Home and Community-Based Services for Persons with Developmental Disabilities in New Jersey

Observations from a site visit of February 28 through March 3, 2000

Submitted to:
The Health Care Financing Administration

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

The Lewin Group

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INTRODUCTION

This report summarizes findings and observations of a site visit to New Jersey 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 serving individuals with mental retardation and related conditions (MR/RC).

Authorization of the Medicaid Home and Community Based Services "waiver" program (HCBS) was contained in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), passed on August 13, 1981. It granted the Secretary of U.S. Department of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The HCBS program was designed to provide home and community-based services for people who are aged, blind, disabled, or who have mental retardation or a related condition (MR/RC), who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid certified, institutional facility. HCBS regulations were published initially in March 1985. Since then a number of new rules and interpretations have been developed, including revised regulations published in July 1994, none of these 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. HCBS recipients must use their own money, usually from cash assistance provided by other Social Security Act programs to fund room and board portion of residential services. In June 1999 about two-thirds (68.6 percent) of HCBS recipients in the 43 states reporting such data, received services in settings other than the home of natural or adoptive family members (Prouty & Lakin, 2000).

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

CASE STUDY OVERVIEW

Purpose

All states have been expanding their services to individuals with MR/RC and families through community services programs. States use a variety of mechanisms to fund these services, including their regular 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 (HCFA) 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 6 states to describe the financing, delivery and outcomes of Medicaid HCBS for people with MR/RC and site visits to another six states to describe similar features of HCBS programs for older and younger people with physical disabilities.

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

The case studies examined key program features, including (a) the context of the program, (b) the philosophy and goals, (c) coordination with the State Medicaid agency, (d) administration, (e) eligibility criteria, (f) financing, reimbursement and contracting for services, (g) quality assurance and monitoring, and (h) challenges for the future. This report is a summary of the case study of New Jersey's Medicaid HCBS program. The New Jersey site visit was conducted February 28 and March 3, 2000 by K. Charlie Lakin (report author) and Mary Hayden of the University of Minnesota.

Methodology

State Selection. States were selected for participation in this study based on a variety of features intended to sample HCBS programs so that both the relatively well-developed program as well as programs that were still developing would be represented. With the assistance of the Technical Advisory Group, factors were identified to order states for sampling purposes including: the number of HCBS recipients as a proportion of all long-term care recipients with MR/RC, HCBS recipients per 100,000 of state population, HCBS expenditures as a percentage of all Medicaid long-term care expenditures for people with MR/RC, the proportion of all ICF-MR and HCBS recipients served in congregate housing, and the location of the state. Based on these factors 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 New Jersey 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 New Jersey viewed the effectiveness of the organizational structures created in achieving the objectives established for the program. Site visitors probed for the perceptions of different stakeholders about what was working well in New Jersey's 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 they asked were intended 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 New Jersey attended to broad HCBS program design and implementation, including:

1. What principles, goals and objectives guide the states 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 delivering HCBS and how and what is the extent of their cooperation, coordination and co-involvement with each other and with the state in pursuing the principles, goals and objectives established by the state for the HCBS program?

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

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

Document review. In addition to interviews there was extensive use of document and data review in this case study. We gathered and examined the following types of documents: 1) the New Jersey HCBS waiver application; 2) the state HCBS procedural manuals and circulars; 3) documents developed and disseminated by the Department of Human Services/Division on Developmental Disabilities for service users, families, service providers and the general public, including reports, newsletters, brochures, and information packets and so forth, including the reports of the Division appointed "Waiting List Planning Working Group;" 4) reports and other publications of related state agencies, especially New Jersey Protection and Advocacy (P&A) agency and state Planning Council of Developmental Disabilities (DD Council), including periodicals, commissioned studies and other documents; 4) documents developed by individual service provider agencies for external presentation of mission, programs, services, clientele, organizational challenges and futures directions, and internal documents related to general operations, organizational development and provision of HCBS-financed community services; and 5) other state or provider agency materials and correspondence relevant to HCBS.

Cooperation of the Division on Developmental Disabilities and Others

We had extremely gracious support from Leon Skowronski, HCBS Waiver Administrator, in preparing for this site visit. During the visit Mr. Skowronski's time and counsel, the involvement of Division Director, Deborah Trub Wehrlen, and the assistance of other Division central office and regional officials and officials of related units with expertise in licensing, quality assurance, data management, Medicaid oversight and other topical areas were also greatly appreciated. We were also deeply appreciative of the involvement of key leaders and staff of state and local agencies with responsibility for advocacy, planning and consumer protections. New Jersey's provider agency leaders and staff were extremely open and helpful in describing their experiences in the community services system. Finally, we are especially grateful for the opportunity to speak with individuals who receive HCBS services to learn of their experiences, needs and hopes for the program.

Review of the Draft Report

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

Selection of Sites and Interviews

The selection of individuals and sites that were visited was carried out by the site visit coordinator, key contact, Leon Skowronski in consultation with the University of Minnesota site visit team leader. As in other states, this visit was designed to include key staff members in the state's administration for community services/HCBS, including 1) key officials of the New Jersey Division on Developmental Disabilities, Medicaid, and other agencies with a role in licensing, monitoring and consumer protections; 2) directors and key officials of the Regional Assistant Directors Office and sub-regional Community Services Offices; 3) Executive Directors of the state Protection and Advocacy agency (P and A) and state Planning Council on Developmental Disabilities (DD Council); 4) county case managers; 5) service provider agency administrators, program directors and direct support staff and individual developmental home "hosts" who were contracted by the state as HCBS providers; and 6) community service/HCBS recipients and their family members.

At the time of our visit HCBS-financed services were being provided in all of the counties of New Jersey. Because of the relatively small size of the state, the site visit team was able to visit three of the four subregional Community Services Office areas. Individual "sites" were selected to include areas that represented both urban and relatively "non-urban" catchment areas.

Evaluators interviewed nearly 50 key stakeholders in New Jersey. HCBS recipients and family members were interviewed in a range of settings from on an individual basis at their homes to in groups of five or six in a conference room at a sheltered workshop. Everyone we asked agreed to be interviewed. All interviewees were extremely accommodating of the site visit team's requests and schedules. The week was structured so that evaluators had the opportunity to see and meet with a variety of recipients and other key stakeholders.

All respondents were promised anonymity. All interviews began with an explanation of the purpose of the site visit and assurances that the evaluators had no regulatory or enforcement roles in HCBS. We also made it clear that we were not employees of HCFA. When it was perceived that the site visit team might be able to affect an individual's services or public policy more generally, it was explained that the team had no such power, but that the concerns raised would be passed on to appropriate public officials.

Major Areas of Inquiry

The major areas of inquiry described in this case study correspond to the primary topics from the interview protocol. Major areas of inquiry that are reflected in the outline of the report include: 1) the context of the program, 2) the philosophy and goals, 3) coordination with the State Medicaid agency, 4) administration, 5) eligibility criteria, 6) financing and reimbursement, and 7) quality assurance and monitoring. A final heading on "challenges in the future" was added to capture issues not easily subsumed under the general headings above.

CONTEXT OF NEW JERSEY'S HCBS PROGRAM

Institutional versus Community Services

New Jersey offers a mix of institutional and community services to persons with MR/RC. It still uses public institutions for persons with MR/RC is still extensive. The reported 3,596 people in New Jersey's seven state institutions ("developmental centers") on June 30, 1999 was the third highest state total in the United States and also third highest in the number of state institution residents per 100,000 of the total state population (44.2), less only than Arkansas and Mississippi and 246 percent of the national average (18.0). Five of the 20 largest public institutions for people with MR/RC in the United States are located in New Jersey.

New Jersey has had some success in reducing its institutionalized populations. In the past decade, between 1990 and 1999 average daily populations of New Jersey's state institutions were reduced by 28 percent. While this reduction was substantially less than the national average of 41 percent during the same period, it certainly should be noted that the 1,433 person total decrease in New Jersey's developmental center populations during the 1990 to 1999 period was substantial. As an indicator of both the challenge and accomplishment, New Jersey officials note that the state's decrease in state institution populations after 1990 was greater than 30 states total number of state institution residents in 1990. It was also noted that average daily populations in the second half of the decade decreased at higher average rate (172 people per year) than in the first half (149 people per year).

During the 1990s New Jersey also made significant progress in developing its community services programs. For example, persons residing in community residential settings increased by 53.2 percent between June 1991 and June 1999. Although this was again substantially below the average national rate of growth (71.9 percent), it did reflect a net increase in community capacity of 400 people beyond the reductions in public and private institution residents over the eight-year period (or 50 people per year). Unfortunately this modest growth was less than the growth in demand, so that by January 31, 2000, the 4,503 people in the two highest categories of New Jersey's residential waiting list was almost half the total number of people actually receiving residential services in institutions or community. By the end of the decade of the 1990s, the “waiting list crisis” in New Jersey was a highly visible and high priority issue to government officials, advocates and other stakeholders.

The extensiveness and visibility of New Jersey’s waiting list for services demands that it be a priority. Responding to the needs of people waiting to enter the community service system form their family homes while maintaining attention on the needs for community services among approximately, 3,400 persons still living in the state developmental centers is a substantial challenge in New Jersey.

