A Review of the Medicaid Home and Community-Based Services Program in Louisiana for Individuals with MR/RC

Final Report

Submitted to:
Health Care Financing Administration

Submitted by:
The University of Minnesota Research and Training Center on Community Living

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INTRODUCTION

This report summarizes findings and observations of a site visit to Louisiana 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 (HCBS "waiver") program serving individuals with mental retardation or a related condition (MR/RC).

All states have been expanding their services to individuals with MR/RC and their 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 HCBS "waiver", 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.

The HCBS "waiver" program grants states 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), and 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.

The non-institutional services that can be provided in a 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 that 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 percent) 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. Since 1992, HCFA has relaxed the previous administrative requirements that HCBS waiver applications show reductions in projected ICF-MR residents and expenditures roughly equal to the projected increases in HCBS participants and expenditures. As a result, there has been dramatic growth in the number of HCBS participants. On June 30, 1999 states provided HCBS to more than four 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

While it is committed to promoting non-institutional services, the Health Care Financing Administration has relatively little information about how states organize and deliver HCBS or about the effectiveness of services in contributing to the health and well being of those who receive 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. The team conducted site visits to six 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 to 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 Louisiana's Medicaid HCBS program. The study was conducted February 21 to February 25, 2000 by Amy Hewitt (team leader) of the University of Minnesota, Beth Jackson of The MEDSTAT Group, and Steven Lutzky of The Lewin Group.

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, he proportion of all ICF-MR and HCBS recipients served in congregate housing, and the location of the state. Based on these factors an 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 Louisiana 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 Louisiana 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 Louisiana

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 the 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 Louisiana attended to broad HCBS program design and implementation, including:

- 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?
- What are the origins, design, internal organization, financing and program relationships of the public and private agencies delivery HCBS and how and what is the extent of their cooperation, coordination and co-involvement with each other and with the state in pursuing the principles, goals and objectives established by the state for the HCBS program?
- 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?
- What are the primary accomplishments and challenges facing the state and its HCBS provider 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 Louisiana'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 protocols 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 protocols 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. The following documents were gathered and reviewed for the Louisiana case study: 1) State agency brochures regarding HCBS and other related services, 2) State of Louisiana Licensing Requirements for Client Placing Providers – Supervised Independent Living, 3) Waiver Rewrite Recommendation Committee: Report to the Secretary, 4) Section 1915 Waiver Requests dated April 1, 1990 and May 20, 1999, 5) Division of Home and Community Based Services Waivers Policy and Procedure Manual, and 6) User Manual for Waivers Prior Authorization System, June 1999.

Coordination of the Site Visit and Collaboration with the Department of Health and Hospitals' Division of Home and Community-Based Waivers

The logistical arrangements and scheduling for the site visit were arranged by Linda Wascom, Health Services Financing Policy Analyst of the Waiver Management Unit. Ms. Wascom arranged for the site visitor interviews with State officials and Parish representatives. Waiver Operations staff arranged for interviews with Parish staff, provider agencies, family members and individuals who receive services. Amy Hewitt (lead site visitor) arranged for the interviews with advocacy organizations including the Protection and Advocacy organization, Arc of Louisiana, self-advocates, Families Helping Families and the Governor's Council on Developmental Disabilities. The State personnel, regional staff, provider organizations,

advocacy groups, families and individual service recipients were all extremely helpful and willing to discuss Louisiana HCBS with the site visitors. Their time, enthusiasm and commitment were greatly appreciated. In particular, the advocacy agencies were willing to rearrange their schedules, solicit participants and meet with site visitors, even when given very short notice of the desire to conduct these interviews.

Review of the Draft Report

The initial draft of this report was provided to selected key Louisiana State informants. They are in the process of reviewing the draft and will provide corrections, criticisms, and questions to the site visit leader. Clarifications will be accomplished through follow-up correspondence and telephone interviews. Appropriate corrections to the draft report will be integrated into the final report.

Selection of Sites and Interviews

The selection of the sites that were visited in Louisiana was coordinated by site visit staff from the University of Minnesota and Lynda Wascom, Health Services Financing Policy Analyst of the Waiver Management Unit, who served as the site visit key contact. Two primary geographic regions were selected for the site visit including Region II – Baton Rouge and Region VI – Alexandria. However, it should be noted that a number of the provider, case management and advocacy organizations provide services across many Parishes (regions). Additionally, a state-organized provider meeting was observed by site visitors in Region II. During the site visit, interviews were conducted with the following individuals or groups of individuals:

- State and regional Medicaid Waiver Management and Operations staff
- State and regional OCDD staff
- Protection and Advocacy Agency - Director
- Arc of Louisiana - Executive Director and Board Members
- Self-Advocacy Organizer
- Families Helping Families - Executive Director and several state and regional members
- Governor's Council on Developmental Disabilities – Executive Director and several members

- Five case management agencies
- Six provider agencies
- Three direct support staff
- Six family members of service recipients
- Eleven service recipients

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

All respondents were promised anonymity and service recipients were asked to provide written informed consent. 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. It was also made clear to all interviewees that site visitors 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 that form the interview protocol. Major areas of inquiry that are reflected in the outline of the report include: 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 faced in Louisiana" has also been added.

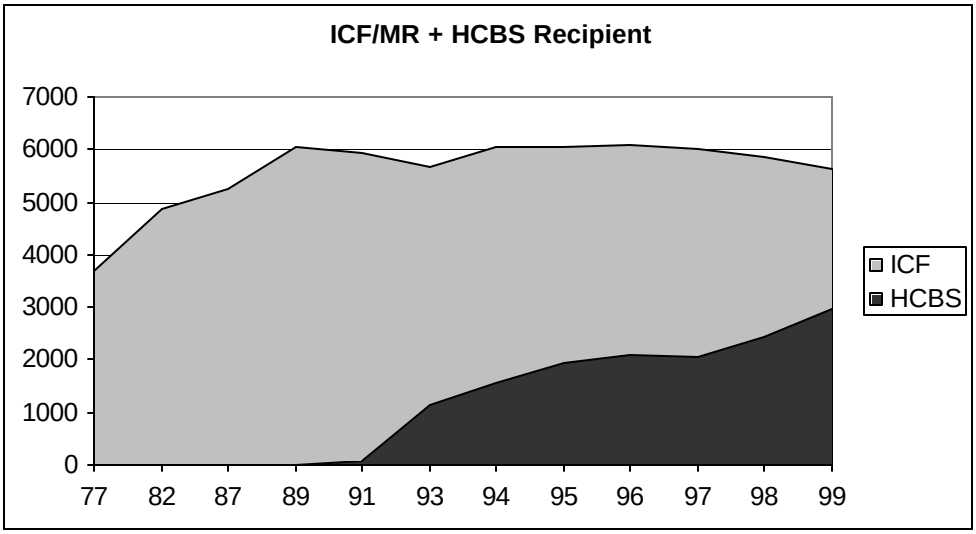
CONTEXT OF LOUISIANA'S HCBS PROGRAM

History and Utilization of Long Term Care for Persons with MR/RC

Louisiana began later than the rest of the country providing HCBS for persons with MR/RC. Their application was approved in 1990, but they did not begin offering waiver

services until 1992. The initial use of the HCBS waiver was to convert apartment training programs that had previously been funded solely by state funds to HCBS. During the first four years of the Waiver program in Louisiana, the number of recipients grew from 56 people in 1991 to 1,926 people in 1995. Growth in Louisiana's HCBS waiver slowed thereafter with the program growing to 2,407 recipients in 1998. Additionally, unlike many states that have seen a simultaneous growth in HCBS and decline in the number of ICF/MR services provided, Louisiana has experienced a steady growth in both ICF/MR and HCBS over the past eight years as is indicated in ***Figure 1*** (Prouty & Lakin, 2000).

