectedness with the communities served, RSP leaders communicate a degree of responsibility for their catchment areas and pride in creation of sizable thriving organizations that provide a comprehensive range of services and enjoy widespread community trust. RSP administrators are proud of the fact that their individual agencies and all their peer agencies enjoy 3-year national accreditation by

CARF (the Rehabilitation Accreditation Commission), the longest accreditation period awarded by CARF.

As a group RSPs hold an annual conference for training personnel and sharing information about innovations and operations within the various agencies. Because they are visible grassroots organizations within their local communities, they are well-connected with the legislative representatives of those communities and play a significant role in the substantial support provided for services to persons with developmental disabilities in the state legislature.

There is a respectful tension between the RSPs and the state DDD. In the state's view a Regional provider system in which a single organization provided all the services in a specified area does not meet Medicaid's requirements for choice of service providers. Although RSPs tend to recognize this reality there is also a level of defensiveness about efforts to promote, develop and support competing organizations. As a result of a state promotion, through policy, statewide training and service development efforts of the Area Resource Specialists, a large number (855) of small and individual providers have been developed to provide various HCBS, but in 1999 only 14 organizations were of sufficient size (i.e., 3 residential or day habilitation service recipients) to require CARF accreditation (McKee, 1999, p.1), and the non-RSP agencies of 3 or more residential or day service recipients averaged fewer than 8 persons each served in residential habilitation and day habilitation.

Although the established Regional Services Providers of Wyoming are large by Wyoming standards, they are of moderate size by standards of more populous states, providing residential and day habilitation services to a general range of 100-125 people. These agencies typically provide a full range of services, including most but seldom all of the authorized HCBS services (most typically excluded are certain therapy services). In addition to providing services in standard HCBS categories, RSPs exhibit a wide range of specialties and innovations. One is known nationally for its outdoor recreation program, another for its work with people who have psychiatric as well as intellectual disabilities. A number of programs offer services related to the "culture of Wyoming," notably involving large animals and outdoor activities. A number of programs operate services of visible contribution to the local community, including recycling centers.

General impressions of the RSPs among advocates and Area Resource Specialists are positive. Clearly some are viewed as more contemporary on their practices than others and there is substantial consistency in opinions about which agencies are relatively better in reflecting progressive practices. It was observed on a number of occasions, including by two RSP agency directors, that is very easy for these agencies to become isolated within their catchment area. Interviewees tended to give the state high marks for efforts in the past 3 years to break down the isolation through training and other dissemination. They noted, however, that there is a need for continued and expanded efforts. This is widely viewed as a major challenge for Wyoming because it is so sparsely populated, because existing agencies are less driven by market conditions to stay at the cutting edge of their enterprise, and because consumers and case managers are not viewed as being well-educated about reasonable contemporary expectations.

Developing New Providers

Despite the concentration of service recipients among fewer larger traditional providers, Wyoming actually has a remarkable total number of service providers. A majority of the total number of service providers in Wyoming are individuals contracted to provide one or two of the authorized services, typically respite care, in-home support or personal care (habilitation), homemaker services and/or various therapies. Currently only 6 non-RSP organizations provide residential habilitation and/or day habilitation to 3 of more individuals. Individual service providers supplement services provided by RSPs, support individuals and families when children and adults with MR/RC are living at home and provide comprehensive services to a small number of individuals.

Recruitment of new service providers in response to unmet individual needs is a primary role of Area Resource Specialists (ARS). In recent years, however, the ARS interviewed reported that their time has been increasingly consumed with management of the ICAP assessment process, because of the importance of it to the eligibility determination/redetermination process and the substantial implications that ICAP ratings have on the amount of funding allocated to each individual. One ARS expressed concern that

"paperwork is increasingly taking over our lives and less time is available to develop new resources and to learn and teach new things." Another ARS commented that the state "leaves it up to us to find ways to learn about new things."

An advocacy and agency director noted that some non-agency case managers have been particularly effective in developing options tailored specifically to the needs and circumstances. There is in this director's view great potential merit in bringing these case managers into "a more professional-to-professional" relationship with agency-based case managers to teach person-centered planning and designing and recruiting individual providers who can often better respond to people's specific needs and wants. For the most part, however, there is substantiated approval by most advocates, ARSs, case managers and service providers of the nature of change taking place in Wyoming, although differences of opinion are more evident with respect to the adequacy of the pace of change.

ELIGIBILITY REQUIREMENTS

Wyoming has designated its HCBS programs as serving persons with mental retardation and related conditions in need of the ICF-MR level of care. It has established precise standards regarding potential service recipients' eligibility under such criteria.

