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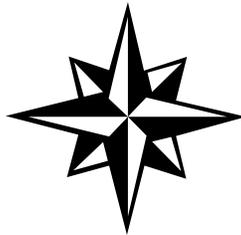
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Today's Choice: Tomorrow's Path

An Evaluation of the System for People With Developmental Disabilities in North Carolina

Prepared for the North Carolina Legislative Oversight Committee



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Background and History



Context of the Study

National Trends

The concerns expressed in the Request for Proposal issued by the North Carolina Joint Legislative Oversight Committee on Mental Health/Developmental Disabilities/Substance Abuse System Reform to guide the study of the developmental disabilities system in North Carolina were a reflection of concerns and issues confronting the field of developmental disabilities in North Carolina as well as in states around the country. They included:

- **Service configuration** – There is a continuing debate in virtually every state regarding the ideal configuration of services. Specifically, states that still have public institutions are reassessing their roles and the proportion of resources that such arrangements should command. For instance, California is currently in the throes of deciding whether to spend a billion dollars in capital costs required to bring the facilities up to code versus expending these resources to expand community alternatives. Within the community, there continue to be discussions regarding the future of segregated resources such as sheltered workshops and large private institutions.
- **Quality assurance** – Issues surrounding the assessment of performance and the assurance of quality have become increasingly complex as states are managing systems in transition from institutions, to community residences, to individual supports. Finding QA approaches that are relevant and responsive to each setting – and that capture the outcomes of services – is a significant challenge.
- **Self-determination** – The next step in the reform of services for people with developmental disabilities in many states is the creation of systems of support based on individual budgets and on individual choices and preferences. To create an administrative infrastructure to make it possible to individualize services in this way is proving a very complex task.
- **Waiting list initiatives** – As many states have concentrated on the movement of people out of institutions over the past several years, the needs of people living at home have been given short shrift resulting in growing waiting lists all over the country. During the past few years, either because of public pressure or litigation, many states – such as Maryland and Massachusetts have been faced with the task of finding resources to serve these individuals. Prouty and Lakin (1999) estimate that in June 1998 there were 61,373 individuals who were on waiting lists for residential services. They conclude that:

States would need to expand their current residential services capacity by 17.6% to create residential services for all the people presently on waiting lists for them. This does not include growth in specific types of services needed to serve persons wishing to move from one type of residential setting to another (e.g., a large facility to a community residence) (p. 78).

In addition, these estimates do not address the thousands of others who may be waiting for daytime vocational services (e.g., supported employment).

- **Olmstead decision** – The Supreme Court’s decision in Olmstead two years ago renewed the intensity of the debate about the appropriateness of institutional services for individuals who would prefer or are capable of living in the community. It has also focused interest on individuals with developmental disabilities in nursing homes – a group of individuals who are frequently not part of the public debate.
- **Shortage of direct support staff** – The shortfall in the numbers of trained staff available to service providers is reaching crisis proportions in many states. Even states where funds have been made available to expand and enhance services, some providers have been unable to use the funds because they cannot find staff. Further, the necessity to raise wages has put significant economic pressure on providers who have not been given rate increases to compensate for the costs. Finally, states like Massachusetts are beginning to see a decline in the quality (as measured by the QUEST) of providers primarily because of the lack of trained staff.
- **Medicaid waiver** – The home and community-based services waiver authority affords states considerable flexibility in program design and management. Key to effective use of the waiver authority is an understanding of the basic regulatory requirements as well as the many successful, effective practices allowable within waiver programs. Maximizing the waiver in terms of creating opportunities for home and community-based services is at the top of the list of priorities for public DD managers around the country.

The analysis envisioned by the North Carolina Legislative Oversight Committee was ambitious and wide-ranging. To satisfy these expectations, the Human Services Research Institute employed a range of strategies (identified in Section 2) including an examination of the recent history of similar initiatives over the past several decades.

History of Initiatives in North Carolina

Mental Health Study Commission

The State of North Carolina and the North Carolina (NC) General Assembly have had a long-standing interest in the area of human service delivery that includes the field of developmental disabilities (DD). In 1973, the NC General Assembly established the Mental Health Study Commission and charged this legislative body with oversight of the delivery of mental health, mental retardation, and substance abuse services. In 1986, the Mental Health Study Commission produced the State’s first legislative Developmental Disabilities Plan.

At the height of its influence, the Mental Health Study Commission was guided by Senator Kenneth C. Royall, Jr., who was Chair from 1973 to 1985, and Co-Chair from 1986 to 1992. During Senator Royall’s tenure, the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) received significant budget increases; began pursuing Medicaid dollars; and developed a series of long-range plans, including the DD “Ten-Year” Plan, discussed below. For more than two decades, Senator Royall was a dominant force in shaping and supporting the public MH/DD/SAS system. North Carolinians point to the precedent he set—putting people with disabilities at the top of the State’s priority list—as a benchmark of leadership.

In 1985, the General Assembly allocated funds to study the unmet needs of people with developmental disabilities (DD). The study, completed in 1986, reported that at least 7,000 people with DD were without services. The most frequently mentioned needed services were respite, residential, transportation, supported employment, parent training, recreation, and in-home supports.

The 1986 study endorsed the adoption of a federal definition that would include those with DD as part of the group eligible for services in the State. In 1987 the General Assembly adopted statutory changes, patterned on federal law, which re-defined the parameters for significant, life-long disabilities. With these changes, North Carolina moved from the use of a limited number of specific diagnoses (e.g., mental retardation, cerebral palsy, autism, epilepsy) as the basis for identifying its service population to a functional definition: “developmental disability.” Generally, the term “developmental disability” defines a target population based on criteria that includes: an age of onset prior to 22; substantial limitations across specific areas of major life activity; and a life-long need for coordinated, individually planned services.¹

Developmental Disabilities Consortium

In 1990, the Developmental Disabilities Section of the Division of Mental Health, Developmental Disabilities and Substance Abuse Services and advocates for the expansion and full funding of services for this newly defined population formed the Developmental Disabilities Consortium as a way of creating representation for this larger, more diverse group. The DD Consortium was initially comprised of people with disabilities and parents. They were joined by professionals, who became the dominant force in the Consortium, representing many statewide, “provider-advocacy” associations such as United Cerebral Palsy, the Arc, Easter Seals and the Association of Rehabilitation Facilities. The DD Consortium, and the more recent Coalition 2001, have long played a powerful role in the NC General Assembly. Although the Consortium has traditionally shied away from a collective public policy and advocacy agenda, it has been highly successful in building consensus around and securing increases in funding, tied to unmet service needs identified by its membership. The DD Consortium has once again welcomed into its midst people with developmental disabilities and their families, but the direct representation of their interests by people with disabilities/families remains small. Today, the DD Consortium includes close to 40 groups with wide and, sometimes, disparate interests. A number of smaller, grassroots groups have recently formed in the state, creating a new, participant and family-focused counterpoise to the DD Consortium’s emphasis on the business of managing and providing DD services.

In 1991, the Mental Health Study Commission (MHSC), concurring with policymakers and advocates that funding priorities for MH/DD/SA services must be driven by a consensus among the various constituencies, launched an extensive, statewide planning effort. The initiative included the task of updating the 1986 Developmental Disabilities Plan. Separate plans in several areas across mental health and substance abuse. The MHSC named Senator Russell Walker and Representative Theresa Esposito as Co-Chairs for the DD effort and appointed a thirty-six member DD Planning Committee. Eighteen months later, the Committee, with support from DMH/DD/SAS and the NC Council on Developmental Disabilities, produced its Plan. The process was the first in the State in which people with DD and their families were directly involved as full partners in a major policymaking endeavor.

DD Ten Year Plan

In December 1992, the Mental Health Study Commission endorsed the “Comprehensive Plan for Services and Supports for Persons with Developmental Disabilities” (or DD Ten Year Plan). In 1993, the NC General Assembly adopted the Ten Year Plan as policy guidance for the State. In 1995, the Study Commission authorized the Implementation Advisory Committee, charging the Committee with making recommendations regarding the DD Plan’s implementation. Between 1995 and 1998, the Implementation Advisory Committee prepared and presented the General Assembly with three progress reports on North Carolina’s DD Ten Year Plan.

¹ The General Assembly has made several, progressive amendments to the State’s definition of developmental disability. The child “at risk” component of the definition has laid a firm foundation for early intervention services, birth to five. The definition also includes people with traumatic brain injury (TBI) when, regardless of age of onset, the individual’s disability meets the definition’s functional criteria. Notably, however, other than State’s exception for TBI, the term “developmental disability” does not include people who have acquired equally significant disabilities after the age of 21.

The Ten Year DD Plan was unique. It modeled partnerships in policymaking with people with developmental disabilities and families, and related state agencies, the universities, and other stakeholders. Just as importantly, it advanced a shared vision for the evolution of services and supports for people with DD and their families. The 1992 Philosophy Statement affirms the person-hood and full citizenship of North Carolinians with DD, and asserts their role as “primary participants” in shaping all aspects of service delivery. It envisions:

... a service system that ensures the “most inclusive, most appropriate environment” for each person; emphasizes inclusion in community life; affirms choice; and prioritizes the development of family- and person-centered services and supports in North Carolina’s communities.

The MHSC Planning Committee developed the Ten Year DD Plan with the goal of building stronger collaboration and enhanced coordination among the major agencies responsible for the delivery of DD services. The Committee received detailed reports from nine state departments and crafted a plan crossing multiple State divisions and Departments.

Key policy directions outlined in the 1992 Plan include:

- Setting the priorities for the development of approaches that “demonstrate active consumer involvement and family empowerment”
- maximizing use of the Home and Community Based Medicaid waiver (CAP-MR/DD)
- developing a flexible array of service and supports
- creating an accurate data base for identifying service needs
- improving quality management, including assessment of consumer and family satisfaction
- building a qualified workforce
- advancing home ownership and tenancy
- supporting the development of self-advocacy
- gaining access to independent advocacy

The development of the DD Plan, its vision, and efforts to implement it mark the state’s entry into “the era of community membership.”² The decade-spanning Plan saw the State take significant strides towards the development of individualized, community services and supports. Notable accomplishments include: the passage, in 1993, of Single Portal legislation (including a statutory requirement of person-centered planning); the development of a waiting list data collection system; the initiation of a 4% annual census reduction in the Mental Retardation Centers; the formation of an Assistive Technology Consortium; an increase in the availability of community services for children at risk of institutionalization; significant increases in the number of infants and toddlers receiving family-centered, early intervention services; the birth of the State’s family

² Bradley, Valerie, “The New Paradigm” (1994). Bradley compares the era of community to the earlier era of institutions and era of de-institutionalization. Community membership is an individual support model. It identifies the citizen as the person of the concern; the person’s home, business, neighborhood, and school as the typical setting for services; service organization through the development of a unique array of supports tailored to the individual; service planning through a personal future plan; planning decisions controlled by the individual in the context of a “circle of support;” self-determination and relationship as the highest priorities; and change of the environment and attitudes as the objective underlying the approach.

support movement (“First in Families”) and, in 1996, the first family support pilot demonstrations; improvements in access to specialized health care services for children; the introduction of school-to-work transition coordinators in local education agencies; the addition of supported employment as a covered services under the Home and Community Based Medicaid waiver (CAP/MR-DD); the inclusion of children with and at risk for DD in the State’s “Smart Start” Initiative; annual Self-Advocacy Conventions, with attendance regularly topping 1000; the development of supported living and certain, more flexible community options (e.g., through use of residential subsidies); and the creation of a DD Coordinator position in the Department of Correction.

Despite these and other accomplishments, the DD Ten Year Plan may have fallen victim to both its virtues and its flaws. There was extensive discussion, during the process, of public and private Intermediate Care Facilities (ICFs-MR). Ultimately, however, the goals and the objectives set out in the Plan for reducing census were modest. With respect to the public MR Centers, the Plan proposed a 4% annual reduction in census and left out the future utilization and role of private ICFs/MR (other than upholding a moratorium on new development that predated the Plan by a year. According to key informants who were present during this period, the sheer breadth and ambitions of the Plan made securing adequate support for its implementation--across state divisions, Departments, and localities--a daunting task. Competing strategies for addressing key systems change issues; structural fragmentation at the state level; unresolved state-local governance issues; and the distraction of a series of DMH/DD/SAS re-organization efforts conspired to slow up and constrain implementation of the plan.

Recommendations for Integrated Funding

Beginning as early as 1990, a series of reports and studies of North Carolina’s MH/DD/SAS system identified the State’s disproportionate investments in large, public mental health institutions. Notably, in 1990 integrated funding was already seen as critical to moving the system from one that is predominantly facility-based to one that is community-based. The relevance of funding to systems structure was clearly delineated in the 1990 Mental Health Study Commission “Report of the Integrated Funding Task Force.” The report proposed area programs as purchasers of service, including those services from state psychiatric hospitals. After a 1993 Government Performance Audit Committee study, a “Uniform System of Service Planning: Interim Report” was issued in 1994. The integrated funding recommendation appeared once again in the 1999 State Auditor’s Report. By 2001, key stakeholders across the mental health, developmental disabilities and substance abuse service systems were articulating the linkages among a community policy advocating that dollars follow people; a uniform portal of entry; and integrated funding structures.

Thomas S. Lawsuit

In 1982, the Thomas S. class action lawsuit was filed against the State. The plaintiffs were individuals with mental retardation who, the Federal Court determined, were inappropriately placed in state-run, psychiatric hospitals. The Court ordered the State to develop services and supports in the community that comported with “best practice.” While most of the class members had multiple disabilities, with mild to moderate mental retardation, Thomas S. services and supports were walled off from the rest of system. By the time the Court dissolved the injunction in 1998, the State had served 1,166 individuals, at an average gross cost in 1997-1998 of \$94,000 per person. While services and supports to those affected by the suit improved significantly, it was at a significant cost -- a cost that could not be sustained for people with disabilities who were not members of the Thomas S.³

³ See “The Unhealthy State of Our Mental Health,” The Journal of Common Sense, vol. 6, no. 3, winter 2000-2001. This article notes that in FY 1998-99, two court-ordered treatment programs, Thomas S. and Willie M., consumed nearly one-third of total state mental health funding and supported less than 1% of the individuals served by the system - some \$215 million of total mental health resources of about \$650 million.

Managed Care

In 1997, the DD Section of DMH/DD/SAS formed the DD Managed Care Policy Work Group. At the time, there were widespread concerns of shortfalls in system capacity if Congress moved forward with plans to block grant Medicaid to the states. The committee was to advise the State as to the direction of its response. The make-up of the Managed Care Policy Work Group was diverse. Its recommendations ranged from the adoption of a participant-driven, managed supports approach and consumer-based methodology for resource allocation to a “carve out” of ICF/MR-DD. With changes in the federal climate, discussions of large-scale, Medicaid managed care approaches abated. DMH/DD/SAS reconfigured the committee the DD Policy Advisory Work Group (DDPAWG) and continued to seek its input. The group has been comprised of representatives from area programs, providers, and advocacy groups, as well as some individuals with disabilities and their families. Between 1998 and 2000, the group tackled diverse issues, including the implementation of the NC Support Needs Assessment Protocol (NC SNAP), systems re-design, CAP/MR-DD waiver renewal, delineation of area program and contract provider roles, and regulatory reform.

Mental Retardation Centers Futures Team

In 1997, the DD Section established the MR Centers Futures Team. Its role has been to assist in devising a process for a planned census reduction in the MR Centers and a means of accessing specialized services in the community. From the initiative’s inception, the Committee’s vehicle of choice for systems change has been gradual transition of the five MR facilities from a residential focus to Regional Resource Centers. Services delivered by the Centers are seen as forming the foundation of a state-wide structure that could respond, in communities, to individuals who need highly specialized services and supports. The goal of the process continues to be the provision, in the community, of a wide range of clinical services, both short-term, intensive interventions and long-range supports.

In 1998, DMH/DD/SAS expanded the Futures Team to include area program staff, regional MR Center Staff, representatives from the Arc/NC and the Mental Retardation Association. Over the course of the next several years, a number of potential strategies emerged from the group, including: creation of neurobehavioral, dual diagnosis, and TBI units within the MR Centers; the se of HB 1395 to move ICF/MR certified beds, along with Center residents and funds to support them, into the community; development of small, ICF/MR-DD group homes in the community, initially run by the Centers then transitioned to the private sector; development of Medicaid-funded clinical community teams; and transitioning MRC residents to existing private ICFs/MR-DD. Notably, the Futures Team has not yet identified strategies that all of its members can support, but continues to work towards this end.

DD Policy Work Group

Between 1999-2000, the DD Policy Work Group divided into several sub-committees to focus efforts on DD systems re-design. These sub-committees were: Funding/MIS, Quality and Accountability, Array of Services and Supports and Organization and Structure. The sub-committees presented the Division with a number of recommendations in spring of 2000, including:

- individuals with DD and their families should drive the funding of services
- performance outcomes should be more clearly defined
- “report cards” on providers should be made available to families and people with DD
- specific competencies and training should be provided to program staff and providers
- community infrastructure must give participants real choices

- quality of services and supports must be based on meaningful, individual outcomes
- the DD system should be organized on a regional basis
- the DD system must include “supports brokers” (individuals who assist people with disabilities/families in accessing or creating services and supports to meet their unique needs)

The year 2000 was characterized by efforts to develop consensus regarding the state’s organizational structure for DD services. Support among DD advocates for a separate Division, within which to house the State’s DD Authority, reached an all-time high; but, closure on the issue was defrayed until the Legislative Oversight Committee could review consultant recommendations in the State Auditor’s Report.

Olmstead Plan and Additional Studies

In the Summer 2000 the state initiated a plan in response to the US Supreme Court’s ruling in Olmstead v. L.C. The DMH/DD/SAS Steering Committee agreed to focus on large institutions, including the Mental Retardation Centers and some residential facilities, but not on adult care homes. There was no agreement to close any of the MR Centers. Olmstead Interim Plan hearings were scheduled for winter 2001, with the discussion of the future of MR Centers and privates ICFs/MR and plans for those living there likely to resume.

A variety of consultant reports have also contributed to the policy context in North Carolina. Specifically, the PCG/HSRI study completed in 2000 provides a thorough examination of the state DD context and the range of governance issues that are critical to the accomplishment of the state’s mission. The mental health portion of the study provided the foundation for the recently passed Mental Health Reform legislation. A study conducted by UNC Charlotte of the status and skills of direct support staff in the state also provides valuable information on the status of manpower issues. Work done by Robin Cooper as part of the Department’s report to the Legislature in May 1999 which explores waiting list issues and streamlined administration of the State’s Home and Community-Based waiver, provides a much needed backdrop for the examination of the utilization of the Medicaid waiver for DD Services.

Legislative Oversight Committee and Mandated Systems Reform

Finally, in 2001, the Legislative Oversight Committee for Reform of the Mental Health, Developmental Disabilities and Substance Abuse System engaged in extensive deliberations regarding key governance, finance, service array, hospital, and DD issues. The Oversight Committee appointed a Developmental Disabilities Subcommittee that met on several occasions to address concerns specific to DD. Most notably, the Subcommittee addressed the need to tailor systems reforms to conform with public policy and best practice in the field, and the utility of creating a separate Division of Developmental Disabilities. At the end of the 2001 session, the legislature passed HB 381 which set in motion a five year change process across the MH/DD/SA system. Responding to requirements in the proposed bill, the Secretary of DHHS convened a state planning group. The DHHS and the stakeholder group produced a Plan for MH/DD/SAS services that sets guidelines for the business operations of state and local systems.

This vast reservoir of information and history provides a ready platform and backdrop for the ensuing review of services and supports to people with developmental disabilities in North Carolina in the Year 2001.