Figure 1. Louisiana ICF/MR and HCBS Recipients



Source: Prouty & Lakin, 2000.

In 1999, the year prior to the site visit, Louisiana had 1,751 people with MR/RC-RC still living in state-operated institutions; 5,627 people living in public or private ICF/MRs; 1,267 people with MR/RC-RC living in nursing homes; and 2,973 people with MR/RC-RC receiving services funded by HCBS. Of these individuals, 2,304 lived in small residential care places with six or fewer other people; 779 lived in homes with 7 to 15 people; and 2,753 people lived in residential care places where 16 or more people live. The overall utilization rate for people with MR/RC-RC per 100,000 of the population was 134 (Prouty & Lakin, 2000). In addition, approximately half of the recipients of the HCBS MR/RC waiver in Louisiana were children.

Department of Justice Oversight with Pinecrest and Hammond Developmental Centers

Since 1995, the Federal Department of Justice (DOJ) has maintained oversight of the services provided at Pinecrest and Hammond developmental centers in Louisiana. This involvement has never reached the point of formal litigation and DOJ and OCDD are working toward reaching a settlement without litigation. At the time of the site visit, a settlement agreement appeared to be near completion. Since the time of the site visit, this effort has been slowed somewhat due to OCDD budget cuts and a recent re-organization of the Medicaid Waiver Unit that has resulted in a significant decrease in the amount of OCDD regional staff. This decline in the number of OCDD staff is reported to be of concern to DOJ. The involvement of DOJ in Pinecrest and Hammond and the desire on the part of the State to reach a settlement agreement has influenced the decision to give people who currently live in large institutions priority for waiver "slots."

Waiver Services Beyond MR/RC.

Louisiana is authorized to provide four different HCBS waiver programs. All four of these programs are managed out of the Department of Health and Hospitals, Bureau of Health Services Financing. In addition to their MR/RC-RC Waiver program, Louisiana also has Adult Day Health Care (ADHC), Personal Care Attendant (PCA), and Elderly and Disabled Adults (EDA) Waiver programs. These three additional Waiver programs are briefly described in the following paragraphs.

Adult Day Health Care Waiver. Granted in 1985 and in its fourth contract period, this Waiver targets adults and elderly Medicaid recipients who choose HCBS as an alternative to a nursing home. Adult day health care, which has to be provided at a licensed health care facility on a daily basis, is the only service offered under this Waiver.

Personal Care Attendant Waiver. This Waiver was first authorized in 1992 and has been renewed one time. Adults with disabilities currently served by an Independent Living Center, which receives funds under Title VI of the Rehabilitation Act, and who are deemed nursing home level of care are eligible for this waiver. There are only three designated centers

that meet these criteria in Louisiana, however, they are reportedly able to meet the needs of people across the state through satellite offices.

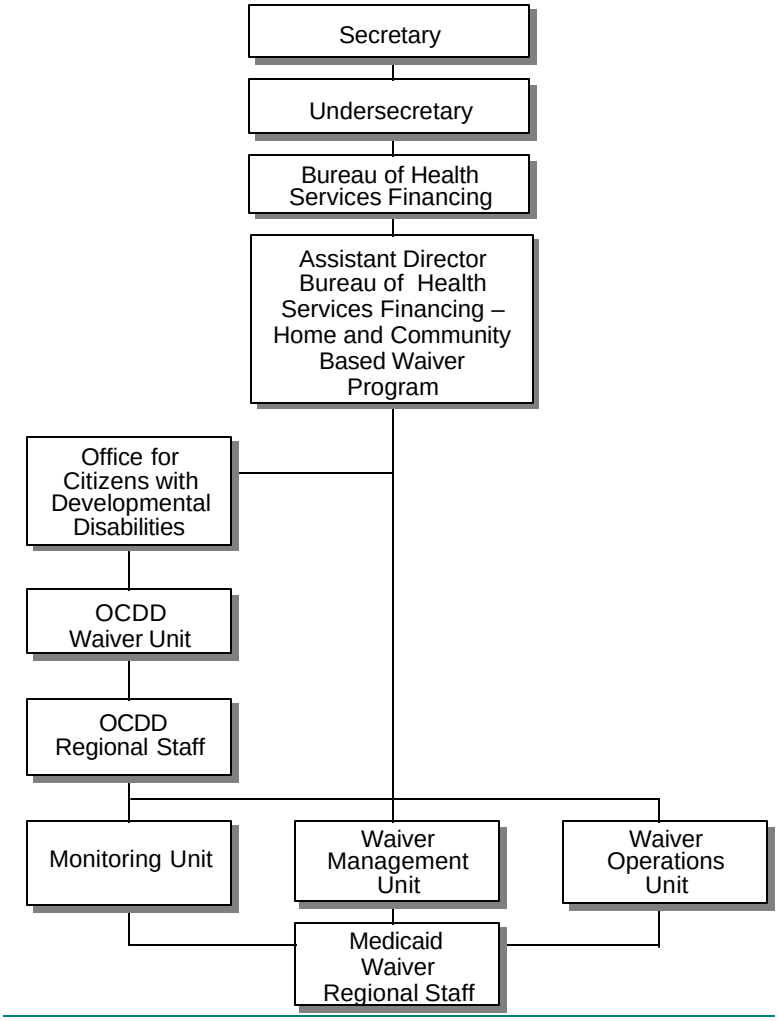
Elderly and Disabled Waiver. The Home Care for the Elderly Waiver was first approved in 1993 and was renewed in 1996. In 1997, this program was expanded to include younger adults with disabilities. To be eligible, a person must meet nursing home admission criteria and be able to be served sufficiently and safely under the services extended through this Waiver program. Available services under this Waiver program include: case management, personal care, household supports and personal supervision, personal emergency response system, and environmental modifications.

ADMINISTRATIVE LOCATION OF HCBS

General Organization

The Medicaid Home and Community Based Waiver Program falls under the administrative responsibility of the Secretary of Health and Hospitals within the Louisiana state governmental structure. Responsibility for the MR/RC waiver is split across two units that are located in different Department of Health and Hospital Divisions and are housed in different buildings. These two divisions are the Medicaid Waiver Unit, which is responsible for the management of all four of the HCBS Waiver programs in Louisiana, and a unit focused on the MR/RC waiver within the Office for Citizens with Developmental Disabilities (OCDD). Though separate units, ultimately both report to the Secretary of Health and Hospitals. ***Figure 2*** presents the organizational structure of the Medicaid Home and Community Based Waiver program in Louisiana.

Figure 2 Louisiana Medicaid HCBS Organizational Structure



The Commissioner of Health and Hospitals decided in 1998 to develop a separate Division within the Bureau of Health Services Financing that would be solely devoted to developing, managing, and overseeing the operations and monitoring all of the Home and Community Based Waivers including the MR/RC Waiver. While this reorganization may have facilitated coordination across waivers, it created a separation of authority for the MR/RC waiver between the waiver agency and OCDD that was still problematic at the time of our site visit. In addition, just prior to the development of this new division within Health and Hospitals, several administrative positions related to the waiver turned over, including the hiring of an OCDD Director and several staff in key leadership roles within the Division of Health and Hospitals. At the time of the site visit, the position of Waiver Division Director was occupied by an interim

staff person who subsequently declined and announced that she was leaving the Division. A new permanent director has since been appointed.