Eligibility Definitions

In general a person is eligible for HCBS if "the person has a confirmed diagnosis of mental retardation or related conditions." In Wyoming an individual must have mental retardation with a full scale intelligence quotient of 70 or below and an ICAP (Inventory of Client and Agency Planning) age adjusted service score of 70 or below to receive HCBS or they may be eligible on the basis of related conditions if they have a "developmental disability" and also have an ICAP age adjusted service score 70 or below. Specifically, that includes "individuals with a severe, chronic disability attributable to cerebral palsy or a seizure disorder or any other condition other than mental illness, that is found to be closely related to mental retardation because this condition results in impairments of general intellectual functioning or adaptive behavior, requiring treatment or services similar to those required by persons with mental retardation," when "manifested before person reaches age 22; is evident in substantial

functional limitations in three or more of the following areas of major life activity; a) self-care, b) understanding and using language, c) learning, d) mobility, e) self-direction; and f) capacity of independent living." "Age-adjusted" means that age-normed ICAP scores are used for children and youth to reflect their lower functional development relative to "fully-developed" adults.

In summary, to be categorically eligible for ICF-MR or HCBS services in Wyoming a person must be diagnosed as meeting one of two diagnostic standards. First a person may have mental retardation as diagnosed by a licensed psychologist, with a full-scale IQ of 70 or less *and* a service score of 70 or less on the Inventory of Client and Agency Planning (ICAP). Second a person may have a chronic condition closely related to mental retardation *and* an ICAP service score of 70 or less. (The HCBS manual identifies "cerebral palsy, epilepsy, or a neurological condition" as related conditions and in Appendix B of the manual lists in addition to mental retardation, 17 "diagnostic codes in the DSM-IV that will meet the definition of related conditions," although the Appendix B listing excludes cerebral palsy, epilepsy and other neurological conditions). A signed psychological report and/or medical report from a licensed practitioner is required.

In addition to meeting diagnostic and functional assessment criteria for eligibility "the person's needs are such that 24 hour/day supervision is necessary;" and "the person is in need of and receiving active treatment" as defined in the ICF-MR standards (42 CFR 483.440):

> "Active treatment is defined as a continuous program for each resident which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health, services and related services that is directed towards (1) the acquisition of the behaviors necessary for the resident to function with as much self determination sand independence as possible; and (2) the prevention or deceleration of regression or less of current optimal functional status."

Process of Eligibility Determination

People applying for eligibility for HCBS must establish both clinical and financial eligibility. This process begins with application to the Division of Developmental Disabilities (DDD). Upon receipt of the application, DDD instructs the individual to select an independent

service coordinator (ISC) from a roster of case managers. Once the selection is made, DDD gives the chosen ISC (or case manager) authority to begin the process of determining clinical and level of care eligibility for HCBS (or ICF-MR) participation.

Level of care eligibility is determined by the State Level of Care Committee, known around the state as "SLOCC," a committee of DDD staff and Medicaid staff. The first stage in the SLOCC's process of determining level of care eligibility is the confirmation of determination of clinical eligibility described above. The diagnostics aspects of the determination process are straightforward, the functional assessment requires brief description.

The ICAP is a central part of clinical eligibility determination, state management of information and rate setting in Wyoming. As such it warrants a brief description. The ICAP is a 123-item standardized rating scale of individuals' functional skills, problem behavior and service needs. The functional skills assessment includes domains of a) social and communication, b) personal living, c) community living and motor skills. Problem behavior includes domains of a) internalized, b) externalized, and c) asocial. ICAP psychometric testing has shown the instrument to have test-retest and interrater reliabilities in the .8 to .9 range.

ICAP scores are summarized as positive numbers on the functional skill dimension and negative numbers on the problem behavior dimension. These are combined as a weighted service score based on functional skills (.7 of the composite) and problem behavior (.3) to yield a service in the range from 1-19, "total personal care and intense supervision" to 90+ needing "infrequent or no assistance for daily living." People just outside Wyoming's cut-off score of 70 are defined as needing "limited personal care and/or regular supervision."

Wyoming allows variety in the assessment instruments and evaluators for determining eligibility and developing plans of care, but the ICAP is both required for all HCBS recipients and is further required to be completed by a state "Area Resource Specialist" (ARS). Although the process is managed by the ARS, the completion of the behavior rating scale is carried out by "a team," family members, the individual's service coordinator and/or others who have worked with the individual for 3-4 months (the later condition reportedly is not always met). Wyoming interjects careful control over the ICAP administration not only to serve its tightly controlled eligibility process and as the basis of individual rate setting, but also because it

provides foundational data for the state's well-managed and actively-used management of information system.

Although the clinical eligibility determination process in Wyoming is carefully controlled and well-managed one of the most frequently expressed concerns about the Wyoming HCBS program derives from the rigidities of its "70/70 rule" of I.Q. and ICAP service score. The state DDD notes that it has been able to administer a system with currently available funding that serves all people with disabilities so substantial that they meet the "70/70" criteria, only because they are not responsible with currently available budgets for serving people who are above the threshold in I.Q. or ICAP. Advocates understand the logic of this position, but also cite examples of ineligible persons with needs equal to or greater than those of eligible persons who are without needed support. At a meeting with the State Developmental Disabilities Planning Council (DD Council) during the site visit, it was a consensus position that the Department of Health, including DDD, the DD Council, the PAS and others need to work together to understand and address the needs of persons who are just beyond the boundaries of the "70/70 rule."

