

A Review of the Medicaid Home and Community-Based Services Program in Indiana

Final Report

Prepared for:

Health Care Financing Administration

Prepared by:

**The University of Minnesota Research and Training
Center on Community Living**

The Lewin Group

March 30, 2001

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INTRODUCTION

This report summarizes findings and observations of a site visit to Indiana 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), 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. Final HCBS regulations were published in March 1985. Since then a number of new regulations and interpretations have been developed, although none have 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. Administrative requirements that prevailed in the HCBS program's first ten years, that applications to provide HCBS show reductions in projected ICF-MR residents and expenditures roughly equal to the projected increases in HCBS participants and expenditures have been relaxed considerably since 1992. 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 was provided 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) (117,900), for which HCBS is the non-institutional alternative.

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 component of this study was 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 and September 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, 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 Indiana's Medicaid HCBS program. The study was conducted February 7 to February 11, 2000 by Amy Hewitt (team leader) and Mary Hayden, both from 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 relatively well-developed programs, 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, 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 Indiana 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 Indiana 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 regarding what was working well in the Indiana 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 Indiana 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 of services 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?
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 Indiana’s HCBS program to describe the nature, quality, and outcomes of relationships among state and regional agencies, and the agencies that provide and receive HCBS. A wide range of documents supplemented the interviews. 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. The project team drafted interview protocols. 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 particular case study. The following documents were gathered and reviewed for the Indiana case study: These include:

1. The Comprehensive Care Management Standards and Proficiency Review for Indiana State In-Home Services Program;

2. Coalition of Professional Case Managers – Proposed Outcome Measures for Case Managers;
3. The Central State Discharge Study Special Tracking Report on the Status of Developmentally Disabled Clients;
4. Outcomes of Community Placement at Six Months for People Who Moved From new Castle and Northern Indiana State Developmental Centers (including all survey instruments);
5. Summary Activity Report on all Waivers in the Last Twelve Months – 12/10/99 and 5/12/99 reports;
6. BDDS Quality Monitoring Packet (including all forms), DDART Incident Reporting Database;
7. Division on Disability, Aging and Rehabilitative Services Bureau of Aging and In-Home Services and Bureau of Developmental Disabilities Services Present an Overview of the Quality Assurance Process (presentation slides);
8. An Overview of Quality Assurance in Indiana’s Medicaid Waivers for Persons with Developmental Disabilities prepared by NASDDDS, Inc., dated (August, 1999,);
9. ICF/MR Waiver Quality Assurance Process Summary, dated J(January 28, 2000);
10. Memorandum to provider agencies from BDDS regarding Incident-Event Reporting;
11. Draft Memorandum to providers regarding the Mortality Team;
12. Report of Expenditures for Home and Community Based Services Waiver for Developmentally Disabled in ICF/MR, (November 1999);
13. Memorandum From BDDS and BAIAS Regarding Care Plan Development and Updating, (February 3, 1999);
14. Statement of Eligibility Developmental Disabilities,
15. Waiver Provider Agreement;

16. Memorandum of Understanding Between the Division of Disability, Aging and Rehabilitative Services and the Office of Medicaid Policy and Planning;
17. Draft Comparison of Results from the Department of Justice Visits (August 1999), the Mock Waiver Surveys (July – August 1999) and the Center for Outcome Analysis Report (September 1999);
18. Indiana Home and Community Based Services Medicaid Waiver Information Packet;
19. Indiana Medicaid Home and Community-Based Waiver Services: A Guide for Consumers;
20. Home and Community-Based Care Medicaid Waiver Case Management Manual for Aging and Disabled, Autism, ICF/MR Deinstitutional Waiver, ICF/MR Diversion Waiver and the Medically Fragile Children Waiver;
21. The HCBS Provider Manual; and
22. The initial and subsequent renewal applications for the various Indiana HCBS programs.

Coordination of the Site Visit The logistical arrangements and scheduling for the site visit were arranged by T. G. Williams, Assistant Director Medicaid Waiver Unit, Bureau of Aging and In-Home Services, Division of Disability, Aging & Rehabilitative Services. Mr. Williams arranged for the site visitor interviews with State officials and with Area Agency on Aging staff, provider agencies, family members, individuals who receive services, the Protection and Advocacy organization, Arc of Indiana, and the Governor’s Council on Developmental Disabilities. The State officials in Bureau of Developmental Disabilities (BDDS), Bureau on Aging and In-Home Services (BAIHS), Office of Medicaid Policy and Planning, Area Agency on Aging staff, provider organizations, advocacy groups, families and individual service recipients were all extremely helpful and willing to discuss Indiana HCBS with the site visitors. State employees from BDDS and BAIHS were extremely helpful in sending collateral information to the site visitors prior to the site visit for review and in providing support to the visitors in obtaining directions on how to get to the various appointment locations. Their time, enthusiasm and commitment were greatly appreciated.

Draft Report Selection of Sites and Interviews

The selection of the sites that were visited in Indiana was coordinated by site visit staff from the University of Minnesota and T. G. Williams, Assistant Director Medicaid Waiver Unit, Bureau of Aging and In-Home Services, Division of Disability, Aging & Rehabilitative Services who served as the site visit key contact. The two primary geographic regions selected for the site visit were the Indianapolis metropolitan area and southern Indiana, including Monroe, Owen, Lawrence and Brown counties. However, it should be noted that a number of the provider, case management and advocacy organizations provide services throughout the entire state. During the site visit, interviews were conducted with the following individuals or groups of individuals:

1. State Bureau of Aging and In-Home Services staff
2. State Bureau on Developmental Disabilities staff
3. State Office of Medicaid Policy and Planning staff
4. Area Agencies on Aging – Executive Directors, Case Managers and other staff
5. Protection and Advocacy Agency – Director and several staff members
6. Arc of Indiana - Executive Director and Board Members
7. Governor’s Council on Developmental Disabilities – Executive Director and several members
8. Case management agencies
9. Provider agencies
10. Direct support workers
11. Family members of service recipients
12. Service recipients

HCBS recipients and family members were interviewed on an individual basis in their homes, places of work, or at private settings arranged by agencies. State employees from the BDDS and BAIHS accompanied site visitors to all appointments but did not sit in on interviews

with families and consumers of HCBS. If agreed to by provider agencies, Area Agencies on Aging, advocacy organizations and case management agencies the State employees did observe the interview process to benefit from hearing from these stakeholder groups what was working with HCBS in Indiana and what needed improvement. State employees were asked by the site visitors not to ask questions and to refrain from discussing issues with the key informants.

Everyone who was 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.

Service recipients and their family members 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 or the State of Indiana. 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

Review of the Draft Report

The initial draft of this report was provided to selected key Indiana 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 that will be submitted to HCFA.

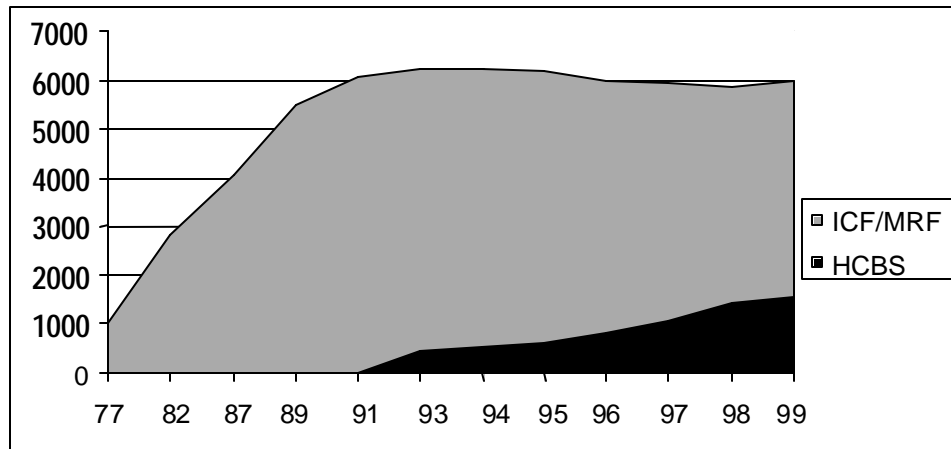
CONTEXT OF INDIANA'S HCBS PROGRAM

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

Indiana was rather late as compared to the rest of the country in providing both small community ICF/MR and Home and Community-Based Waiver Services (HCBS) for persons with mental retardation and developmental disabilities. In 1977, Indiana served 638 individuals

in small 1-15 person settings which included family support, semi-independent apartment programs and small ICF/MR. During this same year, a total of 3,438 people with mental retardation lived in state institutions and 1,026 lived in ICFs/MR (which could have been a certified ICF/MR unit in a state institution). By 1991, Indiana served 4,439 people with mental retardation in small 1-15 person settings and a total of 1,756 lived in institutions and 6,048 in ICFs/MR. Clearly between 1977 and 1991 the growth in small ICFs/MR assisted in the deinstitutionalization of many persons with mental retardation in this state.

Indiana began providing ICF/MR Home and Community-Based Services in 1992 and Autism HCBS in 1990. In 2000 this state began providing HCBS to people with traumatic brain injury. Growth in Indiana's ICF/MR HCBS program was steady between 1993 (447 people) and 1999 (1,554 people). Unlike many states that have seen a simultaneous growth in HCBS and decline in the number of ICF/MR services provided, Indiana has experienced a relatively steady growth in small 1-15 person ICFs/MR and HCBS over the past seven years as is indicated in *Figure 1* (Prouty & Lakin, 2000). However, there has been a slight decline in the population of people living in large (more than 16 people) ICFs/MR and the total ICF/MR population has also slightly declined from 6,213 people in 1993 to 5,964 people in 1999. Of importance to the growth in HCBS in Indiana is the significant decrease in the numbers of people with mental retardation and developmental disabilities living in nursing homes from 2,587 in 1991 to 1,262 in 1999. There has also been a decrease in the state institution population from 1,756 in 1991 to 1,004 in 1999.