Both the Medicaid Waiver Unit and the OCDD have regional (Parish) offices where local personnel are engaged in eligibility determination and referral. The State Medicaid Waiver Unit is divided into eight regions and, for the most part, the OCDD regional offices are similarly located and divided; however, OCDD has ten regional offices.

Roles of OCDD Waiver Unit and the Medicaid Waiver Unit in HCBS Management

Medicaid Waiver Unit/Division of Community Based Waivers Regional Offices. The Medicaid Waiver Unit has the primary responsibility for administration and financial management of MR/RC HCBS in Louisiana. In this role, they develop all policies and procedures for the program, write the MR/RC HCBS proposals and amendments and serve as the primary liaison between the regional Health Care Financing Administration staff regarding the Louisiana waiver. The Medicaid Waiver unit also approves financial eligibility and authorizes services and approves all plans of care for HCBS waiver recipients. In addition, the unit serves as the primary liaison between Health and Hospitals and their fiscal intermediary, Unysis. In this capacity, they are also responsible for ensuring that management information systems are working adequately and they provide assistance to providers with billing issues and problems with prior authorization. The Medicaid Waiver Unit also identifies approved vendors of HCBS services and contract with outside organizations to provide case management. The Medicaid Waiver Unit together with OCDD regional staff, conduct pre-certification home visits for all newly eligible recipients. These visits are designed to where they place particular emphasis on ensure the feasibility and safety of the services identified in the plan of care.

The mission of the Division of Home and Community-Based Waiver within the Department of Health and Hospitals is to: "ensure that resources dedicated by the Louisiana Legislature for community-based services are effectively and efficiently delivered and received by eligible recipients." Similarly, the goal of the Medicaid Waiver Division is to: "create and maintain an organizational structure necessary to efficiently administer home and community-based waivers operated by the Department of Health and Hospitals. In addition, to ensure that

quality health care services are provided to waiver recipients through monitoring, when appropriate, and to ensure that corrective action is implemented in a timely fashion."

OCDD Waiver Unit/OCDD Regional Offices. The OCDD is the state governmental agency that is ultimately responsible for administering and coordinating all non-Waiver and non-private ICF-MR services and supports to citizens with MR/RC. These services include nine state developmental centers (institutions), thirteen community homes that are associated with the developmental centers and a wide array of state funded services, such as day habilitation, supported employment, individual employment, group model employment, individual and family support, cash subsidy, early intervention, supported living, and extended family living. Consumer advocates contended that OCDD is the state agency that seems to be "on the pulse" of the issues that are important to citizens with developmental disabilities in Louisiana. This agency is charged with collaborating with key stakeholder groups to conduct future planning and to identify ways of strengthening the entire support system for citizens with MR/RC. OCDD provides technical support and training to provider agencies, governmental agencies, case management entities, direct support personnel, families and other interested stakeholders on issues related to quality community support.

The OCDD Waiver unit has both state and regional level staff that serve as the point of entry for HCBS in Louisiana. The OCDD maintains the waiting list of people who want HCBS services and they also determine if the individual who is applying for services meets the state's definition of mental retardation and/or developmental disability. OCDD regional staff assist individuals in applying for Medicaid and SSI benefits. For individuals who are entering HCBS from state institutions, specially trained OCDD transition staff provide intensive case management services. For all other HCBS recipients, OCDD staff help consumers or their representatives identify and select a private sector, case management agency. The vision of OCDD is "to ensure a person-centered approach to services for individuals who have developmental disabilities which empowers individuals to more fully experience quality of life and achieve maximum potential; to be a leader in providing and promoting quality service delivery system that provides opportunities for individual choices; and to serve as Louisiana's primary resource on state-of-the-art services."

Fragmentation. Interviewees contended that the Medicaid Waiver Unit and the OCDD Waiver unit have different and somewhat incongruent philosophies and that their respective roles, different locations, and differences in the knowledge and experience of their personnel often exacerbate the extent to which these two agencies fail to work together. Consumer representatives, providers, case management agencies and state personnel all expressed the belief that these differences in philosophy, expectations, experience and roles lead to what could be considered a fragmented MR/RC HCBS system within Louisiana. One of the biggest issues pointed out by numerous stakeholders was differences in the perceptions about who could be "safely and feasibly" served in the community through MR/RC Waiver services. Stakeholders consistently indicated that the Medicaid Waiver Unit staff come from a financial and medical background and often take a more conservative approach to this determination whereas the OCDD staff come from a more person-centered approach and feel strongly that people with MR/RC, irrespective of their level of functioning, can and should be served in the community through the MR/RC Waiver program. One interviewee summarized this fragmentation by stating that the "Medicaid Waiver Unit was developed so that they [the Medicaid Waiver unit] would have the fiscal responsibility and ultimate accountability that would balance out the liberal ideology of OCDD."

Another commonly stated opinion from stakeholders was that changes in policy and procedures often would be made by the Medicaid Waiver Unit without obtaining input from self-advocates, other key stakeholders and OCDD. Additionally, many providers and case management agencies indicated that when procedures or expectations changed, they were often not informed of the changes by State or regional Medicaid Waiver Unit staff and rarely were any of these changes communicated in a written form. At a regional provider meeting, the site visitors observed that providers and case management agencies were extremely frustrated by this practice of not presenting written descriptions of decisions and changes in procedures. Despite several requests during the meeting for written descriptions of new decisions and changes in procedures, Medicaid Waiver staff did not agree to this.

To improve the HCBS Waiver program in Louisiana, the State recently established a "Waiver re-write group," which was charged with making recommendations on changes to the HCBS program to be included in the renewal packet for the MR/RC HCBS Waiver. This group

included key stakeholders (with the exception of self-advocates) and had a mission to "develop a comprehensive set of recommendations to assure a consumer-driven, flexible, person-centered, HCBS Waiver whose supports will ensure each individual's choice of where they live, work, learn and play." The group came up with several general conclusions about the HCBS program and made a number of recommendations to the Medicaid Waiver Unit. The group's major recommendation was to simplify the categorization of services into two service types: 1) individualized supports for adults and 2) family support. This recommended change would in turn reduce the complex authorization, billing and monitoring/auditing system required under the current HCBS Waiver plan. The recommendations of this committee, however, were not built into the Waiver re-authorization. The Waiver re-write plan was submitted to an outside consultation firm for review and independent assessment of the recommendations included within the report. At the time of the site visit, this independent review process had not yet been completed.

Both OCDD and Medicaid Waiver Unit State and regional personnel indicated that they were aware of these differences in philosophy and the fragmentation of the system. It was also noted that there were specific strategies and new practices being employed to address these differences and the related fragmentation. For example, at the time of the site visit, OCDD was hosting training on person-centered planning and individual outcomes and many of the Medicaid Waiver Unit staff were participating in the training and were encouraging others within their Department to attend. Additionally, recent efforts have been made to increase the amount of joint activity conducted by OCDD and Medicaid Waiver Unit regional staff. At the regional/parish level, OCDD and Medicaid Waiver regional staff now conduct regional pre-certification visits, engage in joint monitoring of service activities and jointly review plans of care. However, our interviews suggested that the success of these efforts differed, sometimes dramatically, in different areas of the State. Respondents consistently reported that efforts to collaborate were only working effectively in a few (2-3) of the regions. One additional strategy that was being used to further understand and address the fragmentation felt by stakeholders between these two governmental entities was the appointment of a special liaison to the Commissioner of Health and Hospitals, Raymond Jetson.