Milestones in Brief

1982

- Thomas S. lawsuit initiated

- Incorporation of North Carolina Council of Community MH/DD/SA Programs

1983

- First Home and Community Based (HCB) Medicaid Waiver for people with MR-DD (CAP/MR-DD)

1984

- NC Center for Public Policy Research finds that 65 percent of the State's funding for mental health, mental retardation, and substance abuse services was spent on state institutions, while 85 percent of people were served at the community level.

1987

- Adoption of functional definition of developmental disabilities
- “Pioneer” system establishes four levels of service with goal of targeting those with most severe disabilities as the priority population for services

1989

- Division of Mental Health, Mental Retardation and Substance Abuse Services changes name to Division of Mental Health, Developmental Disabilities and Substance Abuse Services

1990

- Formation of the DD Consortium
- Early Childhood Intervention Services network reaches goal of covering all 41 Area Programs

1991

- Initiation of waiting list data collection
- Moratorium placed on expansion of private ICFs/MR
- DD Ten Year Plan development begins

1992

- General Assembly adopts DD Plan as State policy; passage of Single Portal legislation
- Passage of Single Portal legislation
- Closure of regional MH/DD/SAS Offices; DD Section retains Regional DD Coordinators

1993

- General Assembly adopts DD Ten Year Plan

1995

- Medicaid coverage expands to cover people who are elderly, disabled and blind who receive SSI
- DD Ten Year Plan Implementation Advisory Committee forms and issues annual reports, 1995-1998, to General Assembly

1996

- Start up of first two Family Support pilot sites in Wake and Mecklenburg Counties
- General Assembly special provision creates independent study commission to study reorganization of Department of Human Resources. Guiding principles include maintenance and development of workforce; provision of leadership/support to facilitate quality outcomes; delivery of services based on participant need and desired outcomes; management of public resources to achieve appropriate administrative costs, maximum revenues, cost-effective services. Contract with KPMG Peat Marwick.

1997

- “Thomas S. Diversion Law” (SB 859) prohibits entry, without specific permission, of people with mental retardation into state-run, psychiatric hospitals
- Statewide Summit on Supported Employment and formation of Association for Persons in Supported Employment (NC APSE)
- Development of Traumatic Brain Injury (TBI) Plan
- DMH/DD/SAS establishes Home Ownership Loan Program
- DD Section initiates planning process for future of MR Centers
- DD Managed Care Policy Work Group formed
- Department of Human Resources becomes Department of Health and Human Services
- General Assembly Budget Bill requires reduction in Medicaid annual growth to 8% by 2001
- Operation of Home and Community Based Medicaid waiver, CAP/MR-DD, from DD Section to Financial Support Section of DMH/DD/SAS

1998

- Dismissal of Thomas S. lawsuit
- DD Policy Advisory Work Group succeeds Managed Care Policy Work Group
- MHSC Implementation Advisory Committee recommends re-designation to private sector of Protection and Advocacy System (Governor’s Advocacy Council for Persons with Disabilities (GACPD))
- DD Managed Care Policy Work Group adopts Principles of Consumer Choice, separating case management and direct service functions; adoption of Consumer Choice Policy limits Area Program role to case management and administration, with limited exceptions

- KPMG Peat Marwick report identifies disproportionate dollar investment in state facilities, relative to community programs. Recommendations per DMH/DD/SAS result in 1998 General Assembly appropriating \$750,000 to the State Auditor's Office to study overall state and local structure of the MH/DD/SA service delivery system
- Division of Medical Assistance identifies multi-million dollar mismanagement of Medicaid funds in Carolina Alternatives' 10 mental health/substance abuse, 1915(b) Medicaid waiver pilots; adequacy of area program administrative and fiscal structures questioned
- Council on Accreditation (COA) process for area programs begins; 19 programs accredited as of 3/01
- Introduction of special legislative provision to merge Division of Services for the Blind, Services for the Deaf, and Vocational Rehabilitation into single agency. Provision defeated; issue referred to DHHS for study
- \$10 million appropriated by General Assembly in response to DD Waiting List Campaign.

1998-1999

- DMH/DD/SAS sets area program targets for reducing numbers on DD Waiting List. 944 individuals removed from waiting list in FY '98-'99 with state appropriation. With addition of funds to increase CAP/MR-DD, total of 2157 people removed from waiting list in one year

1999

- Disability Services Study Committee convened by DHHS to look at feasibility of consolidating Division of Services for the Blind, Services for Deaf and Hard of Hearing, Vocational Rehabilitation and DD Section of DMH/DD/SAS. Price/Waterhouse/Cooper conducts consolidation study, focusing on organizational and administrative structures.
- Consultation from National Association of State Directors of DD Services (NASDDDS) during consolidation study generates recommendation to take DD "off the table;" delineation of critical DD issues beyond scope of consolidation study, including cross- and inter-division structural fragmentation. Discussion of separate DD Division emerges.
- Office of State Auditor given oversight of study mandated by 1998 General Assembly to address overall structure of MH/DD/SA system

1999

- Carolina Alternatives ends
- US Supreme Court issues Olmstead v. L.C. decision, defining state's obligations, under the Americans with Disabilities Act (ADA), to provide services and supports in the community for individuals living in institutions
- NC Support and Needs Assessment Profile (SNAP) statewide implementation begins
- John Locke Foundation policy report, "Rhetoric or Reform: The Future of Mental Health in North Carolina." Report recommendations support institutional reform/closure, area programs as purchasers of services, and creation of a Division of Disability Services for all programs serving individuals with mental and physical disabilities

- DMH/DD/SAS announces internal reorganization, creating new administrative units (Quality Assurance and Management and Budget, Planning and Administration); reorganization eliminates separate Sections for Willie M. and Thomas S., dispersing staff and resources, but reassigning operations to DD Section. Division rationale: becoming more business-like; and strengthening ability to set policy, determine best practices, develop new service resources, exert clinical and professional leadership, and maintain and improve operation of existing programs.
- DHHS announces implementation of an external utilization management system for all community-based outpatient services. Coalition 2001 insists on stronger stakeholder participation in process
- DD Section adopts components of national DD Core Indicators Project; comparative data collection on system performance in areas critical to achieving broad, systemic goals
- NC Council of Community Programs adopts DD system design principles: standards of care (Council on Accreditation); seamless public service delivery system in least restrictive environment; reduction of census in MR Centers, via admissions and discharges using assigned per capita allocations; unified management of all high resource services, including ICF-MR programs; standardized system of service delivery; DMH/DD/SAS state systems that support movement of people into the community
- DMH/DD/SAS initiates Design Team process to develop strategic business plan for future delivery of mental health and substance abuse services, with input from DD Policy Advisory Work Group
- Early Intervention System removed from DD Section to Division of Education and Early Intervention Services. DD Consortium raises objection to further fragmentation of the service system. Over three years, beginning in 1999, the Early Intervention System was re-located a total of three times and in 2001 was sited in the Division of Public Health

1999-2000

- DD Policy Work Group addresses development of redesigned DD system through work of subcommittees on: Organization and Structure; Funding and Management Information; Quality of Service and Accountability; and Array of Services and Supports
- State Auditor's Study-PCG Team meets with Area Programs, Coalition 2001, and other stakeholders

1999-2000

- General Assembly appoints the Long-Term Care Task Force. Detailed recommendations for "developing a continuum of long-term care services for older and disabled adults." Recommendations included: formation of a long-term care cabinet in DHHS; creation of a uniform entry system for long-term care services; provision of funding for a paraprofessional development initiative and a career ladder front line staff; reduction of institutional bias by increasing the Medicaid medically needy income limits up to 100 percent of federal poverty; expanding the number of people served through in-home Medicaid programs

2000

- Charlotte Observer Series, "North Carolina's Troubled Mental Health System"
- Renewed call for designation of GACPD/Protection and Advocacy System to private sector

- Legislative Study Commission on MH/DD/SAS and Statewide Client Rights Advisory Work Group addresses use of restraints and seclusion in State facilities; enactment of amendments to statutes governing seclusion and restraint in NCGS 122C and 131D facilities. Regulatory reforms proposed
- Commission on MH/DD/SAS passes resolution delaying further actions to create a separate Division for DD until next DHHS Administration and Legislative Oversight Committee can address issue
- DMH/DD/SAS undertakes extensive planning process to develop Olmstead Plan; DHHS forms multi-divisional Steering Committee for coordinated Olmstead planning. DMH/DD/SAS begins assessment of 10% of individuals in psychiatric institutions, child residential schools and ADATCs; assessment all individuals in DD facilities, with goal of identifying those who desire to live in the community and whose decision is supported by parents/guardians and professional judgement
- State hosts Olmstead public meetings
- General Assembly: Legislative Study Commission on Mental Health recommends establishment of Joint Legislative Oversight Committee (LOC) on MH/DD/SA System Reform
- State's first four Self-Determination sites. Collaboration of DD Section, Division of Medical Assistance, Division of Vocational Rehabilitation, Council on DD and four local sites (Orange-Person-Chatham Area Program/Easter Seals; Mecklenburg; Arc/NC at Wilmington; Blue Ridge, Smokey Mountain and Trend Area Programs). Goals: implement structural changes that offer participant/family authority over an individual budget; freedom to select, train, and discharge direct support staff; access to personalized services and supports, including "support broker"
- Office of State Auditor issues report on MH/DD/SA services (PCG); recommendations regarding structure of DD services support the creation of a separate division for the State's DD Authority.
- Early Childhood Intervention (ECI) Futures Committee formed, with goal of developing new Community Plans for carrying out ECI responsibilities in coordination with local Smart Start plans
- Joint Legislative Oversight Committee (LOC) on MH/DD/SA Reform established, with Sen. Stephen Metcalf and Rep. Vera Insko appointed as Co-Chairs: Committee established by 2000 legislative session to refine and implement the redesign plan developed by the Office of the State Auditor.
- LOC Governance Subcommittee on Developmental Disabilities Services formed, along with Subcommittees on Governance, Services, Finance and Hospitals.

2000-2001

- General Assembly issues Request for Proposal for study on the amount, sufficiency, duration, and scope of Medicaid services. Lewin Group examines Medicaid Plan; existing Medicaid waivers; provider operational procedures; administrative rules; and relevant statutory base

2001

- Legislative Oversight Subcommittee on DD Services considers separate DD Division
- RFP for comprehensive study of DD services released and awarded (Human Services Research Institute).

- Governance and Finance Subcommittee reports presented to General Assembly
- Five-year renewal of CAP-MR/DD Medicaid waiver approved
- Early childhood intervention system moved to Division of Health, Public Health Branch
- DHHS Secretary announces “no new DD Division” for present
- General Assembly passes “No Death Penalty/MR” legislation
- Legislative proposal to increase income eligibility for community alternatives programs to 300% of income eligibility for Social Security Income (SSI) benefits
- DHHS awarded \$1.6 million Center for Medicare and Medicaid Services (CMS) “Real Choice” grant, to promote Olmstead implementation by addressing cross-divisional, direct support workforce issues affecting community capacity, quality, and access
- Fall 2001-Mental Health System Reform (HB 381) passes. New structure to be phased in between 2002-2006
- MR/MI and other positions cut from DD Section
- \$2.9 Million reduction in MR Center budgets to address state budget shortfall
- DHHS Secretary’s State Plan Advisory Committee describes DMH/DD/SAS mission/vision; develops elements for local management entity business plans; identifies target populations; sets criteria for oversight of system; report presented to General Assembly in November
- General Assembly appropriates 47.5 Million for one-time funding for needs of MH/DD/SAS system, referencing Olmstead plan

Organization of the Report

The following report is divided into the following additional sections:

Study Methods – This section includes a brief discussion of the tasks undertaken by HSRI, the protocols used, and extent of information reviewed.

System Principles – This section provides an overview of the person-centered principles that guided the project and initial information about the extent to which these principles are translated into the lives of individuals being served by the system.

Access to Services – This section includes a review of data from those on North Carolina’s waiting list, and an analysis of key system capacity issues including behavior supports, health supports, and workforce issues.

Eligibility for Services – This section includes a review of the way in which individuals are made eligible for the system and the effectiveness of the Single Portal process

Service Configuration – This section reviews the various components of the system of services and supports of people with developmental disabilities and makes recommendations regarding the future outlines of the system.

Financing – This section provides a comprehensive review of the administration the state’s Medicaid waiver as well as other financing issues.

System Performance and Oversight – This section provides a review of the components of the state’s quality assurance and quality improvement approach for services and supports to people with developmental disabilities.

Today’s Choices – This section reviews the strategic decisions facing policy makers in North Carolina regarding the future of the developmental disabilities system.

Tomorrow’s Path – This final section provides a blueprint for targeted change that will move North Carolina toward a more person-centered, effective and efficient system for people with developmental disabilities.

Study Methods



Overview of Methods

The multiple content areas of this project required the application of multiple methods. In order to assure the most efficient, informative and timely results, the project team utilized varied qualitative and quantitative approaches to gather and analyze data and to develop recommendations.

HSRI and its subcontractors used the following techniques to gather and analyze information about the developmental disabilities system of North Carolina.

- Key Informant interviews
- Paper Surveys
- Electronic Surveys
- Policy document review
- Review of National Benchmarks
- Plan Reviews
- Site visits and reviews
- Review of data on individuals with developmental disabilities and their families

Key Informant Interviews

Key informant interviews were conducted by project staff and consultants with the following categories of individuals:

- State officials in the Division of MH/DD/SA, DD Section, Division of Medical Assistance, and Division of Facility Services, as well as the Secretary of the Department of Human Services;
- Area program Directors, DD Directors, case managers, and providers;
- Family members and people with disabilities;
- State legislators and staff;

- MR Center personnel;
- Adult Care Home administrators and residents;
- State advocates including representatives of the NC Arc, United Cerebral Palsy, Brain Injury, Providers Association, NC Council of Community Programs, NC Association of Rehabilitation Facilities,
- State Developmental Disabilities Council;
- Representatives of Families First;

Paper Surveys

Paper surveys are a cost effective method to assure that the broadest number of people are afforded the opportunity to provide information and insights on an issue. In this instance, HSRI employed paper surveys to survey the needs of those individuals and families on the state’s DD waiting list. The North Carolina Waiting List Survey was developed by HSRI, in consultation with program staff from the Developmental Disabilities Services Section. The goal of this survey was to ask individuals and families on a waiting list for any service to tell us about their current situation, their needs, and their ideas for how the state could best serve people on the waiting list.

In total, HSRI mailed 6196 surveys. Of those, 546 were returned undeliverable. The total number of valid surveys returned was 1206. The resulting sample represented 38 out of 39 area programs and 95 out of 100 counties in North Carolina. A copy of the survey form is included in the Appendix of this report.

Electronic Surveys

Electronic surveys provide an emerging means of canvassing the opinions of a wide group of constituents in a timely and convenient fashion. For this project, HSRI designed four surveys aimed at the views of Area Program Directors, DD Directors, residential and day services providers. Provider respondents were recruited via email with the help of the North Carolina Council of Community Providers, the Providers Council and the North Carolina Association of Rehabilitation Facilities.

The survey asked respondents to share their insights about various aspects of the developmental disabilities System in North Carolina. Copies of the surveys can be found in the Appendix of this report.

As is shown in Table 1, the online surveys drew a about a third of Area Program personnel and a modest number of provider respondents.

Table 1. Online Survey Respondents	
Respondent Group	Number of Replies
Area Program Directors	14
DD Program Directors	12
DD Service Providers	16
Vocational Providers	13

Policy Document Review

Policy reviews entail the careful review of the written documentation (administrative and legislative documents, policies and procedures, guidelines, etc.) against the perceptions of key informants and according to the expert's understanding of other similar policies and best practices. For purposes of this project HSRI staff and consultants reviewed a range of documents including licensing regulations, data on provider deficiencies, state legislation including the recent Mental Health Reform statute, previous studies and analysis, waiver policies and manual, rate setting structure, policy papers from a variety of state organizations, accreditation materials, waiting list statistics, Core Indicators data, national comparison data, and other relevant material. A list of those documents reviewed is included in the Appendix.

Review of National Benchmarks

One of the tasks envisioned in the Oversight Committee's Request for Proposal was a comparison of the system of services for people with developmental disabilities in North Carolina to national norms and other state best practices. To complete this review, HSRI analyzed the most recent national data regarding the size of living arrangements, trends in the phase-down of public institutions, utilization of the waiver and ICF/MR program, waiting list data and other information that sheds light on the status of North Carolina on a variety of relevant variables.

Plan Reviews

In order to understand the approach to managing challenging behavior as well as the extent of person-centered planning, HSRI expert consultants reviewed a total of 24 behavior support plans from the Mental Retardation Centers, and 37 person-centered plans – 29 of which were from state centers. Consultants also reviewed samples of technical support plans and discharge plans

Site Visits Reviews:

Physical site visits and their corresponding reviews are necessary for the reviewer and others understand the context and setting in which services are provided (including both facility and community based operations) in order to make accurate and fair assessments of the context and setting.

HSRI visited each of the five Mental Retardation Centers. In preparation for each visit, the team prepared an inquiry and observation guide to ensure that a range of issues was covered. Additionally, the Project Team prepared inquiry and observation guides used in visits to twenty four community service settings and in speaking with area program personnel in diverse locations throughout the state. Locations and names of key informants interviewed during these visits are located in the Appendices.

Review of Consumer Data

In order to gain an understanding of the experiences of people with disabilities and their families receiving services and supports in North Carolina, project staff reviewed data collected by the state as part of the National Core Indicators Project

System Principles



Person Centered Principles

“Person-centered supports” means furnishing services and supports that are animated by and informed by each person’s unique needs and desired personal outcomes. Support strategies are designed to be carried out in everyday locations and living arrangements in the community in order to promote community integration and membership and preserve and support families. A system that embraces the principles of person-centered supports engages individuals, their families and allies, and community organizations in active collaboration to support each individual “one person at a time. Person-centered supports are the polar opposite of organizing the service system around set piece, categorical responses to disability. The standard for evaluating developmental disabilities service systems now is the extent to which they embrace and reflect the essential principles of person-centered supports in their day-to-day operations.

In the Year 2000, the National Association of Directors of Developmental Disabilities Services, the Human Services Research Institute, and the Institute for Community Inclusion convened a national meeting to articulate the principles that underlie person-centered systems. The group, composed of people with disabilities, family members, administrators, providers and policy makers, developed the following statement:

Each person shall have the authority to define and pursue his or her own vision. Person-centered supports start with listening to the person and honoring each person’s vision. The individual’s vision must be honored, respected, and supported. The goal must be to promote each person’s empowerment, dignity, and positive self-image.

Self-determination is a must. People and families are entitled to the freedom, authority, and support to control, direct, and manage their own services, supports, and funding. Individuals and families have the right to select their own services and supports as well as decide how and by whom supports are provided.

Personal relationships and community membership are valued. It is absolutely vital to promote the inclusion, presence, and participation in community life for all individuals, at all ages and across all dimensions of life. People must be supported in their social and spiritual life, friendships, and intimate relationships.

All networks and systems of support must collaborate in support of the person’s vision. Families, neighbors, friends, co-workers, and classmates play important roles in the lives of people with developmental disabilities. These rich, vibrant networks of support connect people to their communities. Public systems must work hand-in-hand with these networks in supporting individuals.

People and families must participate as valued and empowered partners in all decision-making. People and families must have meaningful leadership roles at all levels. It is crucial that government, providers, and community organizations welcome, listen to and collaborate with people and families in solving problems, making decisions, and pursuing excellence.

Individuals must have supports to contribute to their communities and engage in meaningful work. People with developmental disabilities want to and can make valuable contributions to their communities. There must be supports that assist people to make a difference. Youth and adults must be supported to have real jobs, earn money, or run their own businesses.