FINANCING AND REIMBURSEMENT FOR SERVICES

Financial eligibility for HCBS is determined by the Department of Family Services, which performs similar functions for other means tested programs in Wyoming. Wyoming has developed an innovative, personalized ("DOORS") system for distributing resources to individual HCBS recipients. As noted in the previous section Wyoming bases its resources for service allocations on the assessed needs as well as certain specific circumstances of each HCBS recipient. With the individual allocation established the individual and family, assisted by their case manager can develop a service plan and contract for services needed and desired by individual service recipients.

DOORS Methodology

State officials identify a number of motivations for designing and implementing a computerized model to establish specific resource allocations to specific individuals based on objective assessments of their needs and circumstances. A first motivation noted was concern

that Wyoming's rapidly growing community service system in the early 1990s was in danger of becoming too centralized in its controls, with state officials being in roles of creating arbitrary caps on allowable expenditures, reviewing cost-effectiveness of service plans for people they had never met, and negotiating rates with provider agencies. A second motivation was that despite the centralized oversight HCBS expenditures were increasing rapidly, and with what was viewed as a less than desirable relationship between expenditures and individual needs and/or to the quality of services being received.

In response to the DOORS funding model was developed to achieve 3 major goals: 1) to empower the individual family, individually-selected service coordinator, and other members of an individual's "team," to be the decision makers about how the resources available to an individual are spent to meet the person's service and support needs; 2) to establish an available amount of funding for each individual that is determined in the same fair way for all individuals based on key characteristics of individuals and their circumstances rather than the established rates of provider agencies; and 3) to establish a system capable of controlling overall expenditures.

The DOORS goal of basing funding on the characteristics of the individual not the prices established for services responded to a perception, later statistically validated, that over time people of similar characteristics and circumstances were receiving services of substantially varying total cost. The process undertaken to arrive at a rational and consistent means of establishing individualized resource allocations has gone through several stages of evolution, but essentially follows the pattern of using multiple regression techniques to establish a rate setting formula based on: 1) consumer needs including 16 unique and composite measures of individual characteristics established by the ICAP assessment (e.g. service score, deafness, severe mental illness, psychotropic medications, hand washing, wandering, street crossing, hurting self, hurting others, destruction of property); 2) services authorized for the individual (e.g. residential, day habilitation, therapies, personal care, adaptive equipment, home modifications, in-home support); 3) economic factors such as county employment rate; and 4) provider characteristics, including number of people served and agency income.

The establishment of the DOORS allocation reflects both a search for the best, most parsimonious set of statistical predictors of expenditures with rational decisions about which of those predictors pass the test of face validity. Over the years of its evolution, the DOORS model has increased in its ability to account for variability in actual expenditures. Part of this improvement in the predictive power of DOORS has been the effects of each iteration in bringing resource allocation into line with the DOORS criteria, a process begun by the recognition of "irrational allocations" in which initially less than 50% of cost variability could be accounted for by individual predictor variables. Today state officials report that the DOORS based allocations on behalf of individuals account for 89% of the variability in actual expenditures for services.

It is important to note that DOORS has not been designed as a means to promote any particular direction in service delivery. Although provider characteristics are a feature of the allocation, they are viewed in the broadest sense. Whether a person lives in a group home or his/her own apartment, or attends a sheltered workshop or an integrated job is not a factor in the allocation model. Neither is the individual allocation an "individually controlled budget" in which the individual makes independent decisions about how funds are used. State officials in Wyoming remain committed to the notion that decisions about what services are preferable should be made at the local level jointly by the individual, family, independent case manager and team members, but they are cautious about advocating the use of funds in ways other than purchasing authorized services from certified providers. Interviews with family members also indicated that the individual resource allocations in Wyoming are considerably different than "individually controlled budgets," with a number of family members in Wyoming reporting that they would be interested in finding out how funds were being spent on their family member's individual services individually and for his/her total service package.

The resource allocations generated by the DOORS model are available to the individually-selected service coordinator (case manager) and team prior to the team meeting to develop the service plan. The team works with the resource amounts available, to and the broad service categories to develop a plan of service and service providers. Because most service recipients receive all their services from the same agency, distribution of fixed resources

across specific services, including the fixed cost of case management, is more easily accommodated than it might be in circumstances where multiple providers were typically involved. But for the most part, providers seem satisfied with the amounts of resources available to individuals and suggest that dividing those resources across more than one agency can be accomplished without perceived hardship to any one agency. State officials also point out that they do retain resources in a pool that can augment the DOORS resource allocation if it is inadequate to meet an individual's needs, or if unexpected needs arise, and other intra-agency accommodations cannot be achieved.