Reorganization since the time of the site visit. Since the time of the site visit another major re-organization has occurred under the leadership of the newly appointed Medicaid Waiver Director. This re-organization combined the OCDD Waiver unit and the Medicaid Waiver staff into one operational Division that reports directly to The Commissioner of Health and Hospitals and his specially appointed liaison. This re-organization was not determined in a collaborative manner with OCDD or any stakeholder groups. Approximately 16 OCDD staff (3 state level and 13 regional level) were recruited into this new Division and left the OCDD.

PHILOSOPHY AND GOALS

Purpose and Mission

As a result of the fragmentation and organizational change previously described, OCDD, the Medicaid Waiver unit and key stakeholders did not appear to ascribe to a single specific agenda or a set of specific goals. However, the Medicaid Waiver Policy and Procedure manual and the MR/RC Home and Community Based Waiver Services brochure describe the Louisiana Home and Community-Based Waiver as a program whose purpose is to offer non-institutional supports to citizens with developmental disabilities in which citizens have greater flexibility to choose where they want to live, and receive services and supports that best meet their needs while receiving Medicaid benefits. Medicaid Waiver Unit representatives emphasized a desire to ensure that recipients of HCBS were safe and could be feasibly and cost-effectively served in the community. OCDD emphasized serving children and adults with all types and levels of disabilities in the community through person-centered HCBS.

Perhaps one illustration of stakeholder opinion as to what the philosophy and purpose of the HCBS Waiver in Louisiana "should" be is summarized in their recommendations for the development of the needed components to support a person-centered HCBS Waiver program for persons with mental retardation and developmental disabilities in Louisiana:

- A commitment to the person-centered planning process as the driving force behind the comprehensive plan of care;
- A commitment to providing information as well as capacity building opportunities to individuals with disabilities and their families;

- Policies and structures that assure service and support decisions are made by the person with disabilities and by those who know him or her best;
- A commitment to intensive and ongoing training for case management, provider, and regulatory agency staff in the values and methods of person-centered planning, including the strengthening and/or creation of informal supports and community inclusion; and
- A quality assurance process that focuses on monitoring in terms of outcomes generated by the person-centered planning process.
- Eligibility Requirements
- Individuals who receive HCBS in Louisiana must meet the following criteria:
- Be a person with a developmental disability as defined by state law.[1]
- Require the same level or type of care that is provided in an institution.
- Have an individual income below three times the monthly SSI benefit rate.
- Have countable resources of less than $2,000 for an individual or $3,000 for a couple (minus any allowable exclusions).

Process of Eligibility Determination

OCDD regional staff complete a diagnostic and evaluation process (if there is not sufficient and recent collateral documents) that can be used to determine if the individual meets the functional criteria. Psychological evaluations, Individual Education Plans, Individual Family Support Plans and medical records are often obtained and reviewed to support the eligibility determination process. Once this determination has been made, the OCDD staff also screens the person to determine if they are likely to be eligible for SSI and Medicaid, although they do not make the eligibility determination.

Individuals (with the exception of people moving out of developmental centers) are then asked to choose the case management agency from which they would like to receive services.

[1] State law defines a developmental disability as "a severe or chronic disability that is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or any other condition other than mental illness, found to be closely related to mental retardation, because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, or requires treatment or services similar to those required for these persons. The disability is manifested before the person reaches age 22, is likely to continue indefinitely, and results in substantial functional limitations in three or more of the following areas of major life activity: a) self-care, b) understanding and use of language, c) learning ability, d) mobility, e) self-direction, and f) capacity for independent living." (Act 659 of the 1983 Legislature)

This case management agency is then responsible for developing the Comprehensive Plan of Care (CPOC) and for collecting any other information that is missing from the eligibility determination packet. Once the CPOC has been completed, it is given to both the regional OCDD office staff and the Medicaid Division of Community Based Waiver regional staff. The packet is initially reviewed by the Medicaid Waiver staff and if they find anything that is incomplete or raises questions, they refer it back to the case management agencies for further revision. Once the CPOC and Waiver packet are approved by the regional Waiver Division, regional Waiver and OCDD staff then conduct joint pre-certification home visits. It is during this review process that issues of "safe and feasible" are often reviewed. If the pre-certification is approved, then the Waiver packet is referred to the state Medicaid Eligibility Office for the financial eligibility determination. Once this is determined, the case manager is notified and the individual is assigned a prior authorization number.

Case management agency staff, providers and families consistently reported a five to six month wait from the time a person is notified that they have been given a "slot" to the time they actually get an approved CPOC and are able to start services. The most frequent reason given for these delays was that the CPOC is reviewed by regional Medicaid staff and returned to the case management agencies several times to be modified. Case management agencies reported that most modifications were requested to reduce the number of hours or types of supports included in the CPOC. State and regional Medicaid staff reported CPOCs are often returned after initial review due to errors in how they were completed or for "safe and feasible" issues.

Who gets Waiver "Slots"/The Waiting list. Louisiana currently has a 10,000-person waiting list for HCBS services. However, this number is likely to be inaccurate because of the way in which the waiting list was developed and is maintained. Prior to 1995, the people who were on the waiting list were not screened to ensure their eligibility for HCBS, suggesting that there are likely people on the waiting list who are not eligible for HCBS. Additionally, people who are on the waiting list might be served elsewhere by now, and not desire HCBS. The overwhelming majority of the people on the waiting list are described as individuals who want in-home family support or individual community living support and have not been living in an out-of-home placement prior to being placed on the waiting list. Reports from OCDD staff, as

well as advocates throughout Louisiana, indicate that there are very few people on the waiting list who are currently living in private ICF/MRs or state developmental centers (institutions).

Individuals who live in the community either with family or in other service settings are given a waiver "slot" based on a first-come, first-serve basis depending on how long they have been on the waiting list. People who were given HCBS slots in 1999 had been on the waiting list since December 1993 to May 1994. Once notified that they are at the top of the list and have an available "slot," people have 30 days to decide whether or not they still want HCBS. If they turn down their available "slot" then they are bumped to the bottom of the waiting list irrespective of how their circumstances might change in the future. This process creates an incentive for individuals to get their names on the list as soon as possible and a strong disincentive to turn down a slot once it becomes available in anticipation of possible future need rather than in response to current need.

The only exception to this first-come, first-serve policy was a recent decision to make 160 "slots" available for individuals who live in two developmental centers (Pinecrest and Hammond). At the time of the site visit, approximately 125 of the designated 160 "slots" for Pinecrest and Hammond recipients had been filled. Additionally, if any current HCBS recipient "slot" opens, for whatever reason (e.g., they move, die or decide to receive a different type of service), then their "slot" is made available to any person who currently lives in any of the state operated developmental centers.

SERVICES AND SERVICE PROVIDERS

HCBS Services Available in Louisiana through the HCBS Waiver

A wide variety of services are provided to people in Louisiana who have mental retardation or a developmental disability and receive HCBS. These services include:

- Personal care attendant: Assistance with bathing, dressing, eating, light housekeeping and companion or supervision services.
- Assistive devices: Adaptive aides which enable individuals to increase their abilities to perform tasks of daily living.
- Respite care: Personal care attendant services in the absence of the primary unpaid caregiver, or provides such services in a licensed center.