In discussions with state level advocates in New Jersey “concern” (and sometimes “embarrassment”) was frequently noted about the number of people with MR/RC left in public institutions. A number of factors were noted about the limited focus on deinstitutionalization and development of community alternatives for current institution residents. It was noted, for example, by a state official that because of state's attention to the quality of care in New Jersey’s institutions and strong ongoing efforts by the families of residents in support of the institutional option and its overall quality, they have never been subject to lawsuits or major scandals. As a result and unlike a majority of states, New Jersey has never experienced a court-ordered action with respect to closure, downsizing or substantial investments in existing institutions. Respondents also noted the power of unions in general and the public employee union specifically as a major factor in relatively limited efforts at institution depopulation and closure. As one state official noted “unions still have a lot of influence in New Jersey” and “loss of developmental center jobs is something they will fight.”

State advocates conceded that these barriers to deinstitutionalization exist elsewhere as well. It was their opinion, however, that relative to other states there has been less visible leadership from the Governor, the Department, from advocates and from an informed and united constituency in New Jersey around the issue of institutional placement. They especially noted a lack of strong independent advocacy in New Jersey. One Executive Director of a service provider/advocacy agency observed that “organizations that provide grassroots advocacy elsewhere are major state contractors in New Jersey” ... so that “risk avoidance becomes advocacy avoidance.” Other respondents noted that the state office of the Arc of New Jersey is a committed advocate for housing, employment and family support services, but is somewhat constrained by the fact that its affiliates are major state contractors for service delivery.

Whatever interviewee’s position on the state of independent advocacy, there was broad consensus that all issues of progressive state policy are subordinated in New Jersey to the “waiting list crisis.” Not only does New Jersey have a major challenge in responding to the large number of people waiting (4,503 people in the two highest categories of New Jersey's residential waiting list as of January 31, 2000), but it had 3,345 of those people categorized as “urgent”. State advocates note that the resulting level of concern and political activism and the “easy call” of taking a stand against waiting lists, has made it more difficult to get a hearing on the more contentious discussion of reducing the number of people currently institutionalized. In fact, the New Jersey Family Coalition compromised largely of families of developmental center residents strongly opposes closures of developmental centers.

HCBS in the Context of New Jersey’s Community Services

A question that is sometimes raised about the Medicaid HCBS waivers generally is whether it is a “program” or simply a “funding stream” for community services for Medicaid eligible people with MR/RC. New Jersey has an unambiguous perspective on this question. New Jersey views itself as having a single community services program with the same services available to people irrespective of whether those services are financed through the Medicaid HCBS waiver “program”. All community procedures are spelled out in a single set of regulations for community service providers. Distinctions between HCBS waiver and non-HCBS waiver recipients are designed to be administrative distinctions without effect on the service delivery practices. All services provided are viewed as state-financed services to people who meet the state definition of developmental disabilities. A separate Community Care Waiver unit and the Bureau of Medicaid assure the billing of Medicaid for those services which are authorized in the state's approved Medicaid HCBS application, are provided as specified, and are received by Medicaid eligible persons.

The Medicaid HCBS program was described by one service provider as "kind of invisible." This summary was echoed throughout the state. People report knowing very little about how the Medicaid HCBS waiver program works or how it might be used to accomplish certain goals. As described the HCBS waiver "program" in New Jersey is an administrative program by which the state recoups from the federal government when it is appropriate to do so, cost-share for services provided with state funds without regard to whether federal cost share can be claimed. While in technical substance this may not be greatly different than the situation in other states, the relative invisibility of HCBS in public discussions about developmental disability policy seems quite unique to New Jersey, although conforming to the state's philosophy of providing services based on need without regard to HCBS eligibility.

PHILOSOPHY AND GOALS

Mission and Principles

The Division of Developmental Disabilities (DDD) in New Jersey identifies its mission to "provide services in the least restrictive environment possible, to foster individual development and independence to people with developmental disabilities" according to principles including:

- "All people with severe developmental disabilities must be eligible to received needed services regardless of age, sex, creed or nature of disability…"
- "Services for people with developmental disabilities must be designed to meet the specific needs of the individual."

- "Consumer choice must be maximized among services and to promote individualization."
- "People with developmental disabilities who require services and support are to be provided with personal options on their lives…"
- "Adequate professional treatment and services, ensuring continuity in the least restrictive and segregated venue possible (which ideally is the person's own community) must be assured…"
- "Opportunities and sites designed to provide training and experience in developmental disabilities must be enhanced."
- "Any support services required by individuals and their families… to assist the person with developmental disabilities to live at home must be arranged for and provided."
- "Planning is to be a participatory process that includes all relevant constituents."
- "Those who work with people who have a developmental disability will be valued." (http://www.state.nj.us/humanservices/)

The general goals of the DDD and the services it provides (including those for which claims are made for federal reimbursement under the Community Care Waiver) are contained in a May 27, 1999 circular (Division Circular #4) entitled, "Principles and Goals of the Division of Developmental Disabilities."

State Agency Goals

- Among the goals articulated for the DDD in the "Goals and Responsibilities" statement of Circular #4 are:
- To provide evaluation, functional and guardianship services to eligible persons;

- To ensure and advocate for the rights of individuals served, to provide for their health, safety and welfare, and to protect individuals served from abuse, neglect and exploitation;
- To develop an Individualized Habilitation Plan with each eligible person admitted to ongoing service;
- To promptly provide effective and individually appropriate care, treatment, training and habilitation to eligible persons;
- To establish and implement procedures for the determination of eligibility for services of the Division;
- To develop an array of services to enable eligible persons to be sustained in their own home or other safe, wholesome and supportive living arrangements as may be most appropriate for the individual;
- To help the families of eligible persons develop an understanding and acceptance of both the capabilities and needs of their relatives;
- To plan for and assure appropriate utilization of generic and specialized private and public resources and to recommend and secure alternate services when needed;
- To establish standards for services, whether provided or purchased on behalf of eligible persons. Such standards shall address the scope and quality of services as well as recognized unique needs;
- Through continual assessment of the Division's programs, to ensure that the individual's needs are met and that established program standards are maintained;
- To provide consultation to organizations and committees (public or private) which work toward improving opportunities for persons who are developmentally disabled;

- Through research and public education, to continue and increase understanding of developmental disabilities;
- To integrate and maximize the use of federal, state or local and private resources in providing essential services to eligible persons and their families;
- To develop and sustain working relationships with other public and private agencies to ensure a continuum of services;
- To provide effective management of the Division's programs and services within the appropriation.

State Commitments to Community Services

There is no more visible issue in the philosophy or specific goals of service delivery for persons with MR/RC in New Jersey than responding to the vast numbers of people who are waiting for services. According to the state's "Waiting List Planning Work Group" in an interim report issued August 1997, between 1986 and 1997 the number of people on New Jersey's waiting list for community service increased from 767 people to 5,124 people (Waiting List Planning Work Group, 1997). As the interim "Waiting List Planning Work Group" report of 1997 noted, "The Division of Developmental Disabilities cannot provide services it cannot pay for. It cannot provide permanent living situations, day programming or other supports without equally permanent ways of funding those services" (p. 7).

Recent measures and efforts to pay for community services in New Jersey have lagged considerably behind those of other states. According to a recent analysis of state developmental disabilities services expenditures per $1,000 of state personal income, New Jersey's "fiscal effort" to finance community services in FY 1998 was 61 percent of the national average. New Jersey was reported to be one of only 3 states (plus the District of Columbia) which recorded a decline of 10 percent or greater in overall "fiscal effort" in all community and institutional developmental disabilities services between 1993 and 1998 (Braddock et al., 2000). However, there have been substantial increases in spending in New Jersey since 1998. By 2001 New Jersey's expenditures for community programs is planned to increase by about 158.6 million dollars or about 36% more than reported for FY 1998. This increase includes reallocated funds from the closure of the North Princeton Developmental Center, waiting initiatives each year through FY 2001, and a community transition initiative in FY 2001 to provide homes in the community for people living in New Jersey developmental centers.

Although survey indicated that New Jersey's total number of persons with MR/RC receiving community and institutional residential services on June 30, 1999 per 100,000 of state population (119.5) was somewhat less than the national average (132.4) and considerably less than the "use rates" of comparable neighboring states like New York (195.6) and Pennsylvania (143.7) (Prouty & Lakin 2000), state officials expect that the growth in resources allocated to community services will close this gap by the end of FY 2001.

Despite its mission, principles and goals, an increase of more than 200 million dollars in annualized allocations for community service since 1996 and the closure of two state developmental centers since 1992, respondents throughout New Jersey identify the Division of Developmental Disabilities as being quite neutral with respect to an organizational commitment to community services, perhaps in part it is suggested because the state institutions ("developmental centers") are programs within the division. Because of the severity of New Jersey's challenges of responding to its waiting list and the drive to achieve consensus around the need for the state to commit sufficient funding for services the attention of the state and advocacy organizations has been more visibly focused on increasing the supply of services than on institution depopulation. But January 1998 final report of the Division's Waiting List Planning Work Group did link the challenges of responding to the state's enormous waiting lists and addressing the state's high rates of institutionalization. The Work Group observed,

> "Decreased reliance on developmental centers is vital, from both a fiscal perspective and a human right perspective…..Any serious attempt to eliminate the Waiting List must include a plan to reduce the number of people living in developmental centers and the subsequent closure of some of these highly restrictive facilities. It is

> estimated that nearly $30 million can be redirected to the Waiting List through the closure of at least three of New Jersey's remaining seven developmental centers." (p.9)