Provider agency officials and case managers interviewed seem satisfied with the DOORS model. They feel in general that the amounts generated, by it are both adequate and fair. Such perceptions are undoubtedly enhanced by the overall enthusiasm for HCBS generally and the remarkable increases in overall public funding for community services associated with it. Perhaps more importantly, Wyoming DDD has engaged the provider community in evaluating the effects of the DOORS allocations on overall agency budgets. In general, however, with one notable exception, the larger agencies in Wyoming tend to serve broad attachment areas, not specialized subpopulations, so that balance is reported to be maintained between beneficial and detrimental allocations as compared to previous allocations.

QUALITY ASSESSMENT AND ENHANCEMENT

Wyoming has a remarkably comprehensive and well organized system of quality assurance. The Wyoming system contains several levels of review, but with a focus on assuring congruence among those levels. Importantly, DDD HCBS management personnel are fully engaged in the implementation of the Wyoming quality assurance system, including active and visible participation in the actual site visits involved in quality assurance reviews.

CARF Standards

The *Weston* consent agreement specifically required Wyoming to develop a system of assessing the quality of community services. The formal application of the current quality assurance system is, therefore, relatively new and has been an integrated part of the creation, growth and maturation of the state's HCBS program. A major foundation of that system has

been the standards and accreditation processes of CARF (the Rehabilitation Accreditation Commission) which were chosen because they represented an established and well recognized quality assessment system and because the state's Regional Service Providers (RSP) were active in the CARF accreditation program prior to the implementation of the formal HCBS requirements. The familiarity of the RSPs with CARF certification was noted as helpful in implementing the "new" requirements of quality assurance included in the Weston settlement and state officials were praised by service providers for honoring their history of CARF participation and their perceived value of the CARF standards in assisting in quality improvement through peer review.

CARF Standards and Peer Review

In Wyoming every organization providing residential or vocational habilitation services to 3 or more people must obtain CARF accreditation. The commitment to CARF accreditation enjoys wide acceptance in Wyoming and its achievement is viewed as a valued status and source of pride among Wyoming's service providers. The actual standards and processes by which the standards were developed and are monitored and enjoy broad acceptance as valuable among Wyoming's service providers. The standards are viewed as focused on important goals and achievements within agencies and providers express appreciation of CARF's orientation toward peer review, consultation and collaboration. CARF accreditation certificates are conspicuously mounted in the primary office of service providing agencies. CARF certification reviews are a major event for provider agencies and are taken very seriously, so much so that in one day program visited staff were playing "CARF Jeopardy" with clients to review with them some of the possible questions that might be asked by CARF accreditation team members and what their answers to those questions might be.

CARF standards have been undergoing substantial changes in recent years from an administrative or "process" orientation toward a consumer-outcome focus, with heightened expectations that agencies will develop procedures to gather consumer input and measure consumer outcomes. The pace of the required changes and the support available to assist providers in responding to these new standards was generally acknowledged as helpful to the

agencies and to their overall quality of services. Agency administrators expressed appreciation for the value of the effort within the CARF to replace inspections of compliance based on large numbers of detailed prescriptive standards with more general areas of performance. In general, although administrators note that the "dread of being inspected" is not entirely absent from the CARF experience, there is a sense that what is examined in the most recent evolution of the CARF process is more reflective of each agency's and the state's overall long-term goals than the CARF reviews had previously been. Introduction of the new CARF standards in Wyoming led to a number of agencies to revise mission statements, introduce elements of "person-centered planning," and develop consumer satisfaction interviews.

Although agency administrators acknowledge their respect for the knowledge, resourcefulness and commitment of state DDD personnel, they also note that there are benefits of CARF accreditation teams being made up of external members of service providing peers. One agency CEO noted that while CARF surveyors generally appreciate the realities of service delivery, including those unique to a rural state, there is no concept of "no deficiencies" or good enough on the peer reviews. Exit interviews, he reported, always include suggestions for areas to focus on to improve the agency's performance.

In sum, providers acknowledge CARF accreditation as a valuable learning process that affects how agencies think and operate in Wyoming. Accomplishment of certification, specifically 3-year accreditation is viewed as an important agency goal and source of pride. There is a sense that CARF participation also contributes to innovation in a state that is both isolated and generally conservative in areas of human services.

State DDD Reviews

On an annual basis Wyoming's DDD personnel conduct what is also referred to in Wyoming as a "CARF review." Although not done under the official auspices of CARF, this review follows the general principles, format and expectations of the CARF certification review.

The Wyoming DDD Site Review for the larger 9 regional providers typically involves a site visit team ranging from 5-8 state employees and lasts from 2-4 days. Smaller agencies may

be visited by as few as 2 people for a single day. Although these reviews follow the general format of CARF surveys, they lack the "peer review" nature of CARF surveys themselves.