Families are supported and valued. Families support people with developmental disabilities of all ages. Support networks must partner with families and offer critical services that not only address the needs of the family member with a disability but also support and strengthen the family itself. The unique needs and preferences of each family shall be acknowledged, respected, and accommodated.

All people and families must have access to supports when and as they need them. Every individual must have easy and timely access to vital services and supports in order to achieve his or her personal vision and enjoy quality of life. There will be energetic outreach to all our nation's diverse communities so that they can access supports on their own terms.

The personal security and well being of people must be ensured. People must be secure in their own lives. They must not be exposed to neglect, abuse, or exploitation. They must have high quality health care. Ensuring the personal security and well being must not sacrifice the right of individuals to live everyday lives of their choosing in the community, exercise choice and pursue their dreams and aspirations.

There must be a resolute, continuous commitment to achieve excellence in all dimensions of supporting individuals and families. High quality services enable people to realize their vision. Excellence in person-centered supports demands a strong, sustained commitment to securing and maintaining a high quality workforce, ongoing training and education, and continuous quality improvement. Individuals and families are essential partners in promoting excellence.

This section reviews some of the more obvious indices of whether a person-centered system is in place including the state of person-centered planning

Where North Carolina Stands Nationally

Person-Centered Indicators

One way of assessing whether a state system is person-centered is to identify proxy indicators that align with assumptions about the ingredients of such practices. The following is a list of the criteria we used to compare North Carolina to national norms and the data points that we explored.

Community Inclusion and Integration

- Percentage of individuals living in community ICF/MR as a proportion of all individuals residing in the community.
- Number of individuals with MR/DD receiving HCBS waiver services per 100,000 population.

Deinstitutionalization

- Percent change of the number of individuals in institutions from 1990–99.
- Number of individuals with MR/DD living in small (under 6) residential settings per 100,000 population.

- Number of individuals with MR/DD living in state-operated or privately operated large (+16 beds) residential settings per 100,000 population.

Integrated Employment

- Percentage of individuals engaged in supported employment programs as a proportion of all individuals enrolled in day/vocational services.

Fiscal Effort

- Annual per family expenditure for family support services.
- Annual per capita expenditure on HCBS waiver.
- State fiscal effort in community spending.

System Organization and Efficiency

- Number of individuals with MR/DD on a waiting list per 100,000 population.
- Total number of individuals with MR/DD receiving residential services (regardless of type).
- Number of individuals served per 100,000 population.

Overview of Findings

In order to assess how North Carolina compares on these indices, HSRI staff prepared a comprehensive analysis based on a multiple national data bases. The full report, *Gauging North Carolina's Level of Effort in Support of Its Citizens with Developmental Disabilities*, is included in the Appendix of this report. The following is a summary of these findings.

The 1990s saw real gains in North Carolina's financial support of services and supports for people with developmental disabilities. After controlling for inflation, total spending more than doubled between 1990 and 2000.

- In 1990, North Carolina's spending for developmental disabilities services was sub par compared to the nation as a whole. By 1998, North Carolina's spending had reached approximate parity with the nationwide level.
- Although the proportion of North Carolina's expenditures devoted to community services and supports increased significantly during the 1990s, North Carolina still earmarks a greater share of its dollars to congregate services than is the case nationwide. North Carolina's financial support for community services is less than the nationwide level while its spending for congregate services is appreciably higher.
- Like other states, North Carolina relies heavily on the federal-state Medicaid program to underwrite the costs of services and supports for its citizens with developmental disabilities. However, North Carolina lags behind other states in leveraging its tax dollars to secure federal Medicaid dollars.
- Based on available indicators, North Carolina appears to furnish specialized services to a relatively low proportion of its citizens with developmental disabilities. The overall number of people receiving services and supports appears to be at least one-third or more below levels observed in other selected

benchmark states. Moreover, the population-indexed rate at which North Carolina furnishes residential or services in the family home is appreciably below the nationwide rate.

- This “top-line” view of North Carolina’s developmental disabilities service system reveals that the amount of dollars available for services falls about in the middle of the states. However, a significantly smaller proportion of the state’s citizens with developmental disabilities are able to access services than in many other states.

The Mental Retardation Centers

- In North Carolina, only 8% of all persons were served at the state’s five Mental Retardation Centers. However, the Center spending accounted for 27% of total outlays for developmental disabilities services. Nationwide, large state-run facilities accounted for about 22% of all expenditures in 1998.
- In 2000, more North Carolinians with developmental disabilities were served in large, state-run facilities than the nationwide norm. Relative to population, about 43% more individuals were served in North Carolina’s Centers than in comparable facilities nationwide.
- The pace at which North Carolina has been scaling back the number of individuals served at its Centers has been significantly slower than the rate of institutional census reduction nationwide.
- Despite the reduction in census during 1990s, MR Center spending – adjusted for inflation – was higher in 2000 than 1990.
- Center per resident costs increased at a rapid rate between 1990 and 2000, growing by almost 50% after taking inflation into account. In 2000, Center per resident costs were greater than the nationwide average but near the nationwide median.

Residential Services

- In 2000, the rate at which North Carolina made residential services available to people with developmental disabilities was slightly greater than the nationwide average rate.
- However, residential services were appreciably less available in North Carolina than in states that occupy the top 25th percentile in providing these services.
- It is much more common for North Carolinians with developmental disabilities to be served in relatively large living arrangements than other states. A higher proportion of individuals were served in large, state-run facilities and ICF/MR group homes than nationwide and a significantly lower proportion were supported in living arrangements for 1-3 individuals.

Medicaid Services

- In 2000, North Carolina’s use of ICF/MR services was more than one-third higher than the nationwide level.
- While the utilization of costly ICF/MR services has dropped markedly nationwide since 1993, in North Carolina it has remained about the same.
- On a per resident basis, North Carolina’s ICF/MR costs are in line with costs elsewhere.

- Fewer people with developmental disabilities receive Medicaid HCB waiver services in North Carolina than nationwide. In 2000, North Carolina's utilization of the HCBS waiver program was appreciably lower than most states.
- On a per participant basis, the cost of furnishing CAP/MR-DD waiver services was about the same in North Carolina as elsewhere in the nation.
- Compared to HCBS waiver programs elsewhere, more CAP/MR-DD participants live with their families. In other states, the HCBS waiver program plays a more central role in underwriting community residential services for people with developmental disabilities.
- When the ICF/MR and CAP/MR-DD waiver programs are considered together, North Carolina furnished Medicaid long-term services to fewer individuals relative to population than most other states in 2000.
- North Carolina's total spending for Medicaid long-term services for people with developmental disabilities was about the same as the nationwide level.
- On a per beneficiary basis, North Carolina's cost of furnishing Medicaid long-term services to people with developmental disabilities was significantly above the nationwide average. The state's relatively high costs are attributable to the high percentage of individuals served in ICFs/MR.

Integrated Employment and Family Support

- North Carolina has stepped up its performance in aiding people with developmental disabilities to obtain integrated jobs in the community.
- However, North Carolina's performance still falls short of the levels achieved in top ranking states.
- North Carolina appears to provide non-daytime services to fewer individuals who live with their families than is the case nationwide.
- However, North Carolina earmarks significantly more dollars for such services than most other states.

North Carolina's Waiting List

- The number of North Carolinians waiting for services is large. Additional funding and the expansion of the CAP/MR-DD waiver program aided in stabilizing and even reducing the number of people on the waiting list up until the beginning of this year. However, most recently, there are signs that the waiting list is beginning to spiral upward again.
- There is no evidence that North Carolina's waiting list figures are inflated. In fact, overall service demand in North Carolina appears lower than would be expected in light of observed demand levels in other states. The same is true with regard to residential services.
- In order for North Carolina to eliminate or significantly reduce its waiting list, the state must significantly increase and sustain population-indexed service rates that are at least 15% above present levels.
- Over the long-term, it is more likely than not that North Carolina will see the demand for developmental disabilities services increase beyond present levels. This means that the state must develop strategies to expand the developmental disabilities service system over and above the expansion required to satisfy present demand.

Summary

These figures suggest that while North Carolina's budget for people with developmental disabilities is comparable to other states, the resources are going to fewer people and to support larger, more congregate settings. They also suggest that, unlike many other states, North Carolina has not taken as much advantage of the more flexible resources available under the Medicaid waiver to create person-centered supports. The statistics also suggest that the proportion of the system devoted to families and individual supports is minimal. Finally, this review suggests that while North Carolina's waiting list may not be larger than most states, but that its sheer volume indicates a major challenge insofar as equity and future resource allocation.

Person Centered Planning

Before discussing the specific strengths and weaknesses of the plans we reviewed, it is important to clarify what it means for a plan to be "person-centered". Based on the plans we reviewed,⁴ there seems to be a clear understanding of what the "person" part of person-centered planning means. The specifics of the plans were obviously based on the team's knowledge of the specific person. The weakness or limitations of the plans were primarily related to what the plans were "centered" on. The rhetoric of person-centered planning is that: (1) the planning process should be focused on discovering and then *documenting what is important to the person* and (2) achieving the goals of the resulting plan should result in an improved quality of life, *as judged by the consumer*. Put simply, the plans should "center" on the *wishes* of the consumer, not on their *needs*, especially as defined by others.

Viewed from this perspective, the plans we reviewed were not truly person-centered; and given current rules and regulations they can't be. The teams planning for people living in ICFs/MR are mandated by federal and state regulations to ensure that specific aspects of the person's life and behavior be addressed, whether the consumer agrees or not. For example, people who are overweight are likely to have restricted diets, others who are dangerous to themselves are going to be closely supervised, and so forth. Further, these regulations obligate members of the team to assess the behavioral and health needs of the person and make recommendations as to how these needs can be best met. While the regulations governing services for people in other setting may be less prescriptive, the planning teams are usually not allowed to address only the wishes of the person. This reality results in service/support plans that usually do not answer all the person's wishes because of such issues as a lack of funds, the team not agreeing with the person, or safety concerns. At the same time the plans are likely contain many things that the person never asked for, such as assistance in tooth-brushing, training in activities of daily living, staff supervision, and so forth.

Example

A high school age boy living at home and receiving services through the CAP Waiver. He attends school in the community.

According to Mom, he wants to:

- ◆ Play with nieces, nephews and kids his age.
- ◆ Wants to be around family, doesn't like to be alone
- ◆ Continue school, remain healthy and happy
- ◆ Continue to receive CAP services
- ◆ Cooperate with therapists

His plan says:

Develop an action plan focused on self-care, positioning, and other important self-care components.

The things most important identified above are not mentioned in the action plan and the plan states that he spends most of the time in bed.

⁴ Most of the plans came from state-operated Mental Retardation Centers. It is not clear whether the conclusions stated here can be generalized to the community, especially the supported living program.

While the appropriateness of such goals can be debated, there can be no disagreement that this is the current state of affairs for almost all consumers and the teams that are supporting them. The best most teams can do is ensure that their planning process does document what is important to the person and that they make a good faith effort to act on as many of the issues that are important to the person, as possible.

Our review of service and support plans shows that, even taking into account the systemic limitations described above, the plans are not as person-centered as they could and should be. We reviewed plans that-

- Contained very little information about what was important to the person;
- Had long-term goals that dealt almost exclusively with what the team thought was important as opposed to what the person wanted. For example, an analysis of plans for four people at one of the centers showed that there were a total of 28 goals in the health area, 26 goals that related to either increasing or decreasing the person's behavior and only 6 that dealt directly with issues that seemed to be based on the person's wishes.⁵ The point is not that inclusion of the health and behavior goals was inappropriate. They were surely intended to benefit the person and the person might even have later appreciated that they were included. However, the fact that only 10% of the goals seemed directly related to the wishes of the person shows that not much importance was attached to what the person might want.
- When actions, based on the wishes of the person, were called for in the plans, they were often stated in general terms, which had little accountability. This was in contrast to the typical instructional objectives which had detailed teaching instructions to staff, along with precise descriptions of the skill level expected of the person.
- There did not often seem to be a connection between the instructional objectives chosen for the person and what had been described as important to the person earlier in the plan. For example, one resident of a Mental Retardation Center had three "formal" objectives in the areas of work and functional academics. Earlier in the plan she had been described as having a number of strong interests. The three formal objectives could easily have been "connected" to these interests, but they weren't.
- Directly acting on the person's wishes was sometimes put on hold because teams relied on a "readiness" approach. For example, the most important thing to one person was said to be spending more time with his family. However, he was sometimes aggressive which made contact with his family more difficult. The team chose to act on this wish only by developing an objective to decrease his aggressive behavior. He was, at least implicitly, judged as not ready for more family contact. While it makes sense that they developed such an objective, there were probably other things they could have also proposed that might have led to increased time with his family more directly and quicker. For example, they could have investigated whether staff support during home visit might have made such visits more acceptable to his family.

Given the above concerns we recommend that the following actions be taken to improve the support/service planning and move it to having a more person-centered focus:

- The training curriculum⁶ developed by the Developmental Disabilities Section provides an excellent introduction to the basic philosophy of, and rationale for, person-centered planning. However, the curriculum does not seem intended to teach the staff about the nuts and bolts of applying person-centered planning concepts in the context of the specific service program staff are working in. For example, the realities of applying person-centered planning concepts in a very individualized supported

⁵ In most cases it was not even clear that these goals were directly tied to the person's wishes. For example the goal might have been to change the person's living or work setting was counted a person-centered goal, unless there was clear evidence that the person did not want the change.

⁶ *Elements For Person Centered Planning*, April 2001.

living setting are very different than those involved in developing an Individual Program Plan in a large ICF-MR setting. Given the wide variation in planning procedures between different programs it makes sense not to include this level of detail in a general curriculum. However, training should be provided at this level, as early as possible in staff training.

- Require that, as much as possible, teams translate what they have learned about what is important to the person (what the person wants), into proposed action steps. Use these potential action steps as the *starting point* for all service/support planning.
- Following the planning meeting, teams should formally report on how much of what the person wanted was actually approved for inclusion in the plan. Teams should, of course, not be pressured or required to accept or act on all the person's wishes. They have a legal and ethical responsibility to do what they think is right and best for the person. However, on the other hand, they should be accountable to documenting what they did not act on and to briefly explain why.
- There should be an analysis, across consumers and over time, of what requested actions were not accepted by the team and why. An analysis of these data would reveal whether teams are seriously considering what people want, whether there are consistent barriers to action such as a lack of resources, staff, etc.
- As plans are implemented teams should be required to report on whether the goals, which were based on what the person wanted, were actually achieved. While much can be learned using standard outcome measures, as is done regularly for former Thomas S. class members, it still important to document whether specific outcomes, requested by the person were achieved.
- Analysis of these data, across consumers and over time, would reveal what the major barriers are to developing and implementing person-centered plans of support and service within individual agencies, within specific area programs and across the state.

Consumer and Family Data

This section looks at preliminary Core Indicators Project results from data collected in 1999-2000. North Carolina figures are presented in comparison with the aggregate figures across all participating states.

Children/Family Survey 2000

Methods

The CIP Children/Family Survey was administered for the first time in 1999-2000. Five participating Core Indicator states elected to send out this survey, which was mailed to families of children with developmental disabilities under age 18 and living at home. The five states included Arizona, Minnesota, North Carolina, Utah, and Washington. Results were submitted to HSRI between February and June 2001.

Each participating state was asked to mail this questionnaire to 1,000 randomly-selected families who met two criteria: (1) a child under age 18 with a developmental disability was living in the household and (2) either the child or the family was receiving at least one service or support besides case management. If fewer than 1,000 families met this criteria, the state was instructed to mail the questionnaire to all qualified families. The requirement that questionnaires be mailed to 1,000 families was based on an expected return rate of 40%, which in turn would yield 400 completed questionnaires in hand for each state. Since all states used the standard questionnaire, the results are comparable state-to-state.

The Children/Family Survey addresses general satisfaction with services and supports, as well as targeting issues specific to family involvement, control, and access to necessary services and supports. Additional questions probe areas related to self-determination, such as whether or not the family knows how much money is spent on behalf of their child, and whether they decide how this money is spent. The survey also includes questions pertaining to the outcomes of family supports provided, e.g. whether or not the supports received have improved the family's ability to care for their child at home.

The instrument is constructed so that the family member may select from three possible responses to each question ("yes or most of the time", "some of the time", and "no or not at all") or indicate that they don't know the answer or that the question does not apply. The instrument also contains a background information section where the family member is asked to provide certain information about the family and the family member with a disability and to indicate what services and supports are being furnished to the family member and/or the family. Finally, the instrument provides the family member the opportunity to make open-ended comments concerning any topic.

Results

North Carolina mailed out 1049 Children/Family Surveys and received 319 returns. Their return rate of 30.4% was slightly lower than the overall return rate, 39.3%. After cleaning the data, the number of valid surveys used in the analysis was 285 from North Carolina and 1947 total across the five states.

In this section, we summarize the survey findings by topic area (e.g., information, support planning, satisfaction, etc.) for ease of review.

Information & Planning

In North Carolina, 38.4% of respondents indicated that they receive information about available services and supports "most of the time." This result was slightly lower than the overall score of 41.4% across all five states. However, NC scored higher than the average on all other items related to information and planning. For example:

- 55.5% of NC respondents said they receive information about the status of their child's development "most of the time," compared with 37.2% overall.
- 64.0% of respondents in NC reported that they get enough information to participate in planning services for their child, compared to 45.1% overall.
- 82.4% of respondents in NC reported that their service plan includes things that are important to them, compared to 69.5% overall.

In the comments section, several respondents noted the lack of information being circulated regarding children's services and low income supports. Some case managers are not well-informed, and information does not seem to be distributed to parents. The best way for parents to get information seems to be through networking with other parents.

Access to Services & Supports

Generally, North Carolina scored slightly higher than the average on the questions about access to services and supports. 52.1% report getting the services they need "most of the time" (average across states = 41.7%); 55.2% report that the supports meet their family's needs (average across states = 42.6%); and 44.5% report that supports are available when they need them (average across states = 37.2%). Results were mixed for some of the more specific questions:

- In NC, of those who had asked for assistance in a crisis, only 27.4% reported receiving help right away. This figure was slightly higher across states, 32.2%.
- Availability of translators for those who do not speak English was about the same in NC as the average score – 63.0% have access to translators when needed vs. 64.5% across states.
- Access to health services was lower in NC than across states. 88.5% of NC respondents indicated having access to health services for their child “most of the time,” vs. 92.6% overall.
- Access to special equipment and accommodations was higher in NC at 67.4%, compared to 59.2% across states.

Comments at the end of the survey showed that some people were satisfied with medical services, while others were frustrated with their inability to get affordable services, especially dental services.

Choice & Control

North Carolina’s results in the area of choice and control were slightly higher than average. 65.2% of NC respondents report that they choose the providers that work with their family, compared to 60.1% overall. 54.7% choose the support workers that work with their family, compared to 48.5% overall. 51.8% have input over the hiring and management of their support workers.

Satisfaction with Family Supports

Satisfaction measures were also slightly higher for NC compared to the average. 74.4% reported that family supports have helped them keep their child at home (average across states = 70.1%); 73.5% report that family supports have made a positive difference in their lives (average across states = 68.6%); and 70.4% feel that family supports have improved their ability to care for their child (average across states = 65.8%).

Additional comments pointed out that turnover of staff seems to be a concern to many people in North Carolina. Some people are pleased with the services they are receiving, but many more would like to see more consistency in the quality of care workers. For example, comments about the quality and availability of respite care were varied. For those that were not pleased about respite services, a large portion of the problem seems to be the difficulty of finding quality care givers, and other problems associated with high turnover rates.