ADMINISTRATIVE LOCATION OF HCBS

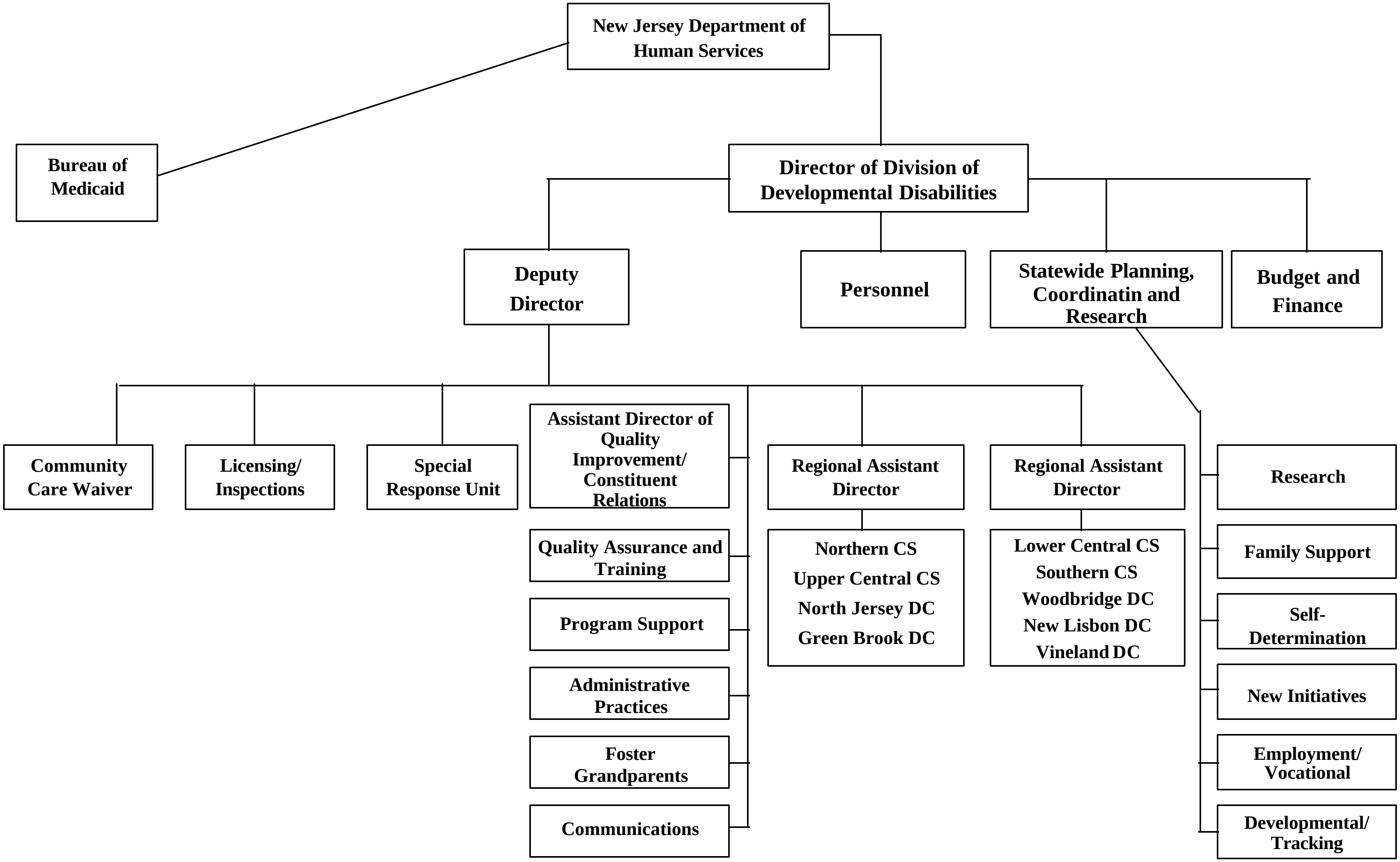
New Jersey's Department of Human Services, Division of Medical Assistance and Health Services (Medicaid Agency) is a Single State Agency responsible for the assurances contained in New Jersey's HCBS application. The Medicaid agency assumes responsibility for fidelity of the state licensing and certification requirements, eligibility and level of care determination, financial accountability, quality of care monitoring and other requirements of HCBS administration to the assurances in the state's HCBS application.

The actual operational and oversight responsibilities for the state's HCBS program are delegated through interagency agreement to the Division of Developmental Disabilities, which is also an agency within the Department of Human Services.

Organizational Chart of Community Care Waiver

The organization chart in Figure 1(next page) shows the organization of New Jersey's Division on Developmental Disabilities and the units associated with the Community Care Waiver. As shown the Division is located within the New Jersey Department of Human Services which provides policy and administrative oversight. The Department's Bureau of Medicaid provides procedural oversight.

Figure 1: Organizational Chart of New Jersey Community Care Waiver



LEAD AGENCY ORGANIZATION

New Jersey's Division of Developmental Disabilities (DDD) is the lead agency for New Jersey's HCBS program. As a division of the Department of Human Services (DHS), the Director of DDD is appointed by the Commissioner of DHS. DDD administers both the institutional (ICF-MR) and HCBS and non-HCBS financed community service for persons with MR/RC in New Jersey. The current director of DDD is relatively new to the role, coming from the role of Executive Director of a non-profit community services agency. Her commitments to community services are clearly articulated and are supported by advocates and service providers in New Jersey.

The community services of New Jersey are organized into regional programs. Designated regions include the Northern and Southern, each is managed by a Regional Assistant Director, whose jurisdiction includes both the community and state institution programs. Within the two primary regions there are four Regional Community Service Offices: Northern, Southern, Upper Central, and Lower Central. These regional Community Services Offices have subregional, county-based offices and county administrators which are the primary point of intake, eligibility, information and referral, service development and case management in New Jersey.

Although personnel of the units are state employees, New Jersey's community services (HCBS) program as well as its institutions, operate with substantially decentralized authority delegated to the regional and community service units. In discussions with service providers there seems to be a general consensus that the regionalization is well-suited for community services management in that it locates the administrative involvement, support and oversight at the community level where the people live, where services are provided and where community resources are better known.

Interviews with state advocates and local service providers indicated that regional and sub-regional administrative offices are generally viewed as committed to the support of the provider community and smooth operation of the system within the requirements of law and regulations. There was a general consensus that regionalization contributes to effective administration of the system, effective communication of state policy and rules and was able to assure generally faithful adherence to state rules and policy. From the perspective of specific HCBS administration, in the words of one Regional Assistant Director ("RAD"), "At the RAD level it doesn't make a difference whether the person is a waiver recipient."

RESPONSIBILITIES AND DIRECTIONS IN HCBS ADMINISTRATION

Role of the Medicaid Agency

The role of New Jersey's Medicaid agency the Division of Medicaid Assistance and Health Services (DMAHS) in the State's Community Care Waiver is largely one of procedural oversight and claims processing Specific responsibilities include processing billings through the state's Medicaid billing system, preparing the required claims and 372 reports for HCBS, and reviewing the processes and outcomes of eligibility determination and plans of care development (with direct review of 40 plans of care annually).

Because New Jersey's seven to eight people Community Care Waiver unit also provides an administrative oversight role with respect to HCBS, it might be viewed as supplementing the review functions of the Medicaid agency. Most notably in the regard the waiver unit conducts an annual "look behind" review of a three to four percent sample (260 people) of HCBS recipients. These reviews attend to primarily paper compliance issues in the eligibility and level of care reviews, proper and timely development of plans of care ("Individual Habilitation Plans"), presentation and completion of freedom of choice forms, case manager visits as required and so forth.

HCBS Management and Policy Development

New Jersey's HCBS administration has been designed to manage and assure financing of existing community services for HCBS eligible individuals within state and federal expectations. As such HCBS per se has not been viewed by some as a mechanism for promoting system change. Stakeholders suggest that this may be both a result of and a contributor limited concerted activity involving DDD and advocacy agencies (especially the DD Council, Protection and Advocacy, and state Arc) in discussions of service reform generally and more specifically about how HCBS options could be used to promote desired policy directions. Stakeholders observe that there has been only a very limited concerted effort to define a progressive agenda for services, and there is very little information about New Jersey's use of HCBS, what other states are doing with it and what New Jersey might consider as options to use HCBS to improve services and/or increase federal and state contributions for them.

But such observations are disputed by state officials who point to the Community Care Waiver as the mechanism for developing and promoting New Jersey's self-determination and new Integrated Therapeutic Network services. Other stakeholders observed that regionalization of service decision-making and service delivery may limit the extent to which the state DDD and the HCBS program are able to be an instrument of statewide change. But whatever the underlying reasons, stakeholders in New Jersey, including service providers state level advocates and state officials indicated that they have experienced fewer than desired opportunities to try to build statewide consensus and concerted planning and advocacy around the design and delivery of community services, and look to a future of better communication and cooperation.

The importance of creating new opportunities for better communication and concerted action appears to be a goal of New Jersey's new Director of DDD. In the February 2000 in a lead article in the Division's new newsletter, "DDD Newsbrief, " she promised that:

> "We will continue to question what changes are necessary and what needs are unmet. But this is not a task the Division can undertake alone. It is my intention to strengthen our communication with all stakeholders to find these answers. Despite diverse perspectives, we share many goals, concerns and visions. Rather than dividing us, our varying experiences and insights can be powerful assets if we focus on our commonality of purpose, exchange information and ideas freely and commit to maintaining our partnership."

This promise appears largely congruent with strong recommendations from the Division's Waiting List Planning Work Group (1998). It recommended a major DD service planning component outside of the Division, guided by all participants in the service delivery system, “in order to provide a participatory process that is removed from the more immediate informational needs of the Division. This planning component should manage and integrate information analyzed from many perspectives, including data management, policy, knowledge or the professional literature, and fiscal and legal aspects. This body should evaluate the Division's current resources and anticipate where the Division should focus its efforts to develop effective services and supports for individuals with developmental disabilities.”