- Day habilitation: Services to enhance social development and daily living skills that is provided out of the home.
- Personal emergency response systems: Devices which allow emergency contacts.
- Supervised independent living: These include companions, skills training, behavior management and consultation necessary to maintain independence in the community.
- Supportive employment: Services to enable waiver participants to be employed with the necessary supports.
- Substitute family care: Support services from a family with whom the recipient lives.
- Home modifications: Adaptations to the existing home to make it more accessible.
- Pre-vocational habilitation: Day services that are provided out of the home in order to train participants in basic skills of work readiness.

We met with a number of recipients of HCBS in Louisiana and their respective families. Their stories, experiences, and situations regarding HCBS varied greatly. In an effort to illustrate the variety of types of people served by HCBS and situations in which HCBS are used, some of these stories are shared below:

(JC): This young man was in his twenties and lived with his family in their home. He had muscular dystrophy as did his brother and his father. All three of these individuals used ventilators. His mother served as the primary caregiver for JC, his brother and his father. JC received 27 hours of respite and 35 hours of PCA each week from a private provider agency. His mother said that she is "very happy with the services and that the staff who provide JC with support are competent and show up on time." JC reported that being able to get HCBS has meant that his mother gets some help and that "she is not as grouchy." He said that he rarely gets outside of the house, except to go to doctor appointments and to Wal-Mart for shopping. He said one of the biggest barriers preventing him from community inclusion was that he had a bladder problem and since his PCA/respite worker and Mom were female it made it difficult for him to be able to get to the restroom when he needed to while out in the community.

(LH): LH was a 43 year old man who lived in an apartment with his brother who also received HCBS. Prior to this, he had lived in an institution and then in a substitute family care situation. He attended a sheltered day program and worked part-time at McDonalds. He reported that he really liked living in his apartment and seemed proud when showing his key to the site visitor. He indicated that he wanted to be able to see his mother (who lived in a nursing

home) more frequently and that he did not feel safe in his neighborhood. He and his brother had 24 hour support staff.

(JL): JL was a 21 year old woman who was one of the first people to begin receiving HCBS in Louisiana. She lived with her parents and received 32 hours of PCA and 8 hours of respite each week. Her parents reported that they were generally pleased with the services she received and that the amount of support they receive was "just right." They were extremely pleased with the staff who provide PCA and respite and reported that their worker had been providing JL with HCBS supports since she began receiving them. They described her staff person as being reliable, stable and one of the family. One complaint the family had about their services was that they had to have "set" hours for respite which they reported was a "new policy." This meant that there was very limited flexibility when JL received the supports. Also, they expressed that they were never able to "relax" because they were so fearful of program cuts and weren't sure how they'd make it without the help.

(GC): GC lived with his parents and was in his late twenties. Prior to receiving supports he was on the waiting list for five years. At the time of the site visit, he had been receiving services for one and one-half years. His family received about 30 hours of respite per month. GC's mother reported that she was pleased with his respite worker, case manager and agency. She said the case manager visits about once every other month. Currently, she said GC doesn't really have any needs that she cannot take care of. But, she said she had "peace of mind" knowing that he was received HCBS, which she reported meant that “in the future when he needed support, it would be there for him through the HCBS program”.

(TX): TX was a young mother with a developmental disability who received HCBS. She lived with her two young sons in her own home that she was purchasing. Both of her sons also had developmental disabilities and received HCBS. This family had support 24 hours a day with PCA, day companion and night companion services. In addition to HCBS, she received SSI for herself and both of her children. TX reported that her HCBS staff assisted her with financial management, shopping, making sure she and her sons get to medical appointments and with raising her two children. TX was not eligible to receive dental services through the waiver or Medicaid, however, both of her sons receive these services because they are under the age of 21.

TX reported that she goes to adult education classes five times a week. She stated that she is lonely most of the time, has no friends and does not get out into the community much to socialize with others. A staff member who had provided her with supports for 2.5 years reported that she was paid $6.25 per hour (she had 10 years experience), did not get reimbursed for mileage, made less than minimum wage if she worked night companion hours, did not make overtime and put in a lot of hours for which she was not paid. At one point during the interview with TX, the site visitors heard the staff person yell, "shut up," to one of TX's children.

(TW): Site visitors met with the parents of TW who was a young man with mental retardation and significant health related issues. TW was described by his parents as having an over-reactive pancreas that was caused by seizures shortly after he was born. They reported that he spent the first few years of his life in the hospital and was the first child with this disorder to actually live. His daily care needs included: blood tests every 3 to 4 hours around the clock, insulin shots, gastrostomy care, positioning, lifting and transferring, feeding, changing adult diapers and self care. Additionally, he needed to routinely go to see medical professionals. Currently through HCBS, TW is authorized to receive 54 hours of LPN/RN care a year and 20 hours of PCA per day. TW's parents report that HCBS had, "been a nightmare and does not meet their sons needs." They reported experiences with PCA's who never showed up for their shifts, one who showed up drunk, others who fell asleep while they were supposed to be working, many who stole from the family, and some that made medication errors among other stories. Prior to turning 21, TW received a great deal more nursing care then he is currently receiving. When he turned 21, he was no longer eligible for the program that was funding his nursing care and he did not automatically begin receiving HCBS because there was no system to support an automatic transfer from one program to another when children "aged-out." It was clear to the site visitors that this family was highly strained with the care requirements of their son and they were terribly displeased with the amount and quality of the HCBS they were receiving. TW's mother reported that inadequate PCA staff skills make her hesitant to ever take a break and that she would never consider leaving TW alone in the care of a PCA. TW's parents clearly stated that they wanted an out-of-home placement for their son and they indicated that they were told by TW's case manager and many State level officials that TW could not go into a developmental center because they were trying to reduce the populations of those centers and that an appropriate ICF/MR was also not available that could meet TW's needs. The site visitors were shown a letter

in which a State level official had put in writing that the state of Louisiana was unable to meet TW's needs. TW's father had actually moved to another state to try to get more appropriate services started for TW in a different state, which had obviously increased the burden of the supports on TW's mother.

(ML): This individual was a 38 year old woman with muscular dystrophy who lived with her nephew in the home in which she grew up. She directed her own HCBS and was clearly able to tell the site visitors about her needs and her opinions regarding HCBS. ML received 24 hours support each day; at night her staff slept. She reported that she currently had seven staff people who provide her with supports and she was extremely pleased with their professionalism and with the agency from which she received services. She stated that: "HCBS keeps me out of a nursing home and for that I am grateful." Prior to receiving HCBS, ML was on Medicare, which paid for three hours of nursing support a day. The remainder of her support at that time was provided by her mother and by aides that the family paid for out-of-pocket with ML's Social Security money. ML required assistance with eating, dressing, positioning, transferring, lifting, home care, self care and she is on a ventilator 24 hours a day. One opportunity that HCBS had provided for ML was the purchase of a computer that she used to connect to the Internet and to network with other people. ML reported that she is rarely able to get out of the house and the computer had "opened the world up to me." At the time the site visitors were there, she was working on researching her family genealogy using her computer. She stated that she was often bored and lonely and wished that HCBS would fund supported employment for her so that she could work from her home using her computer.

(AF): AF was a 15 year old girl who received HCBS at home where she lived with her siblings and her mother. AF had been on the waiting list for HCBS since she was age three and had just begun receiving HCBS a few months prior to the site visit. AF attended school during the day and received PCA/respite services 55 hours per week. AF's mom was able to choose a person she knew to become AF's PCA/respite worker and then this individual was referred to the provider agency where she became an employee. In addition to AF's PCA/respite, her CPOC included environmental modifications to build a ramp and widen the bathroom and to purchase a new wheelchair that will better meet her needs. Also, AF had been able to have some needed dental work. Her mother stated that the HCBS “is good because it frees me up to spend some

time with my other children and it also means that my other children do not have to provide so much care to their sister." She did state, however, that she really could get by with fewer hours but was advised against this in fear that she might not ever get additional hours authorized in the CPOC if she needed them in the future.