Adult Family Survey 2000

A separate survey was administered to families who have an adult family member with developmental disabilities living at home with them. In North Carolina, 422 completed Adult Family Surveys were received. Many of the questions on this survey were similar to those on the Children/Family Survey. While the aggregate data is not available at this time, we can highlight some findings to provide a comparison with the Children/Family Survey results.

- Only 37.1% of respondents with adult family members at home receive information “most of the time” about supports that are available to them.
- Fewer respondents with adult family members at home choose providers (57.9%) and staff who work with them (43.2%).
- Only 32.5% of respondents report that staff help them get what they need “most of the time.”

- 59% report that they receive information to participate in planning services for their adult family member, and 64.6% report that they helped participate in the plan.

Additional comments echoed those of the Children/Family Survey respondents – concerns about case manager turnover, lack of information about services, and the need for respite care. Many of the respondents also addressed the issue of employment. Some people are very happy with the employment services their family member is receiving. Other people have not been able to find a workshop or supported employment to fit their needs. Other issues that were brought up include: the continued difficulties of individuals transitioning from the high school to the work world, and the frustration and problems that arise from there being inequality of resources and services across the state of North Carolina.

Consumer Survey 2000

Methods

The Core Indicators Project Consumer Survey was developed by the project's technical advisory subcommittee with the purpose of collecting information directly from individuals with developmental disabilities and their families or advocates. The goal of each state is to conduct a minimum of 400 interviews. Each state draws a random sample of individuals over age 18 who were receiving at least one service, besides case management.

Results

In 2000, North Carolina submitted 322 valid consumer surveys. Eleven states submitted data, for a total of 5821 valid surveys altogether. Note: the highlighted results presented here for North Carolina (and aggregate results in parentheses) are preliminary, unadjusted figures.

- 82.6% of people surveyed like where they live (86.8% across states)
- 90.5% of people surveyed like their work or day program (89.4% across states)
- 93.6% of people surveyed know their case manager (87.1% across states)
- 71.1% had input in choosing home (49.5% across states)
- 51.4% had input in choosing roommates (39.9% across states)
- 36.0% have input in choosing home staff (26.4% across states)
- 42.5% had attended a self-advocacy meeting (31.9% across states)
- 29.0% said there are services they need but are not getting (27.0% across states)

Access to Services



Who is Waiting for Services?

Methods

The North Carolina Waiting List Survey was developed by HSRI, in consultation with program staff from the Developmental Disabilities Services Section. The goal of this survey was to ask individuals and families on a waiting list for any service to tell us about their current situation, their needs, and their ideas for how the state could best serve people on the waiting list. A copy of the survey form is included in the Appendix of this report.

A statewide database of waiting list information is maintained by the DD Services Section and is updated every six months with local information from the Area Programs. As of January 2001, the DD Section reported that there were 7922 individuals on the waiting list for services in North Carolina. The figures reported out from this data system represent a “snapshot” in time of how many people are waiting for services, as well as other detailed information such as the types of services needed and relevant demographic information. Efforts to conduct “waiting list surveys” in other states typically involve case managers or service coordinators filling out the surveys. We decided to take the approach of collecting self-reported information directly from the people who are waiting for services. The results of this survey are not intended to supplant the reports generated at the state level; they are intended to provide a first-hand perspective of a sample of individuals waiting for services in North Carolina. *The results reported in this section refer to the direct mail survey of people on the waiting list, not to the waiting list database that is maintained by the DD Services Section. An analysis of the waiting list database information is presented in a separate chapter of this report.*

The target population for this survey was anyone on a waiting list for any DD service in North Carolina. We asked single portal coordinators at each area program to print out mailing labels of all people listed in their area program waiting list database. Given differences in tracking systems across programs, the actual target recipients were somewhat difficult to pinpoint, and the person who ultimately ended up with the survey in hand was not always the best person to fill it out. The labels were addressed to either the individual with disabilities, a parent or family guardian, a state guardian, or in some cases a provider. In some instances, there was confusion about who should fill out the survey, particularly if the recipient was an individual who lived in an institutional setting. Where possible we requested that these surveys be forwarded to a family member or guardian who could respond to the questions appropriately. Because of the way the mailing list was generated, there may have been a response bias toward families who have a person with disabilities living at home with them. These families were more likely to receive the survey directly and to help the person fill out the survey if necessary.

In total, we mailed out 6196 surveys. Of those, 546 were returned undeliverable. These envelopes were forwarded to the DD Section so that the contact information could be updated in the appropriate area program database. The completed forms were entered into a database using a scanning system, which is an efficient and accurate method of entering data. The total number of completed surveys entered and analyzed

was 1206. The overall response rate was 21.3% (1206 out of a possible 5650). The resulting sample represented 38 out of 39 area programs and 95 out of 100 counties in North Carolina.

Results

Demographic Summary

Part One of the survey asks respondents to provide basic demographic information. The majority of respondents to the survey were parents (78%, n=908), and the mean age of respondent was 46.1 (median = 45.0). Across basic measures of demographics, the characteristics of the sample were generally in line with what we expected. The average age of individuals waiting for services was 22.7 (median = 20.0). The sample consisted of 63% (n=736) males and 37% (n=434) females. Racial categories reported included 66% (n=773) white, 30% (n=351) black or African American, and 4% (n=52) other or mixed race. Two additional measures are worth highlighting:

- Of those individuals who live with parents (n=654), 71% live in a one-parent home.
- Over 50% of respondents have annual incomes under \$25,000.

Most of the individuals in the survey sample live at home with family. Figure 1 displays the breakdown of the sample by type of residence. Over half (56%, n=680) of the individuals in the sample have a diagnosis of mental retardation. Other common disabilities reported include: physical disabilities (23%, n=280), autism (19%, n=228), behavioral challenges (19%, n=235), and cerebral palsy (17%, n=200). For percentages of all disabilities reported, see Figure 2.

Figure 1. Type of Residence (N=1145)

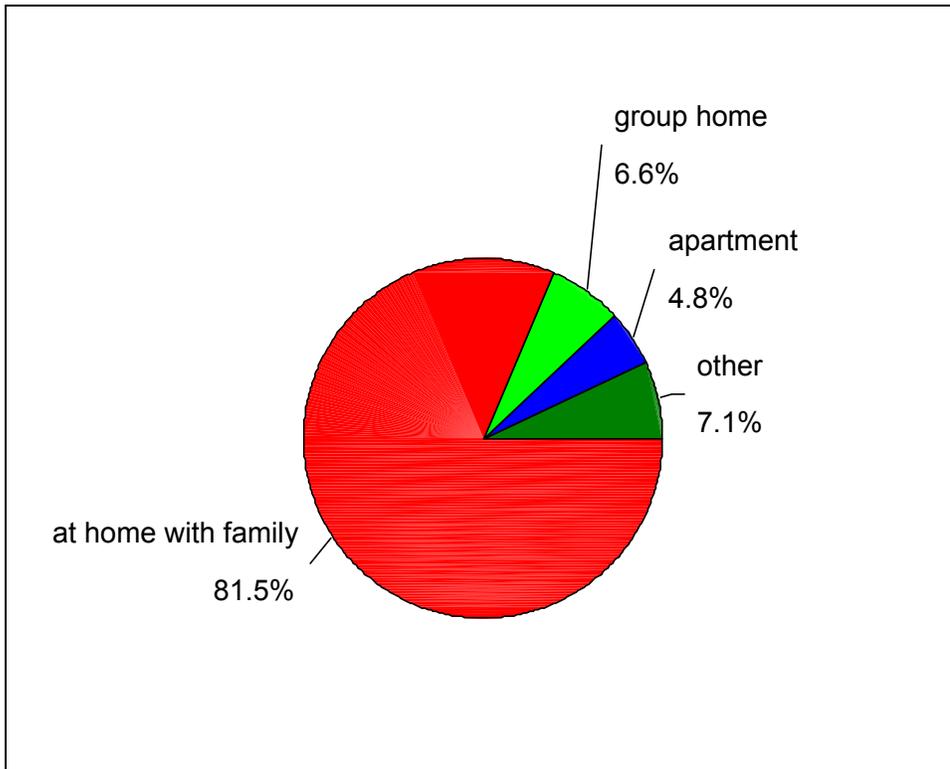
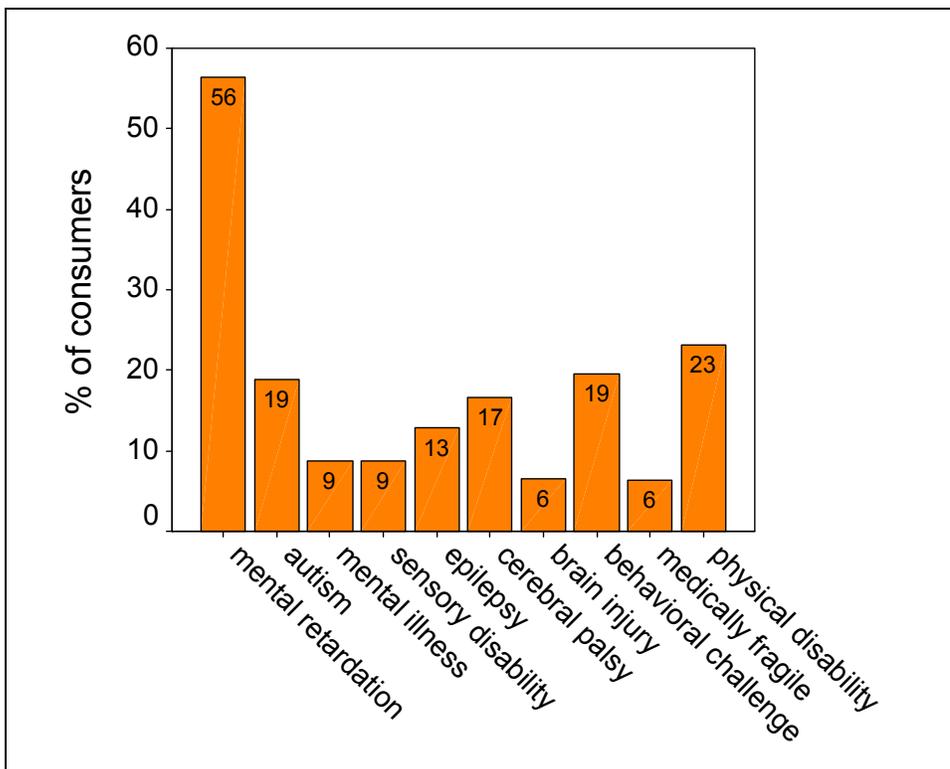


Figure 2. Nature of Disability (Duplicated Counts, N=1206)



Current Service Situation and Needs

Part Two of the survey asks respondents to provide information about their current situation, such as current service status, needs, and preferences. The majority of respondents report that they currently receive case management services (57%, n=651). Figure 3 shows the percentage of people receiving different types of services. In regard to services people are waiting for, in-home support was the most common response (30%, n=311). Figure 4 includes percentages of people waiting for services by service type. For the following services: residential, sheltered workshop, out-of-home respite, day program, and transportation, 20% or more of the respondents indicated that they have been waiting three years or more for this service.

Figure 3. Percent Receiving Services, by Type of Service

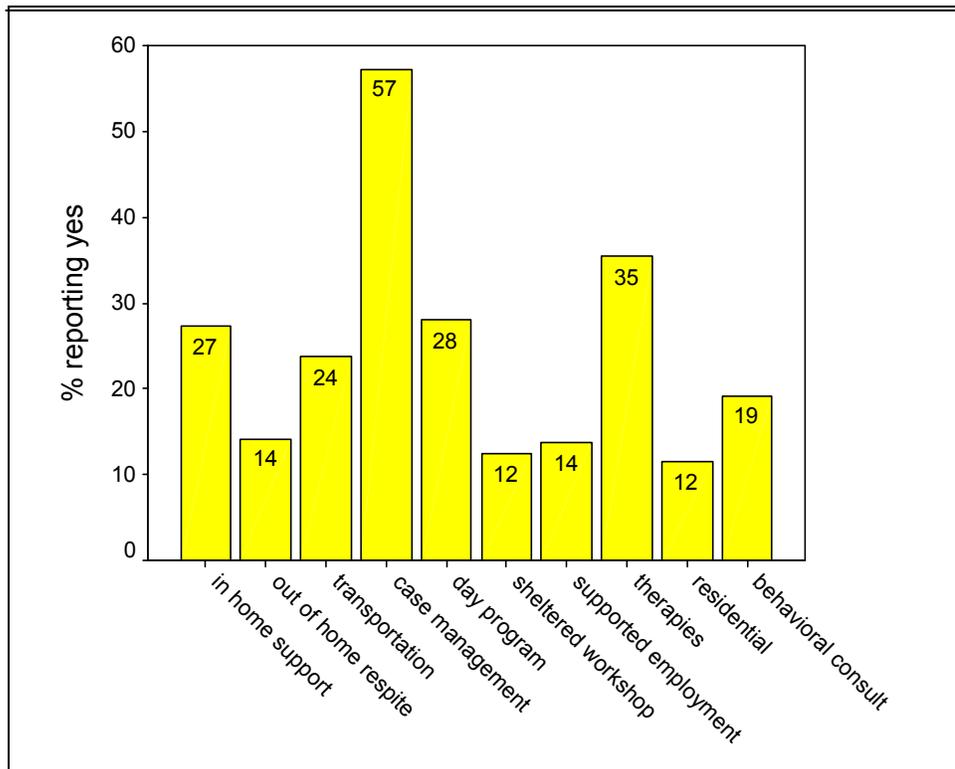
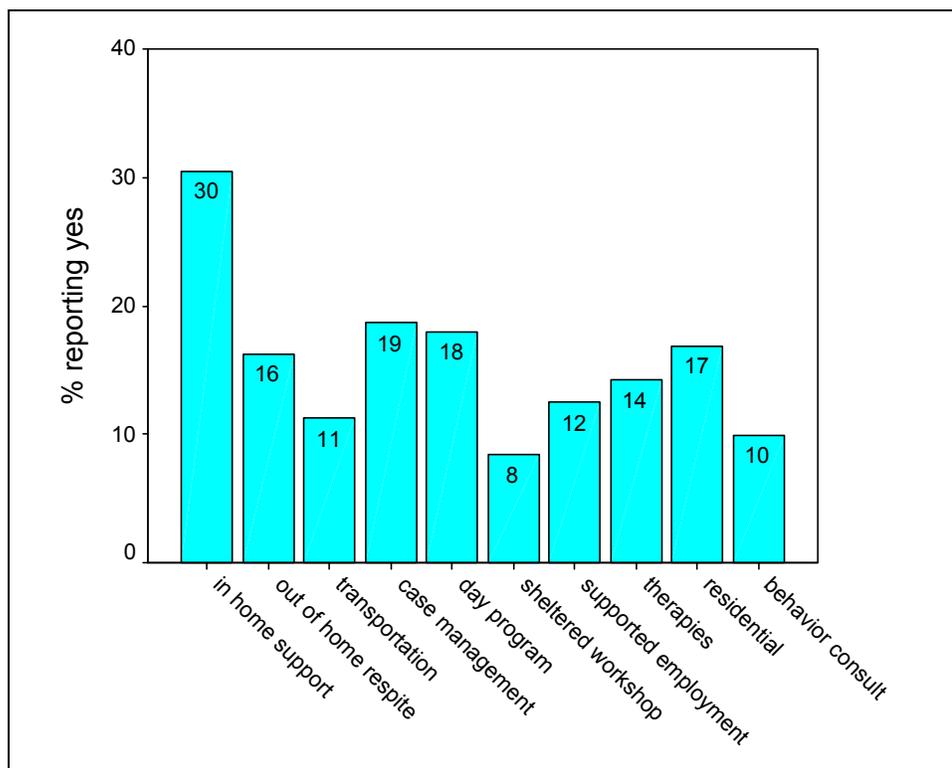


Figure 4. Percentage Waiting for Services, by Type of Service



The survey probed for further details about the types of respite care people are waiting for. Out of 651 respondents who are waiting for respite care, almost half (48%, n=315) indicated that they need in-home respite care during the day. The other types of respite were marked as follows: 31% (n=204) need out-of-home respite during the day, 28% (n=185) need in-home respite care overnight, and 22% (n=145) need out-of-home respite care overnight.

For each service the respondent is waiting for, they were asked to indicate how urgently the service was needed. The three options were: “right away,” “within a year,” and “in the future (over a year from now).” These were designed to correspond roughly to priority designations⁷ used in other states (and planning to be used in North Carolina). The results generally fell to one extreme or the other. That is to say, people felt strongly that they either need the service immediately, or that they will need it some time in the future. For all service types except residential and supported employment, the majority of respondents waiting expressed an immediate need for the service. For example, regarding special therapies (occupational therapy, physical therapy, speech therapy), 80% (n=250) of respondents indicated needing the service right away. In contrast, only 37% (n=99) of respondents indicated needing residential services right away. Table 1 shows more detail on the reported urgency of services needed.

⁷ Note that “priority status” generally refers to a determination made by a case manager or intake coordinator. Here, we are asking individuals and families to rate their own level of need. Perceived “level of urgency” in this case is a subjective rating based on self-reported responses.

Type of Service	% reporting “need right away”	N	Total N who report needing this service
Therapies	80%	250	314
Behavioral	73%	157	215
Case management	70%	212	301
In-home support	69%	300	434
Day program	60%	208	348
Out-of-home respite	58%	177	303
Transportation	57%	150	265
Sheltered workshop	51%	100	195
Supported employment	46%	121	261
Residential	37%	99	271

Regarding contact with Area Programs, 72% (n=811) of respondents reported having an Area Program case manager. 37% (n=398) report that the Area Program keeps in touch, and 30% (n=314) report that the Area Program helps them access assistance. Availability of information about Area Program services seemed to be somewhat limited. The most commonly checked sources of information included: school systems (28%, n=332), advocacy organizations (26%, n=307), and friends (22%, n=268).