Figure 1: Indiana ICF/MR + HCBS Recipients

The overall utilization rate for people with MR/DD per 100,000 of the population was 134 in 1993 and 164 in 1999 (Prouty & Lakin, 2000). Of importance, in 1995, about 5% of the state institution population were children and in 1999 there were no children living in state institutions.

Five Waiver Services Programs.

Indiana is authorized to provide five different Waiver services programs. These include the ICF/MR Waiver, the Autism Waiver, the Aged and Disabled Waiver, the Medically Fragile Children's Waiver and a recently added Traumatic Brain Injury Waiver. A person with a developmental disability could be eligible for one or more of these Waiver programs and, depending on waiting list prioritization, might get "targeted" for one program before another. A brief description of each of these Waiver programs, including their target population, size, eligibility criteria and the services provided, are described in the following paragraphs.

ICF/MR Waiver. This HCBS program in Indiana is targeted to serve individuals with mental retardation and other related conditions. Applicants for this program must have a diagnosis of developmental disability and must meet the level of care determination requirements for an ICF/MR. The ICF/MR waiver is designed to deinstitutionalize people residing in ICF/MR settings as well as to divert individuals from being placed in ICF/MR settings. The services offered under this HCBS program include: case management, personal assistance, respite care,

adult day care, personal emergency response system, environmental modifications, assistive technology, family and caregiver training, residential-based habilitation, day habilitation, prevocational services, supported employment services, behavior management, supported living services, speech/language therapy, physical therapy and occupational therapy. This HCBS program was last renewed in 1995 for a five-year period. Approved growth over this period of time would result in this program serving 3,557 people by 2000 (contingent upon the appropriation of additional state funding).

Autism Waiver. In 1990, Indiana began providing HCBS to people with autism. People who receive this service must have challenging behavioral deficits and for whom, without specialized training and intervention, institutionalization would be necessary. People who apply to receive this HCBS must have a diagnosis of autism and require a level of care determination for ICF/MR services. Other common developmental diagnoses that are often given to people who display characteristics of autism (e.g. pervasive developmental disorder) but have not yet been diagnosed are not eligible for this program. For many stakeholders, this was an issue because especially for young children, it is not uncommon for practitioners to avoid “labeling” a child autistic until they have been observed by that clinician for a number of years. Additionally, it was reported by stakeholders that this program was not as well funded and that adults with autism who want out-of-home placement are better off being served under the ICF/MR waiver. The services offered under the autism HCBS program include: case management, personal assistance, respite care, adult day care, personal emergency response system, environmental modifications, assistive technology, family and caregiver training, residential-based habilitation, day habilitation, prevocational services, supported employment services, behavior management, transportation, supported living services, speech/language therapy, physical therapy, and occupational therapy. This HCBS program was last renewed in 1998 for a five-year period. Approved growth over this period of time would result in this program serving 400 people by 2002 (contingent upon the appropriation of additional state funding).

Non-HCBS Services and Supports Available in Indiana

There are a number of services available to people with mental retardation and developmental disabilities that are not funded by HCBS in Indiana. These additional services are

often funded by Indiana's Medicaid State Plan and/or by other State funded programs. Room and board expenses are not allowed to be covered under HCBS. In Indiana, these services are paid for through a person's SSI and RSDI payments, and when needed, through a room and board state line item accessed through BDDS called residential living allowance (RLA). People who receive HCBS may also receive some type of non-HCBS funded service as well. Additionally, people who are on the waiting list for HCBS likely are receiving one or more of these non-HCBS as well. For these reasons, many of the programs that offer other types of services and supports are identified below.

State Developmental Centers/State Hospitals. The State of Indiana operates these large congregate care settings. In some cases, the person might be receiving ICF/MR services while living on a unit or in a home on the grounds of a developmental center that is certified by HCFA and meets ICFs/MR standards. However, not all state developmental centers in Indiana are ICFs/MR certified. Medical, nursing, habilitation, behavioral supports and nutrition supports are all provided within these programs. At the time of the site visit, Indiana had three ICF/MR units in state hospitals (Evansville, Logansport and Madison) and they had two state developmental centers, Muskatatuck and Ft. Wayne. The Muskatatuck developmental center had recently been de-certified as an ICF/MR facility and the state was in the process of trying to get this ICF/MR certification renewed.

ICFs/MR. Intermediate Care facilities for the Mentally Retarded are small group homes (six to eight people) and other larger congregate care settings, in which people with mental retardation and related conditions receive services. These services are generally more community based than services offered in a state developmental center. People receive health and safety related supports, have staff supervision 24 hours a day and also receive habilitation and training services.

Nursing Homes. Nursing homes are congregate long-term health care facilities in which skilled and intermediate care nursing services are provided. People with all types of health care related services reside in nursing homes. Indiana had 1,262 individuals with MR/DD living in nursing homes in 1999.

Regular Medicaid. There are many services that are specific to regular Medicaid that are not included in the waiver (e.g., physicians, lab work, mental health). Since the waiver recipient is also enrolled in regular Medicaid, the two programs are used in concert to satisfy the needs of the waiver recipient.

Family Subsidy Program. This service provides limited financial support for families to keep the family member in their natural home. There is a variety of assistance that family members can access, such as, respite care, emergency medical supports, and assistive technology support.

CHOICE. CHOICE is a state-funded program that is intended to provide support to both the elderly and people with disabilities. It is not targeted to individuals with MR/DD. In-home services such as respite care, home modification, personal assistance and other types of services can be accessed.

Department of Education Wraparound Support. This program supports children served in special education who because of their disability are having difficulty maintaining academic placement. A wide variety of services can be accessed under this program but are subject to individual approval of the Department of Education.

Employment Supports. A wide range of supports is available for persons seeking employment who have a disability. These services are often funded through Vocational Rehabilitation Services and include sheltered workday programs, vocational evaluations, supported employment and other work related programs not funded by HCBS.

Recent Developmental Center/State Hospital Closures

In 1998, Indiana completed a substantial effort to close several large ICF/MR and state developmental centers (institutions). These closures included New Castle State Developmental Center (NCSDC), Northern Indiana State Developmental Center (NISDC) and three private ICFs/MR operated by Res Care, Inc. Ninety percent of the individuals who were moved out of these facilities moved into residential supports funded by the HCBS Waiver program. This effort was made possible through a 1996 amendment to the ICF/MR waiver program in which HCFA approved an additional 500 “slots” to support the potential ICFs/MR institutional bed

closings. Prior to these recent closings, in 1993, Central State Hospital also was ordered closed and, at that time, 86 people with MR/DD were discharged into community services.

In planning for these closures, the State worked to develop a person-centered approach toward the transition of individuals from the institutions into community services. This process included person-centered planning with interdisciplinary teams and with people who knew the individual well. It also assured that individuals and families were given a choice in determining who their case managers and provider agencies would be. The State offered transition “fairs” in which families and individuals could meet many case management and provider agencies and learn about the services and support options each of these agencies offered. Efforts were made to provide support, such as transportation to assist people in attending these “fairs.” Most of the advocates and stakeholder groups we met with applauded the concept and the effort that was undertaken to support these “placement fairs.” However, it was mentioned by many that, when families did attend, they were overwhelmed and had a difficult time in trying to understand all of the options and the process they were going through to find community placement for the loved one. Additionally, some advocates suggested that not all of the families were informed about the “fairs” in a timely manner.

For people who moved out of Northern Indiana State Developmental Center and New Castle State Hospital, efforts were made to hire an outside contractor (The Center for Outcome Analysis) to monitor the outcomes of the people who moved to determine if their lives had improved or worsened. This independent contracting agency was not hired to follow individuals who moved from the three privately run ICFs/MR. According to the report provided by the contracting agency, the outcomes, generally, for the 191 HCBS recipients who moved from NISDC and NCSDC that were monitored (e.g. behavioral progress, integration, productivity, earnings, opportunities for choice making, individual planning and supports status, health care, medications, satisfaction, and costs) were positive (or didn’t indicate anything was worse).

At the time of the site visit, there were many advocates and individuals who were questioning the outcomes for the people who moved from the three private ICFs/MR into the community. In particular, nine to fifteen deaths (depending upon who was reporting) had occurred from the group of people who moved into the community from these private ICFs/MR.

These concerns had recently been reported in the newspaper. At the time of the site visit, the State reported to the visitors that 12 deaths had occurred in a fifteen month period of time for people who had transitioned from the two state developmental centers and the three private ICFs/MR. The State reported that some portion of these individuals who died had previously lived in one of the three privately run ICFs/MR and, that “at this point, we have not found anything that indicates maltreatment or neglect and that all of the individuals who died during that 15 month period had medical and health related issues.”

Recent HCFA Review

Just prior to the time of the site visit a HCFA review had been conducted. The State Officials who were informants for this case study reported that the HCFA review was a part of their normal review process because the Indiana ICF/MR waiver was due to expire on 6/30/00. Some of the individuals with whom site reviewers met were aware of or had participated in the recent HCFA review. This recent experience with HCFA contributed to much of the misconception on the part of interviewees that the site visitors were from HCFA. At the time of the site visit, the results of the recent HCFA review had not been received by the State officials.

ADMINISTRATIVE LOCATION OF HCBS

General Organization

The Medicaid Home and Community Based Waiver Program falls under the administrative responsibility of both the State Division of Disability, Aging and Rehabilitative Services and the State Office of Medicaid Policy and Planning. The Office of Medicaid Policy and Planning is the single State Medicaid Agency. The ICF/MR HCBS program is state administered with certain responsibilities delegated to local offices. A memorandum of understanding between the Office of Medicaid Policy and Planning and the Division of Disability, Aging and Rehabilitative Services exists to clearly identify each agency’s respective roles.