CASE MANAGEMENT

Private/contracted case management. The majority of HCBS recipients receive case management services through private agencies that have contracts with the Medicaid Waiver Unit. The average caseload size for a typical HCBS case manager is 35. When HCBS first began in Louisiana, case management services were provided by a far larger number of agencies. A year and a half prior to the site visit, the Medicaid Waiver Unit decided to limit the number of possible case management agencies by going to a "contracted case management system." A Request for Proposals was issued requiring that interested agencies apply to become case management entities for MR/RC and aging and disabled HCBS, as well as infant and toddler programs in Louisiana. The new contracted system would allow for three to four case management agencies within each region. At the time of the site visit, most of the regions had more than one contracted case management entity.

DHH Medicaid Unit staff reported problems related to having numerous private case management agencies prior to the new contracted system. They also reported a number of these private agencies were not getting their job done and reported of fraud with a few of the private case management agencies. The Medicaid Waiver Unit's reasoning for going to a smaller number of providers through a contracting process was to improve the quality of case management services by placing new accountability and reducing the number of case management agencies they had to monitor. Other positive aspects of this move were requests within the RFP for the contracted case management agencies to ensure person centered planning and outcomes as a part of their case management and planning processes.

The move to contracted case management was met with mixed opinions by families, providers, advocates, case management agencies, OCDD and the Medicaid Unit. Most were not pleased with the process used to select contract awardees - stakeholders felt left out of this process completely. As a result of this new system, many individuals ended up losing case

managers that had supported them on the Waiver program for quite some time and they were not pleased when they were "forced" to choose another agency.

In addition to contracted case management services, just prior to the site visit the Medicaid Waiver Unit had begun "enforcing" rules that had been in the case management contract all along, but not necessarily enforced by the unit. These changes in enforcement also changed case management practice in the field. At the time of the site visit, case managers were reported to have the following responsibilities: 1) development of the Comprehensive Plan of Care (CPOC) through an interdisciplinary process, 2) quarterly home visits to recipients, 3) and monitoring of agencies that deliver HCBS. Stakeholders reported mixed opinions about the case management services they currently received through contracted services. Most families reported satisfaction with case management services, but consistently reported that recent changes had resulted in them seeing their case managers less and when they did see them, their case manager came to their house to review paperwork and spent less time talking about issues. One advocacy representative reported that right now it seemed that: "case management in Louisiana is all about trying not to get sanctions;" while another said, "now you may as well call case managers auditors, they're nothing short of accountants."

Case management agencies themselves reported that the recent changes in what they are to do and the expectation that they have "error free" or "100% compliance" with their paperwork had resulted in a detrimental effect on service. They reported a fear of sanctions that could potentially be large enough to put the agency out of operation, had forced them to focus on avoiding sanctions. This focus resulted in them spending more time focusing on paperwork and less time working with families to assist them with needed HCBS. The case management agencies claimed they could receive large sanctions for "coding errors and typos." Although there is an appeals process, the appeal occurs after the money has already been deducted from their reimbursement check. Many of the case management agencies claimed that this would result in them being unable to meet payroll and meet other basic business expenses.

In an effort to avoid sanctions, case managers reported spending one-third to one-half other their hours auditing paperwork within provider agencies. Case managers were expected to review time sheets, the number of hours billed by an agency, and the types of services for which

hours were billed. In addition, the case managers had to match these records against information from the prior authorization system by hand.

Case management agencies and advocates also reported that forcing case managers to be auditors has resulted in case managers being identified as "agents of the State DHH." They reported that, in this role, it seems case managers are expected (and in one case specifically told) that they "cannot be an advocate against the State when it comes to HCBS." Many of the advocates and the case management agencies reported that this situation represents a conflict of interest because DHH pays for, monitors and sanctions the case management agencies who are also responsible for developing the Comprehensive Plans of Care and authorizing the initial service units (which are then approved or denied by regional OCDD/Medicaid staff and state Medicaid staff).

OCDD transitional case management. For a small number of HCBS recipients who are moving out of the public developmental centers (institutions) and into HCBS, case management services are provided by OCDD regional staff. This transitional case management is designed to foster the successful transition of people who have lived in institutions into community supported living situations. OCDD transition specialists facilitate person-centered planning as the beginning step to prepare for the transition. They are responsible for developing the CPOC for these individuals and they are able to provide more intensive case management services to people once they have moved because their caseloads are much smaller, averaging 10 to 12 people. OCDD reported that this transitional case management is their benchmark for assuring quality and that these folks are able to spend more time observing what is actually happening in the service agencies and can monitor service outcomes.

Technical assistance and training. OCDD has played an important role in the coordination and delivery of recent training of case managers employed in contracted agencies. This training has been in an effort to make case management services more person centered and outcome focused. OCDD reported that they have had their five regional transition coordinators delivering more than 120 hours of training on person centered planning and personal outcomes.

Service Providers

Site visitors met with a number of service provider agencies during the site visit. The agencies included in this review were non-profit and they varied in size and scope ranging from a small provider serving as few as 20 people in one region, to a larger provider serving several hundred people across the entire state. Almost all of these agencies were multi-service agencies that provided more than just HCBS waiver services. In many cases, they also provided early intervention to young children, family supports, work-based supports and in some cases ICF/MR services. Most had been providing services to people with developmental disabilities prior to HCBS being an option in Louisiana. Most of these agencies provided a wide variety of specific HCBS services including respite, PCA, and day/night companion. Almost all of the agencies included in the site visit provided supports to a wide variety of individuals including young children, people who were aged, people with challenging behavior and people with significant health care needs. All providers were licensed by the Division of Social Services (DSS).

Agencies reported several issues or barriers that have made the delivery of HCBS difficult in Louisiana. Perhaps the biggest issue identified is that the rates for services had not been increased at all, not even to account for inflation, since the program was first implemented in 1992. Many providers reported that they had taken large financial losses for Waiver clients.

A related challenge faced by these providers was the difficulty in finding, keeping and retaining direct support staff. In most cases, agencies were unable to provide full benefits and they paid their employees minimum wage or slightly higher. Many reported that their employees were paid sub-minimal wages for overnight shifts. Turnover of case managers and overall continuity of care were also cited as issues of concern.

Vendors who provide environmental adaptation services must be approved as an HCBS provider agency and the state Medicaid Unit maintains a list of approved providers. Providers, case managers and families reported that it was difficult to find approved providers to complete environmental adaptations and that the expectation to have three bids from approved providers was unrealistic.

FINANCING AND REIMBURSEMENT FOR SERVICES

Determination/authorization of services. The case manager is responsible for developing the initial plan of care that authorizes the various types of HCBS an individual or family will receive. Once developed, this plan is reviewed by the regional OCDD and Medicaid waiver offices and then the state Medicaid waiver unit office. Theoretically, this plan of care identifies exactly what the family needs and is not limited by caps or historical approval patterns used by State and regional Medicaid offices.