Service Preferences

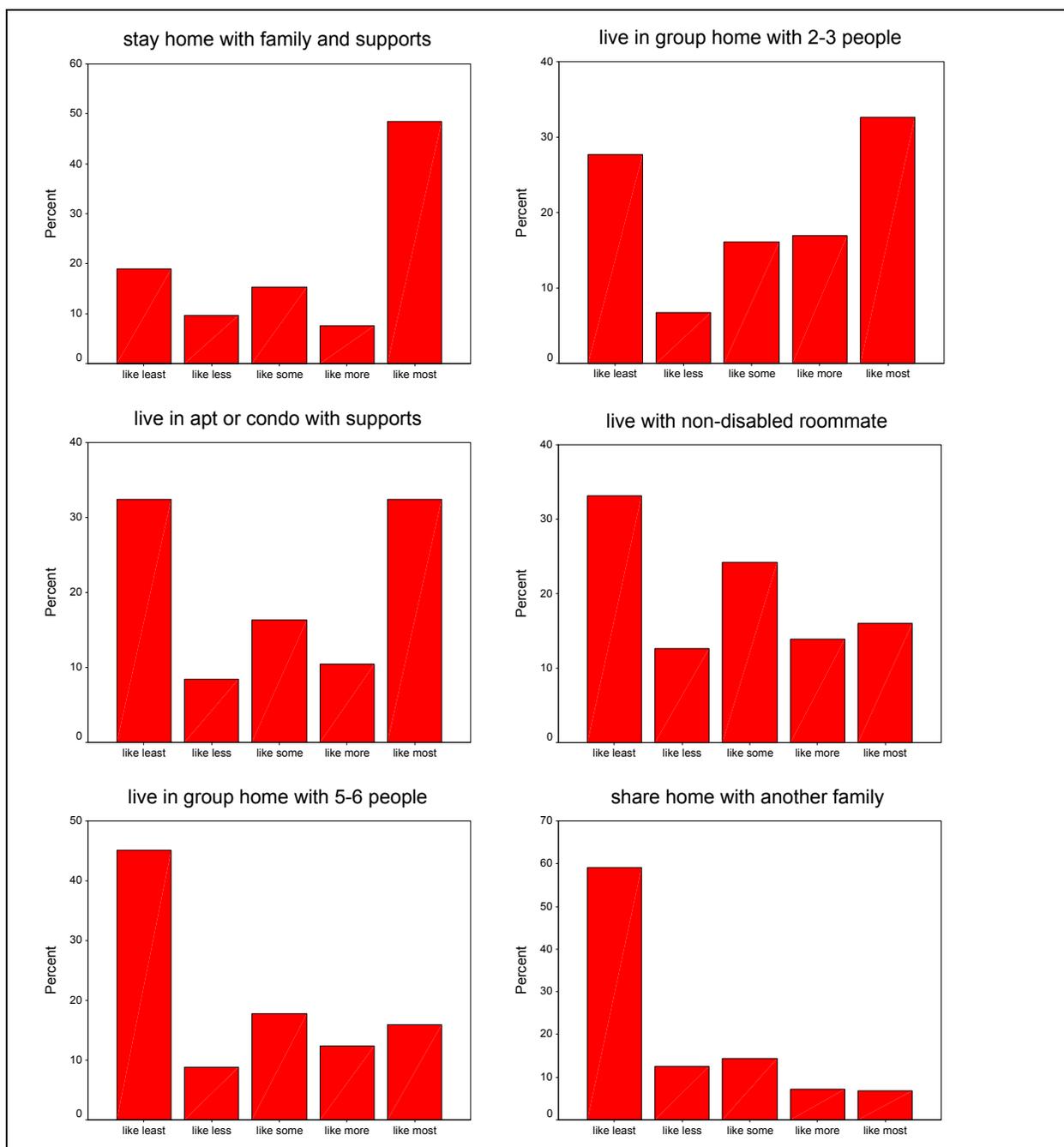
Two follow-up questions regarding residential services were asked, including reasons for requesting residential care and preferred housing options.

Those respondents who have requested residential care were asked to rate a list of possible reasons for seeking residential services as “very important,” “somewhat important,” or “not important.” Table 2 displays the percent of respondents who rated each reason as “very important.”

Reason	% rated “very important” (n)
S/he needs to have a life of his/her own	64% (n=245)
We are no longer physically able (or will soon be unable) to give the person the care s/he needs.	41% (n=145)
S/he needs personal or medical care that we cannot provide.	34% (n=113)
S/he has challenging behaviors that we are not able to handle.	34% (n=114)
Our home is not accessible.	18% (n=57)
We can no longer afford the cost of caring for this person.	17% (n=55)

The survey also asked respondents to rate a number of housing options from least desirable to most desirable. Figure 5 illustrates how people waiting for residential services rated each of six types of housing options, from “like least” to “like most.”

Figure 5. Housing Option Preferences



Open-ended Comments

Approximately one-third of the surveys we received included additional written comments, which were reviewed by HSRI staff. While the text is too long to report in full, we have attempted to summarize below the major themes that emerged from the open-ended comments, and to share some selected quotations.

Many of the comments were related to aspects of the CAP waiver program. Numerous parents and caregivers remarked on the helpfulness of CAP services, and particularly on how these services have allowed them to maintain their jobs outside the home. Conversely, many respondents who are waiting for services spoke of the difficulty of holding a job due to care-giving responsibilities, the fear of losing a job due to absences, and the inability to work for fear of losing benefits. Several people commented on the need for “more CAP funds” or “more CAP slots.”

“I need respite for my child so I will not have to miss work anymore.”

“I am waiting for my son to receive his CAP waiver to return to work...I can't afford to lose his Medicaid.”

There were strong feelings about the need for respite care, supports provided inside the home, and services that will enable people to live independent lives. Additionally, many families asked for more flexibility around scheduling services – not everyone needs full-time, year-round support.

“Services should start inside the home.”

“Funds for supported living [are] greatly needed.”

Some respondents expressed frustration about not having information on services that are available to them. Specifically, families had many questions about how to access behavioral consultation and intervention services, various therapies, and specialized medical services.

“I know that there are many services available...but we don't know how to get these services.”

Lastly, many respondents expressed positive feelings about receiving this survey. They were pleased to be asked for their opinions and saw this effort as a sign that the state is committed to expanding and improving existing services.

“It is my hope that this survey assures the state that help and resources are greatly needed and appreciated.”

Summary

These data strongly suggest that:

- Most respondents would prefer supports for their family member in their own homes;
- Another large group of individuals are waiting for some form of day supports;

- The respondents were by and large low income and needed supports in many instances in order to keep their jobs. Given that many were single parents, this presents a series economic crisis for these families;
- A high proportion of people indicated that their needs for therapies, etc., are immediate.

Clearly, the group surveyed are very vulnerable. If their needs are not met and they are faced with the economic consequences, these same individuals may be unable to continue to provide care and will therefore require more expensive residential services or may end up on the welfare rolls. To fail to address at least the most emergent needs is to invite social and resource consequences in the future.

Behavioral Support Services

The adequacy of behavior support services in North Carolina and across the country is vital, given the fact that out of home placements are usually triggered by the need for supports and services to ameliorate behavior challenges⁸. The above review of waiting list data reinforces this need given the high proportion of individuals waiting for behavioral therapies. Further, the major reason that people are prevented from leaving large congregate settings, is because the available community programs are not seen as adequate to support them, given the severity of their behavior challenges. For example, of the latest eleven, either first or readmission, to one of the Centers, all were said to have occurred because the people had behavior challenges that could not be dealt with in their home communities. During our visits to the state Mental Retardation Centers administrative staff told us that they “serve people who are unable to be handled in the community” and that the centers provided a “safety net” for people living in the community. One Director indicated that, “We have 350 people that no one [community service agencies] seems, at this point in time, to support now.”

Given this situation it is obviously important to try to assess:

- The adequacy* of behavior support services in the state Mental Retardation Centers.
- The adequacy* of the supports provided by Mental Retardation Centers in the community, in terms of training, technical assistance and back-up residential or crisis services.
- The adequacy* of current community-based behavior support services.

The rest of this section provides information related to the above issues and is followed by recommendations for change.

Behavior Services/Supports in the Mental Retardation Centers

Assessment of Behavior Support Plans (BSPs)

A significant measure of the quality of behavior support services can be seen in the Behavior Support Plans (BSPs) that are developed to guide the staff in dealing with the person’s behavior challenges. It is of course possible to help a person with behavior challenges, in the absence of a written plan and it is surely true that a well written plan is no guarantee of success. However, in the developmental disability field it is assumed that a clearly written plan that is: 1) based on a reasonable understanding of the cause(s) for the person’s behavior challenges, and 2) contains step-by-step procedures for staff to follow in preventing behavior challenges, keeping the person and others safe and helping the person learn more acceptable behaviors, is

⁸ The other major reason being the persons need for medical supports and services.

* Defined in terms of both quality and quantity

fundamental to long-term success. These factors and other commonly accepted criteria were used to review 24 Behavior Support Plans that had been developed and implemented in the state operated developmental centers.

The major strengths of the plans were:

- They addressed aspects of the resident's behavior that were meaningful as opposed to changing behaviors simply for staff convenience.
- The language used in the plans was not overly technical and was almost always respectful to the resident. There were still too many examples of labeling taking a resident for a walk as "treatment," people who can eat independently being described as "self-feeds," but most of the language in the plans was typical and respectful.
- Careful attention was usually paid to providing staff with specific instructions as to what to do in a crisis, to keep the person and others as safe as possible.
- All the plans reviewed had a section dealing with prevention of the person's behavior challenges. However, almost none of the plans contained organized, objective information concerning potential causes for the person's behavior challenges – such as the information that would be developed during a functional analysis of the person's behavior challenges. Absent this information, it was not possible to determine whether the prevention strategies chosen were appropriate for the behavior and the person.
- Other than restrictive crisis intervention procedures such as restraints, used to keep the person and others safe, few of the plans contained aversive or overly restrictive procedures. None of the plans involved the use of physical pain to control the person's behavior.
- There were however, significant weaknesses in the plans that were not consistent with minimum practice standards. For example:

A major goal of most Behavior Support Plans should be to help the person learn appropriate, alternative behaviors that can take the place of the behavior challenges that are to be reduced or eliminated. For example, if a person has learned to be aggressive as a means of escaping or avoiding unpleasant situations or activities, the BSP should contain teaching procedures for staff to follow to help the person learn more acceptable ways to deal with such situations. This critical component was missing from more than 90% of the plans. Most plans contained "boiler-plate" language that called for staff to reward the person for going periods of time without having a "behavior problem". At best, such plans provide a reason not to engage in the challenging behavior but do nothing to teach real competencies and skills.

- As mentioned above, all the plans had a prevention component. However, most of the prevention instructions dealt only with staff responding quickly to initial signs of disturbance to prevent further escalations in behavior. Almost none of the plans called for alterations in living or work settings or significant changes in the person's schedule of activities and tasks. The plans did little to decrease the disparity between what people want out of life versus what they actually get. This disparity is often the major driving force behind the person's behavior challenges. However, the plans might not have been significantly different, even if this issue had been seriously addressed, given the inherent limitations of a large segregated setting, that by its nature has great difficulty in individualizing services and supports to fit the person.
- While there were sometimes references, in either the BSP or the Comprehensive Functional Assessment, to a functional analysis having been completed, this component was missing from almost all the documents reviewed. The success of any BSP is seriously jeopardized if its procedures are not based on the cause(s) for the person's behavior challenges. It is obviously possible that functional

analyses were completed, but simply not included in the documents reviewed. However, almost none of the BSP made any reference to the proposed procedures being based on an understanding of the cause(s) for the person's behavior challenges. This component, as in the case of the teaching procedures described above, has long been accepted as playing an integral part in the development of an adequate BSP. It was surprising to see how little attention the antecedent cause seems to have received in these plans.

- Almost none of the plans provided staff with clear descriptions of the person's behavior challenges and adequate criteria to use in data collection. Such descriptions and criteria are critical if staff are to collect data that reliably reflects the actual behavior of the person. It was not possible to reach any conclusions about the actual reliability of the data because reliability checks do not seem to be a standard component of the data collection system at any of the Centers.
- As in the case of no assessment of data reliability, described above, the evaluators could find no information on the accuracy and consistency of the staff's implementation of the BSPs. Without such information, when the desired outcome is not being achieved, it is not possible to determine, whether it is because the plan is not adequate or that the staff are simply not carrying it out consistently and/or appropriately.
- The rationale for the use of psychotropic medications was frequently stated as "for" or "to deal with behavior" – as if there are specific drugs for specific behaviors, such as aggression, self-injury, non-compliance, etc.. Accepted practice is to prescribe medications to deal with the underlying physical and psychiatric conditions that are thought to be playing a role in the cause(s) for the person's behavior challenges and not to directly decrease behaviors such as aggression and self-injury, which are almost never considered to be direct symptoms of these underlying conditions. When physical and/or psychiatric conditions were referenced as playing a major part in the cause for the person's behavior challenges, the presence or absence of these conditions were never documented, independent of the person's behavior challenges. Therefore, it was not possible to determine whether these assumptions were ever correct.

There are at least two special, state-wide programs within the Center system worth noting. They are the BART and PATH programs at Murdoch Center. Both programs are designed to serve people with specific characteristics. The BART program (10 persons, one respite bed) serves people with severe behavior challenges that have not been successfully supported in at least three prior placements.. The PATH program (eight people, two therapeutic respite beds at the center and a four person group home in the community) serves young people with autism and severe behavior challenges. It is appropriate that both programs are designed to provide relatively short term services, six months to a year for BART and a maximum of two years for PATH. Because such services do not exist in the community, these programs play a vital role.

Related Support Services

Services provided by a wide variety of different disciplines, not just psychology, are needed to provide adequate support for many people with severe behavior challenges. Medical and psychiatric services, occupational therapy, specialized training in communication and vocational training, etc. are often needed to develop the comprehensive array of services and supports needed by many people with severe behavior challenges. An obvious strength of the Mental Retardation Centers is that they have at least some of all these services available for their residents. It was not possible to complete an adequate assessment of whether there are enough of all these services, nor their adequacy, specifically with respect to persons with behavior challenges. However, even assuming that each discipline or service area is making a meaningful contribution to the person's overall habilitation plan, there seemed to be a marked lack of input, involvement or interaction with these other disciplines from the perspective of the person's BSP. Other than the mention of medications being prescribed by the psychiatrist and medical services provided to treat medical conditions thought to be influencing the person's behavior challenges, there were very few examples of interdisciplinary efforts described in the BSPs. Residents who were assessed as having behavior challenges that served a

clear communicative function did not have communication specialists working with the psychologist to help the person learn more appropriate ways to communicate. Residents who were judged to often be agitated and tense did not have occupational therapists working with the psychologists to find ways to help them calm and be more relaxed. Again, such interdisciplinary activities may have been taking place, but they were not described or even referred to in the BSPs. Based on the content of the BSPs, it seemed as though the psychologist and in some cases the psychiatrist, had the sole responsibility for dealing with person's behavior challenges. This does not meet the minimum standards of acceptable clinical practice.

Technical Assistance and Training Provided to People/Families/Agencies in the Community

All of the Centers were actively involved in providing technical assistance, consultation and training to assist families and agencies in the community that were attempting to support people with severe behavior challenges. For example, one center had averaged more than 100 "Behavior Consults" a year since 1994/95. Some of the Centers "released" staff from their Center duties to provide technical assistance and training while other Centers staff positions dedicated to these functions. It was not possible to directly assess the adequacy of these services, but the feedback we received from the community recipients of such services was consistently positive. Following are two representative quotes from area staff and private providers:

"Anytime we call (the Mental Retardation Center] they respond. They have expertise we don't have. They excel in meeting people's medical needs and in assistive technology."

"We used their technical assistance one time and it worked out pretty well. Haven't needed to use it more because we are a big company, with state-wide resources. I'm sure it is a valuable resource for smaller providers".

However, if the BSPs developed as a result of these consultations have the same limitations as those in the sample from the Mental Retardation Centers, there would be a clear need for improvement.

Another positive feature is that it was clear that at least some of the centers are able to provide *ongoing* technical assistance and consultation if needed. While they do not describe themselves as providing crisis assistance⁹, they can help in later stabilizing the person's community placement, if it survives the intensity of the crisis.

Finally, a significant influence on what the center outreach staff can do and how fast they can respond is the size of the catchment area they serve. A one-way drive time of two to three hours is a serious limitation of what can be provided.

Behavior Services/Supports in the Community Programs

Given the wide variety of different programs across the state, it was not possible to review a representative sample of BSPs. Most of what was learned about behavior support services in the community came from interviews with case managers, representatives of area programs, private providers, staff at Mental Retardation Centers that provide technical assistance and training in the community, DD section staff and observing residential and day programs in the community. Also, given the wide variety of different programs in the community, ranging from large privately operated ICFs-MR to individual placements funded by the CAP waiver it is not possible to speak of "the community", as it were a single program. As you will see, each of the different components in the community have their own strengths and weaknesses.

⁹ One center reported that there could be as much as a nine week delay in their ability to respond to a service request.

At first glance, it would seem as though the many privately operated ICF-MR programs in the community would be a major resource in supporting people with severe behavior challenges. They have to meet the same federal regulations regarding the breadth and adequacy of their programs as the state operated centers. However, their reimbursement rate is significantly less than that of the state operated centers. This leaves them with the disadvantages of not having the resources of the larger centers while at the same time being too large to be able to provide intensive, individualized supports and services. Therefore, they find themselves in the position of trying to support a person with severe behavior challenges, while at the same time trying to ensure the safety of others and prevent the person with behavior challenges from disrupting the lives of his/her co-residents. This can result in the person being discharged to a state operated center. We were told that this was not an uncommon experience.

The group and rest home programs are in possibly an even worse position when it comes to supporting people with severe behavior challenges. Their reimbursement rates are significantly lower than the private ICFs-MRs and their only hope is that a local psychologist will be able to develop an appropriate behavior support plan and/or that they will find a physician who can work with them to develop an effective medication regime. There seemed to be general agreement, with a few exceptions in the more urban areas, that there is a significant shortage of competent community-based psychological and psychiatric services across the state. Secondly, even if a psychologist was available to develop an appropriate behavior support plan, the group homes and especially the rest homes often do not have enough trained staff to actually implement the program.

The best hope for supporting people with severe behavior challenges in the community is through the Medicaid waiver program. Many states across the country have utilized the flexibility of this funding stream to develop living and day programs that can be individualized to help the person have the life they want and at the same time meet the person's specific needs for support. North Carolina's supported living programs also suffer from the lack of clinical services in the community, but their increased ability to narrow the disparity between what people want versus what they get out of life often decreases their behavior challenges and makes it easier to support them. However, helping the person get a better life doesn't make chronic mental health conditions go away, and doesn't teach the person more acceptable ways of behaving. Similar to all the other community programs, the lack of competent psychological and psychiatric services in communities across the state is a major reason that the waiver-funded, supported living programs, are often not able to adequately support people with severe behavior challenges. The other major barrier to success is the fact that such programs only receive a fraction of the funds that would be available if the same person were living in a private or state operated Mental Retardation Center.

The day program situation for people with severe behavior challenges is in some ways worse than the residential. It seems even harder for people with behavior challenges to be accepted into an appropriate day program, especially one in supported employment. Most of these folks don't do well in large sheltered settings, where the work contracts may not reflect their interests and talents. These settings also have a limited tolerance for disruptive behavior or anyone who might require close supervision. The funding for providing ongoing staff support in real job settings is very limited.

Other issues that must be addressed to increase the capacity of communities to support people with severe behavior challenges are:

- Crisis intervention services are sorely lacking in most areas of the state. There are not enough residential back-up services that can support the person for a few days or weeks to allow for cooling off period or the time necessary to make necessary changes in the person's supports and services. Those programs that do exist are often "full" and have to deny service at the very time the person needs it most. The Director of a community residential program indicated that at least 10% of the people requesting crisis services were denied because the agency's six-person crisis home was at capacity. As mentioned earlier, while outreach staff from Mental Retardation Centers may be able to help out over time, they do not play a crisis assistance role and are therefore not setup to provide immediate assistance in times of a crisis.

The lack of such services can result in the person being admitted to a Mental Retardation Center or placement in the psychiatric program of a local hospital that may not be interested in or competent to support the person.

- There seemed to be widespread agreement that the universities in North Carolina are not training their psychology students adequately in areas such as applied behavior analysis, person-centered planning, and developmental disabilities. This seems to also be true for the school psychologists. We were told of many examples of school programs approaching the local area programs for assistance in supporting students with developmental disabilities and severe behavior challenges.
- As has been mentioned in other areas of this report the salaries of direct service staff in most community programs is outrageously low. Just as the funding available to support people is significantly reduced when they leave a state or privately operated ICF-MR program, the wages paid to the staff who support the person are also drastically reduced. This, combined with the minimal training that is often provided, results in an unacceptably high rate of staff turnover. Most people with severe behavior challenges rely heavily on their support staff. The tremendous turnover in staff is disruptive to both their lives and behavior.
- The services for persons with severe behavior challenges who also have a mental illness¹⁰ in addition to their developmental disability (such as persons who were the subject of the Thomas S. lawsuit) need to be looked at carefully. There has been no increase in funding over the past three years and funding for “new” people is very limited. Only approximately a dozen people have been accepted for service in the past two years. Given that a significant number of people currently living in state operated centers are dually diagnosed¹¹, this lack of funds is a major barrier to their return to their home communities. Also, very little training is available for the staff who support these individuals and given the high rate of staff turnover, this represents a very serious problem.