Annual reviews are taken very seriously by the state DDD and by the provider organizations. They yield comprehensive and well-written reviews, substantially augmented by the authoritative and respected status of the state officials involved. The reviews are well-integrated into the culture of community services in Wyoming. Detailed results of these surveys are available to all interested parties through the DDD website and in hard copy if requested.

Following the organizations of CARF surveys, one major area of the annual review is "Standards for Organizational Quality." It focuses on organization mission, values, leadership, human resources management, community access, health and safety standards, financial practice and the organization's efforts to gather and use input from service users and other stakeholders for organizational evaluation and development. A second major area is "Standards for Achieving Quality Outcomes," which looks at the organization's internal outcome measurement system and how those measures are used to manage and improve services. "Standards for Quality Individualized Services" focuses on the way organizations involve individuals making the decisions that affect their lives and provide the kind of information and opportunities that people need for real choices. Review in this area also attends to the organizations communication about and attention to the individual rights of consumers. The review of "Standards for Employment Services" focuses on services intended to provide achieve employment goals. Agency services reviewed include identification and development of employment goals and opportunities, development of employment goals in service planning, and the identification and use of community resources to achieve and maintain employment, with attention also given to organizational efforts to tap into community employment opportunities, provide community leadership, establish systems of data collection, and review and use input from employees and employers to improve organizational performance and individual outcomes. Finally, "Standards for Community Services" attends to the organization’s efforts to assist people to access community resources, experiences and services. It includes examinations of agency efforts to develop and organize services to meet the needs and desires of the full range of people services,

and to provide information to individuals and families about the opportunities and choices available to them.

The public documents reporting on the DDD review of individual recognitions are replete with both commendations and suggestions. The latter are summarized in a concluding section of the report of the review team. Reviewing each of these reports communicates both the enthusiasm of reviewers for well-organized and innovative programs within agencies as well as their serious commitment to the health, safety, rights, inclusion and responsiveness of the service providers. Recommendations for agencies within these reports reflect the reviewers' attention to the details of regulatory compliance (e.g., "It is suggested that the agency clearly label it's spill kits and first aid kits…[and] that the kits' contents be listed and dated for possible expiration." "The organization is encouraged to follow through by having all furnaces and air vents inspected prior to use this winter. During the site review, many furnaces and vents appeared to have excessive lint and dust in them which could be a potential fire hazard").

The reports of the reviews also convey demanding attention to performance of specific expected service functions: "ISCs are encouraged to periodically observe the implementation of individual outcome and/or goals to ensure that the goals are implemented as written and intended." "Nine individual plans of care in the past year could have been enhanced by additional information about the persons serviced preferences, desires, interests and choices"). There is also frequent attention to the efficiency and quality of agency management (e.g., "[Provider] is encouraged to evaluate the logistical and financial feasibility of designated staff members providing CPR and First Aid instruction to new employees and re-certifications as opposed to outsourcing this training." "It is suggested that [provider] review and strengthen its use of individual outcomes in its overall outcome-based system in conjunction with the new CARF standards.") The publication and easy access of these reports appear to provide an additional means for consumers, families and case managers to obtain important information about the major agencies serving their communities.

The fact that these reviews are conducted in a framework established for CARF accreditation reviews brings a number of benefits. First it has allowed the quality assurance approach of Wyoming to evolve as the prevailing wisdom and expectations of the broad

disability and service provider community has changed (and become reflected in CARF standards). Although the evolution in CARF standards has not always been easy for providers their origins are not the state "bureaucracy," and their philosophic underpinnings is recognized as a reflection of the progressive evolution of the professional field. Second, the state reviews are congruent with the required CARF accreditation process so that efforts to respond to the one efficiently contributes to the ability to respond to the other. Third, in a state with limited central office resources adopting a set of national standards and review procedures that are evaluated and improved on an ongoing basis reduces the time and effort required at the central office to so the same.

Protection and Advocacy System Monitoring

As part of the *Weston* Settlement, the Wyoming Protection and Advocacy System, Inc. (PAS) was given a major role in monitoring the health, safety and quality of life of people with MR/RC. The PAS has 11 staff members dedicated to monitoring the health, safety, quality of life and services of persons with MR/RC, 2 in the state MR/DD institution, 1 in the state psychiatric institution, and 8 who are focused primarily on community service delivery. The financing of the PAS reviews comes jointly from the PAS national grant and from DDD. DDD's commitment of support for PAS monitoring is a further reflection of Wyoming's commitment to extensive quality assurance and to inter-agency responsibility for the quality of community services generally and HCBS more specifically.

Working in groups of 2-5 PAS monitoring teams visit agencies annually and within agencies individual service sites and samples of service users. Usually visits are on an announced basis, but with unannounced visits were recently added as an option as they are perceived to be needed.