Office of Medicaid Policy and Planning. This division of the Indiana State government is responsible for the development and coordination of all policy regarding the HCBS program. It oversees the Division’s Waiver Unit by monitoring activities and discussing problems or

issues. It is responsible for approving all formal Medicaid Waiver requests, amendments and renewals prior to them being submitted to the HCFA. This agency also completes initial and annual level of care determinations and conducts independent quality assurance reviews on a sample of HCBS recipients. The Office of Medicaid Policy and Planning reviews Electronic Data Systems (EDS) monthly expenditure reports and supervises this agency on the development of the annual HCFA 372 report. This Office is also responsible for payment of all HCBS claims and responds to inquiries about claims payments. In this capacity, the Office is responsible for providing information to vendors about proper billing procedures.

The Division of Disability, Aging and Rehabilitative Services. The Divisions of Disability, Aging and Rehabilitative Services has the responsibility (as delegated by the Office of Medicaid Policy and Planning) for assuring that necessary safeguards have been taken to protect the health and welfare of HCBS recipients. This includes developing and enforcing standards for providers and reviewing all plans of care for issues of safety and feasibility. It is responsible for ensuring quality related to: 1) the cost-effectiveness of budgets, 2) plans of care and 3) freedom of choice regarding providers and case management agencies. This agency is also responsible for approving and enrolling new HCBS providers, training case managers and drafting HCBS Waiver amendments, renewals and new proposals.

The Division of Disability, Aging and Rehabilitative Services assists the Office of Medicaid Policy and Planning in the developing new policies, setting rates for services and in identifying new services to be offered by the program. It is responsible for maintaining data sets on the HCBS recipients and expenditures as well as other types of information.

Bureau of Developmental Disability Services. The Bureau of Developmental Disabilities is responsible for planning, managing and oversight of all non-HCBS services to people with developmental disabilities in Indiana. They are also the agency with the statutory authority to find placements for people with developmental disabilities who are in need of services. These services include, but are not limited to, developmental disability eligibility determination, work and employment programs, and ICF/MR programs. The BDDS has a central office located in the state's capitol city and nine regional offices. At the time of the site visit, there were 52 Regional Service Coordinators and 19 newly hired Quality Monitors

employed in the BDDS system. The state-defined role of BDDS in the delivery of HCBS to people with developmental disabilities in Indiana is to ensure feasibility and safety of HCBS recipients. BDDS Service Coordinators are not case managers. They do, however, have a broad knowledge of the service delivery system for people with developmental disabilities in Indiana and in this capacity they assist in coordinating the entire package of services that are made available to a person who receives HCBS.

Areas Agencies on Aging. The Area Agencies on Aging (AAA - private non-profit agencies that contract with the Division of Aging and In-Home Services) are considered the single point of entry agency for HCBS in Indiana. There are 16 AAA organizations throughout the state. These agencies determine eligibility for HCBS recipients, provide the initial case management services, complete the intake and arrange for assessments and they participate in the development of the initial and on-going individual plans of care.

Site visitors met with Executive Directors and case managers of two Area Agencies on Aging. The level and sophistication of the knowledge these individuals had about developmental disabilities, the broad service delivery system in the state for these individuals, and the amount of hands on experience they had supporting people with disabilities was less than site visitors had expected, given the important role the AAA agencies play in the determination of eligibility, authorization, and monitoring of HCBS for people with developmental disabilities managers. At the time of the site visit, this role for the AAAs was a relatively new function. In fact, some of the case managers that were interviewed by site visitors indicated that if the case involved a person with significant behavioral support or other specialized needs, they often contacted private case managers and asked them to make a contact with the family to see if the family would “choose” the private case manager to deliver case management services because they did not feel qualified. These same case managers reported that their Executive Directors would not be happy if they knew they were turning down cases but that they really felt the private case managers were more qualified to handle the “harder and more complicated” cases. Almost every AAA case manager that the site visitors met had an educational and work experience background in nursing and aging services. In fact, none had ever worked in positions where they solely provided supports to individuals with developmental disabilities.

This administrative structure of the HCBS appears to be complex to both the site visitors and the stakeholders. Many of the individual stakeholders that the site visitors met with reported that they never knew who, within the various state agencies, was responsible for what. They also reported that, depending upon the region of the state, there was significant variability in the “actual” roles these various local players took in the process of getting a person enrolled in the HCBS program. However, it should be noted that, at the state level, it did seem that the various agencies involved were clear about their respective roles and functions and, in many cases, specific memorandums of agreement and understanding had been developed to clarify these roles and responsibilities.

PHILOSOPHY AND GOALS

The purpose and mission of the ICF/MR HCBS program in Indiana is to provide meaningful and necessary services and supports to persons receiving services, to respect the person’s personal beliefs and customs and to ensure that services are cost-effective. In so doing, the program hopes that people who receive HCBS will: 1) become involved in the community where s/he lives, 2) develop relationships with people in that person’s home and work communities, 3) develop skills to make decisions about how and where the person wants to live, and 4) be as independent as possible. One significant purposeful use and intended outcome of the Indiana ICF/MR HCBS program has been to provide opportunities for people who have been living in state institutions or nursing homes to move into their home communities. Also, to prevent people in the community from having to move into an institution or nursing home.

ELIGIBILITY REQUIREMENTS / ACCESS

Eligibility Requirements

Individuals who receive any type of HCBS in Indiana must meet the following criteria:

1. The recipient must meet Medicaid guidelines.
2. The recipient would require institutionalization (e.g. nursing home, state developmental center, ICF/MR, hospital) in the absence of the waiver and/or other home-based services.

3. The total cost of serving the recipient on the waiver (waiver cost plus other Medicaid costs) cannot exceed the total cost to Medicaid for serving that person in an appropriate institutional setting.

In addition to the above criteria, an individual who receives services under the ICF/MR must meet the criteria for having a developmental disability. This criteria is:

1. The person must have a condition (other than a sole diagnosis of mental illness) that has been diagnosed by a licensed psychologist and is characterized by subaverage general intellectual functioning (Full-scale IQ score of 70+/- 5) and concurrent deficits in adaptive behavior. Adaptive behavior is defined as the effectiveness with which the individual meets the standards of personal and social responsibility expected of his/her age and cultural group. Deficits in adaptive behavior would be the inability to perform to these standards.

OR

2. The person must have a condition that has been diagnosed by a licensed physician and is characterized by aberrations in motor functions (e.g. paralysis, weakness, lack of coordination), and often other manifestations of organic brain damage such as sensory disorders and seizures.

AND

3. The eligible condition must have originated prior to age 22.
4. The condition has to have persisted for at least 12 months and should be expected to continue (for a lifetime) or, in the case of an individual less than 22 years of age, is expected to continue for a period of at least 12 months.
5. The individual must require developmental services similar to the specialized types of teaching and training and at the same level of intensity which are characteristic of the needs of persons with mental retardation. The person must require the specialized kinds of interventions and habilitation activities – including an interdisciplinary team

- approach that develops an individual intensive habilitative sequence of special or generic care.
6. The individual must also have deficits in three of the following seven major life areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. A level of needed intervention is also required to be determined for each of these areas using the following scale: independence, supervision, assistance, and dependence. “Substantial limitation” is defined as requiring assistance or being dependent.