Change Recommendations

It is important to first understand that the major reason that other states have been able to help so many of their citizens with developmental disabilities and behavior challenges return to their home communities is that *they developed the capacity to support them in those communities*. While the people may have benefited from the services and supports provided in Mental Retardation Centers, the major reason that so many have been able to return home, is not that all of their needs for specialized services were “fixed” at the Centers, but because the specialized and intensive services they needed and may always need, were developed in their home community. This does not argue against improving the behavior support services in Mental Retardation Centers. For as long as people live in the centers they should have access to appropriate services. However, if North Carolina is committed to serving as many as possible of its citizens in their home communities it will be necessary to increase the capacity of its community-based programs. The states that are doing a better job of supporting people in their home community have stopped pointing to the people’s behavior challenges as the reason for needing center services and have set about developing the services and supports the people require to live successfully in the community.

Likewise, not much real change will happen until our plans for future development are based on what we have learned from our past mistakes. The state Mental Retardation Centers play such an important role today in the support system for people with severe behavior challenge in North Carolina because, until about the last twenty years or so, we had the mistaken belief that these large facilities were necessary and also the fact that federal matching dollars were only available to be used in such congregate settings. In other words, the service capacity is in these centers today because that’s where it has always been, not because it makes the most sense, in terms of what we now know about behavior support services. The experience of those

¹⁰ Dual diagnosis or MR/MI

¹¹ One Center Director estimated that close to 33% of the people at his Center were dually diagnosed.

states that have drastically reduced their reliance on large congregate programs, proves beyond doubt that all but a few people with severe behavior challenges can be well supported in individualized, well integrated community settings.¹²..All these states had at least two things in common – the will or dedication to serve as many citizens as possible in their home communities and the ability to gradually shift the resource capacity and funding to community-based settings. However, while advocates for community living may appreciate this aspect of our recent history, there is also another historical lesson that must be understood, which is that there have been too many examples of service programs being phased out, before as good or better programs were developed to take their place. There is no doubt that, if the service resources and funding were gradually shifted to community all but a very few could be successfully supported. In fact, if North Carolina is like most other states, there are already more people with behavior challenges currently living in the community than there are residing in the state operated Mental Retardation Centers. However, at the same time, it is true that the service capacity does not exist in the community system today, to immediately serve all the people who would be moving from the state operated system.

State Operated Mental Retardation Centers

- Develop more specific guidelines and/or implement a more intensive review process to ensure that the quality of the Behavior Support Plans meet minimal standards. The major areas that need attention are:
 - Increase emphasis on helping the person learn appropriate alternatives to their challenging behaviors.
 - Encourage teams to consider more fundamental changes such as where the person lives, who with, daily activity schedules, etc. in developing the prevention sections of the plans.
 - Require that, as much as possible, the procedures called for in the BSP to be based on an understanding of the cause(s) for the person's behavior challenges.
 - Improve data collection procedures for client behavior, reliability measures and assessment of the accuracy and consistency of program implementation.
 - As appropriate, encourage more interdisciplinary involvement in the development of BSPs.
- Do not allow for expansion in the *Center-based components* of statewide programs such as PATH and BART. We were told that the BART program has a Community Link-Up Team that is involved in assistance to community agencies and families to prevent admission to the institution and to facilitate the return of BART clients back to their home communities. These are critical services, and until the success of such preventive and community support services can be assessed, as they are made available across the state, it would be premature to expand the residential programs in the Centers.
- As state operated centers are downsized over time, try to develop as small and individualized living and work settings as possible, at the centers. This effort would clearly have to be balanced against the costs savings of closing entire buildings or cottages, but it is important to recognize the barriers to providing appropriate support services which are inherent in the current large group settings.
- If the centers are to become involved in providing residential services in the community, which would be a questionable development at best, focus their efforts on the provision of supported living services funded by the waiver. To allow them to become involved in the provision of ICF-MR group homes would simply further the state's commitment to an already over developed and increasingly outmoded service delivery model. Direct involvement in supported living services would also provide the center staff with an

¹² A relatively small number of people with very dangerous behavior such as extreme aggression, setting fires, engaging in sexual behavior with children remain difficult to support no matter where the effort is made.

experience base that would likely enhance the effectiveness of their technical assistance and consultation services to community programs.

Community-based Services

The theme that runs through most of the concerns raised concerning community services for persons with severe behavior challenges is one of resources and capacity, or more precisely the lack of resources and capacity. North Carolina, like most states is moving in the direction of more and more community-based programs. However, unlike most states it still has a significant portion of its available funding and much of the service capacity necessary for this move to the community to be successful located back at the state operated Mental Retardation Centers. There must be a concerted effort to carefully move these resources and the control over them, to the area programs. Specific change recommendations are listed below.

- Begin to incorporate the best of what was learned in implementing the Thomas S. services throughout the larger community-based service system. The key features seem to be a melding of “traditional managed care strategies with the principles of person-centered planning and self-determination ”to create a new approach to service design and delivery currently referred to as Participant Driven Managed Supports¹³. While there is still more to learn about best implementation practices the goals of participant self-determination, having a flexible array of services and support, developing community partnerships, involving personal advocate/brokers and administrative intermediaries, unified funding, outcome focus and cost containment surely apply to the larger community service system.
- Changes must be made in the current CAP waiver program to make it more flexible and especially allowing for more than the current \$7000+ /month ceiling for persons with extraordinary support needs. The specific changes needed are outlined in Chapter 6
- The resources allocated to at least some components of the outreach departments at the state operated Mental Retardation Centers should be moved to the area programs. It may make sense to keep the service and training components related to such areas as medicine, dentistry, etc, at the centers but it does not make sense that large segregated centers are seen as appropriate places to provide training to community staff, an ever increasing number of which will be working in small integrated settings, where the working conditions are very different from those at the centers. While the technical assistance and consultation services provided by the centers was generally rated positively by community representatives, it is likely that they could be even more effective if they were to become an integral part of area programs. While it is true that the centers offer a wide variety of competent outreach services, it is important to note that if the millions of dollars that have been spent over the years to develop this competence and capacity in the centers had instead been spent in the area programs, we would now be talking about the valued technical assistance and training services of the area programs.

This shift to the community could occur in a number of ways, beginning with a shift in control of the dollars that fund the outreach services. There could be a shift in control of the funding for technical assistance and training. Currently, the area programs have the role of a recipient of state funded services provided by the centers. However, if area programs had control of the dollars their role would shift to one of a “customer,” who has the funds to buy technical assistance, consultation and training services from the centers or anyone else that can meet their needs. If the centers are generally offering quality, accessible services the area programs could choose to continue to use them, but they would be in a better position, as a customer, to ensure that the services meet their needs. Some outreach staff might choose to move to a position in the area programs or establish a privately operated agency that provides technical assistance and training. Given the wide geographic areas currently served by some Mental Retardation Centers, there would probably be the need for inter-area agreements. In the long run it is simply more likely that the specific and sometimes unique technical assistance and training needs of

¹³ From Thomas S.: A Cross-Disability, Community-Based System of Specialized Supports, Third Report to the Legislature, May 1999.

each area are more likely to be met if the locus of planning and control of the funding is at the area program level.

Support Services

- Ensure that the Mental Retardation Center guidelines as well as the review process used to ensure that the quality of the Behavior Support Plans meets minimal standards is also applied in the community.
- A comprehensive, multi-layered approach will be necessary to meet the crisis intervention needs of community-based residential and day programs. Such a system would have to be able to, at a minimum:
 - Provide a flexible and rapid augmentation to the budgets of community agencies, on a short-term basis, to meet the needs of a crisis situation.
 - Ensure that immediate (within two three hours of the request) consultation services of an interdisciplinary crisis team are available.
 - Ensure that additional support staff are immediately available to augment the efforts of existing staff, for as long as the crisis lasts.
 - Ensure the availability of short-term community-based residential and day program placements, when it becomes impossible to support the person in their current placement. This function is most often served by small crisis homes.
 - Ensure that competent consultation assistance is available to help in revising the persons basic support plan to help prevent crises in the future.
- Develop a comprehensive and standardized means of assessing what happens when people “lose” their placement because of their behavior challenges. Documents related to this we reviewed, most often attributed the cause for loss of placement to be that the community program was not able to provide “the structure needed” to manage the person’s behavior. A more detailed analysis is needed if we are to learn about the strengths and weaknesses of the community system. There should also be some means of consistently collating, analyzing and routing this information to all the relevant stakeholders. It might also be very helpful to complete a similar analysis on at least a representative sample of “success” stories. This might help you learn more about the strengths of the system.

Cross- Systems Issue

The truth is that there are serious problems and limitations in both the center and community-based service systems, especially when it comes to supporting people with severe behavior challenges. It would require significant time, energy and funds to deal with all the needed changes in both systems. Even if the funds were available, it would probably not be prudent to maximize the capabilities of both systems and, given the reality that there are not likely to be major infusions of new dollars into the DD service system, hard decisions will have to be made. The hope is that it will make sense to the stakeholders in North Carolina to invest most of the state’s dollars and the energy of its service system in the future, which surely will be in a community-based services system, that is person centered in its approach to service delivery.

Health Supports

Another important aspect of ensuring that the state has sufficient capacity to serve people with developmental disabilities is the quality and availability of dental and health care. The following review is based on the observations and interviews conducted by HSRI's consultant team.

Dental Care

Dental care in North Carolina remains the number one healthcare concern for people with developmental disabilities. The dental care in the Mental Retardation Centers seems to be more comprehensive and accessible than that provided by private providers in the community. Community dentists are reluctant to take on new DD/MR patients due to their perceptions that reimbursement schedules are insufficient. This is a view widely held by dentists throughout the country.

Most dental work in the community seems to be done on an emergent basis with little or no attention to restorative or cosmetic areas. There does not appear to be much cooperation between the state's dental schools and the DD Section with regard to serving the needs of individuals with developmental disabilities and improving knowledge of training dentists about these needs. There is little or no exposure to this population during the last two years of clinical instruction in the dental curriculum. More outreach of dental services from the MR Centers to the community should be encouraged. It is suggested that perhaps forgiving the dental school loans of graduates who include DD/MR dental patients in their practice might be an incentive to encourage more participation from new graduates. Without exposure to the challenges and rewards of working with this population as an undergraduate dental student, it is doubtful that new graduates will pursue this avenue of specialization even with the loan incentive. Additional incentives regarding tax deductions for dental practices might also be considered.

Failing the participation of the state's community dentists in caring for people with developmental disabilities living in the community, the state should consider using dental hygiene clinicians to institute a program of preventive care for this population. The equivalent of "dental assistants" (to physician assistants or nurse practitioners) might be a consideration for development to meet the needs of this population, which historically has a multitude of dental problems from years of neglect. This might be attractive with the current trend of declining dentist to patient ratios and the shrinking size of the dental school classes.

The definition of "medically necessary" dental work needs to be reviewed in light of the potential consequences from delay or neglect of dental care which includes: postponement of bone marrow and organ transplants, cardiac and other critical surgeries, failure to thrive, breathing difficulties, septicemia, brain abscesses, and other serious complications including aggressive behaviors.

Dental care for citizens with DD/MR in the rural areas of North Carolina appears to be in even more critical jeopardy except for those areas with an MR Center.

There is little or no evidence of a comprehensive program of preventive ongoing dental care in group homes, Adult Care Homes or the MR centers. Direct support professionals have had little training or encouragement for dealing with situations of non-compliance or non-adherence to regular brushing. Challenging behaviors, staff turnover and accountability structures are factors that must be considered in efforts to better prepare direct support staff in optimum dental health support..

Hospital affiliations should be encouraged for dentists who provide services to people with developmental disabilities due to the high incidence of hospital based dental care for patients with complex dental problems requiring sedation.

A Task Force on Dental Health for Citizens with DD/MR should be created to explore the above suggestions and this coalition should include members of the several existing professional associations with an interest and expertise in DD/MR oral healthcare as well as other key stakeholders such as direct support staff.

General Healthcare Concerns

On the average citizens with developmental disabilities in North Carolina (in accord with national statistics) require one-and-a-half more visits to the primary care office, twice the time per visit, five to ten times more hospitalizations, and two to three times more physician contact time overall than non DD/MR patients. They also receive almost four times the amount of medications, but are historically under-treated for pain. This is partially

due to some people's inability to express pain, the physician's inability to obtain a pain history and a lack of awareness and concern about pain in people with severe disabilities. This backdrop underscores the critical nature of healthcare for this group of individuals.

Based on site visits and interviews in the community and in the MR Centers, project staff and consultants suggest that the following areas of healthcare to people with developmental disabilities require significant attention and expansion:

- Preventive practices aimed at obesity and other nutritional concerns, post-menopausal issues, oral health, cardiovascular health, cancer, rheumatology, and mental health should be expanded; specific examples include the need for mammograms, colonoscopies for at risk individuals
- End of life health issues need to be addressed and protocols developed
Transitional health issues should be explored (e.g., we found instances of forty year old females being treated by pediatricians) including the improvement in the availability of family practitioners, internal medicine clinicians and gerontologists to treat citizens with DD/MR
- The availability of developmental gerontology is critical given the age of this population (e.g., in the programs reviewed, there were very few referrals being made to geriatricians, including psychiatric gerontologists)
- Depression and other mental health issues, including dementia, Alzheimer's disease and other cognitive issues inherent in senescence (over and above the baseline mental retardation) need to be addressed
- Pain management for chronic conditions is lacking and the team saw little or no evidence of pain charts, explanation of atypical or compensatory pain expressions or charted evidence of pain abatement protocols; no reference to observations or input of direct care staff regarding pain patterns
- With respect to arthritis and other rheumatological conditions; the team saw little evidence of disease altering treatment plans
- The team saw no evidence of sleep patterns, sleep disturbances being reviewed by clinicians; there was little or no evidence of the "question" of sleep patterns even being asked by clinicians.

An important element of good healthcare for people with developmental disabilities is the direct support professional (DSP). DSPs need to be incorporated into healthcare and treatment issues: they need to be better educated in healthcare issues, compliance issues, they need to learn to become health advocates for their clients and their input needs to be invited in issues regarding compliance, subtle changes in their condition, pain, impact of treatment plans

Pharmacy

According to key informants, the State of North Carolina terminated their director of pharmacy services within the Developmental Disabilities Section. This raises some concern for the well-being of those who receive health services directly from Division at the MR Centers and in the stimulation of best practice among community based practitioners serving people with DD. The director of pharmacy position plays (potentially) a vital and critical role in the prevention of poly pharmacy (multiple medications), medication administration errors, drug-drug interactions, drug-food interactions and in assuring the quality management of seizure medications, psychotropic and psychoactive medications. In addition in terms of pharmacoeconomics the State needs a pharmacist to examine (on an ongoing basis) all protocols, procedures, and formulary concerns as well as overseeing the dynamic nature and impact of medications in this population.

Summary

The review of health and dental issues was conducted over a relatively brief period of time and requires continued attention by the DD Section. Building a healthcare network in the community that can provide quality attention to the often specialized needs of people with developmental disabilities is a key task. There is some initial data collected as part of a healthcare addendum to the Core Indicators Project Consumer Survey that underscores the importance of these issues. Of the approximately 322 consumers surveyed,

- 30% report mental health problems
- Nearly 20% were treated with two or more psychotropic medications
- Access to health care services is a problem, particularly dental care and women's reproductive health services
- 1/3 of adults in community never engage in physical activity
- 1/3 of respondents were concerned about being overweight
- Behavioral "lifestyle" risk factors are increasingly similar to general pop...5.5% drink alcohol and 17.4% report smoking tobacco

It is strongly suggested that the DD Section in conjunction with representatives of the major medical and dental schools in the state convene a workgroup to explore both the expansion of training in developmental disabilities for health professionals and also to think through the creation of regional technical assistance units that can work with local communities to address the issues noted above and that can track the health status of individuals with developmental disabilities. There are several states that are addressing similar issues including Pennsylvania, Massachusetts and California

Workforce Constraints

Background

Direct support practitioners represent the bulk of employees who interact directly with people with developmental disabilities in North Carolina's service system as in other human service systems, and are also those people who spend the most time with service participants. For these reasons direct support performance is a key factor in achieving desirable consumer outcome and should be a primary focus in creating conditions that promote quality. Without a stable and competent direct support workforce, many people with disabilities do not have access to requisite safeguards to health and safety much less the opportunity to learn and grow. Factors pertinent to the current and projected conditions of the direct service workforce are therefore a key metric in the evaluation team's considerations.

One important indicator of staff and system stability is the average annual direct service turnover rate. Workers who are satisfied with working conditions typically do not leave their jobs for conditions that are within the control of the employer. In any industry, some amount of turnover is expected due to changing life circumstances but when turnover rates are high or increase significantly, as they have in human services across the country, it is an indication of dissatisfaction with work conditions such as nature of the duties, wages, hours, supervision, career opportunity and the like. In the field of human services, there is a tremendous human cost to service participants and co-workers who must weather a constant stream of new, inexperienced employees as well as the financial loss attributed to investment in recruiting and training workers. Such human and fiscal costs can be reduced by utilizing the many proven short and longer-term strategies to improve recruitment and retention rates and to encourage employee commitment over time.

The effectiveness of support work (and hence outcomes of service participants) is highly dependent on their knowledge of their work and of the people they support as well as continuity in their relationships with service participants over time. High turnover is extremely detrimental to these factors. Poor employee preparation is also implicated with poor outcomes. Progress toward goals is not achieved, and worse, service participants suffer an unremitting stream of interrupted relationships as workers move in and out of their lives.

The scope of this study did not permit a comprehensive, longitudinal study of workforce conditions, however detailed analyses of North Carolina direct service labor issues are available in two fairly recent reports. One focuses on conditions of direct staffing in community settings (Test, 1998) and the other on conditions of direct staffing in the publicly funded congregate facilities within the Department of Health and Human Services (Health Care Technicians Recruitment and Selection Work Group, 1998). Both studies provide some information about turnover and its determinant factors as well as important information about training and preparation of the direct service workforce.

Current Conditions

The findings of this study and data from other studies of the North Carolina human service workforce suggest that the availability and stability of direct support practitioners is a serious and present threat to the quality of support for people who rely on human services in North Carolina, including those with Developmental Disabilities. Current workforce conditions are compromising the quality of care provided throughout the North Carolina system as they are throughout the nation as a whole and will require strategic interventions to prevent further deterioration of quality.

The problems related to the instability of direct support, the bedrock of day-to-day support, (as seen in difficulties with recruitment and worker retention) are exacerbated by evidence of high levels of case manager turnover and shortages in nursing staff. In addition to affecting the quality of key functions in case management and nursing, shortages in these roles and direct support supervisor shortages also have a cascading effect that can further destabilize direct support whose turnover rate is significantly correlated to the stability of supervisors. With these critical work forces in turmoil, the possibility for desirable service outcomes are gravely diminished and the basic health and safety risks to those receiving support are increased.

It is difficult to ascertain the exact nature and conditions of the human service labor force in NC because data are not systematically and regularly collected. Some indications of current conditions are known through the recently piloted data set known as the "Core Indicators." In future years, North Carolina is planning to collect these data, which will provide some basis for analysis.

Staff Stability

In North Carolina's community settings Test reported an average turnover rate in 1999 of 41% with 74% of agencies reporting problems in hiring. (compare to Rose data) . One limitation to the Test data on turnover is the poor return of administrator responses on this part of his survey. Of the 108 surveys returned to Test

(29% return rate) only 69 included responses to the turnover question. It is likely, however, that if more agencies provided turnover figures that those data would trend the turnover data upward toward the higher national averages seen in other research in recent years. The poor response rate on this question, may signify a lack of technical capability among providers in tracking key workforce statistics that signify relative health of the workforce.