The PAS reviews look much more of a traditional compliance review than the CARF and "state CARF" reviews. Although review teams actually visit people in their own homes, much of the review effort focuses on records. Attention is given to the quality of service plans, access and use of medical and dental services, protection of rights, and assuring that services

correspond directly to specific goals. The PAS reviews are guided by a "Client Monitoring Form" which structures the areas of the review.

Questions on the PAS' Client Monitoring Form ask reviewers to determine findings such as: “Has appropriate individual signed all documents (Guardian, Client if no guardian)?”; “Did Client choose ISC [Individually-Selected Service Coordinator]?…”; “Is there a goal/objective for each "Service Available" which has been checked on the Clients IPC [Individual Plan of Care]?…”; “Does Client's goals/objectives address 3-5 most important needs as identified on his/her current IPC?”; or “Are "Current Medications" listed on Client's IPC still current?"

Although some items in the PAS monitoring address procedures and outcomes related to enhancing community inclusion, they too are quite compliance oriented, such as “Is there information to support the percentage of time, as documented on the Client's IPC, when the Client spends time with people, at least half of whom do not have developmental disabilities?…”; “Does IPC document barriers to increased community integration?”; “If barriers to increased community integration are documented, are plans in place to overcome those barriers?…”; “Does the Client express a positive attitude re: residential placement? Day habilitation placement? Employment?”

Attention is given to general issues of well being through items like: “Are Client's living accommodations suitable to his/her needs?” or “Are required health and safety needs for this individual being met?” In this review the individuals’ specific goals and objectives are also inspected to see that they are a) "measurable," b) "charted as prescribed," c) elicit Client growth/achievement and d) report a "methodology" for implementation.

Although the "Client Monitoring Form" appears somewhat incongruent with the CARF approach, actual reports of site visits appear much more friendly and insightful than the monitoring form might lead to expect. Concerns are detailed and include such items as dirty linen, smells of urine and people capable of doing so not having keys to their own home. Expressions of "fun to watch," "pleased to see," "appreciated" are sprinkled through reports that also raise concerns about the basic attention to people's safety and well-being. One individual

engaged in the PAS monitoring observed that it is remarkable how much the PAS and DDD reviews agree with respect to the positive aspects and problems in individual agencies.

In addition to regular reviews the PAS staff respond to specific complaints primarily with adult service providers. Within the *Weston* settlement there had been established an Ombudsman role for reporting complaints about this system. This position was eventually eliminated with the expiration of the settlement. Although one PAS official considered the loss of that position a detriment to consumer protections, the consensus around the state appears to be that PAS services are more than adequate in resources and commitment to accomplish the intent of that role.

Internal Agency Outcome Measurement

CARF standards, Individually-Selected Service Coordinator (ISC) regulations, and consequently those of the annual DDD site visit require provider agencies to gather and use stakeholder satisfaction and consumer outcomes to assess organizational effectiveness, efficiency and satisfactoriness to consumers and to use such information for continuous improvement of overall service design and/or delivery. Review of the various agency instruments and methodologies reveal considerable variation among the agencies in the nature and quality of consumer input in such surveys-from substantial to none. This observed variability in settings visited was confirmed in reviewing the annual survey reports by DDD on agencies that were not included in the site visit.

The development and use of internal outcome measures by agencies is clearly an important expectation of CARF and an area of consistent focus in the state's annual reviews. Agencies that have developed adequate systems for consumer input are commended and those that have not are encouraged to do so. Commendations include: "[Agency] has for a number of years, made use of formal program evaluation reports. Key [agency] staff members have received training on the newest approaches in program evaluation from CARF;" and "the organization has continued to refine its program evaluation system to include some latest enhancement on the Commission's standards [and] displays well designed graphs showing the high level of satisfaction among those served in a variety of services." One agency with an

inadequate system of consumer input received a recommendation that: "The organization is urged to enhance the overall outcome measurement system for each program…incorporat[ing] and us[ing] information gathered from its various stakeholders."

Clearly as Wyoming's agencies prepare for and undergo CARF accreditation reviews, more consistent attention has been given to performance measurement systems. This expectation that agencies develop, implement and use systems designed by and for the specific agencies appears well-accepted and well-meshed with the service delivery culture of Wyoming.

In addition to outcomes as experienced and reported through consumer interviews and questionnaires, agencies also display performance through monitoring of individual and organizational objectives. These are reported in statistics related to the agencies service delivery. Examples include: in percentages of residential, employment and/or day habilitation goals achieved, percentage of service recipients in integrated work settings, percentage of people needing adaptive equipment who received, average number of residents per home and average earning of employment program participants. Examples of administration performance on specific goals include measures of staff turnover and longevity, overtime wages, total people served and revenues, and so forth. Agencies consistently use the organization performance measures to set goals and measure progress overtime. These are consistently summarized and available. When they are not, the state DDD "encourages" them to do so.