Data Management, Evaluation and Information Reporting

Information systems are widely viewed as a significant problem in program management in New Jersey. Although the state DDD does maintain a limited data system and has a small but skilled research unit, data systems development and their integration into planning and policy is a recognized need.

The state is currently planning to commit substantial resources to improving the infrastructures of data management. This commitment is in line with a recommendation of the Division's "Waiting List Planning Work Group," which observed that,

"The level of planning needed requires the collection and analysis of relevant data about the people presently served by the Division and those who will be served in the future, as well as outcome data and quality assessment measure. The development and availability of a sophisticated Management Information System (MIS) would contribute to the efficiency of case managers/service brokers and be a significant tool in enhanced planning. Consideration should be given to the ways in which data will be used in order to insure that the data that is collected is meaningful and useful, both for individual consumers and their families, and for the Division's overall planning process." (Waiting List Planning Group, 1998, p. 20).

The same report also to recommends a minimum data set that the DDD should implement in order to achieve basic levels of database management. It further recommends specific data uses, accessibility and reporting periods to respond to New Jersey's information needs.

A number of interviewees traced the limited availability of information in New Jersey to substantial budget cuts in 1992 that reduced the central DDD office personnel in Trenton from approximately 200 to 100 staff members. One respondent noted that the, "Budgets pressures of the early 1990’s cut into DDD’s administrative capacity and there is not much sense that program and information management is valued enough to restore the capacity that was lost."

SERVICES AND SERVICE PROVIDERS

Services Available

New Jersey makes available to its service recipients with developmental disabilities a wide range of community services.

Residential Services. Residential services range from group homes and supervised apartments to children and adult foster care/ "host family" models with training as needed (skilled development homes) to "supported living" services with less than full-time supervision. Of the available types of residential services, the most commonly used in June 2000 were, state institutions (3,514 residents), group homes (3,079 residents), foster homes (1,779 residents) and supervised apartments (922 residents). Another 1,466 were reported to be in non-DDD institutions and 791 were in supported living, boarding home or unsupervised settings. About 545 people lived in private “purchase of care” residential facilities in New Jersey and other states settings.

Day Services. Day services in New Jersey are available in adult day activity centers, sheltered workshops and supported employment agencies. In June 2000 there were reported to be 5,191 people in adult day activity centers, 970 in workshops and 1,623 in supported employment arrangements.

Family Support Family support is available in the form of respite care and in-home services, to families supporting individuals in own their family home or to “foster families” skill development homes. Support for families is also available in the form of case management, day services for persons living at home, transportation and other services to individuals and families. Altogether New Jersey identifies 16,431 service recipients of DDD (out of 28,527 total) as living in their own family home.

Case Management. Case management is the most widely available of services in New Jersey. In December 1998 there were an estimated 23,804 persons receiving DDD case management from a total of 248 case managers (or an average consumer/case manager ratio of 96.0).

Self-Determination. New Jersey's newest program, available to HCBS recipients, is "self-determination." There are about 245 program participants. Self-determination is available only for people currently on New Jersey's waiting list for residential services who are identified in the "urgent" category. Funding available through the self-determination option cannot be used to purchase "packaged" residential services from an agency (i.e., cannot be used for group homes, supervised apartments, or supported living). Persons authorized the self-determination option may hire a support broker to develop a support plan and budget or do it with family or friends. Even though a person hires a support broker, he/she still is assigned a case manager for the monitoring of services and well-being.

The self-determination option provides many possibilities. The state's brochure on the option notes that, "Self-determination is best suited for people and their families who wish to have authority and control over their own supports and services…for managing the budgets associated with them…[and] have some resources - like friends and families - but need additional support for a more independent life style."

Budget caps are set at what the DDD estimates the costs of a traditional service programs for the same individual. Although individuals construct their own budgets with guidelines and certain cost-center limits, the budgets are actually administered by a fiscal intermediary agency. Although "self-determination" is not itself an HCBS service category, HCBS authorized services provided to self-determination participants are claimed for Medicaid reimbursement. Regional administrators observe that self-determination is not for everyone: "It’s a lot of work." Right now the greatest interest is reported to be among younger families. Some are reported to be those who "can't imagine not being in charge." Other families are reported to have selected the self-determination option because "you've got to take whatever you can get."

Other Services New Jersey also provides environmental and vehicle modification services, and personal alerting systems to people with MR/RC, which are claimed for Medicaid reimbursement for eligible persons. The state also provides an "Integrated Therapeutic Network" service for persons who need assistance in areas typically covered by occupational, physical, speech and language, psychological/ psychiatric services. These services include assessment, planning, direct therapy, training staff and family members to provide therapy, and monitoring outcomes. As such it extends the direct professional therapy services typically available in Medicaid state plan programs in ways that are more conducive to ongoing habilitation in natural environments.

As noted New Jersey's HCBS reimbursed services are congruent with its general menu of services such that, if a service recipient is eligible for HCBS, the cost of the services provided are claimed for reimbursement. It might be noted, however, that the specific service categories identified in the HCBS application and in the Medicaid payment system are not identical in name to the "menu" of services provided under the auspices of DDD. Seven broad categories are included in the service contracts for Medicaid billing: 1) case management; 2) respite care 3) habilitation (with special subcategories of day habilitation, and supported employment); 4) individual supports (or residential habilitation in group homes, skill development homes, skill development homes for children under 12 years, own homes, and self-determination); 5) personal emergency response system; 6) environmental/vehicle modifications; and 7) Integrated Therapeutic Network Services.

Case Management and Service Planning

Role of case managers. In New Jersey case managers are entrusted with primary responsibility for the well-being of persons with disabilities and their families and for attending to the quality and appropriateness of the services people receive. Case manager responsibilities include maintaining on going contact with consumers and families, visits with consumers at service sites, developing and monitoring the Individual Habilitation Plan (or Plan of Care), and attending to the current adequacy of residential, vocational, health and other needed services. A foundation of the integrity of the service system is the acceptance of the case managers as an authoritative, involved and valued representative of the interests of the individuals with disabilities. One of the major impediments to accomplishment of such acceptance is the large case loads of case managers in New Jersey. The DDD reports that in December 1999 case managers had on average 96 consumers. This compares with a reported 70 in 1989 (DDD, December 1999). According to a 1995 report of the National Association of State Directors of Developmental Disabilities Services only one other of 41 reporting states had case manager caseloads larger than New Jersey's (Cooper & Smith 1998).

The case managers interviewed view the strength of their role to be the extent to which they are permitted and encouraged to have an integrated and cooperative involvement not only in the lives of service recipients but also with the service sites and agencies they oversee. Case managers describe their advocacy role as first addressing the problems that may arise through direct dialogue with program level staff and supervisors, second taking the problem to the agency management and last, and rarely, bringing problems up with the County case management supervisors, the regional administration or the Division of Licensing and Inspections. But they note that caseload and paperwork demands interfere with achieving the ideal. Observations from service providers about the ability of case managers to fulfill the ideal included that case managers tend to work during normal 8 am to 5 pm business hours while over 90% of people's residential services are received before 8 am after 5 pm and on the weekends.

Organization of Case Management. New Jersey has an interesting model of case management designed to provide services commensurate to an individual's general circumstances and to allocate scarce case management resources where they as most badly needed. The case management system has three levels.

Primary Case Management is provided to people considered to be relatively more vulnerable because of potential isolation and/or need for special attention. People in skill development (family foster care) homes, boarding homes, and some with “urgent” status on the waiting list for services are assigned a "primary" case manager. The caseloads of primary case managers are ideally about 35 individuals, but respondents report that, in reality at present they are more typically 40 to 45 individuals. Primary case managers visit service recipients monthly on a face-to-face basis.

Program Case Management

Program case management is provided to people who are enrolled in structured programs in which they can be expected to experience regular oversight by a range of people. People receiving "program" case management include people living in group homes, and supervised apartments, people enrolled in day programs, and self-determination participants. The caseloads of program case managers are recommended to be about 90 individuals, but again actual caseloads are reported to be slightly higher. Caseloads of up to 100 individuals were reported in interviews with case managers.

Visits with individuals who have program case managers are expected to be made on at least a quarterly basis. But in reality program case managers often have several service recipients in the same program and may see people more frequently. In fact it appears that many program case managers are very highly integrated into the operations of relatively few agencies. They are frequently on-site, are well-known to staff and know the program and program staff well. A positive aspect of program case managers integration into the programs is their knowing the staff and seeing what is going on with fair regularity. One limitation noted was that the familiarity and comfort of case managers with the programs of a particular agency may limit advocacy on behalf of the participants. Another limitation is that program case managers may have relatively few programs in their experience with which to make critical comparisons.

Resource case management. Resource case management is intended for people who may not need ongoing traditional case management. Resource case management is a connection to the system to identify and respond to problems with services received, to provide information and referral, and to attend to changing circumstances of people who are living with family. Resource case management is provided primarily to people living in their family home. “Resource” caseloads are typically around 250 and at least one contact is made with the service recipient or family member per year. A major purpose of resource case management is to assure access to information and advice and to assure awareness within the service system of changes in people's lives that may require new or different services.

Observations on Case Management

Agency administrators and direct support staff frequently note that there is substantial variability in attitude, skills and knowledge of case mangers. One agency administrator observed that, “Some are excellent, others you really need to push.” A direct support provider lead worker agreed: “Some do a pretty good job to make sure people’s needs are met, others not so much."