Families who responded to the Consumer Survey of the Core Indicators praised staff support. They did, however, mention several areas of concern, including frequent turnover, and also suggested that staff should have greater knowledge of available resources and greater competence in serving those with autism spectrum disorders and people with visual and hearing impairments.

The Health Care Technicians Recruitment and Selection Work Group (HCT Work Group) reported that turnover in public, congregate facilities for 1997 was 18 %. This rate exceeds average turnover in all other classes of employment in state government by 5%. Averaging these community and facility turnover rates the overall turnover of crucial direct service personnel averaged about 30% in 1997-98. It is likely that this rate is currently higher due to the data limitation reported above and the continued rapid growth of the service and retail sectors, including human services, creating intense competition for the limited pool of laborers likely to take entry level jobs in these sectors. In highly competitive recruitment environments, human services employers do not fare well due to relatively poorer wages, benefits and career opportunities than are found in many competing service industries.

There are no recent studies of the causes of reportedly higher case management and nursing position turnover. Qualitative evidence gathered in visits to a number of area programs to talk with administrators and case managers offered some insight into that situation. A number of key informants report that case manager documentation requirements have increased by 50% in the past two years primarily driven by demands of CAP waiver documentation and other Medicaid billing requirements. Caseloads are relatively low making these demands somewhat manageable, but such demands transform the role from one of connection to service participants and coordination among providers and resources to a largely administrative role. For case managers who place more value on spending time with service participants, generating creative support interventions and assuring quality through personal contact, the paperwork demands contribute to job dissatisfaction. Our review indicated that this is one factor in case management turnover.

Impact on Consumers and Co-Workers

The UNC Study included measures of consumer response to turnover indicating that staff turnover results in sadness and hurt feelings, difficulty building trust with new employees and a tendency for service participants to blame themselves for staff leaving. Many (50) also reported that quality of services decreased due to a decrease in the number of staff available per consumer.

Community based co-workers reported increased stress levels, reduction of job satisfaction and difficulty in completing paperwork as a result of the revolving employment door. Turnover in congregate settings resulted in long periods of forced overtime and stricter rules regarding requests for time off contributing to poorer morale among workers. The HCT Work Group Study also reported that employees were frustrated with the lack of opportunities for career advancement and opportunities for an incremental pay plan.

Direct Service Workforce Characteristics

Test reports that of the estimated 27,700 direct service employees in community settings in developmental disabilities services, most (82%) are women (of administrators only 56% are women) , half are single and a significant number are the primary supporter of their family (42.9%). Salaries average \$19,226 annually. Given this profile, it is not surprising to learn that 66% of these practitioners say that their salary does not meet basic living expenses and 35% work other jobs to make ends meet.

Thirty nine per cent of community based direct service employees are African Americans while the number of African American administrators is only 21.3% (African Americans are 22% of the state's overall population (1990 Census). While there is reportedly no significant presence of other minority groups in the workforce, given current national labor demographics and projections, it must be anticipated that émigrés (many from non-English speaking cultures) will become a primary factor in the workforce of the future. The HCT Work Group study does not address ethnicity but does note that a majority of the publicly employed direct support workforce are women. Data on ethnicity and gender of supervisory level employees in the publicly operated service centers are not available in the HCT Work Group study but may be available through employer data bases.

Recruitment Issues

A majority of community agencies (70%) as well as the congregate centers are having significant difficulties in finding staff to hire. The HCT Work Group reported a significant disparity between what a desirable applicant demonstrates and those who were applying at the time of the study. This candidate pool is further narrowed when individuals who cannot manage physical aspects of the job or who do not pass background screening checks are eliminated. The community agency data indicates that the median cost for advertising for candidates is \$1000 with a range of 0 to \$2000 (most likely range is dependent on agency size). Geographical and regional economic factors affect the availability of staff with more rural areas and areas with limited economic opportunities having less trouble in finding workers. The current downturn in the economy will have a positive effect on the recruitment problem but other structural factors involving future high growth in human services and other service industries along with continued, limited population growth portend continued difficulty with recruitment into human service roles. Many parts of the country also report difficulty with hiring into middle management positions, but it was not possible in this study to determine if this is a problem in North Carolina.

Employee Education, Development and Experience

Both studies state that direct service employees are relatively inexperienced. In general, the direct service employees in the community are better educated (41% with a post-secondary degree) contrasting with lower educational levels in congregate settings, where the majority of employees have achieved a high school degree.

Test reports that two thirds of new direct support employees receive less than one week of training and 25% receive less than 8 hours. This study also reports that a majority (60%) desire additional training especially in Crisis Intervention (81%), Professional Development (76%), Advocacy (75%) and in teaching Community Living Skills and Supports. Other topics mentioned included "Health & Safety" and "Behavioral Health."

Little information is available regarding the costs of recruitment, training or development in North Carolina or return on these costs. The HCT Work Group reported that it costs as much as \$2300 to train an HCT in the psychiatric hospitals. National data demonstrates a range of \$2000 to \$5000 to cover initial employee training & recruitment costs in decentralized community arrangements. High turnover drives these costs up and greatly diminishes the return on investment in training.

Test reports that a majority of agencies find it difficult to obtain coverage to release employees for training activities. Other challenges community agencies report are difficulties in: finding reasonably priced employee training opportunities (49%); finding resources to pay trainers and consultants; finding training opportunities close to the agency (43%) and finding events that cover the most important topics (38%). 80% of agencies report providing in-house training, but only 63% have a dedicated budget for this.

Qualitative probes indicate that professional development of direct support staff is often geared toward a health related certificate, particularly a Certified Nurse Assistant (C.N. A.) certificate. This is not surprising in

that there is a reported shortage of nurses in the system, thus administrators facilitate employee development in that direction. Also, the educational and career path is explicitly defined for the nursing track enabling employees to make informed choices about continuing education and its contribution toward career advancement. It is a problem that no similarly well-defined path exists for non-medical direct support.

Our visits throughout the system also revealed that the level of awareness and implementation of best practices in developmental disabilities is limited to pockets of excellence that have been driven by the intensive resources and training associated with Thomas S. Class Members. Outside of these situations, it was clear that direct support staff had few opportunities to learn and effectively implement self-determination principles, and person-centered planning practices. This is a problem as well among administrators and providers throughout the system. Some progressive providers and administrators provide leadership in these areas but as currently operated, the developmental disabilities system does not consistently promote and support best practice. The system is largely “slot-oriented” vs. person-centered and is unable to provide the individualized approaches necessary to progressive support. More will be said on this in report sections addressing the CAP Waiver and provider capacity.

System Challenges

The impetus for the UNC and HCT Work Group reports was the recognition that front line staffing stability is a serious problem along with a desire to seek solutions to remediate labor instability both in public and private service settings. While relative to private support settings, there is greater stability in publicly operated facilities, both settings are troubled. Moreover, the primary reason for better stability in the public settings is the higher wage paid to front line staff in these locations.¹⁴ This illustrates the impact of inequities in pay across these settings and puts people who perform community support work and who rely on community support at a disadvantage. Many other causes of the labor difficulties are pertinent to both settings, thus solutions must address the support system as an integrated whole rather than the creation of a separate agenda for public and privately operated services.

These problems cannot be ignored because quality is currently suffering and there will be an insufficient workforce to meet future demands for expansion. Examples of this system failure are seen in other states. For example, in a recent independent evaluation of Minnesota’s Home and Community Based Waiver it was demonstrated that 30% of families were unable to use dedicated resources for in-home support because they could not find staff to do the work.

In addition to the fiscal and human costs described above, the system of the future must become strategic about workforce development to assure an adequate supply of workers and to assure that the new and incumbent workers are well prepared to work in a reconfigured system that emphasizes facilitating self-determination, natural support and working well with families and self advocates:

A variety of factors (detailed in many sections of this report) are fueling a demand for the expansion of developmental disabilities services as well as a reconfiguration of existing resources – these include:

Demand Drivers

- Addressing current waiting list demand (6,927 currently waiting for service with over half having no service at all)
- ADA “Most Integrated Setting: Mandate” (*Olmstead* Ruling)

¹⁴ Braddock, D., & Mitchell, D. (1992). *Residential services and developmental disabilities in the United States: A national survey of staff compensation, turnover and related issues*. Washington D.C.: American Association on Mental Retardation.

- Anticipating demand resulting from rapidly rising incidence of people afflicted with autism spectrum disorders and traumatic brain injury
- Estimates of 5000 to 7000 people with developmental disability currently inappropriately placed in rest homes who do not appear on waiting list¹⁵
- Current plans to launch additional waiver programs

Reconfiguration Drivers

- New generations of families who want community living arrangements rather than congregate care, and work opportunities outside of sheltered environments
- Significantly more people in ICFs/MR care when compared with national norms
- Significantly higher average costs per care within ICFs/MR when compared with national norms
- Comparatively meager level of resources provided for in-home family supports when compared with national norms and demand
- Strong stakeholder demand to transform system centered services to supports characterized by principles of self-determination
- Fiscal consequences of economic slowdown
- Intensified reviews of state HCB waiver programs
- Reactivation of federal ICF/MR “look behind” reviews

Recommendations

Becoming strategic about workforce development is of paramount importance. A group of stakeholders, including those with labor expertise and state and regional labor responsibility as well as the potential customers (direct support staff), should convene to create a comprehensive workforce development plan that details interventions for the stabilization (short term) and development (long term) of the direct support supervisory role and direct support practitioners. The plan should address the following elements:

Data Collection

The state should develop a system of on-going, systematic and reliable, measures of workforce stability including turnover and job vacancy measures. Information must be useful at both an agency level and at a macro level (statewide). In addition to recruitment and retention information, it will be useful to track workforce development costs, workforce demographics including educational profiles, salary profiles, gender and ethnicity profiles and self-sufficiency indicators such as home ownership, and reliance on second jobs.

Organizational Development to Improve Recruitment and Retention and Employee Development:

A state-wide system of technical assistance to employers should be launched to build capacity in:

¹⁵ Hawes, C., Lux, L., Wildfire, J., Green, R., Packer, L.E., Iannacchione, V., Phillips, C. (1995). *Study of North Carolina Domiciliary Care Home Residents*. Raleigh: Research Triangle Institute.

- data collection
- developing customized workforce development plans based on data
- using effective recruitment practices
- using effective orientation practices
- using effective employee recognition and development practices
- establishing local consortia of human service employers to develop joint recruitment campaigns, conduct career education activities with local schools and workforce recruitment entities, and other collaborative activities
- Mentoring of new and incumbent direct support workers

Employee Quality of Life & Work Initiatives:

State DD officials should work with state legislators and administrators to create benefits and programs specifically targeted to human service employees including:

- Scholarships and tuition entitlements to public post-secondary schools for employees and their dependents (employee benefits may be restricted to human service related courses)
- Reduced rates of admission to state operated recreational opportunities such as state parks, state museums, publicly funded arts and entertainment
- Dedicated mortgage pools to assist employees with purchasing homes, and cars.
- Dedicated funds to assist employees with child care costs
- Tuition free workshops in Money Management, Investment and Planning
- Agency based assistance with linking to programs for income enhancement including food stamps, first time home-buyers, etc.

Career Path Initiatives

- 1) Create strategies for developing and strengthening the direct support supervisory level as a **primary** focus. (As a first order priority the stabilization of this group will have positive effects on front line direct support staff even if other interventions were not pursued).
- 2) Create a series of linked direct service job steps leading to and beyond direct service supervisory levels that are the similar across public and private settings
- 3) Create dedicated, high quality, parallel OJT and post-secondary, voluntary certificate programs throughout the state to support this career path. Characteristics of these programs should include:
 - Multiple, articulated award levels
 - Tuition free

- Competency based
- Criterion referenced - based on valid occupational standards that draw from best practices in the field (A legal necessity if certificates will become one basis for promotion);
- Criterion draws from key domains including, validated skill and knowledge sets and ethical guidelines.
- Reliable, progressive (authentic) assessment methods
- Functional context (theory linked to field practice)
- Explicitly articulated with relevant post-secondary degrees and certificates as well as secondary levels of vocational and technical preparation
- Educational methods based on best practices
- Instructors competency based not on educational degree but on recency of experience and recognition as content expert and competent instructor by peers and learners
- Self-advocates and family members included as instructors
- Guided by a coalition of stakeholders
- Content and program operation regularly updated and evaluated.
- Use of Portfolio or other method of worker directed charting of professional development goals, accomplishments and benchmarks.

Wage and Benefit Enhancement

- 1) Work with legislators to improve wages using “pass through” legislation and tying wage baseline to automatic economic indexes (based on living wage) and tying wage enhancement to a combination of seniority and advancement of competency as demonstrated by established criteria (obtaining requisite certificates)
- 2) Establish statewide employee insurance and benefit pools to improve quality of benefit packages for employees and reduced costs of benefits to employer
- 3) Develop projects to demonstrate/pilot progressive strategies including worker run cooperative service agencies
- 4) Develop fiduciary intermediaries that can serve consumers as fiscal agents for self-determination type of supports and that can serve as organizers of benefit pools for independently employed support brokers who work directly for consumers.

Case management and nursing stability

- 1) Conduct additional research to determine factors contributing to instability of these positions including instituting exit interviews with departing employees

- 2) Separate case management function from service verification function and reduce paper oriented verification processes (see other report sections).
- 3) Create or sustain continuous feedback loops with consumers and families at local, regional and statewide levels to sample consumer opinion regarding staff quality and availability.
- 4) Create or sustain continuous feedback loops with direct support staff and other direct service roles including case management to determine quality of preparation programs, supervision and career progress.

Secretary Buell must be commended for including an in-depth chapter on Staff Competency in her draft of a new Comprehensive State Plan for Mental Health, Developmental Disabilities and Substance Abuse. Many of this reports recommendation are already found in the seminal concepts of this plan including:

- Emphasis on non-degreed employees
- Focus on competency-based staff development
- Clarification and articulation of career and educational paths
- The need for baseline and regular data collection of data about the status of turnover, retention, and the quality of service as seen through key indicators such as medication errors, and injury rates.
- The importance of developing collaborative partnerships reaching beyond the boundaries of the human service community
- Promotion of personal responsibility for professional development through a professional development plan (annual supervision plan)
- Verifying the capacity and quality of training and education providers

In reviewing the plan there are several comments we would offer for the Secretary's consideration in further improving an already strong agenda for workforce development as it pertains to the developmental disabilities division including the following:

- Revisit the recommended "core competencies" with a broader group of stakeholders to ensure that the recommended domains meet the fundamental requirements of face validity, content validity and, wherever possible, empirical validity evidence is offered to support these choices. For example in the area of technical knowledge for DD Qualified professionals and associate professionals, many in the DD field would suggest while it is important to recognize the functional characteristics of specific developmental disabilities (e.g., cerebral palsy, autism spectrum disorders, traumatic brain injury, Down syndrome etc.) that it may be more important to adopt a paradigm that is useful across divergent conditions such as recognizing personal strengths and preferences and using this information in planning and intervention. Another area for review may be the dimension of ethical practice. Recent activities in the DD field suggest that this dimension may be better placed as one of the fundamental areas of core competence. Further, it is likely that the dimension of clinical skill would be revised to a more functional description of competence that is less oriented to a medical model. It seems as well that this dimension is duplicative of competencies identified in other dimensions. Finally, a DD group may wish to compare the proposed competence matrix with skill and knowledge sets that have been nationally and regionally validated in the field including the Community Support Skill Standards, The Minnesota Frontline Supervisor Competencies and competencies proposed in the supported employment movement.

- Expand the focus of this section of the plan to incorporate capacity building strategies around recruitment and retention and to prioritize short term interventions such as teaching effective recruitment techniques, disseminating best practices in employee orientation, recognition and mentoring.
- Clarify what positions will be encompassed by the proposed QP and AP roles. Consider creating additional competency based roles and associated competencies that relate to these roles. For example where does case management fit into the matrix? What are the core competencies for case management?
- Consider adopting a voluntary approach to employee development and certification requirements beyond basic elements.
- Minimize the extent of verification of credentials. The current system expends extraordinary resources for this purpose without significant benefit.

Provider and Area Program Responses

Availability of Services

The On-line surveys provide field perspectives on the availability of services. Specifically, 76.9% (10/13) Area Program Directors characterized the adequacy of services and supports to people with developmental disabilities in their areas as “good.” 23.1% (3/13) rated the adequacy of services as “average.” DD Program Directors and all providers were asked to rate the adequacy of specific services in their areas. Below, we report the number and percent of respondents who rated these services as “not adequate.”

Service/Support Category:	Number (%) Rated “Not Adequate”	
	DD Directors N=12	Providers N=28
Transportation	8 (67%)	12 (43%)
Dental services	9 (75%)	16 (57%)
Supported employment	2 (17%)	7 (25%)
Supported living	1 (8%)	6 (21%)
Recreational activities	2 (17%)	5 (19%)
Services for MH/DD	4 (33%)	8 (29%)
Behavioral supports	2 (17%)	7 (26%)
Specialized therapies	0	7 (26%)
Commun/ adaptive equipment	0	3 (12%)
Medical services	0	3 (11%)
Day activities	2 (17%)	6 (21%)
Supports for elders	6 (50%)	11 (46%)
Respite	3 (25%)	11 (41%)
Family supports	7 (58%)	7 (26%)
Early intervention	0	7 (27%)
Case management	N/A	7 (25%)

Both groups felt that transportation, respite services, elderly services, supported employment, and crisis stabilization services were lacking.

DD Program directors specifically mentioned the need for...

- Before and after school services, developmental preschool, and summer programs
- Non-vocational day programs for adults
- Ability to facilitate natural supports, increased knowledge and opportunity for community inclusion
- More funds to expand current services
- More providers to expand choices
- Residential services for the following populations: children with MR/MI, people with severe behavioral issues, people with traumatic brain injury, transition age adults 18-22
- Different types of residential supports, specifically: supervised living, DDA group homes, and ICF-type residential care
- Services for people with autism

Providers had additional suggestions about supports that are needed...

- Ability of families and consumers to make informed choices
- Flexibility in use of funds
- Ways to make self-determination work (e.g. fiscal intermediaries, individualized budgets)
- Improved dental (especially surgical procedures) and medical services -- specifically Medicaid providers are limited
- Programs for those with substance abuse problems
- Programs for sex offenders
- More employment funding for pre-vocational services for people with severe disabilities, and more funds for long-term follow up services for people in supported employment
- Case manager turnover and long waiting list also cited as problematic

Constraints on Providing Services

The respondent groups were asked slightly different questions regarding the current configuration of services and their ability to serve people in the community.

Area Program Directors

Assuming that you had the fiscal resources, please comment on your ability to accommodate individuals with developmental disabilities from your area currently living in state Mental Retardation Centers:

Could serve them all within the year	2/12 (16.7%)
Within the next 2 to 3 years	5/12 (41.7%)

Within the next 3-5 years	4/12 (33.3%)
It would take more than 5 years	1/12 (8.3%)

AP and DD Program Directors

What constraints, if any, prevent you from moving more individuals with developmental disabilities from the Mental Retardation Centers?