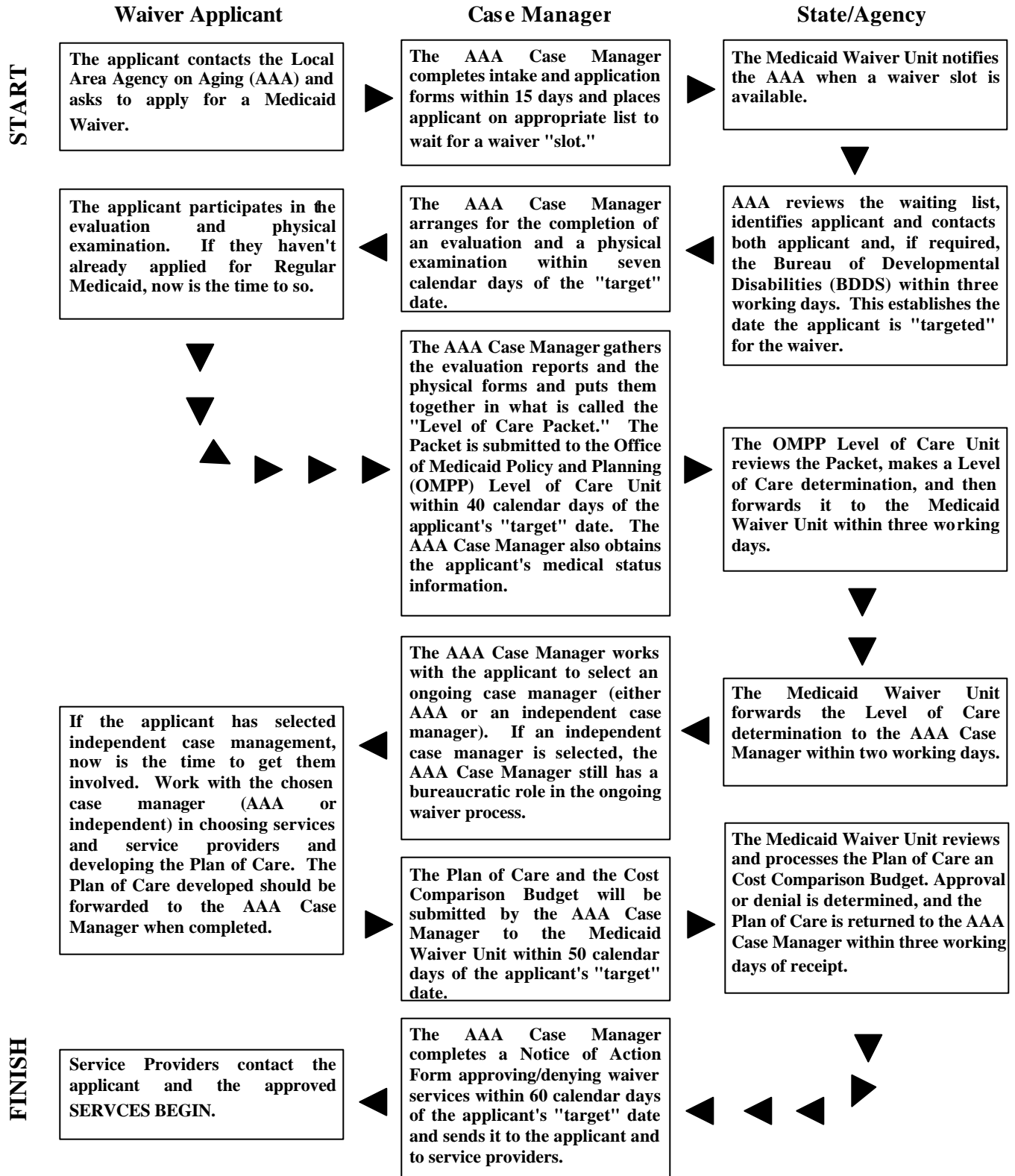
Process of Eligibility Determination

The eligibility determination process in Indiana requires the potential recipient to come into contact with numerous local and state offices and is a lengthy and perhaps confusing process. This process involves: the Area Agency on Aging, Bureau of Developmental Disabilities, the Office of Medicaid Policy and Planning Level of Care Unit, the Office of Medicaid Policy and Planning Waiver Unit, the County Department of Family and Children, an independent Diagnostic and Evaluation Team, a physician, a case manager, and a selected service provider(s). Each of these many players has a specific role in the eligibility determination process. The chart included in *Figure 2* is designed to provide a visual overview of these steps.

The eligibility process from start to finish was reported by AAA agencies to take minimally three-five months. During the application and eligibility process a number of key people from various agencies have specific roles and responsibilities. These roles are highlighted in the brief descriptions that follow.

Area Agencies on Aging (AAA) Waiver Role. The role of the Area Agencies is to be the "single point" of entry for In-Home Service Programs. They are to provide oversight of the waiver programs based on principles of Case Management and State and Federal guidelines, and to give final review and approval of the Plan of Care/Cost Comparison Budgets.

Figure 2: Process of Eligibility Determination



Office of Medicaid Policy and Planning (OMPP) Role. The role of OMPP is to approve policies for all Medicaid programs; approve Level of Care as waiver appropriate; to conduct on a case-by-case basis, quality assurance reviews for the waiver programs; and to data enter the case for Medicaid reimbursement. Also, all waiver Plans of Care are subject to OMPP approval.

Medicaid Waiver Unit Role. The role of the Medicaid Waiver Unit is to provide oversight of all waiver programs; notify the Waiver Liaison when waiver slots become available; conduct quality assurance reviews; maintain the statewide waiver waiting lists (when applicable); process information for data collection and reimbursement purposes; and provide information and guidance regarding policies and procedures.

Area Agency Waiver Liaison Role. - The role of the Area Agency Waiver Liaison is to monitor the waiver programs; assure the use of a standardized process for the waiver programs; provide assistance with provider management; maintain the local waiver waiting list; consult the Waiver Unit when necessary; provide assistance and information to Area Agency Case Managers and Supervisors; act as a liaison to the Bureau of Developmental Disabilities (BDDS); act as a liaison to provide oversight of the Diagnostic and Evaluation (D&E) process; provide information and assistance to OMPP and the Waiver Unit on an as needed basis; and forward necessary data to the Waiver Unit for processing.

Area Agency Case Manager Role- The role of the Area Agency Case Manager is to complete the assessment of the applicants for all Home and Community-Based Service programs; provide preliminary Case Management services during the initial assessment process; review of the D&E, if applicable; assure appropriateness of services to need; assure completion of the initial Plan of Care/Cost Comparison Budget; coordinate the initial plan of care conference meetings; attend ongoing plan of care conference meetings; sign as Case Manager on the initial Plan of Care; and provide ongoing Case Management services when selected as the clients' Case Manager.

Waiver "Case Manager of Choice" Role. - The role of the Waiver Case Manager is to:

- Coordinate annual assessments by authorizing D&E services, if applicable;

- Submit Level of Care assessments to the Waiver Unit;
- Coordinate plan of care conferences;
- Seek input from the Area Agency; BDDS; and the recipient;
- Submit Plan of Care/Cost Comparison Budgets to the Area Agency; and BDDS, (if applicable) for final approval; and
- Provide for the on-going monitoring of client provider activities and services.

This includes providing ongoing Case Management, monitoring the Plan of Care, conducting quarterly reviews of the Plan of Care, and coordinate coordinating the delivery of services with providers.

Bureau of Developmental Disabilities (BDDS) Service Coordinator Role. - The role of the BDDS Coordinator is to:

- Notify the Waiver Liaison on targeted deinstitutionalized waiver applicants;
- Certify developmental disability status;
- Manage D&E teams;
- Provide information on additional funding sources;
- Assure appropriateness of services;
- Provide input into the Plan of Care;
- Serve as the placement authority in developmental disability cases; and
- Approve the Plan of Care/Cost Comparison Budget.

One aspect of Indiana's eligibility determination process is the use of independent Diagnostic and Evaluation (D&E) Teams. These teams are specialized regional agencies that are under contract with BDDS to provide D&E assessments for individuals who are seeking

placement in an ICF/MR, applying for ICF/MR waiver services or applying for other types of services for people with developmental disabilities. The initial diagnostic and evaluation assessment includes the following components: case analysis, functional limitations screen and a psychological evaluation. This assessment package is used in the determination of eligibility for developmental disability services, including waiver services. When available, current and relevant collateral reports can be used by the Service Coordinator and the D&E team members in the eligibility determination process. The D&E Teams also conduct annual reviews for all individuals who receive the above mentioned services.

As indicated in *Figure 2*, the eligibility determination process begins with the family or individual contacting their local Area Agency on Aging. In most cases the family has heard about this entry point through some other entity such as their Bureau of Developmental Disabilities local office or an advocacy agency. Repeatedly during the site visit the site visitors were told by stakeholders that an educational process had to occur so that families could learn and understand how to access HCBS because the process is so confusing. It was reported that it was not intuitive to families to pick up the phone and call the local aging agency about services to people with mental retardation and developmental disabilities. This lack of intuition is likely caused by families having had no previous contact with Area Agencies on Aging for any other related services their family might have received (e.g. sheltered work, in-home family support, respite, transition planning) for their family member with a developmental disability. One strategy the State has developed to assist with this issue of access is to develop a 1-800 number that, when called, links families directly to their local AAA agency. Additionally, many AAA agencies had changed their names so that their agency name did not just reflect services to people who are aging but also services to people with disabilities.

Who gets “Targeted” for the Waiver/The Waiting list. Any person who desires may apply to receive HCBS waiver services in Indiana. No one is to be discouraged from applying even when “slots” are not available or if there are any suspected eligibility issues. People are “targeted” to receive HCBS services on a first come first serve basis in regions depending on the date and time on which their name was placed on the waiting list.

ICF/MR Deinstitutional Waiver. Each local BDDS field office maintains a waiting list for the deinstitutional slots based on the date and time of application (first come, first serve) for the ICF/MR deinstitutional Waiver. They forward this information to the Medicaid Waiver Unit each quarter where a “master” waiting list is maintained. As new ICF/MR deinstitutional waiver slots become available, the Medicaid Waiver Unit notifies the BDDS Central Office of the number of slots available. The BDDS Central Office allocates the slots to each local BDDS field office.

When a slot becomes available within a district, the local BDDS field office reviews the local waiting list and “targets” the individual whose name is at the top of the list. Slots become available because new slots have been allocated by the central BDDS Office, a person who was previously “targeted” withdrew or was denied services prior to going on the waiver, and/or a slot was vacated during the previous year.

ICF/MR Diversion Waiver. When an ICF/MR Diversion Waiver slot becomes available, the Medicaid Waiver unit will allocate the slots to each Area Agency on Aging based upon the percentage of the state’s general population which resides within the area. If 16 or more new slots are available, each area will be guaranteed a minimum of one slot. If an area has an available slot, but no one on the waiting list, the slot will be reassigned to the area with the largest waiting list. When a specific slot becomes available, the local Area Agency on Aging reviews the waiting list and targets the person at the top of the list. Slots become available for the same reasons as identified above for the ICF/MR deinstitutional waiver. There are usually a designated number of “priority slots” available for people who live in the community and have an emergency situation such as the death of a primary caregiver. However, all AAA staff, case managers and BDDS staff reported that these “slots” are difficult to obtain.

One issue brought up by both the state and several stakeholders is that, when “slots” are assigned, they are assigned for a year and, therefore, if someone drops out or moves away from services in month two of a twelve month period then their “slot” may not be re-assigned until the end of the twelve month period of time. This results in under-utilization and necessitates people remaining on the waiting list longer than they needed.

Additionally, it was reported to the site visitors by several stakeholder groups that it is extremely difficult for families to know and understand where they are on the waiting list in a given region nor can they reasonably project how long they might have to wait for services. Many families interviewed by the site visitors reported that they had been waiting to receive HCBS for up to four years prior to actually getting services.