Good case managers were characterized by a group of program directors as being a partner with the service provider agency staff in improving each individual’s life. They appreciated case managers who were able to answer questions or were willing to find the answer when it was not known. They most appreciated case managers who were willing to look for resources, able to help research and brainstorm solutions to a particular problem and would carry an agency’s ideas and needs through the bureaucracy.

Some case managers were described as creating impediments to person-centered service goals by "not being accessible”, and by being “negative about change” and “poorly informed”. In general case managers were not viewed as primary sources of information and advocates for innovation related to person-centered services. Instead they were seen as “having a good deal of faith in agencies” to provide the drive for needed change and innovation. Investments in the development of knowledge, skills and progressive person-centered commitments among case managers and case manager supervisors were viewed by some stakeholders as potentially beneficial. But most consistently stakeholders throughout the state viewed reductions of caseloads to allow case managers to be meaningful involved in people's lives as essential first steps establishing more to effective, responsive case management in New Jersey.

Residential Supports

Residential supports are offered to New Jersey "community care" recipients in a variety of settings, including skill development homes, group homes, people's own homes and people's family home. Although the sample was relatively small, residential service recipients generally expressed at least satisfaction and sometimes high enthusiasm for the places they were living. A visit to an agency that described its mission as helping people “achieve the greatest degree of independence and productivity, and become responsible and proud member of society" was impressive in the sense of personal success felt by service users interviewed. The use of the word proud was notably reflected in discussions of individual's experience. Two former institution residents said that they were “proud” that they had made it out of the institution and that they were "proud" to be a part of their community.

Agency attention on getting people involved in trying new roles in the community, especially through participation in community volunteer activities, seemed an important part of people's identity as being involved in productive and prideful roles. The greatest enthusiasm encountered was from two young adults who were living in their own (separate) apartments in larger apartment complexes with non-disabled companions. Both expressed pleasure with not having to live with other roommates with disability, both after having lived in shared housing with people they report not having liked. Both described pleasure and satisfaction the process of shopping for and choosing their own housing. In addition, both described enjoying their companionship with their live-in support provider and their time together watching television, shopping, and "being funny".

Group home residents also expressed general satisfaction with their residential situations. One exception (of six interviewed) was an older woman who had spent most of her years in a state institution. She was living in a group home with five other people and had been for 13 years. She described a life of relatively less personal control. She noted that there was a housemate of whom she is afraid, who she described as loud, breaking things, and whom she would like to see "sent to live somewhere else." She reported that staff "sometimes knock before they enter her room and sometimes not" and that she said she had to "wait quite a lot" for things as basic as "getting out of bed, going to the bathroom, things like that." Although this one interviewee described patterns in her life that reflected what is often called "group treatment," such as waiting for basic needs to be met according to the schedule of staff, being dependent on facility van schedule, and "always going places in groups" and staff sometimes putting expediency above individual respect and dignity (e.g., not knocking before entering a private bedroom), such reports were uncommon among the individuals interviewed (for the most part persons with more mild intellectual and communication impairments).

Although New Jersey has one of the highest proportion of HCBS recipients living in family foster care arrangements ("Skill Development Homes), none of the people interviewed came from such settings. Interviews with case managers and regional office staff suggest that skill development homes offer a range of provider quality and motivation as well as a range of residential experience. Case managers report that the lower case management ratios for people in skill development homes permit closer attention to people's experiences, but that because the individuals are living in another person's home and family there is no way (nor usually any desire) to overcome the family culture. This makes effective matching of individual needs and interests with those of the skill development provider especially important.

HABILITATION/SUPPORTED EMPLOYMENT

Interviewees reported that New Jersey's day programs for HCBS recipients are heavily facility-based work and non-work programs. This observation was supported by a national study that indicated that in 1996 New Jersey had 22.3 people with developmental disabilities in integrated supported or competitive employment experiences per 100,000 of the state's population, as compared with an average national rate of 40.1 per 100,000 (Butterworth et al., 1999).

Work Programs

The HCBS service recipients in integrated work experiences expressed high levels of satisfaction and desire for expanded opportunities and hours of paid work. People with jobs expressed pride in themselves, their work and the company that employed them. They reported that they were proud about being paid and about having and using their own money to pay for cable, purchase televisions, books and clothes and even for personal savings.

Individuals with MR/RC who were working reported engaging considerable amounts of their free time around the possibilities of and actual use of earned wages. People with jobs identified the role of "consumer" as one of their favorite roles in life and viewed it as a role that provided both freedom and respect. They viewed managing their own money as an important challenge and responsibility. One interviewee reported with appreciation to the service provider agency that, "We have someone who helps us every other week so we can do our budget, pay our bills and write our checks."

Several people who were employed, but who were limited in the hours they could work were supported by agencies to supplement their desire to work with volunteer roles. Voluntary roles were developed by a number of New Jersey service providers for part-time employees and service recipients spoke with enthusiasm about their activities and the people they met through them.

Day Center and Community Immersion Programs

The work and non-work activities were very traditional in the day centers visited. Their programs appeared to be relatively passive in assisting people to be included with the communities in which the centers were located. Although not particularly notable in the programs provided, the center-based activity and sheltered work settings visited appeared well-staffed and were well-monitored by the case mangers of individual service recipients. Because a single case manager of ten has many individuals from his/her case load in a single day, case managers appear to spend a good deal of time at the centers, know the center administration and have a good understanding of individual's experiences in the centers. People in non-work day programs expressed general satisfaction with their experiences.

The most enthusiastic of non-employed interviewees were involved in various out-of-facility “Community Integration” or “Community Immersion” programs. Three agencies were visited that had created community integration/immersion pilot programs for people who generally were coming from off the DD waiting list and would otherwise have been placed in non-work, center-based activities. As explained, these programs by design make sure that people spend more than half of their program time outside the center. The integration programs not only focused on getting people into the community, but appear committed to allowing people to sample a range of new experiences so that they are better able to make informed decisions about preferred ways to spend program time. For the most part the programs provided for a mix of leisure and volunteer community-service activities.

In addition to the enthusiasm of program participants, direct support staff spoke very positively about the integration/immersion programs and the alternative they provided to day center-based services. They liked creativity required to make a program in which “every day is a new and different day,” and noted the sharp contrast with routine space and activities of day centers. Both parents and staff agreed about the beneficial outcomes of people's participating in and contributing through community volunteer and social activities. One staff member who had previously worked at a day center reported that "People who never wanted to do things in the

[day] center, when they get out in the community really surprise you." But she also viewed community roles as a process more than a program: "We need to expose people to a lot of things, have them see what's out there. We need to help them find their interests."

Although community acceptance was widely viewed as a problem in promoting community integration, different agency administrators and staff approached it differently. While some direct support staff viewed the lack of that community acceptance as a barrier, others viewed it as a challenge. One direct support staff member noted that, "Community uneasiness is the biggest thing in the way of integration and the only answer to the problem is people-to-people contact."

SERVICE PROVIDERS

The Community Agencies

The service provider agencies in New Jersey are recognized as the heart and soul of the community services system of New Jersey and as the primary determining factor in the experiences and benefits that HCBS provides. Most community services in the state are provided by established non-profit community organizations that have a history in and strong sense of responsibility to and standing within the area they serve. There appears to be a strong sense of trust, security and comfort within the geographic communities served and within the developmental disabilities system about dependability and commitment of the established community service agencies.

Visits with families provided remarkable stories of love, support and compassion. The stores sometimes extended beyond service recipients to their families as well. A 75-year old mother whose daughter lives at home and who has no support other than the daughter's day program, described a number of very personal and needed supports from the day program staff, including how the day program staff bring meals to the family home for her and her daughter when she is sick. She says, "Its unbelievable how they are."

Visits to community service agencies suggest that they vary considerably in how they view the nature and goals of their service, and the challenges they face. It is clear that there is considerable range in organizational cultures and orientations to community supports. These differences are reflected not only in the ways that agency administrators describe their services, but also in how direct care staff and front-line supervisors describe their roles. Because the system entrusts so much to community agencies, the leadership of those agencies and their levels of knowledge and commitment, their interpretation of the mission and goals of the agency and their attention to their own personal and professional development are very important to agency effectiveness. They are also clearly related the innovation and personalization of the service provided by the agencies.

It also seemed apparent, albeit from a small sample, that in agencies with leadership and goals focused on person-centered services, direct care staff not only shared the goals, but also talked about being valued, independent and well supported. This was reflected in comments from direct support staff including: "This agency listens more to direct care staff." "The agency finds money or makes the changes to make things happen." "We are really supported to be creative." "The agency responds quickly to new ideas."

While generally confidence is expressed in existing agencies in New Jersey stakeholders note that choice has sometimes been restricted by a relative low number of agencies serving certain catchment areas. Recent efforts at opening the system to new providers is viewed by case managers as a potentially positive contribution to variety and choice, but it is also described by some of them as worrisome because of the difficulty in establishing and maintaining the kind of provider- case manager relationships that currently exist, especially given the size of caseloads of program case managers (often 90-100 people).

In interviews with state administrators, case managers and service providers it was clear that there are agencies that are viewed as motivated to learn and change to be able provide greater numbers of options to people. Specific of agencies are distinctly identified as leaders in doing so. Others are viewed as having invested less and accomplished less in the development of contemporary services. There were examples provided of service agencies beginning to work together as learning communities focused on agency and system improvement, but again the examples seemed limited and without sufficient support from the “system” to be widely effective in promoting change.

Case managers noted in interviews that the state has recently been promoting growth in the number of different organizations and service sites operating in the counties. Some of the case managers interviewed considered the expansion of providers as a “new positive change” that is creating greater diversity of options and challenging traditional providers to reevaluated their services and “to change with the times.” Other case managers viewed some of the new providers as “worrisome” and expressed concern about the primary motivations of the newcomers. Some expressed uneasiness about not feeling as comfortable with agencies whose relationships with case managers were less well established. Case managers also noted that the new providers demanded much more time and intense involvement than existing ones. As one summarized "Its a lot easier to work with established agencies.”