Consumer Satisfaction Survey

In addition to accreditation, state DDD, PAS and internal agency reviews the Wyoming Institute on Disability, University of Wyoming, has conducted periodic surveys of "consumer satisfaction" with HCBS. These surveys ask service users and family members to rate from "very satisfied/good" to very dissatisfied/bad" the quality of HCBS-financed support generally and also specific HCBS services. The surveys also ask about needed services that are not received. This report is submitted to the DDD. Responses to this survey are quite positive more so for children's services than adults, and it reinforces the state's current HCBS practices. It also reports verbatim consumer comments relevant to the HCBS program. The most frequently recurring comments had to do with difficulties in recruitment and retention of support

and related issues of low wages for personnel and limited numbers of independent providers from which to choose. In general, the survey is quite brief and reports from it are often summarative, including all of the comments made by respondents. Specific breakdowns are provided by agency, region or organization. While there appears support for the notion that the survey is a "good idea," a number of people interviewed stated that they did not know how the survey and its results were actually being integrated into program development or modification within DDD.

CHALLENGES IN WYOMING

In the visit to Wyoming interviewees identified a number of areas which they considered challenges in the continued progress of Wyoming toward the system of increased options, freer choice, increased inclusion, fairness, security and stability that were commonly articulated goals throughout the state. After visiting stakeholders in Wyoming there is no temptation to view these as challenges that are more for responsibility of DDD than other parts of the developmental disabilities system, but they are obviously part of the responsibilities of DDD in administering the HCBS program.

Information

Wyoming has developed a remarkable commitment and capacity to develop and disseminate information related to policy goals and service provider performance against quality assurance standards. Interviewees note, however, that information for consumers, especially consumers of adult services, that can increase knowledge of existing and potential options and raise expectations about developing and achieving personal goals is still very limited. A commitment to better opportunities for consumers to develop personalized vision of their future with high expectations through information about real possibilities is an expressed need, one that is particularly compatible with the spirit of interagency trust and desire for collaboration. It was noted that different information projects exist, but they have limited coordination, different messages and different audiences. A member of the Developmental Disabilities Council who is an experienced self-advocate spoke with enthusiasm about videotapes and training about person-centered options that she has experienced in self-advocacy outside the state that she

would like to see available to more people in Wyoming. It was clear in speaking with people across the state that Wyoming has a much stronger family support and training network for children than is presently available for adult self-advocates and their families. Efforts to strengthen the network for adults and their families seems likely to assist in promoting the "demand side of quality" in Wyoming's services, and will help avoid what a parent on the DD Council referred to as "the jolt of transition" to the adult services system.

Real Homes

There is interest among service providers, state officials, service users and state officials in continuing to develop opportunities for people to have homes of their own and integrated employment in the community. People having homes of their own involves in part development of individualized housing. Efforts to help people move to apartments of their own alone or with selected friends were evident in Wyoming as were efforts to help people find homes with well-matched and loving families. But overall there was a sense closer attention and greater sensitivity could be developed about people living with people they like, having control over personal space and having their living space respected by others even if not in personal housing. During the site visit to Wyoming, interviewers were often embarrassed about going to visit people's home's and having the accompanying agency staff member just open the door and walk in. The interviewers did not know whether to acquiesce to what seemed intrusive and disrespectful or to knock individually even though the staff member did not. This sense of agency vs. resident control of homes was also evident in establishing administrative spaces, bulletin boards of staff schedules and agency rules in the middle of home's communal living space, and by posting certificates and other documents in places that most real homes would have paintings, posters or pictures of family, friends and enjoyable experiences.

Real Jobs and Meaningful Days

There is considerable interest in Wyoming about improving supported work opportunities for adults. Fortunately there are also agencies in Wyoming that have been quite committed and successful in developing employment programs. Because Wyoming DDD has been cautious in its adherence to federal regulations, it has financed less supported employment

with HCBS than other states did during the period in which employment programs were finally excluded from Medicaid financing (except for people leaving institutions). Wyoming now offers supported employment services under HCBS and at the state level use of the option is being promoted. Advocates note, however, that not all service users and their families know of the option and that possibilities are changing. They observe that there is substantial need for education and promotion of work alternatives. Interviews with HCBS recipients support the views of these advocates. In interviews consumers frequently speak of boredom and "not doing anything in day centers" and a number of parents of adults shared that same view. Agency administrators and service coordinators talk about community activities and how people like to get out of the center and into the community, but differ in perception with day program participants about the extent to which this happens. Statistical indicators suggest movement in positive directions. Since the spring of 1998 the percentage of reported integration among day habilitation service recipients has increased from 12% to 17% and reported employment integration has increased from 21 % to 27%. Since regulatory changes in the adult HCBS program have allowed paid work, 136 people have added prevocational and 45 people have added supported employment to their Individual Plans of Care (IPC). These changes were in the view of the DDD Adult Services Manager due in part to the "Out of the Box" advocacy group of the State Development Disabilities Planning Council that has been committed to and engaged with DDD around these issues for the past two years. In the DD Council's meeting with the site visit team it recommended that state officials and advocates work even more closely together to promote work as a goal and involve provider organizations that have been successful in job development, employee support and fostering peer job "coaching" in educating and assisting others.