SERVICES AND SERVICE PROVIDERS

HCBS Services Available in Indiana through the HCBS Waiver

A wide variety of services are provided to people in Indiana who have mental retardation or a developmental disability and receive HCBS. However, not all of these services are available under all five of the Waiver programs in Indiana. The sources provided include:

Case Management: Help to locate, coordinate, and monitor waiver services, as well as other services, needed to meet the specific needs of the person and his or her family.

Homemaker: General household activities that are provided when the person or an informal caregiver is unable to manage the home. (Aged and Disabled Waiver only)

Attendant Care/Personal Assistance: Help to meet daily living needs to ensure adequate functioning in a community-based setting. Some allowable activities include assistance with dressing, eating, bathing, personal hygiene, daily living activities, supervision, meal preparation, and household chores.

Respite Care: Short-term care to a person when the family member or the primary caregiver cannot be there or needs rest from his or her responsibilities.

Adult Day Care: Integrated supervision, care, assistance, training, and age-appropriate activities to help a person become involved in the community and have meaningful social experiences. (Aged and Disabled, ICF/MR, and Autism Waivers only)

Home/Environmental Modifications: Necessary adaptations to the home that ensure the health, safety, and welfare of the individual, and enable the individual to function with greater

independence in the home. Without such modifications, the individual would require institutionalization.

Adaptive Aids and Devices/Assistive Technology: Devices (communications equipment, computer adaptations, etc.), vehicle modifications, wheelchairs, environmental controls, safety restraints, or other equipment that increases the individual's independence.

Personal Emergency Response System: An electronic device that enables the individual to secure help in case of an emergency.

Home-Delivered Meals: Meals delivered to individuals unable to prepare their own meals and for whom there are no other persons available to do so. Limited to one meal per day. (Aged and Disabled Waiver only)

Speech Therapy: Designed to improve, maintain, or slow regression of the ability to communicate. (ICF/MR and Autism Waivers only)

Physical Therapy: Treatment and training designed to preserve and improve abilities for independent functioning, such as gross motor skills, fine motor skills, range of motion, strength, muscle tone, and mobility. (ICF/MR and Autism Waivers only)

Occupational Therapy: Evaluation, treatment, and training programs including design, fabrication, and adaptation of materials and equipment to meet individual needs in assisting independence. (ICF/MR and Autism Waivers only)

Behavior Management: Training, supervision, and assistance in appropriate expression of emotions and desires, compliance, assertiveness, acquisition of socially appropriate behaviors, and the reduction of inappropriate behaviors. (ICF/MR and Autism Waivers only)

Day Habilitation: Regularly scheduled activities that focus on training to enhance social and daily living skills apart from the individual's living arrangement. (ICF/MR and Autism only)

Residential-Based Habilitation/ADL: Goal-oriented activities aimed at assisting the individual to acquire, retain, or improve skills that directly affect the ability to reside as independently as possible in the community. (ICF/MR and Autism only)

Supported Employment: Needed supports to individuals to establish and maintain employment in work settings in which persons without disabilities are employed. (ICF/MR and Autism only)

Pre-Vocational Training: Instruction to prepare an individual for paid or unpaid employment, but activities are not job-task oriented. (ICF/MR and Autism only)

Transportation: Limited to transporting individuals on the Autism Waiver "to" and "from" waiver habilitation services. (Autism only)

Supported Living: Designed to assist individuals who live in their own home, apartment, or family home by providing training and/or support to live independently in the community. (ICF/MR and Autism only)

Family and Caregiver Training: Training and education related to disabilities, community integration, parenting, family dynamics, stress management, behavior interventions and mental health to a parent, other family members or primary caregiver. (ICF/MR and Autism only)

Recipient Experiences

The site visitors were able to meet with a number of recipients of HCBS and their families. Their stories and experiences regarding HCBS and their situations were all different. 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:

(RM) was the mother of an adult male who received HCBS. He lived in an apartment with one other individual. His mother described his program as being very unstructured. She stated that he is 40 years old and works at a retirement center. Although she did not like it when her son lived in an institution, she did state that she felt the structure he had in the institution helped him to create a routine. At the time of the visit, he always had one staff to support him and when he or his roommate wanted to do something, they often have two staff.

(EM) lived by herself in her own apartment. She worked 12 hours a week at a Goodwill store and volunteered at Habitat for Humanity. She received PCA and HHA every day but stated

that it was very difficult to find staff. She reported that she needed additional staff to help her at her Habitat Volunteer orientation classes. A month after her request, she did not have these additional staffing support needs met. She reported that she had initially had a case manager from an AAA agency but that this case manager “was slow.” At the time of the visit, she had a private case manager and stated that she liked this individual.

(JH) was a woman with autism who had received HCBS for two months prior to the site visit. She lived with two staff members; one of these individuals had known and supported her in other placements for the past 3.5 years. She had contact with her family every week and spent time with her staff members and their families. She received services from a neurologist every six months, a psychiatrist every three months and had her blood drawn every three months to monitor the effects of her psychotropic and seizure control medications. JH had an independent case manager who saw her one or two times a month.

(LF) was the mother of a young boy who had received HCBS for the past two years. Prior to receiving HCBS, he lived in Northern Indiana Habilitation Center for about four years. His mother reported that she really had no choice regarding his move because they were closing the developmental center. She reported that the process was respectful (yet overwhelming) and that she had attended the placement fairs sponsored by the State, where she met, and later selected, her case management and provider agencies. Since he began receiving HCBS, her son had attended public schools. He was completely dependent upon others for self-care and had no verbal communication skills. She reported that initially there were problems with the provider agency not respecting their wishes and that sometimes they felt left out of the decision-making process because staff from the provider would call the case manager to solve problems and left the family out of the process. Also she reported that the agency is often short staffed.

(NP) was the mother of a man who had received HCBS in a group setting with three other people for only a few months prior to the site visit. Prior to this, he had lived in a state developmental center for over ten years and before that at a state hospital since the age of ten. She reported that she was given a choice among provider and case manager agencies but she said this process was overwhelming and that HCBS really offers only limited choice. She found that it was very difficult to find three other families who, together, agreed on the provider agency.

She also reported that, although she called several provider agencies and case management agencies, most of them never even returned her call. She reported that she ended up selecting the only case manager and the only agency that bothered to return her calls. NP was very pleased with her case manager and reported that this case manager goes out of her way to provide training to support staff and to work with the provider to iron out management issues. She was concerned because her son didn't seem to be doing much during the day and had little activity. Although, she reported she was thrilled that he lived so close to her now and that she visited him almost every day.

(BI) was a 44 year old woman who lived in her own apartment with an independent, personal assistance staff member. Prior to this living arrangement, she had lived in a neglectful situation in her family's home from which she was removed by adult protection services. The independent personal assistant was paid \$14.70 per hour and had to pay self-employment tax and benefits out of her earnings. The annual income the personal assistant received was about \$40,000. If she desired respite services then respite was paid out of her earnings as well.

CASE MANAGEMENT

The case management system in Indiana is designed to offer people a choice in who delivers their case management services. The minimal requirements for a case manager in the ICF/MR waiver in this State include: 1) a Bachelor's degree, 2) a Registered Nurse credential, or 3) employment in an Indiana State Personnel Merit System PAT III position. In addition to meeting one of these requirements, all case managers in this waiver must have at least one year of experience in providing services to persons with developmental disabilities. The average caseload for a typical ICF/MR HCBS case manager varies significantly between 20 and 100, depending upon whether the case manager works for a private case management company or in an AAA agency. . Many families reported that they were confused about case managers and that they had as many as three case managers (private, AAA and BDDS Service Coordinator) and were often not sure who was responsible for what.

Private/contracted case management. Many HCBS recipients receive case management services through private agencies that have contracts with the IFSA Medicaid Waiver Unit. The average caseload size for a private case manager is about 20 people. These

case managers tend to specialize in supporting people with developmental disabilities who have specialized behavioral or medical support needs. The case manager is responsible for assisting in planning of services that address the health and safety of recipients and they monitor the delivery of services to assess the effectiveness, appropriateness and quality of the services being delivered. They are responsible for convening the team that develops the plan of care, assisting people in maintaining benefits and in getting connected to community services. They advocate for the individual to service providers and mediate issues that arise between the individual, their family and service providers. Minimally, case managers are required to make face-to-face contact with recipients every three months to discuss the person's situation and to be certain that the current services are meeting the individuals needs.

Site visitors were surprised at the amount of contact many of the independent case managers had with the people and the families to whom they provided supports. Many case managers reported that they saw the individuals they supported several times a week. In one case, the case manager was actually conducting training sessions for residential staff on how to provide non-aversive behavioral interventions to a person she supported.

Many advocates and independent case managers reported frustration regarding the role and authority case managers have in managing HCBS for the people on their caseloads. For example, if a case manager had an issue with an agency not providing the support they had promised, the case manager can do little more than point out the problem and hope it is resolved. Their only other options are to report issues to Protection and Advocacy or to move the person from the problem provider to a new provider. From the provider perspective, this had become an issue. Many providers reported that some case managers don't seem to value continuity and that a new phenomenon of "provider hopping" had evolved. Providers had often experienced situations in which case managers moved a person to another provider agency without ever notifying the existing agency that a problem existed. This was reported to be extremely frustrating to the providers. Some providers reported that a new sense of "competition" had emerged and that, from a business standpoint, this was a new phenomenon they were having to address. One provider reported that a new for-profit multi-state service provider had recently come into their community and was actively recruiting families of kids in special education programs and promising these families things like "staff stability" and the

“opportunity to choose the homes in which their children would live.” Most families reported that they rely on the knowledge and experience of their case managers in selecting provider agencies.