However, several interviewees contended that there were known historical approval patterns and that case managers were well aware of these "practical limits" that, if exceeded, would lead to the plan not being approved. Case managers repeatedly indicated that they were instructed to reduce the number of units authorized in a plan of care and that types of care recommended were often changed to less expensive options. For example, supported independent living and behavior modification services were changed to day or night companion units, which receive a lower reimbursement rate.

In contrast, several consumers interviewed indicated that they were receiving more HCBS than they needed, but they were advised by their case managers and providers not to change their plans of care because of the difficulty of having additional services authorized if their care needs increased.

Expenditures. In fiscal year 1999, HCBS expenditures in Louisiana totaled $74,549,000. The federal cost share in this state is 70%. The average number of HCBS recipients during this year was 2,690 with an average per recipient expenditure of $27,713 and an average expenditure per resident of the state of Louisiana of $17.05. In comparing these expenditures to the national average, Louisiana is slightly lower then the national average regarding average daily expenditures per recipient, which is $33,324 and significantly lower then the national average per resident HCBS expenditure of $30.69. When compared to other southern states with similar numbers of HCBS recipients and population, Louisiana's expenditures per recipient are higher then Alabama ($20,466), but significantly lower than Georgia ($37,431).

Reimbursement rates. Louisiana has a multiple reimbursement level depending on the type of service that is being delivered. All services are initially authorized by the case manager, but final approval comes from the State and regional Medicaid offices. There are limits on the number of units that can be authorized for each service type and for a few of the service types, there are lifetime caps. Louisiana has relatively low reimbursement rates for HCBS services, particularly for day and night companion rates, which are the most commonly authorized residential support options. Given these reimbursement rates, it was evident in talking with provider agencies and direct support staff throughout the site visit that the ability to pay staff, even minimum wage, was difficult for most agencies. In fact, a number of the agencies paid staff below minimum wage for night companion rates. These agencies reported that they were given an exception to the wage and hour laws because direct support staff in this role were considered "domestic workers." It was not uncommon throughout the site visit to meet direct support staff who were working more than 100 hours in a week or multiple jobs just to make ends meet. Additionally, almost all providers and the staff we spoke with reported that direct support staff received no paid benefits. On more then one occasion, site visitors interviewed direct support staff who reported that they did not get paid overtime when they worked more than 40 hours as long as they were not providing more than 40 hours of the exact same type of service (e.g. day or night companion). Providers who did provide benefits and paid overtime reported that they were able to do this because of their efforts to have successful fund raising campaigns to supplement the amount of money they receive from the State for reimbursement for HCBS.

The following chart identifies the reimbursement rates for various service types at the time of the site visit.

Table 1: MR/RC HCBS Waiver – Reimbursement Rates

MR/RC Waiver Services		
PCA	**Limit - Combination of 1825 Units**	
PCA	$10.05	1 hour
PCA High Need	$11.36	1 hour
Respite	**No limit**	
In-home Respite	$10.05	1 hour
In-home Respite - High Need	$11.36	1 hour
Center-Based Respite	$6.50	1 hour
Center-Based Respite - High Need		1 hour
Substitute Family Care	**Limit -365 units**	
Substitute Family Care	$11.17	day
Residential Habilitation		
SIL	$22.76	day-limit 365 days
SIL Training	$10.70	hour - no limit
SIL Consultation	$45.00	hour - no limit
SIL Companion (Day)	$6.00	hour - no limit
SIL Companion (Behavior Modification)	$10.00	hour - no limit
SIL Companion (Night)	$4.00	hour - no limit
Habilitation/Supported Employment	**Limit - combination of 276 units**	
Ind. Job/Intense training level 1	$36.40	day
Ind. Job/Intense training level 2	$40.75	day
Ind. Job/Intense training level 3	$48.23	day
Ind. Job/Intense training level 4	$62.55	day
Ind. Job/Follow-along 30+ hours level 1	$27.68	day
Ind. Job/Follow-along 30+ hours level 2	$29.86	day
Ind. Job/Follow-along 30+ hours level 3	$33.49	day
Ind. Job/Follow-along 30+ hours level 4	$40.75	day
Ind. Job/Follow-along 20-30 hours level 1	$25.50	day
Ind. Job/Follow-along 20-30 hours level 2	$27.13	day
Ind. Job/Follow-along 20-30 hours level 3	$29.85	day
Ind. Job/Follow-along 20-30 hours level 4	$35.30	day
Enclave/Mobile Crew Level 1	$29.86	day
Enclave/Mobile Crew Level 2	$36.40	day
Enclave/Mobile Crew Level 3	$40.75	day
Enclave/Mobile Crew Level 4	$48.23	day
Pre-Vocational Habilitation	**Limit - Combination of 276 Units**	
Pre-Vocational Habilitation Level 1	$24.25	day
Pre-Vocational Habilitation Level 2	$26.89	day
Pre-Vocational Habilitation Level 3	$29.53	day
Pre-Vocational Habilitation Level 4	$40.10	day

Table 1. MR/RC HCBS Waiver – Reimbursement Rates, (Cont.)

MR/RC Waiver Services		
Day Habilitation	**Limit - combination of 276 units**	
Day Habilitation Level 1	$24.25	day
Day Habilitation Level 2	$26.89	day
Day Habilitation Level 3	$29.53	day
Day Habilitation Level 4	$40.10	day
Environmental Modifications	**Lifetime Limit - combination of $3,000**	
Ramp		each
Lift		each
Bathroom Modifications		each
Adaptations		each
Assistive Devices	**Lifetime Limit - combination of $5,000**	
Adaptive aids - Lifts		each
Adaptive aids - switches		each
Adaptive aids - controls		each
Communications aids - Communicators		each
Communications aids - Speech devices		each
Communications aids - Interpreters		each
Personal Emergency Response System	**Limit - 1 install & 12 units (~~mos~~MOs)**	
P.E.R. System - Installation	$30.00	1 only
P.E.R. System - Month	$27.00	1 per month (12)

QUALITY ASSURANCE AND ENHANCEMENT

Louisiana, like many states, has a multi-faceted quality assurance system. Case managers, OCDD, Medicaid Unit and DSS staff all play a role in ensuring health, safety and quality of life for people who receive HCBS in Louisiana. Each of these roles and quality assurance (QA) monitoring processes are described below.

Complaint Line. Louisiana has a 1-800-telephone line on which complaints can be filed with the State Medicaid Waiver unit. It was reported that all types of calls come in on this line. Most people interviewed reported an under utilization of this line. The State did not appear to have a way of systematically using this data to analyze trends or problems. However, the repeated complaints about the same provider triggers a quality monitoring review.

Case Managers. Each HCBS recipient has a case manager that is responsible for developing their plan of care and ensuring that this plan is fully implemented by the agency and support staff. Case managers are also responsible to see everyone on their caseloads face-to-face

each quarter. Additionally, all case management agencies are required to have their own internal quality assurance system that reviews the nature and quality of the case management services delivered by the agencies. The Medicaid Unit's staff responsible for case management then review these internal quality assurance plans.

OCDD and Medicaid Unit state and regional staff. OCDD and Medicaid Unit staff have been attending training organized by OCDD and delivered by The Council on Quality Leadership to State and regional staff as well as case managers. This training effort is designed to get quality reviews and support services geared more toward outcomes of services and less focused on paperwork. The Council's model adapted by Louisiana identifies 25 broad outcomes that are important to all people in their lives. These outcomes are indicators such as: "people choose and realize personal goals," "people choose where and with whom they live," "people are respected," "people have privacy," "people choose where they work," "people decide how to use their free time," and "people are free from abuse and neglect."