Personnel Recruitment, Retention and Training

State Licensing, Regional Office managers, case managers and service provider agency administrators identified recruitment and retention of qualified staff as a very serious problem in New Jersey that currently affects both the capacity and quality of community services, and especially residential services. Recruitment and retention in residential programs was consistently identified as the most serious problem facing residential service agencies. There were also significant problems noted among vocational programs, but in general these were reported to be less of a crisis than that experienced in residential services.

Staff recruitment/retention. The primary problem contributing to the serious difficulties in recruitment and retention was consistently viewed as the payment rates for residential programs which were not sufficient to attract and retain sufficient numbers of competent employees. Secondary problems were associated with the low unemployment rate in New Jersey and the strong competition for any and all available employees. It was noted by service providers and case managers that the numbers and entry skill levels of persons applying for direct support staff openings have been changing, that improved recruitment, training and retention efforts are needed, and that responsibility for these improvements, while remaining primarily those of service providers should be shared actively and seriously by state and state-level advocacy organizations. They note that the quality and integrity of the entire community service system depends on the entire state system's success in developing and maintaining a sufficient workforce of qualified support personnel.

The problems of staff recruitment and retention were viewed by a number of observers as placing a special burden on service users. Many programs are "down staff" (operating with vacancies) and in the words of one case manager, “Consumers feel it because they don’t get the attention they need”. In interviews consumers report that for them, staff shortages means waiting. For individuals with substantial physical needs or others in need of extensive support it means things as basic as “waiting to get out of bed, waiting to go to the bathroom, things like that.”

Recruitment problems are reported to be leading to staff working more and more hours. It was noted that on the positive side with sufficient overtime direct support staff can earn a living wage. But a focus group of frontline supervisors of direct support staff agreed that there are significant problems in depending on people working overtime. They agreed with our participants observation that many “direct support staff are operating on empty” because of long hours and understaffing of the settings in which they work. Another supervisor noted that recruitment and retention problems have increased the amount of time that experienced staff spend training new direct support staff. In the words of one program director, “Sometimes it's a burden on already strained staff when they need to train new persons on site, but the people who really lose are the people who need help from the person who is busy training someone else.”

Discussions with service provider agency administrators indicated that notable differences existed among service providers in relative difficulty being experienced in recruiting and retaining sufficient members of staff and sufficient quality of staff. To some extent this variability appeared associated with the economics of the local area. But it also seemed related to intra-agency management. An executive director of an agency with a relatively low (and specifically monitored) annual staff turnover rate of 16 percent was quite clear about efforts needed and adopted to maintain staff commitment to the organization and the people served. Direct support staff interviewed from the agency expressed a sense of being empowered and supported to be creative, able to redesign programs and to view their job as working primarily for the consumer, the same basic attitudes that the executive director attempted to promote.

Staff training. Access within New Jersey and its service provider agencies to well-designed, comprehensive entry-level and ongoing training was viewed as a concern by a range of interviewees, from Regional Directors to family members. Many respondents identified training as something that recently is being taken more seriously and about which visible improvements are being made. Some agencies were able to provide a schedule of a comprehensive training program with planned training events stretching for the whole year. In general, however, there is a clear sense that the quality and content of training varies considerably, not only among agencies but within different programs and sites within the agencies, and for personnel who work different schedules and shifts within the same program. While training may often be sufficient for motivated, self-directed, competent support personnel, the reality is that there is a growing difficulty in recruiting people with such characteristics. There is a growing challenge in assuring that staff training is tailored to the entry level skills of the people entirely the field. A number of respondents when asked about sources of training support mentioned the University Affiliated Program (Boggs Center) as a current source of training and one which might potentially play an expanded role.

Families expressed confidence in and gratitude to the agencies that supported them and their family members. The families interviewed universally felt that their service agencies were committed to and caring about their family. Younger parents tended to express higher expectations for inclusion and employment outcomes, and were less accepting of the service provider agency as the primary authority in deciding about what is best for their family member.

Older parents were much more likely to describe the day program agency (especially when a middle age child lived at home with aging parents) as an important sources of emotional and social support both to the individual with disabilities and the family member. One mother reported that, “I have a wonderful relationship with the people at the center. They even gave me a birthday party at the center ...They bend over backwards for [my daughter] and me."

ELIGIBILITY REQUIREMENTS AND DETERMINATION

Intake for community services (whether or not HCBS financed) occurs through the Regional Office Community Services program offices. Intake workers determine whether the services being sought are provided by DDD and if so provide the individual/family with application materials. If not, the individual is to be referred to another appropriate agency. Assistance is offered to individuals or families requesting it for the application process.

Technically independent eligibility determination definitions and procedures exist for community services generally and HCBS specifically in New Jersey. The first determines that a person is eligible for the services of the Division on Developmental Disabilities. The second determines that the person is eligible for the state's Federal Financial Participation in the cost of claiming the services as part of the "Community Care Waiver." As noted, there is no programmatic distinction between the services available to people who meet the first condition but not the second, so that almost any service received by any DDD service recipient can be covered by the Community Care Waiver if the individual meets the eligibility standards and the service is delivered according to the authorized procedures. It is the primary responsibility of the Coordinator and staff of the Community Care Waiver, with review by Medicaid staff, to determine who from among the service recipients of the Division of Developmental Disabilities are persons for whom claims may be made for federal cost share. The Community Care Waiver staff then authorize the submission of monthly claims for service for people on the Community Care Waiver master list.

Eligibility for DDD services in New Jersey is established by modified standard definitions of mental retardation and/or developmental disabilities. Mental retardation for eligibility purposes is defined as an IQ below 59 without regard to additional impairments; or an IQ below 69, and an impairment in adaptive behavior, and/or a chronic medical problem; and/or impairment in behavioral, sensory or motor functioning and limitations in performing basic self-care functions. Eligibility requires that the mental retardation be established to have existed prior to reach age 22 and that it is expected to be of life duration.

Persons can also be determined eligible for DDD services on the basis of a determination of developmental disability, defined as a severe, chronic disability of an individual which: Is attribute to a mental or physical impairment or combination of mental or physical impairments other than mental illness; is manifest before age 22; is likely to continue indefinitely; results in substantial functional limitations, before the age of 22, in three or more of the following areas of major life activity, that is self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living or economic self-sufficiency; and reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated. Developmental disability is defined to include, but not be limited to "severe disabilities attributable to mental retardation, autism, cerebral palsy, epilepsy, spina bifida and other neurological impairments where the above criteria are met."

Eligibility is determined administratively at the regional office based on a case file including basic demographic, medical, other clinical information and current service data. Records are built from records maintained by educational and other relevant agencies. If eligibility is not clearly established the psychologist schedules a face-to-face assessment and outcomes of the assessment are considered by an Intake Team for a decision.

At the same time of eligibility determination there is also an assessment of need for ICF-MR level of care based on the same information. Certification of level of care need is signed by a team member who meets the standards of Qualified Mental Retardation Professional. Re-evaluation of eligibility and level of care needs are carried out annually in conjunction with the development of the Individual Habilitation Plan (Plan of Care).

Persons documenting categorical eligibility for services (i.e., that they meet the standard for mental retardation or developmental disability) also undergo a financial assessment for personal and family ability to pay part of the costs if the individual is seeking out-of-home residential services. Requirements for prior determination of both categorical eligibility and family ability to pay may be waived in urgent or emergency situations in which the Regional Administrator can determine the person to be "presumptively eligible," but subsequent eligibility determination and financial screening is required.

For persons in residential situations financed by the DDD, the Division employs a series of formulas to determine if an individual or, in the case of a minor child, the "Legally Responsible Relative" (i.e., a parent) has sufficient assets to pay for all or contribute towards a part of the state's cost of providing care to the individual. In the case of a Legally Responsible Relative there is a potential contribution of up to 20 percent of family income after certain "family maintenance standard" offsets are applied. For individuals, there is a potential contribution of up to 50% of unearned (generally benefit) income and up to 30% of earned income. Individuals may retain up to 50% of their unearned income to meet special needs arising from living expenses unable to be addressed entirely by the Personal Needs Allowance. Earned income from activities earning less than minimum hourly wage or amounting to less than $131 monthly is exempted."

FINANCING AND REIMBURSEMENT

The HCBS in New Jersey is operated as a billing program for standard community services. The DDD develops, monitors and finances a set of services as part of its community services program. The state seeks and obtains HCFA authorization to provide essentially the same basic set of services in its HCBS application for persons who meet categorical and level of care standards for HCBS. The authorization of HCBS recipients requested and obtained substantially exceeds the number of people who will be provided services. This assures that as people are brought into the community services system in New Jersey all of those who qualify for Federal Financial Participation can be claimed.

The allocation of resources for services provided to people with developmental disabilities in New Jersey is determined by budgets administered at the four Regional Offices. Whether federal reimbursement is available for an individual's services is viewed as irrelevant to the decisions made on the regional level. Those decisions are described as being based solely on the needs of individuals and the state appropriations available for services. The role of the state HCBS and Medicaid programs in this regard is to assure that when HCBS eligible services are provided to HCBS eligible people, such services are appropriately claimed under the waiver authority.