Area Agency on Aging (AAA) case management. When a HCBS recipient chooses a case manager for on going case management services they can select a AAA case manager. In this capacity the roles and functions of this case manager are similar to those described in the above section on private/contracted case management. The average caseload for a AAA case manager is 80-100 people and they have individuals who receive all five types of HCBS on their caseloads. Many stakeholders identified the fact that people can choose AAA case managers as a conflict of interest because these case managers are the ones who have the power to authorize services and that, on appeal, the AAA case managers represent the State interests and not the individual’s interests.

When a HCBS recipient chooses a private case manager, the AAA maintains an administrative responsibility in the recipients' case. Upon the selection of a Waiver Case manager, the Area Agency Case Manager will provide the Waiver Case Manager copies of the approval Level of Care packet, Plan of Care/Cost Comparison Budget and the Notice of Action.

The Waiver Case Manager will provide ongoing Case Management, monitor the Plan of Care, conduct quarterly reviews of the Plan of Care and coordinate the delivery of services with providers. A new Plan of Care/Cost Comparison Budget must be completed whenever there is a change in the Plan of Care. The Plan of Care/Cost Comparison Budget must be submitted to the Waiver Liaison for approval. The Area Agency Representative shall be notified of any changes in the Plan of Care.

In the event that the client requires a major change in the Plan of Care (POC), a plan of care conference must be held and the Area Agency Representative shall attend. Major changes require Area Agency approval.

Major changes in the POC are defined as:

- a. Modifications in the type of service provided;
- b. Noticeable increase or decrease in the cost of services;

- c. Permanent change in the frequency of the services;
- d. Changes due to new provider goals; or
- e. Improvement or declining of the clients condition.

Once the Plan of Care/Cost Comparison Budget is approved, a Notice of Action must be completed by the Waiver Case Manager and sent to the Waiver Liaison and the service providers.

The Waiver Case Manager is responsible for coordinating the annual assessment and the annual Plan of Care. The Waiver Case Manager obtains an updated, signed long-term care services application, authorizes the annual D&E evaluations for ICF/MR the Autism Waivers, collects updated information necessary to complete the Plan of Care/Cost Comparison Budget, obtains the physician certification forms, and coordinates the annual plan of care conference. A copy of the D&E, if completed, should be forwarded to the Area Agency Representative and BDDS Service Coordinator prior to the plan of care case conference.

The annual plan of care conference should be attended by the client, anyone the client designates, the Waiver Case Manager, Area Agency Representative, and the BDDS Service Coordinator, if applicable. The Plan of Care should be developed based on the D&E recommendations, input of all plan of care conference participants, provider progress reports, and an informal evaluation of the service effectiveness for the client over the past year. The client should be reminded of his/her right to choose any approved waiver provider to provide the services on his/her Plan of Care, including Case Management providers.

Once a new Plan of Care is developed, the Cost Comparison Budget must be completed to assure the cost effectiveness of the Plan of Care. The completed POC and Plan of Care/Cost Comparison Budget is submitted to the Waiver Liaison for approval. The Waiver Liaison will forward the signed POC and Plan of Care/Cost Comparison Budget to the Waiver Case Manager.

The Waiver Case Manager will forward the Level of Care packet and Plan of Care/Cost Comparison Budget to the Waiver Unit for review and OMPP Level of Care approval. In addition, the Waiver Case Manager will complete a Notice of Action and forward it to the Waiver Liaison and service providers.

BDDS service coordination. The BDDS Service Coordinators assist case managers in identifying means other than the HCBS to fund certain aspects of a person's support plan. They also review the plans of care to assure that the recipients' needs are being met and that issues related to health, safety and feasibility are included in the plan of care. For individuals who are moving from state hospitals into the community, they coordinate the development of the initial eligibility assessments and the plan of care.

Technical assistance and training. The Indiana Family and Social Service Administration (IFSSA) provides training and technical assistance to case managers, AAA agencies and to BDDS field staff regarding the HCBS in Indiana. Additionally there is an independent ad hoc group, "Community Supported Living Task Force," that has been meeting since 1988 to discuss issues related to community supports. This group hosts best practice forums about three times each year in which they identify a national leader to come in and facilitate discussion about best practices in community supported living.

Crisis Behavioral Support Services

The BDDS has entered into a contractual agreement with Hamilton Centers (a community mental health program) to develop and deliver technical assistance to provider agencies and to other local community mental health centers regarding the provision of mental health and crisis behavioral supports to people who receive community residential services funded by HCBS in Indiana. Site visitors were told that there was a strong desire on the part of the state to avoid using State Developmental Centers as the mechanism through which crisis supports were developed. Provider organizations and case managers that were interviewed during the site visit reported that it was very difficult to find crisis services for people with severe challenging behavior. They reported that often the police, jail, mental health units with untrained staff, and state developmental centers/state hospitals were their only options. Many advocates reported that direct support staff needed improved training to respond properly to crisis situations.

Consumer-Directed Support Options

Indiana does not have a HCBS waiver program that specifically offers a consumer-directed support option in its service menu. However, recent efforts to use person-centered planning as a model of service planning and the insistence on developing services that allow families and individuals to select their own case managers and their own service providers certainly has resulted in a foundation from which to move toward consumer-directed support options. It was noted by the site visitors that virtually every family and individual that was interviewed reported that they had, in fact, chosen their own case manager and their own service providers and they also reported that they had choices in identifying where they live and work, and in some cases, they had opportunities to pick with whom they would live. However, many families reported that there were some realities (e.g. budgets) that determined the pool of people with whom an individual could live.

Service Providers

Site visitors met with a number of service provider agencies during the site visit. The agencies included in this review were both profit making and 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 virtually across the entire state. Many 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 ICF/MR services. Most had been providing services to people with developmental disabilities prior to HCBS being an option in Indiana. Waiver services were always one type of service provided and were often referred to by providers as a “funding stream.” Most of these agencies provided a wide variety of specific HCBS services including supported living, respite care, day habilitation, and residential habilitation. 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 and certified. The Medicaid Waiver Unit within the Bureau of In-Home and Aging Supports serves as the point of entry for new providers and this agency certifies all

providers. Home Health agencies, physical therapists and occupational therapists are licensed by the Department of Health.

All providers reported that HCBS in Indiana look and feel very different than ICF/MR. They reported that HCBS are much less structured, provide individuals with greater choice and flexibility and that the way in which these services are staffed is very unique. Most of the HCBS recipients the site visitors met lived in apartments or homes with one or two other individuals and had staff that provided them with support for most of their waking hours. Many had live-in caregivers. All of the places that site visitors visited looked and felt like real homes in local communities. None had the appearance of institutional settings or looked like previous ICF/MR programs that had been turned into Waiver service settings.

The State has taken an active role in recruiting new provider agencies into HCBS delivery. In almost all areas of the state, families and stakeholders reported that individuals have a choice between at least two or more case management agencies and service providers. During the closure of New Castle State Hospital, the State took an active role in sending flyers to existing employees and in sending out official bulletins requesting the development of new provider agencies. There has reportedly been more success at recruiting independent case management agencies than independent respite and in-home providers. Perhaps the biggest reason for this difference in success is that independent and agency-based case management rates are the same, but for other service types such as respite and in-home supports, the independent rate is about \$4.00 per hour less.

When an issue with a provider's performance is identified, the Medicaid Waiver Unit and BDDS have the authority to de-certify the agency. The State reported that generally, when a serious issue is identified, the first step is for the BDDS District Manager and/or Waiver Unit staff to sit down with the provider and to discuss the issue. Following this discussion, a request is made for the provider to submit a corrective action plan. State informants for this case study reported that, in the past, the Medicaid Unit had de-certified HCBS providers but that BDDS had not. However, it was reported that BDDS had been in a situation where they stopped allowing new referrals and placements to be made with a certain agency until they had sufficiently corrected the identified problem.

Agencies reported several issues or barriers that have made the delivery of HCBS difficult in Indiana. Perhaps the biggest issue identified is that until very recently the rates for services had not been increased since 1990 when the program was first implemented. Increases for the cost of inflation had not been routinely provided. Just prior to the site visit, a rate increase of 4% had been implemented. Although stakeholders were appreciative of this increase, they reported the need to establish built-in mechanisms to adjust rates for inflationary cost increases; beyond inflation, it was reported that significant increases were needed to improve the wages that are paid to direct support staff. Without increases, providers and advocates reported concern in the ability of providers to recruit enough new personnel to be able to provide additional HCBS in Indiana.

Another significant challenge faced by these providers was the difficulty in finding, keeping and retaining direct support staff (DSS). In most cases, agencies were unable to provide full benefits and they paid their employees slightly more than minimum wage. The Protection and Advocacy agency reported that 90-95% of their cases involve issues of direct support staff not having the necessary skills to provide the types of services and supports they are providing to people with developmental disabilities. At one point during the site visit, the visitors had the opportunity to read a memo that was sent to the DSS of one agency by the agency's Administrators. In this memo, the Administrator reiterates to the DSS the agency policy on theft of client belongings describes recent incidents in which personal belongings of HCBS recipients had vanished and directs the DSS to stop "stealing" from residents. At the time of the site visit, it was reported to the site visitors that there were no specific training requirements for direct support staff (DSS) who work in HCBS. The training that DSS receive is dependent upon the organization in which they work.

In general, the site visitors had impressive experiences with the DSS they interviewed and observed during the site visit. Almost all of the DSS interacted with the people they were providing supports to in a respectful and caring manner. They understood what the needs of the people they were supporting were and they were working hard to identify strategies to provide opportunities for the person to make their own choices and to develop relationships with people in their communities. Additionally, the agencies that the site visitors visited and the staff within

these organizations reported that they did provide their DSS with significant amounts of training and support.