A threshold and uniformity of quality

Regional service providers still dominate the services in Wyoming and in large measure determine the options and quality of the services people receive. RSPs are similar in that they reflect the history and flavor of the regions in which they operate and appear to be consistently valued as parts of their communities. But RSPs are also viewed as quite different in the quality,

outcomes and choices reflected in the services they provide. Some agencies appear relatively progressive and aware of changes in philosophies, goals and achievements of services outside of Wyoming, others are more traditional and reflect much less of the evolving sense of quality in service delivery. Obviously one of the challenges in Wyoming is to promote progressive ideas, goals and attitudes within agencies so that there is a threshold of quality available to people wherever they live in Wyoming. This involves finding ways to spread ideas that originate in different areas of the state (e.g., host family models, employment programs, day programs that engage people in community volunteer activities, active outdoor adventure/recreation programs).

Another related challenge is wider access to certain exceptional, but localized resources. As an example, an interesting young man with dual diagnoses being served by the Mountain Regional Services, (MSRI) Agency was experiencing remarkable outcomes in competitive employment and community living, but wanted very much to live closer to his family in another region of the state. Finding ways to transfer the specialized skills like those of MSRI staff to other localities through staff development and training, including distance learning and the "telepsyc" video consultation is of substantial potential benefit to allowing people to live near and often with people who care about them. As an example of this potential, during the last five years DD Televideo conferencing has included 85 individual consultations with not one of the subjects of these consultations subsequently being admitted to a state institution.

Sufficient Numbers and Quality of Support Staff

Interviewees throughout Wyoming indicate that Wyoming shares with other states growing difficulty of recruiting and retaining direct care personnel. The problem is reported to be more serious in some regions than others, especially those with relatively high rates of employment, but few service providers do not consider it a significant challenge and ongoing issue in meeting current needs and anticipating continued community service growth. One human resource coordinator spoke of having participated in a workshop just the day before on the topic of recruitment and retention and noted that materials are now more readily available on the topic that assist with agency level efforts. Unfortunately such materials or the experiences of interviewees offered simple solutions to the growing problem. Pay is viewed as major factor.

Pay derives primarily from per person resources allocated for services. There were some opinions that efficiencies were possible that might make more resources available to staff or require fewer staff, including models like "host families", promoting partial independent living, paying peer workers as job coaches, allowing families to be their own case managers, but the only consensus appeared to be that recruitment and retention is a statewide issue that should involve all the stakeholder groups.

Training was also an area of concern. Advocates expressed concern about the basic delivery of training and a concern about its quality and consistency, but they were also concerned about the extent to which the training provided to people delivered the knowledge, skills and attitudes needed to implement the kinds of person-centered services desired. Again it was noted that agency and regional variations are substantial and that ultimately training reflects the culture and commitment of the individual agencies. Initiatives to cut across the boundaries of agency culture would require much more active participation of state DDD and stakeholder groups in staff training through regional conferences, internet-based training, publications written for direct support staff and other statewide initiatives.

SUMMARY

Wyoming's accomplishments in the decade since the *Weston* settlement and its entry into Medicaid long-term care financing programs has been remarkable and is a deserved source of considerable state pride. People throughout Wyoming are willing and eager to recognize each other a playing important roles in the development and continuation of Wyoming's strong and productive commitment to people with developmental disabilities.

Respondents throughout Wyoming are highly complementary of the post-Weston administration and direction of developmental disabilities services and specifically of the uses of the Medicaid HCBS program to achieve such outcomes. The leadership of the Developmental Disabilities Division enjoys a high level of trust, admiration and high personal regard for its hard work, commitment, technical skill and achievement during the past decade. Among the noted accomplishments of the Division, have been the well-organized administrative structure it has created; the information and guidance it has developed about the processes of HCBS

participation; the information resources it has developed and disseminated about the expectations and outcomes of the HCBS program; the accessibility, responsiveness, high levels of knowledge and technical skill of staff officials and the high levels of time and energy they commit to making the system work; and the continuing press to attend to the individual with developmental disabilities as the central concern of the system.

People who were involved in Wyoming's community services from before 1990 speak with pride and even wonderment about the transformation of developmental disabilities services in the past 10 years. They note many improvements yet to be made, but they speak with confidence that Wyoming's infrastructure of shared values; mutual respect among stakeholders; strong service provider community; state and local community political support; commitment and technical systems to address fairness in access and resources; comprehensive and performance focused approaches to quality assurance and other elements will allow Wyoming to achieve the needed improvements.

REFERENCE

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