While anticipated cost recovery based on estimates of the number of likely HCBS recipients, their costs and the federal cost-share of those costs is reported to be a part of state budget development and approval, it is reported not to be a factor in regional service decisions. State and regional officials report that the separation of billing and service decisions has allowed focus on providing what people need without consideration of whether a person is Medicaid eligible. But critics of this approach say it has also led to a situation in which "relatively few people understand the CC [community care] waiver."

QUALITY ASSESSMENT AND ENHANCEMENT

Quality assurance is clearly a system of substantial concern in New Jersey. In large measure the concerns relate to ambiguity in roles and adequacy of resources.

CASE MANAGEMENT AND QUALITY ASSURANCE

A nearly universal perspective exists in New Jersey that key component of "quality assurance" derives from the relationship between the case manager and consumer. State officials involved in the current monitoring system observed they would like to see greater clarity with respect to the case manager's responsibility and role in quality monitoring. They note that there are "different" ideas among case managers and regional and county officials about the extent to which the case managers are an agent of quality assurance and what their specific role should be. It was urged that the DDD work to establish a clear and informed policy in this regard and to assure that if case managers are to be responsible for aspects of formal quality assurance that their role clearly defined and consistent with the formal expectations and structured formats for assessing quality. Conversely, it was suggested that if case managers are not to have a significant, defined and consistent role be in quality assurance that a clearly focused quality assurance role be established within the DD system.

Program case managers have caseloads in the range of 80-100 persons served by a much smaller total number of agencies. Program case managers have well integrated relationships with agencies, making them available to both consumers and the agencies. On the other hand some case managers are so well integrated into the agencies, it seems hard to expect that they could always function as independent agents of desirable change. As noted earlier, as the primary agents of quality, a number of case managers interviewed seemed quite isolated from evolving standards and concepts of quality and very satisfied with programs that to the site reviewers seemed substantially behind the times and contemporary expectations for service delivery.

INTERNAL AGENCY QUALITY MONITORING

In addition to the integrated role of case managers in agency programs, service providers in New Jersey are also required to establish their own internal quality assurance review system. The establishment of such an expectation is in line with contemporary philosophies of quality (i.e., quality assessment as a design feature or programs). In reality, however, the established internal quality assessment systems vary considerably in their consumer versus agency orientation and in their specific areas of focus. For example, one agency visited counted percentages of consumers who achieved objectives that the agency established for itself (e.g., percentage of consumers participating in a minimum of one community recreation activity per week, percentage of people meeting functional activities standards in IHP goals). Another agency interviewed each service recipient with a focus on how well the individual felt that he/she was being served (e.g., "Are there activities that you would like to be involved in your free time, but have not had the opportunity?" "Do you know what the goals are in your IHP?" "Did you choose your residential goals yourself?" "Are you still happy with goals you chose for yourself?"

"Are you given the assistance you need to work on your goals?"). In short, the instruments and procedures of agency quality assurance varied considerably in the information they gathered to assist in improving their services, or put another way they reflected very different definitions of quality in services and agency performance.

The agencies visited varied considerably in the extent to which they value and use internal quality assurance systems. One agency Executive Director observed that, “This information is a wonderful thing from the agency viewpoint.” He described how each manager of each program manages data collection about that program with a system that is based on consumer and family perceptions of support for their desired lifestyle outcomes. He commented that their information system produces “living, breathing documents,” and that the agency is challenged to view their system as the “outcome documentation we need to grow and change to meet people expectations.” This did not, however, seem to be a prevailing attitude. There were few examples found of case managers and regional staff being involved in and attentive to the internal quality assurance systems and the outcomes of the service providing agencies and the people they serve. In short there was little evidence that such outcome systems and the information from them were viewed seriously outside the agencies. This may be in part because of doubts that the internal quality assurance systems used provided useful information related to quality as it is defined by case managers and regional office staff. It also raises the question of why such investments are required without attention to their potential benefits or actual outcomes.

There were some promising practices in making effective use of the required internal quality assurance systems. There were, for examples, instances in which Arc-provider agencies from different communities shared internal quality evaluation system instruments and methodologies with each other. For the most part, however, agencies appeared to develop their own approaches, implemented them independently and integrated them differently into organizational review and improvement strategies. One Regional Official noted that the state “needs a higher level of sophistication in quality assurance reviews” and “needs to foster more of a continuous quality management approach to them.” An agency executive director observed that, "There is not much support from the state in defining quality and measuring it" and that..."the state needs to be better able to determine what an acceptable quality assurance system is" (e.g., in areas of definition, measurement and data use). Reflecting on such changes in expectations for quality definition and assessment, a Regional Official cautioned that, "New Jersey is risk aversive. People are well-protected, but quality of life needs attention."

LICENSING AND INSPECTIONS

Beyond the roles of case managers and agencies in quality assurance, there is a formal state system of consumer protections. This system includes licensing, special incident reporting requirements and investigations of serious incidents.

Licensing by the Licensing and Inspections unit assures compliance with existing standards for community residences. There are different types of licenses for owner occupied homes, for corporate entity homes serving persons with developmental disabilities and corporate entity homes serving persons with head injuries. Each is licensed under different standards. Corporate entity homes include group homes, supervised apartments and supported living programs. Licensing appears well accepted within the state as a necessary role, but is not viewed as a major contributor to quality in services or as being in and of itself a sufficient safeguard for residents.

Licensing provides initial screening of providers, initial training reviews, home study and inspection and an initial provisional license with full license review at six months of operation. In these roles, licensing was reported by service providers and case managers to be most useful as an agency prepares to begin services, because it is "mostly a walk through and review of paperwork," which may be new to new service sites. Once a program is operating the program's issues and goals become different and often more complex than those attended to by licensing and at these stages licensing is reported to be less valuable to program development. State administrative staff on the other hand, were not generally in agreement with this observation. They noted that initial inspections of owner-occupied residencies, and in essentially the same format those of corporate entity homes, involve lengthy interviews with prospective service providers to measure their retention of training material and to assess their abilities to fulfill obligations related to individual rights, plan of care implementation, medical needs, behavioral support and other areas covered in the licensing standards. They note that in subsequent inspections seek to move beyond paperwork requirements to determine intended and unintended outcomes of the services provided.

New Jersey recently implemented a two-year ("full") licensing period for agencies in compliance with licensing regulations, although a one-year license will still be required for the owner-occupied community care residences. With this change the licensing agency and its current complement of a chief, three supervisors and 17 inspectors will according to state officials, be able to keep pace not only with re-inspecting currently licensed providers, but also with required licensing of new residences as they are developed.

The current state plan to move the "full license" period from one year to two years seemed broadly accepted as viewed as reasonable and potentially helpful. Service providers reported that the difficulty of meeting present schedules for annual review has not allowed the one-year review to function dependably. It appears that these difficulties are primarily due to the steady growth in residences to be inspected (1600 in 1996 to 2500 in 2000) without commensurate increases in staffing.

It is hoped by the state advocates, case managers and certain licensing personnel that reducing the demands of scheduled licensing visits will allow for greater use of resources for unannounced visits. At present unannounced inspections rarely occur unless triggered by complaints, serious concerns or incidents that may be reported by service users, parents, neighbors, visiting nurses, or other community members.

State licensing agency staff joined community agency personnel in noting the need to be able to focus more on quality improvement, not simply on inspecting standards and issuing full or provisional licenses (with correction orders). While there were questions among service providers and case managers about whether sufficient expertise exists within the current licensing unit to fulfill the technical assistance roles needed for the quality improvements that yield more person-centered services, state officials noted that licensing unit staff display a wide array of professional education and experience. They observed that for over 20 years licensing has been providing technical assistance and consultation to service providers with regard to improving outcomes for persons with developmental disabilities. But, case managers in particular noted the very different approach and relationships needed in moving from a role involving inspection of compliance to specific standards to the role of consultant and provider of technical assistance in complex areas of service delivery.

In the area of expanding consumer protection, New Jersey is just now moving toward requiring background checks on all employees working in programs serving people with MR/RC. Certain of the agencies visited already do background checks prior to hiring any new employee and one agency visited not only checks prior to hiring, but runs every employee through an updated background check every three to four months. Conversations with about 25 service users and family members revealed one incident in which an individual was mistreated by a staff member.

One consumer described an incident in which an agency staff member stole some of her money. It was actually the agency that caught the individual. When asked about the incident agency administrators reported that the person was fired and that a report was sent to the individual's case manager. The agency director was unaware of formal changes being brought and does not believe that information about the incident would therefore be available to others who might be considering hiring that individual for similar roles.

CRITICAL EVENT REPORTING AND INVESTIGATION

Critical event reporting is required by all residential and day centers providers when an individual is injured, neglected or exploited. Incident reports are categorized into A and B categories, with A reports being most serious (unexpected deaths, sexual, physical abuse), B’s less serious. Serious (A) reports are submitted through case managers and their supervisors to the Special Response Unit (SRU). The SRU investigates potential abuse, neglect or exploitation of service recipients in community programs licensed, contracted or regulated by the Division. The SRU also serves as the Division's liaison to law enforcement agencies when cases are referred for criminal prosecution. In order to bring greater capacity and consistency to the investigative process, four additional staff were recently added to the seven investigators. This will provide the resources for the SRU to review and investigate Type B incidents as well as Type A. Service providing agencies may be authorized to conduct investigations independently or in concert with the SRU. However, in cases where the agency conducts an independent investigation, the final report must be submitted to the SRU for review and closure.

There is broad consensus that the incident reporting requirements and Special Response Unit provides a necessary function. Still support staff at the agency level report not having much idea about what happens to incident reports once they are submitted to case managers. The agencies that submit these reports reported that they receive no summaries of incidents or their disposition.