OCDD and Medicaid Unit staff collaboratively have been conducting quality monitoring reviews for a sample of 5% of HCBS recipients in Louisiana by region. In addition to this sample, a unique component of their review process is that they purposefully review all cases that are determined to be of "high risk." A case can be identified as high risk in a number of ways, including: 1) repeated complaints about the provider or the person's care called into the complaint line or made by interested stakeholders via reports to State or regional offices, 2) a large number of incident reports involving the person, 3) a person's team determined they were at risk during the development of their plan of care, or 4) the person came from an institution prior to receiving HCBS.

During these visits, some of the reviewers interview the person being served, their family members and their provider agency staff about the individual’s personal outcomes. In addition, there is a paperwork review at the agency and at the person's home where reviewers look at timesheets, billing statements, incident reports, plans of care and other related documentation. This review also includes the review team members looking at the case management agency's records.

Generally, providers said the focus of this review process was still too paperwork oriented and, because many of the reviewers were nurses, the reviews focused too much on medical issues and not enough on quality of life issues. But, they did note that there had been improvements and that, recently, the reviewers had been interviewing the people who receive services and their family members and asking more relevant and important questions about satisfaction and quality of life. Many of the State Medicaid Unit staff also indicated that they were pleased with this new review process and stated that it was very important for them to get out there and talk with people who receive the services. Most of these staff reported that they found the outcomes training that was coordinated by the OCDD to be very helpful and important.

DSS Licensing. All providers of HCBS in Louisiana are required to be licensed by the Division of Social Services. This licensing process involves an annual administrative review at the agency office and does not include meeting the person or visiting where they live or work. During this process, items such as external audits, criminal background checks for employees, personnel files and policies/procedures are reviewed.

Consumer and family involvement. There is no systematic inclusion of family members or self-advocates in the development of, participation in or evaluation of any of the statewide quality assurance systems in Louisiana.

CHALLENGES IN LOUISIANA

Louisiana is faced with a number of challenges and concerns for the future of HCBS. These challenges include areas such as collaboration among state agencies, case management, the waiting list, quality assurance and enhancement, and direct support workforce issues.

Collaboration among state agencies. Perhaps the greatest challenge in Louisiana will be the continued need to unite the Medicaid waiver agency with the designated developmental disability agency. It was clear in meeting with many stakeholders and with representatives form these state agencies that better communication, a shared vision, and collaborative decision-making could have the greatest impact on improving services in this state. OCDD is the state agency that has expertise in how to deliver high quality services and supports to people with developmental disabilities and they are far more in touch with stakeholder opinion. The extent to which their opinions and expertise is sought in all key decision-making (e.g. case management

going under contract, responses to HCFA reviews) will likely enhance the quality of services and the satisfaction of key stakeholders. One example of this working is the co-involvement of these two agencies in modifying how the quality assurance reviews are being conducted by incorporating outcomes and person-centeredness into the design of the reviews.

Direct support workforce issues. Another important challenge facing the Louisiana HCBS program is the ability of agencies to find, keep and train qualified people to provide supports to people who receive HCBS. The current reimbursement rate for services results in many providers paying night companions sub-minimum wages and most direct support staff earning slightly more than minimum wage for all other services provided. In addition to wage issues, most of the staff that site visitors met with did not receive benefits, were not paid overtime and often were not reimbursed for expenditures, such as mileage, when they provided a recipient with transportation to community activities and appointments. Clearly, the ability to find people to work under these conditions will remain a challenge and will substantially effect the ability of the State to increase the number of people served in the community through HCBS. In addition to increasing reimbursement rates and staff wages, efforts to improve the incentives (both intrinsic and extrinsic) for people to enter the field will need to be made. Systemic supports will also need to be explored such as developing effective recruitment interventions and training systems.

Collaboration with stakeholders. Another challenge for the Louisiana HCBS program is the ability to seek and respond effectively to stakeholder concerns and opinions. Clearly stakeholders support the HCBS program and have a strong commitment to its growth; however, they also have legitimate concerns for which they would like to see action taken. The ability for the Medicaid Waiver unit and the OCDD Waiver Unit to work collaboratively to seek out and respond to these concerns will assist in the future improvement in the quality of HCBS in Louisiana.

Communication and information dissemination. It will be a continual challenge for the Medicaid Waiver Unit and OCDD to disseminate changes in policies and procedures and related information in a manner that satisfies the needs of stakeholder groups including regional

offices and providers of HCBS. Web-based dissemination is perhaps one method that could be used to expedite delivery of information.

Case management. Site visitors noted that recent changes in case management practices were not supported by the case managers, their agencies, individual recipients, families, advocates or OCDD. These changes pulled case managers away from their focus on clients and resulted in fewer hours of face to face contact between case managers and HCBS recipients. Thus, the case managers' ability to monitor quality and to ensure that plans of care were implemented was also greatly reduced. It appeared that the case managers were serving an auditing function that in reality, could likely be served by a management information system that compared authorized service units with those that were billed.

The punitive nature of the "fine system" for case management agencies appeared to have the potential to put case management agencies out of business, especially given that an appeal process occurs after the agency has already had the fine withheld from their reimbursement checks. The nature of the infractions (typos and human error) and the punitive nature of the fines seemed incongruent. More importantly, this newly enforced "fine system" resulted in case management agencies focusing on avoiding fines versus ensuring the people to whom they provided case management services were satisfied and that their needs were being met.

Additionally, the contracted case management system offers recipients and families a very limited choice in which agency can provide case management services, and in some regions, no choice. Efforts to expand the number of effective case management agencies to increase consumer and family choice should be considered. Lastly, the role of the State Medicaid Unit in strategically influencing the behavior of case managers (e.g., what service they authorize and how much of it they authorize) given that they are also the contractors and payers of case management services, should be further explored for potential conflict of interest.

The waiting list. Louisiana currently has roughly 10,000 people on a waiting list to receive services. Most of these individuals do not receive case management or other services while they are on the waiting list. Furthermore, there is no active and formal process to determine whether people with MR/RC who currently live in private ICF/MRs want to get on the waiting list. Additionally, in Louisiana the waiting list is handled on a first-come, first-serve

basis. When an individual comes to the top of the list, there is a strong incentive for that individual to accept services regardless of their current need since declining services will entail being bumped to the bottom of the list. An effort should be made to offer a deferment wherein a family or individual could "pass" when their name comes to the top of the list if services are not needed at the time and could be offered again when the next "slot" becomes available

Supporting people with significant health support needs. It was noted by the site visitors that there were people who received HCBS who had significant health related needs. However, one challenge likely to be an ongoing issue in Louisiana is the extent to which people who have significant health needs and require substantial support from nursing staff can be adequately served in the community. Currently, HCBS in Louisiana will not pay for daily nursing care from licensed nurses.

Quality assurance and enhancement. Clearly, recent efforts have been made in Louisiana to improve the quality assurance and monitoring efforts for HCBS. The movement towards meeting face to face with people and asking important questions related to personal outcomes is a positive step. Continued efforts in this direction should be made. Additionally, the extent to which self-advocates and family members can become a part of the process of developing and implementing a quality assurance program in Louisiana should be explored. In addition, the extent to which quality enhancement and assurance methods could include the identification and dissemination of information regarding best practices could likely assist in increasing the availability of information to providers on how they could improve their services. The development of effective management information systems that are designed to address many of the issues that currently are the function of case managers (e.g., agency billing, service unit authorization) would reduce the administrative burden that care managers face and increase care coordination and support to families and recipients.