FINANCING AND REIMBURSEMENT FOR SERVICES

Determination/authorization of Services

The AAA initial case manager in conjunction with a private case manager (if selected by the recipient and their family) uses an interdisciplinary team process to identify the unique needs of each person who is eligible to receive HCBS. People who likely participate in this team process include: the recipient, their family members, the residential and vocational service providers selected by the individual, any specialists that might be involved in the person's life, such as a behavioral support specialist, the D&E Coordinator, the BDDS service coordinator and any other individual that the case manager or the person would like to invite. It is in this planning meeting that the exact types and amounts of HCBS needed by the individual are to be identified and written into the plan of care. Also, at this time, it is expected that natural supports that will be provided by family and friends are written into the service plan. For example, if a family plans to provide the support to their daughter every other weekend, this natural support is built into the comprehensive plan of care. The AAA case manager and the BBDS Service Coordinator review the initial plan of care and submit it for approval from the Waiver Unit.

Expenditures.

In FY 1999, HCBS expenditures in Indiana totaled \$73,133,600. The federal share was 61%. The average number of HCBS recipients during this same year was 1,480 with an average per recipient expenditure of \$49,431 and an average expenditure per resident of the state of Indiana of \$12.49 (5,943,000 state residents). In comparing these expenditures to the national average Indiana, is significantly higher than the national average regarding average daily expenditures per recipient which is \$33,324. The national average per state resident expenditure on HCBS services is \$30.69; Indiana was significantly lower than this average at \$12.49. When compared to other mid-western states, Indiana's expenditures per recipient are higher than Kentucky (\$40,686 annual per recipient expenditure/3,961,000 population), Missouri

(\$22,663/4,468,000) Illinois (\$23,818/12,128,000) and Ohio (\$38,698/11,257,000) (Prouty & Lakin, 2000).

Reimbursement Rates.

Indiana has a multiple reimbursement level depending on the type of service that is being delivered. The case manager initially authorizes all services but final approval comes from the AAA, BDDS, Waiver Unit and the State Office of Medicaid Policy and Planning. There are theoretically no limits on the number of units that can be authorized for each service type but, for a few of the service types, there are lifetime caps. In discussion with state officials, it was reported that there are no longer any individual caps for HCBS recipients but that there are now programmatic caps, meaning that the State reviews plans of care and looks at the total statewide picture to ensure that HCBS will not exceed the maximum allowed to be spent by HCFA. In practice, stakeholder groups indicated a reality of artificial caps and the lack of tailored plans of care based on individual needs because there could be two people coming out of the same developmental center with very different needs and they ended up with the exact same daily rate. Also, an example was provided that, in the three privately run ICFs/MR that were closed, every person who was served by that same agency ended up with the exact same daily rate which, in the opinion of this stakeholder group, did not appear to be very person-centered.

As discussed previously, room and board are most typically paid for by SSI and RSDI. However, there is state line item money – Residential Living Allowance (RLA) – that is given to some individual recipients to assist with purchasing furniture and other start up costs. Some stakeholders reported that they did not observe that there were any criteria for who gets RLA monies and who does not get these monies. Their observation over time has been that people who are moving into the community from state developmental centers usually get RLA but that many people, who are already in the community, do not get RLA.

One critical reimbursement issue identified during the site visit was that case management and provider agencies could not get reimbursed for their services and supports when they are planning for a person's move to the community. This is of concern because successful person-centered planning results in better success rates for community placement and it requires time. When there is no mechanism to pay case management or provider agencies for

their time in connecting people to resources in the community, identifying needs and planning for a transition, then there is a disincentive for them to complete comprehensive planning which could lead to poor placements and increased failures of people being placed into the community.

Most provider agencies bill for their services based on a daily rate, however for some services, the billing units are broken down into 1/4 units. *Table 1* below identifies the reimbursement rates for various service types at the time of the site visit.

Table 1: MR/DD HCBS Waiver – Reimbursement Rates

ICF/MR Waiver Services		
Case management	\$8.00	1/4 hour
Case management assessment – D&E	\$355.00	1 evaluation
Case management assessment - psychological	\$195.00	1 evaluation
Personal assistance (HHA/HAS)	\$14.70	1 hour
Personal assistance (IDDARS-ILS)	\$7.30	1/2 hour
Personal assistance – non agency	\$9.00	1 hour
Respite/attendant (HHA/HAS)	\$14.70	1 hour
Respite/Home Health Aide	\$14.70	1 hour
Respite/LPN (HHA)	\$22.70	1 hour
Respite/RN (HHA)	\$29.90	1 hour
Respite (IDDARS-ILS)	\$7.30	1/2 hour
Respite/Attendant – non agency	\$9.00	1 hour
Respite/group setting (IDDARS-ILS)	\$5.50	1 hour
Adult day care	\$5.50	1 hour
Residential based habilitation	\$6.42	1/4 hour
Day habilitation - individual	\$7.70	1/4 hour
Day habilitation - group	\$1.54	1/4 hour
Behavior management	\$16.69	1/4 hour
Pre-vocational services	\$1.10	1/4 hour
Supported employment	\$8.81	1/4 hour
Environmental modification - initial	\$10,000 – lifetime cap	1 job
Environmental modification - maintenance	\$300 year	1 job
Assistive technology - initial	Prior auth	1 job
Assistive technology- maintenance	Prior auth	1 job

Table 1: MR/DD HCBS Waiver – Reimbursement Rates, continued

ICF/MR Waiver Services		
Personal emergency response system - installation	\$50.00	1 unit
Personal emergency response system – monthly charge	\$50.00	1 unit
Physical therapy (IDDARS – Hab agency/other)	\$17.40	1/4 hour
Physical therapy (HHA)	\$17.40	1/4 hour
Occupational Therapy - (IDDARS – Hab agency/other)	\$17.40	1/4 hour
Occupational Therapy -(HHA)	\$17.40	1/4 hour
Speech/Language Therapy (IDDARS -Hab agency/other)	\$17.40	1/4 hour
Speech/Language Therapy (HHA)	\$17.40	1/4 hour

QUALITY ASSESSMENT AND ENHANCEMENT

Indiana, like many states, has a multi-faceted quality assurance system for HCBS. Area Agencies on Aging, Case Managers, BDDS, Aging and In-Home Services, Adult Protection Services, Protection and Advocacy, the Department of Health and many other individuals and agencies have designated roles in ensuring health, safety and quality of life for people who receive HCBS in Indiana. Each of these roles and quality assurance monitoring processes are described below.

Division of Disability, Aging and Rehabilitative Services. This agency certifies all Medicaid Waiver providers and conducts periodic program reviews within provider agencies. It is charged with investigating consumer complaints and audits fiscal files for compliance.

This Division also has a contract with the Center for Outcome Analysis (COA) to provide a follow along assessment of the individuals leaving State Developmental Centers. This research-based assessment includes pre- and post-measures regarding quality of life issues. Individuals will be followed three times during their first year of community living and annually thereafter. When critical issues are identified by the COA, they are immediately sent to the Bureau of Aging and In-Home Services who notifies BDDS Service Coordinators and Quality Monitors. The outcomes identified from this follow along assessment will be made available to the public through reports.

Bureau of Aging and In-Home Services. The Bureau of Aging and In-Home Services monitors quality assurance plans and compliance with contracts of the Area Agencies on Aging.

In this capacity, they conduct on-site reviews of the case management files, consumer in-home visits and reviews of provider agencies. This Bureau also maintains a 24-hour toll-free hotline number to receive reports of abuse, neglect or exploitation.

Area Agencies on Aging. The monitor the quality of services delivered through the case management process and through their own internal quality assurance processes that are included in their area plans. Additionally, they use providers who are properly licensed and certified.

Each AAA is required to have a Quality Improvement Plan (QIP) which includes feedback to the AAA from consumers on all of the services that are provided under HCBS. This feedback includes information about how the AAA could improve its services. The QIP process is required for all individuals who leave state developmental centers and large ICF/MR programs. For people who receive in-home and community based services and did not previously live in a state developmental center or an ICF/MR, a random sample of 5-10% is required to participate in this quality improvement feedback process. However, it should be noted that one of the AAA agencies that site visitors interviewed reported that they sample approximately 25% of their HCBS recipients through this process. If critical issues are identified in the QIP process, the AAA is required to immediately take action to rectify the situation with providers. The future intent of the QIP is to be able to develop a “report card” on providers that could be used by families and individuals in selecting the agency they want to deliver their services.

Bureau of Developmental Disability Services. One of the most important roles that BDDS staff play in quality assurance is the review and development of plans of care for HCBS recipients who are moving from institutions. This review process is intended to assure that the needs of the person are being met and that staffing and supports are sufficient to address health and safety issues. The Bureau also has a field-based quality monitoring process that involves the 52 Service Coordinators and Quality Monitors. At the time of the site visit, new Quality Monitors were being hired. The majority of the individuals who had been hired by the time of the site visit were previously direct service employees within the State Developmental Centers. Most did not have post-secondary educational degrees. The role of the Service Coordinators and Quality Monitors is to follow up on any items of concern that are flagged to BDDS by the Center

for Outcome Analysis or the Office of Medicaid Policy and Planning. Additionally, it is anticipated that the newly hired Quality Monitors will conduct site visits to all HCBS provider agencies and complete observations and interviews designed to identify issues of concern related to health, safety and feasibility, as well as, to look at varied aspects of quality of life. At the time of the site visit, these field visits were not yet occurring and the monitoring tools and manual was in draft format. Stakeholder groups seemed skeptical and uninformed about the role of the Quality Monitors and they expressed concern that these individuals were coming from backgrounds in state institutions and were not being required to have any specific credentials or training that would assist them in developing skills needed to monitor the quality of community supports.