Although screening of incident reports is conducted by case managers, there is no centralized approach to handing incident reports that are not considered Type A, nor is there is a data base into which incident reports are entered and analyzed to guide monitoring, training and technical assistance. One Regional Office staff member noted that such analyses could be helpful, describing how their recognition of an unusually high number of choking incidents prompted special attention to care of individuals at risk of choking. Perhaps equally important, managers and staff at the agency level noted that they have no idea what happens to reports when they submit them, whether they are screened or what use they may be to anyone. There is a general welcoming of the expansion of investigative functions to include less serious Type B incidents because of lack of certainty about the level of attention they presently receive. Additionally, each county has an Adult Protective Services Unit, authorized by the State to investigate allegations of abuse, neglect and/or exploitation of vulnerable adults (elderly or disabled) residing in community settings, excluding those licensed by others. There is also a state Ombudsman Office in New Jersey available to attend to needs and concerns of persons 60 years and older including those with MR/RC.

Respondents identify two needs for attention in further development of special incident reviews. One identified need is the establishment of a data base to organize reports so that they can be used to guide both monitoring and training. The second is for an ongoing program already proposed to study deaths that occur in the community and in the state institution.

Throughout the visit it was clear that health and safety are high on the list of concerns of service agency administrators and staff, particularly as these interact with efforts to help people live more integrated lives. In interviews with program directors and direct support staff variations of safety on the one hand and increased individual independence on the other were identified as the two major job responsibilities of direct staff. Direct support staff feels considerable tension between personal safety and personal freedom of service recipients. Most staff interviewed acknowledged that they will error on the side of being overly protective if they are unsure about the safety of an individual's choices. Direct support staff also noted that abuse and neglect reporting tend to make people more conservative because there is usually official documentation even when what they view as a relatively minor injury or event. As one noted about the dilemmas, "Sooner or later something will go wrong and we are responsible."

STAKEHOLDER INVOLVEMENT

Interviews with individual and groups of agency administrators, case managers and parents suggested that there is a range of different expectations about the relative weighing of safety and personal choice and appropriate mechanisms to balance the two. These discussions suggested that there might be benefit in focused attention in New Jersey on how to build safety considerations into the formal care planning to produce specific expectations for safety and the means to achieve them even as plans are made for people have new opportunities for people to have more integrated lives. In one agency direct support staff observed that planning for safety and teaching for safety were part of most care planning meetings that they attended. These direct support staff observed that people must learn how to be safe in new situations if they are to expand their world and that people must learn how to be safer without oversight if they are to increase their opportunities to live more independent of staff supervision.

A recurring theme in discussions of ‘quality” in New Jersey is that there is limited effort and opportunity to promote quality as something specific and definable. State advocacy leaders question whether a quality assurance system can really promote quality without defining what quality means and whose definition of quality prevails. There was not a strong sense in New Jersey of stakeholders working together as partners in with equal influence and responsibility in developing definitions and goals for quality, and for planning ways to achieve them. One new front on which a concerted system wide movement is being built is the "wait list" in New Jersey. There is hope that this crisis may lead to other community initiatives of system change.

TEACHING AND LEARNING ABOUT QUALITY

Relatively few opportunities appear available at present for teaching/learning about what kinds and amounts of “quality” can be aspired to, how such quality can be achieved, what agencies are delivering it, what can be done to plan for it, individually, with agencies and/or with other service users. The DDD's sponsorship of “expose” for the purposes of allowing families to learn about agencies and their services and to meet other families who might have similar needs was viewed within the state as a positive step toward responding to the information needs of families.

It was also noted within the state that teaching and advocacy of contemporary visions of quality (consumer controlled services, self-determination, lifestyle planning, career planning, etc.) may be hampered by the fact that the sources of information about best practice in services in some states, advocacy organizations like the Arc, are, in New Jersey, actively engaged in providing services. It was notable in meetings with parents in two different sites in Southern New Jersey that the general discussions about people’s services became information sharing sessions among parents, and provided great interest, considerable learning and new ideas among participants about specific opportunities that were not known to exist.

CHALLENGES FOR THE FUTURE

New Jersey faces a number of challenges in the future. One of the primary ones may well be for the Division of Developmental Disabilities (DDD) to share responsibility for the developmental disabilities services more openly and broadly. Advocates and service providers in New Jersey seek more openness about how the HCBS program works, where federal reimbursements go and how can be used to affect the overall access to services. They would like DDD to involve stakeholders in an assessment of the HCBS options, the needs and ways of sharing information about the program and the services it finances, and how the program might be used to improve access to and quality of services for different groups. It appears that DDD leadership recognizes both the challenge and benefits of accommodating this call for more broad-based community participation in planning and policy development. Its goals of improvement in these areas will be welcomed and potentially could be quite helpful.

People Waiting for Service

New Jersey is greatly challenged by and deeply engaged in efforts to understand and respond to the large members of people waiting for residential services. In response to the statewide crisis in the number of people waiting for services, the Division created a Waiting List Planning Work Group which was actively engaged to gather and analyze data and make policy recommendations related to the waiting list crisis. This Group met until submitting its final report in January 1998. That report provided important recommendations related not only to direct response to the "waiting list" challenges, but also to broader systemic reforms that could increase the effectiveness, efficiency and manageability of New Jersey's service system. Recommendations of the group range from hastening the speed of institution depopulation to improve system cost-effectiveness to improving data systems to allow more effective use of data for managing system efficiency and outcomes. Many of these individual recommendations, although growing out of attention to New Jersey's waiting list, identify many short and long range activities that from the viewpoints of major stake holder groups would improve New Jersey's access to and quality of community services.

Quality Assurance

New Jersey's state operated quality assurance system involves required case manager visits, state licensing and inspections and investigations of critical events. The present system of licensing and inspections and of investigations is viewed as understaffed to meet current expectations. The state is responding by reducing expectations in annual licensing and increasing staff for investigations. Support exists within the state for both plans.

New Jersey's expectation that agencies involve themselves in internal quality assurance programs is well in tune with contemporary practice. It is clearly recognized that in the present system quality is much more a product of individual providers than of a state system. The requirements that individual agencies develop and implement their own systems is accepted, but increased support is needed to use this expectation beneficially. DDD appears challenged to develop a statewide initiative on person-centered performance measurement to teach agencies how to develop, implement, analyze and use performance measurement to improve the community services delivered by the individual agencies.

Improving Case Manager Support

New Jersey case managers have one of the highest average caseloads in the United States (on average about 95 service recipients per case manager). While the state has been creative in establishing a 3-tiered system of caseloads reflected the different levels of used and vulnerability among the people served, the state is challenged in making the caseloads within all 3 tiers sufficiently low to fulfill the assigned responsibilities. Case manager responsibilities include not only monitoring health and safety and assuring that required planning and paper requirements are carried out, but also assuring that people's independence and inclusion are given appropriate attention and opportunity to expand. Providing the necessary case management support within the "ideal" caseloads specified for the "primary," "program" and "resource" case management roles is already a very substantial challenge. Doing so as caseloads drift beyond these established "ideal" levels is not realistic. In increasing the ability of case managers to contribute to the quality of community services requires the state is challenged not only to insure sufficient opportunity for involvement with individuals, but also in the minds of many respondents, to insure that case managers are committed and skilled in assisting people to define and achieve outcomes of importance to them.

Addressing Institutional Populations

New Jersey has a high rate of persons currently residing in state institutions (third highest in the U.S.) and currently operates 5 of the largest 20 state institutions in the U.S. In the post-Olmsted era it is challenged by both contemporary practice and evolving definitions of basic rights to continue its recently increasing rate of institutional depopulation. Although reduction of New Jersey's waiting list is a visible priority, the estimate of the Waiting List Planning Work Group of potential savings of $30 million dollars in efforts culminating in the closure of several existing state institutions cannot easily be separated from the other challenges facing New Jersey. Perhaps use of the Olmsted planning coalition will not only provide significant and appropriate attention to deinstitutionalization, but also to the kinds of services and supports that ought to available to people currently in the community and to people presently institutionalized who need substantial and specialized support in returning to the community.

SUMMARY

New Jersey has a regionalized infrastructure and an established core of community services providers that offer a foundation to efforts to expand community services for persons with MR/RC. New Jersey's leadership recognizes the need to open the system to greater levels of stakeholder involvement and responsibility for the quality of service in New Jersey. Efforts to engage the broader disability community in responding to the challenges of waiting lists and Olmsted compliance are important beginnings. New resources are, however, well recognized as being important as to meeting the needs of New Jersey's citizens. In 1998 New Jersey ranked fourth lowest in the U.S. in the proportion of resources for persons with MR/RC allocated to the community services and was one of the only four states that decreased by more than 10% in MR/RC expenditures relative to state personal income over the previous 5 years. It had the 3rd highest rate of institutionalization in the U.S. and the 2nd lowest ratio of service recipients to case managers (Braddock et. al., 2000; Prouty & Lakin, 2000; Smith & Cooper, 1998). It was recognized that in New Jersey without substantial investments and increased efficiency, the state could not quickly or effectively overcome the challenges it faces.

Important and significant initial steps have been made. Commitments have been made to increase annual funding for community services by 36% over a three year period. Resources saved in the closure of North Princeton Developmental Center have been allocated to community services. New initiatives have been undertaken to develop new community services to persons who have been waiting. There appears within New Jersey a growing capacity and commitment to act as a concerted developmental disability community to bring about substantial change. If efforts to mobilize and integrate that capacity continue to bring success, substantial change will be seen in New Jersey in providing needed access to community services to persons presently waiting on their family homes and person presently waiting in state institutions.

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