Also at the time of the site visit, a new procedure for reporting incidents was being fully implemented. Effective January 1, 2000, all incident reports involving the safety and feasibility of HCBS for individuals with developmental disabilities were referred to regional BDDS office field staff for investigation and further reporting. BDDS staff are then responsible to refer applicable cases to Adult Protection Services and Protections and Advocacy, as needed. Additionally, a new management information system (MIS) had been constructed and was in a pilot phase. This system was designed to identify and track all reported incidents and events of significance. These include situations such as: 1) abuse, neglect and exploitation, 2) death, 3) residence uninhabitable, 4) residential fire, 5) hospital admission, 6) missing persons, 7) serious injury, 8) medication error, 9) criminal action as victim or perpetrator, 10) injury and it's cause, and 11) medical conditions. Information was also identified as to whether or not Adult Protection Services or Protection and Advocacy Services had been notified. This MIS was designed to support BDDS and other state agencies in tracking and identifying issues related to provider agencies or to individual people, especially when the incidents were occurring in different BDDS regions, but by the same agencies or people.

AAA/Independent Case managers. Case managers play a key role in assuring the ongoing health, safety and well being of HCBS recipients. Case managers assist in the planning of services that address the health and safety of recipients and they monitor the delivery of services to assess the effectiveness, appropriateness and quality of the services being delivered. Minimally, case managers are required to make face-to-face contact with recipients every three

months to discuss the person's situation and to be certain that the current services are meeting the individuals needs.

Diagnostic and Evaluation Services. As discussed previously in this case study report, the state of Indiana contracts with D&E teams to complete formal clinical assessment to determine initial eligibility. In addition to these initial assessments, the D&E teams conduct annual reviews to be certain the person still meets level of care requirements. These in person contacts provide another opportunity for the person's situation to be reviewed and to be certain that their needs are being met.

Statewide Waiver Ombudsman. A relatively new position for a statewide Waiver Ombudsman for people with developmental disabilities had been created at the time of the site visit. This entity was charged with receiving, investigating and attempting to resolve complaints that concern individuals with developmental disabilities who receive Medicaid HCBS. A statewide toll-free number was to be established for people to use to report issues and concerns.

Adult and Child Protective Services. Adult Protective Services provides protection to adults who are endangered by abuse, neglect and exploitation. This agency has 18 investigators located regionally who investigate all of the reports that are received by their agency. In addition, the Division of Families and Children is responsible for providing child protection services. The DFC has at least one individual in every county that is charged with following up on complaints and conducting investigations regarding abuse, neglect and exploitation of children.

Provider Certification. All providers offering HCBS to people with developmental disabilities in Indiana must be certified. The certification process assures that all providers meet specific state standards as to the qualifications of personnel, the manner in which the organization is constituted, as well as, the scope of the services the provider is expected to cover. The Bureau of Aging and In-Home Services, Medicaid Waiver Unit does the certification for all HCBS providers. ICF/MR and Autism HCBS provider certification required dual certification from BAIHS and the Bureau of Developmental Disability Services. This dual process is designed to ensure that providers can meet the specialized needs of citizens with mental retardation and other developmental disabilities.

Mortality Review Committee. At the time of the site visit, a recent policy decision had been made to convene a Mortality Review Committee. The purpose of this committee would be to review information relative to the death of persons receiving developmental disabilities services and whose services are paid for by State of Indiana funds. The information that is gathered and reviewed by this independent committee would be used to determine trends, identify training needs, modify procedures and policies and to provide a systematic feedback mechanism regarding these serious issues to stakeholders and providers. The proposed members of this committee would come from the following agencies/professions: private practice physician(s) familiar with the needs of persons with MR/DD, private practice forensic nurse(s), State Department of Health, Bureau of Aging and In-Home Services – Adult protective Services, Bureau of state developmental centers & Transitional Services – Quality of Life Unit, Office of Medicaid Policy and Planning, Bureau of Aging and In-Home Services – Medicaid Waiver Unit, Bureau of Developmental Disabilities Services – Quality Assurance, Division of Disability, Aging and Rehabilitative Services – Legal, and a nurse from the Bureau of Aging and In-Home Services. Although stakeholder groups seemed to think the concept of having a Mortality Review Committee was reasonable, they were disappointed that the proposed makeup of this committee included no family members, recipients of services nor any advocates.

Department of Health. All state licensed and Medicaid certified service providers are required to be surveyed by the Department of Health. This survey process focuses mostly on paperwork compliance, personnel qualifications and physical plant related issues.

Electronic Data Systems. Electronic Data Systems is the State of Indiana’s Medicaid fiscal agent. They review all Medicaid funded services to verify that authorizations, billings and payments line up.

Consumer and family involvement. Families and consumers are certainly informants in many of the quality monitoring activities in Indiana. Their opinions about the quality of services that they receive are sought through conversations, interviews and survey processes conducted by the many agencies involved in quality assurance in Indiana. However, 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 Indiana.

Given all of the various players involved in the QA efforts in Indiana, and the seemingly comprehensive nature of this effort, it was surprising to site visitors that when they asked individual recipients, family members, case managers, providers, and advocates what the HCBS quality assurance and monitoring system was, most replied that they were not aware one existed. When site visitors prompted further by identifying one aspect of the QA system (i.e. the AAA QIP surveys) and asking the interviewees if they knew about that component, many still had never heard of the various efforts. The Protection and Advocacy respondents indicated that, from their perspective, there was not any mechanism for quality assurance that was clearly in place at the time of the site visit and that, in their opinion, what was in place was reactionary in nature. From their perspective, the biggest issue related to QA was that there never seemed to be a person in charge (e.g. case manager, BDDS service coordinator, AAA case manager, Waiver Unit staff) who had the power to make something happen or to quickly rectify a problem once it was identified. Surprisingly, even many providers that were interviewed reported that there were no standards or clear expectations regarding the provision of HCBS in Indiana and that they sometimes wished the rules were a bit clearer.

CHALLENGES IN INDIANA

Indiana is faced with a number of challenges and concerns for the future of HCBS. These challenges include areas such as; collaboration with stakeholder groups, case management, the waiting list, quality assurance and enhancement, and direct support workforce issues. These challenges and their implications are briefly identified and discussed below.

Direct support workforce issues. One critically important challenge facing the Indiana HCBS program is the ability of provider 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 wages that are slightly higher than minimum wage and many direct support staff having few paid benefits, especially if they are working part-time. 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 Indiana HCBS program is the ability to seek and respond effectively to stakeholder concerns and opinions. 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 BDDS, OMPP and the AAA's to continue to work collaboratively to seek out and respond to these concerns will assist in the future improvement in the quality of HCBS in Indiana.

Communication and information dissemination. Indiana is well on its way to developing tools and resources to help consumers and stakeholders better understand the opportunities and procedures that exists regarding HCBS in Indiana. The handbook created by the Governor's Council is clear and easy to read. The extent to which handbooks of this nature could be routinely updated and include visual tools for families to use in understanding the roles and responsibilities that the many state and local agencies play related to HCBS would be useful. Many of the management information systems that are in development or that have been newly implemented will assist in identifying useful information for consumers, families, advocates and other stakeholders regarding trends and issues with provider agencies as well as systemic issues that need to be addressed through policy revision and training. Using these newly created systems in a way that actually gets the critical information to stakeholders in a timely manner will serve to keep people informed and should support the improvement of quality of HCBS in Indiana.

Case management. People who receive HCBS services in Indiana do have choice regarding their case manager. This ability to choose a service coordinator was important and appreciated by all of the individuals, family members and stakeholders that the site visitors interviewed. However, even when people do choose an independent case manager, they still have an AAA case manager and a BDDS service coordinator. This was very confusing to many consumers and was reported to be too complex and unnecessarily burdensome by many stakeholder groups. Efforts to simplify this process and to identify procedures for accountability and authority regarding the role of case management and then to get this information out to

stakeholders would be useful in making this process smoother and more user-friendly to recipients and stakeholders. Additionally, efforts to ensure that case managers in AAA and independent case management agencies have sufficient experience and knowledge about needs, issues and available resources and services to people with developmental disabilities who have all types and levels of disabilities, including people with severe challenging behavior and autism.

The waiting list. Indiana has a growing waiting list for people with developmental disabilities who want to receive Home and Community Based Services. Efforts to reduce this waiting list should be taken with consideration given to the need to provide these supports to people who currently live in the community, as well as, people who currently live in ICFs/MR and nursing homes.

Quality assurance and enhancement. Clearly, recent efforts have been made in Indiana to improve the quality assurance and monitoring efforts for HCBS. Of concern, however, is that stakeholders seemed unaware or knowledgeable about these efforts. Also, the complexity and number of the players involved in this process is confusing and difficult for people not involved in “the system” to grasp. Streamlining this quality assurance process and ensuring that mechanisms to respond to complaints and concerns are in place and will be important in moving forward with quality enhancement in Indiana. Additionally, consideration for including family members, consumers and providers in monitoring and quality enhancement activities would bring valued perspectives and insights into quality improvement processes and might assist in bridging the gap between the stakeholder groups and the State regarding issues of quality assurance related to HCBS.

Crisis intervention and behavioral support services. There was clearly a lack of availability and information regarding crisis support services for HCBS recipients in Indiana. When services did exist, they were not community-based and usually resulted in in-patient hospital stays or returned placements in ICFs/MR or other state developmental services. Efforts to build a community crisis intervention system will be necessary in order to keep people with challenging behavior placed in community HCBS and to enable people, who are currently in developmental centers and have serious challenging behavior, the opportunity to move to the community.