Lack of providers	16/26 (62%)
Rates too low	13/26 (50%)
Lack of capacity	9/26 (35%)
Caps on the MR/DD waiver	16/26 (62%)

Residential Providers

Whether or not you are currently serving people from MRCs, what hurdles would need to be overcome for you to serve additional MRC residents? (Check all that apply)

7 (25%)	Expansion of number of residential sites
6 (21%)	Recruitment of specialized staff (e.g., OTs, PTs, etc.)
9 (32%)	More day supports
14 (50%)	Expanded waiver funding
11 (39%)	Increased rates
6 (21%)	Additional medical supports

Vocational Providers

What hurdles would need to be overcome for you to place more individuals with developmental disabilities in regular work settings? (Check all that apply)

11 (85%)	More support from families
8 (62%)	More community education and job development
5 (39%)	More job coaches
8 (62%)	Removal of financial disincentives (e.g., loss of health benefits)
3 (23%)	Increased leadership from the state
8 (62%)	Increased or reconfigured rates

The major barrier stressed by all respondent groups was that the level of supports needed in the community does not currently exist. More funding is required to develop the community service system, particularly in the areas of housing options, medical and behavioral supports, transportation, and opportunities for supported employment. Providers commented that flexible funds and individual budgets would facilitate the development of community supports.

Priority Problems

The surveys asked respondents to rate several problems in terms of their importance to the quality of DD services in their areas. The respondents identified the following problems as top-priority issues. Table 2 displays the average ratings of by each group, based on a scale of 1 to 10.

Table 2. Average rating of top-priority problems, by respondent group.
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Problem	Average Rating - Directors	Average Rating - Providers
Staff recruitment and retention	8.77	8.18
Provider capacity	7.31	N/A
Level of funding	8.92	9.14
Waiting list	8.17	N/A
Lack of competition among providers	5.62	N/A
CAP MR/DD provisions	8.00	8.00
Local community support	7.23	7.54
Funding incentives that favor larger residential programs	5.75	N/A
Lack of a unified state direction	8.42	8.32
Case manager capacity	N/A	7.11
Inflexible funding	N/A	8.89
Inflexible rules and regulations	8.12	8.89
Lack of consensus among advocate	6.96	6.41
Condition of MIS system	N/A	6.85
Capacity of staff (e.g., supervisors, middle managers)	N/A	7.21

Other problems mentioned by DD Service Providers...

Communication

“The single most problematic issue in this state that negatively [affects] the quality (and quantity) of services is communication. The miserable state of communication between the “State” and the groups invested in DD services...has a negative impact on DD policy.”

Case management

- Need better training
- Disrespectful to agencies
- Not consistent across Area Programs

“High case management turnover is a problem. There seems to be a lack of involvement on the part of most case managers in our area.”

Other comments from Directors:

The system is very under-funded. We have increasing requests for service which we cannot meet. There is no UR system or criteria to limit amounts of service/funding accessed by consumers (especially Waiver participants.) UR could be implemented

At present while the "word" is to avoid duplication or different rules within different departments at DD it still happens. Anxiously await state plan as it relates to DD to give us a common direction as a service area

I have been very frank about some of our local and state systems gaps. I have to say that I don't think that the Division nor the DD Section receive input as constructive.

My concern is the lack of unified state direction and inflexible rules and regulations. Oftentimes changes are made and Area Programs are held accountable without the adequate training and a lot of unanswered questions.

I am concerned with the move toward moving DD services out of the Division of MH, DD &SA. This can only serve to fragment our current service system—our most difficult consumers often have needs that cut across administrative lines within an Area Program.

Issues surrounding removal of successful ECI Program from the Division of MH/DD/SAS

Management of providers at the local level [is a problem]. Roles and authority needs to be clarified. Utilization management of resources...we could make the CAP funds go further if we were allowed to conduct utilization management.

Overwhelming paper work requirements, COA requirements, individual program requirements as well as performance agreement requirements. System is too cumbersome and complex.

The DD world has become less consumer friendly and less client centered as it has made their processes too complex for both case managers and families. This has created a large barrier for access to services.

Too many funding streams. Too many rules. Too much emphasis in micro-requests on documentation. Too much change/confusion.

Eligibility for Services



Single Portal Process

The method of obtaining developmental disabilities services in North Carolina is defined in state law authorizing the Single Portal of Entry/Exit process with which local Area Mental Health/Developmental Disabilities/ Substance Abuse Service Programs must comply. The intent of this statute is to create a single path of entry to developmental disability services to make it easier for individuals and families to get services and to assist public administrators in planning and allocating limited resources for services. The Division of DD-MH-SA is one of the few public human service entities in North Carolina to create a statewide, uniform means of applying for service and at this point it is limited to those seeking developmental disabilities services. A recent report by the North Carolina Institute of Medicine¹⁶ recommends that a single method of service entry should be adopted by all long term care services and that this process should be the same across all agencies. This would undoubtedly improve ease of access for people whose needs cannot be met by a single agency.

Prior to the passage of the Single Portal legislation, the process of gaining access to services was inconsistent and difficult for those in need. The mission of the Single Portal process is to make it much easier for families to access services by providing a single number and place to go. By using the Single Portal, people seeking services can theoretically navigate a complex system more readily and can avoid the frustrating task of calling service providers individually to find out about suitability and availability of their services. It also seeks to provide a process that is fair and objective for everyone and not biased toward those who are best educated or who are better advocates. Within the boundaries of the legislative language, Single Portal procedures vary from area program to area program based upon their local plan.

Responses from the Field

Respondents to the electronic surveys expressed some criticism and suggestions for improving the Single Portal Process. All respondents were asked to evaluate the Single Portal Process. Generally, the Directors favored the concept of the Single Portal system but had some concerns about the process. Most felt that the process is frustrating to both families and administrators. On the administrative side, they felt that the process is lengthy and cumbersome, and there are not enough funds to support the mandated responsibilities. On the consumer side, there are not enough resources to meet the needs that are identified during the process.

Providers' responses focused on the need for a more person-centered process. Their major concerns were that the process should be more inclusive of families and consumers, that coordinators should make families more aware of their options and be realistic with them, and that the process should be more consistent across area programs.

¹⁶ North Carolina Institute of Medicine. (2001). *A long-term care plan for North Carolina: Final Report*. Durham: The North Carolina Institute of Medicine

All respondents were asked to rate a series of statements about the Single Portal Process of entry to the system. Directors gave higher ratings than providers on all aspects of the process except one (“it provides a means to develop individual budgets”).

Response option:	Number (%) of Responses			
	Directors (n=25)		Providers (n=28)	
	<i>Always or Sometimes</i>	<i>Never</i>	<i>Always or Sometimes</i>	<i>Never</i>
It is an efficient means for determining eligibility	23 (92%)	2 (8%)	24 (86%)	4 (14%)
It results in a comprehensive picture of individual needs	25 (100%)	0	24 (89%)	3 (11%)
It provides area programs with the ability to conduct individualized planning	23 (92%)	2 (8%)	N/A	N/A
It maximizes the identification of the most appropriate provider	22 (88%)	3 (12%)	23 (82%)	5 (18%)
It is person-centered and responsive to individual and family preferences	24 (96%)	1 (4%)	24 (89%)	3 (11%)
It provides a means to determine individual budgets	14 (56%)	11 (44%)	21 (78%)	5 (19%)

Is the Single Portal Process Successful in its Mission?

Our exploration of this process indicates that it has partially achieved the goal of helping people to access needed resources in a more planful fashion but that its bureaucratic nature diminishes its responsiveness. Notably, many key informants expressed frustration that the process is “too lengthy and burdensome” and that the procedures are not consistently applied across Area Programs. Many also commented that the process should be more person-centered and inclusive of families. One vocational provider made the suggestion that supported employment funding should be pulled out of the CAP/DD waiver, since this category of service tends to be given last priority during the planning process

Further refinement of the process will be necessary to insure that it improves in accuracy of documenting needs and preferences and to ensure that it is inclusive and responsive to the state’s citizens who need disability support.

Areas for Improvement:

- 1) **Enforce requirement that entry to privately operated ICFs/MR must occur through the Single Portal Process.** Reports throughout the system indicate that operators of ICF/MR services often accept service candidates who have not applied through the Single Portal Process. This illegal entry to services strips the Area Program of the ability to make judicious use of all the resources in the region including the determination that ICF/MR level services are necessary for the individual. Moreover it prevents the Area Program from sharing information about other resources and services with these individuals and families because they are not “known” within the service network. Finally, it diminishes the Area Program ability to respond to ICF/MR residents in times of crisis or future need.
- 2) **Improve Access.** One purpose of Single Portal is to improve ease of access to services. Our findings indicate that Area Programs with fewer resources are not doing an adequate job of making the public aware of services. For example, one better endowed Area Program has a brochure about how to access services, a dedicated voice mail site for access and has posted the access number on its web site. Many areas do not have brochures or dedicated phone lines.

To assist the Area Programs with fewer resources the Division of DD-MH-SA should establish a toll free number where information would be available in several formats and languages to help callers connect with their Area Program if they are seeking DD services or to direct them to other suitable resources. This number should be disseminated widely through public service announcements, through a dedicated brochure and to public libraries, school personnel etc.

Another concern we found with access is the initial reliance on forms vs. telephone or other personal contact we noted in some Area Programs. In one program we visited, the Single Portal Coordinator's response to a third party referral (someone calling to refer someone else) was to send a form to the person referred. If the form was returned, then the Single Portal Coordinator would set up a meeting with the family. This process will undoubtedly exclude individuals who cannot read or write (a significant majority of people with developmental disabilities) as well as those with limited English proficiency and those who may otherwise be unable to complete a form. One response to this problem is to provide more initial personal contact to ensure that people with needs are identified. It is widely recognized throughout the county that patterns of discrimination in service delivery exist. Better outreach and support at the point of initial contact will help prevent such patterns. When forms are used, every effort should be made to ensure that these forms are as simple and user-friendly as possible.

- 3) **Ensure needs are accurately identified and follow through occurs.** The evaluation team found flaws with the accurate documentation of people's needs. In one disturbing example, a Single Portal Coordinator described the situation of someone whose circumstances had been reviewed in the single portal process on more than one occasion. She was a woman who had developmental disabilities and was living in a shelter with her children. This woman's need for affordable housing was not documented as an outcome of the Single Portal review activity. When the evaluation team probed this issue, the Single Portal Coordinator said that the housing need was rightfully the province of the public housing authority. She was unaware, however, of whether this woman appears on the public housing authority's waiting list.

The failure of the Single Portal process to identify this person's pressing need for housing is unacceptable. Further, it is not clear how a responsive administrative process could come to the conclusion that a person with a developmental disability and an urgent need for housing should be referred to another agency. Even if this were appropriate, the failure of the single portal process to assure that this individual received assistance from the public housing system is the ultimate in bureaucratic indifference.

It is possible that this type of bureaucratic indifference is emblematic of the failure of person-centered thinking and planning noted throughout many parts of the system. In North Carolina supports are rarely created in response to the circumstances of a particular person. Instead, the predominant approach is to attempt to fit people into existing programs and slots. In the current environment where “slots” are few due to limits on resources, the Single Portal process becomes an exercise in bureaucratic futility, unless there is a meaningful response to unique and urgent needs of individuals and a way of keeping track of patterns of need throughout the system. The failure to respond to urgent needs extends suffering, and the failure to accurately document such needs can lead to an inaccurate view of what resources are necessary throughout the system thereby skewing planning and budgeting efforts.

Such problems are likely to be improved by benchmarking exemplary and responsive Single Portal Processes found in the state and using these findings to improve the quality of less responsive Area Programs. One approach is to impose stronger guidelines for person-centered approaches to identifying needs, preferences and urgent situations on area programs (based on the exemplary program processes) and by instituting statewide training for Single Portal Coordinators in these processes.

- 4) ***Eliminate expectation that applicants should review their problem before the Single Portal Interagency Council.*** While the legislation does not require that applicants come before the Interagency Council to present their needs, this appears to be a prominent practice and, indeed, a tacit expectation in some Area Programs. The prospect of coming before a group of strangers to describe individual or family needs with those who have an official role in your “fate” seems like a very anxiety producing situation.
- 5) ***Periodic independent evaluation.*** Given the importance of this process, the Division of DD-MH-SA should institute periodic independent evaluations of the quality of single portal implementation throughout the state. Such an evaluation should include sampling the opinion of individuals who have recently used the Single Portal process, identifying best practices and disseminating these among area programs.

Medicaid Eligibility

In terms of the waiver there are two types of eligibility: 1.) Medicaid eligibility and, 2.) Level of Care (LOC). These two types of eligibility are linked, but typically, an individual first must meet eligibility for Medical Assistance under either existing State plan requirements or using the special, expanded eligibility requirements offered under the waiver.

Individuals may qualify for Medicaid by meeting three types of financial standards. The first is **categorical eligibility**, based on receiving public assistance. For individuals with developmental disabilities, this public assistance is usually in the form of Supplemental Security Income (SSI). This group also includes people with disabilities who receive Social Security payments (but not SSI), as long as these payments do not exceed the state’s public assistance standard. (This is typically the federal SSI grant standard plus the amount of a state supplement, if the state adds dollars to the federal SSI payment). Almost all states deem individuals receiving SSI payments categorically financially eligible for Medicaid services.

A state may also make Medicaid available to individuals who have low incomes but whose income exceeds the levels upon which categorical tests are applied. People eligible in this category are labeled “**medically needy**.” A state may extend Medicaid eligibility to such individuals in a variety of ways, including requiring that persons “spend-down” to the categorical eligibility level by paying for medical services or providing that individuals will qualify for Medicaid so long as their income does not exceed 100 percent of the federal poverty level. The current FPL is set at \$8,950 per year, or approximately \$745 per month.

The third option a state may choose is the “**special income standard.**” Under this option, the state offers Medicaid eligibility to institutionalized persons whose income does not exceed 300% of the federal SSI payment standard. Although a state can set a special income standard that is less than 300% of SSI, the maximum cannot exceed 300 percent. Under the so-called 300% rule, individuals whose income (from whatever sources) may be as high as \$1,593 per month may still qualify for Medicaid.

Using this special income standard, the state can make Medicaid available to people who receive benefits (or earn income) that exceeds the SSI standard. This is mainly used to allow individuals who are institutionalized and whose income level would otherwise disqualify them to be Medicaid-eligible, to be spared the instability of the spend-down requirement. In the case of institutionalized persons (i.e., nursing facility residents or individuals served in ICFs/MR), the state collects the income in excess of a specified “personal needs allowance.” For institutionalized persons, this allowance is usually an amount to cover personal items such as clothing. Income beyond this needs allowance is collected from the person to offset the cost of providing care. The collected funds are deducted from a facility’s claim for Medicaid payment. The requirement that this “excess income” be applied to reduce the claim for Medicaid payment is called “Post-Eligibility Treatment of Income” (PETI). PETI requirements apply to institutionalized persons who receive non-SSI benefits (principally Social Security payments) or have other sources of income that are over and above the personal needs allowance amount set by the state.¹⁷

A state also may elect to use a special income standard for Medicaid eligibility under an HCBS waiver, for individuals not eligible for SSI. Because waiver eligibility is linked to institutional eligibility, using this same standard makes a “level playing field” between institutional and waiver services. By allowing the use of the special income standard for HCBS waiver eligibility, the state removes the “institutional bias” otherwise inherent in Medicaid eligibility. The rules for PETI are a bit different, actually allowing states considerable flexibility in treating the excess income (up to the 300% of SSI).

New means to expand eligibility are available to states under Section 1902(r)(2) of the Social Security Act. These new regulations permit states to offer Medicaid benefits to individuals, who, based on their income, would not otherwise qualify. These new rules permit states to disregard certain types of income and resources that otherwise would count in determining financial eligibility for Medicaid. For example, under these new regulations, a state may choose to disregard earned income, or income used to purchase food or home repairs. There is considerable latitude as to the type and amount of income the state can choose to disregard. If the state elects to use these new income disregards, the regulations require application of these disregards to all individuals within an “eligibility group.” In terms of the HCBS waivers, this means the state cannot just apply the new rules to waiver recipients only, but would have to apply them to all members of the recognized eligibility groups such as SSI recipients whose income exceeds the substantial gainful employment limit of \$700 per month.

These options for expanded eligibility are of great benefit to individuals who achieve Medicaid eligibility through the spend-down option. Frequently individuals whose income only slightly exceeds the allowable limits find themselves in situations where they go on and off Medicaid, creating bookkeeping and financial nightmares for themselves and those providing them medical or other Medicaid-funded care and support. In some instances, the amount to which the person must spend-down is so low that very little income is left for living expenses. These new expanded income limits are also an incentive for individuals who are not SSI-eligible, to work. Earned income for non-SSI eligible individuals can be protected, thus allowing individuals to keep more the money they work for. See Appendix for a complete explanation of 1902(r)(2) including all the eligibility groups.

¹⁷ Individuals on SSI who earn income have their earning reduced through the SSI program. Individuals who are SSI-eligible can earn up to \$700 per month but a portion of their SSI benefit is reduced. This acts as an incentive for SSI recipients to work as they do not lose Medicaid eligibility and can keep some of their earnings.

Medicaid also permits states to exclude the income of a spouse or the parents of a minor child when assessing Medicaid eligibility for institutional care or services under a HCBS waiver. This is called “deeming”, whereby the state either chooses to disregard (deem) the income of a parent or spouse, looking *only* at the income of the individual seeking services in assessing financial eligibility. This option is permissible under both the HCBS waiver and the State plan. With regard to children, states can elect to use the TEFRA 134 Option (a.k.a., the Katie Beckett Option) to open up Medicaid eligibility to children whose family incomes would otherwise be too high. TEFRA allows the state to disregard family’s income if the child would face institutional placement without the services available under “regular” Medicaid, and only look at the child’s, not the family’s, income. If the state chooses to offer this option, all children who meet the eligibility criteria (at risk of institutional placement, including hospitals, without access to Medicaid) have access to a Medicaid card. The State cannot set a limit on the number of children served, but must make the option open to all who qualify.

Some states created HCBS waiver programs just so that otherwise ineligible children can gain access to Medicaid services. Using this option states can limit the number of children served by setting caps on the number of individuals served through the waiver. These caps make policymakers more comfortable in expanding Medicaid eligibility to this otherwise ineligible group under the waiver, rather than using the “open-ended” TEFRA option.

NC Approach to Medicaid Eligibility under CAP

North Carolina is a SSI Criteria state. This means that individuals who qualify for Supplemental Security Income (SSI) are automatically eligible for Medicaid. In addition to these individuals, North Carolina also makes Medicaid available to individuals who are aged and/or disabled who have incomes that do not exceed 100% of the Federal Poverty Level, under the “medically needy” option.

North Carolina allows individuals with incomes that exceed the 100% of the FPL to “spend-down” their income on necessary medical and remedial services to become eligible. For waiver eligible individuals, the person must incur medical and remedial expenses that reduce their countable income (for eligibility purposes) to approximately \$715 per month. North Carolina “protects” this remaining income for waiver participants, under a provision called the maintenance allowance. This is an amount set aside for the person to use for their own expenses such as room, board and personal items.

While the spend-down provision help individuals with higher incomes and substantial out-of-pocket medical expenses to become eligible for Medicaid, it has serious drawbacks for persons needing long-term supports. As noted in the CAP MR-DD Manual, Section 5, page 5-4,

While a person is meeting a deductible, the individual is not covered by Medicaid and will not have a Medicaid ID card. Medicaid will not pay for services while the person is in a deductible status.

This means that individuals may periodically lose their Medicaid eligibility and thus lose their waiver services as well. For individuals needing intensive supports, this loss of eligibility could mean the loss of their community placement, day programs or job. The unstable nature of spend-down eligibility is typically very problematic to individuals needing long-term supports. *Thus other options such as the 300% rule or the provisions of 1902(r)(2) offer a more stable platform for Medicaid eligibility.*

Use of the alternative rules also may prove easier for providers. In a move to expand what are allowable deductible expenses under the spend-down requirements, the state permits the cost of services to count toward the deductible amount. In effect, this expands the array of expenses that count toward spend-down. Unfortunately, keeping track of when the deductible is met, making sure that providers don’t claim for these

days, and that they collect the funds from the client can become very tedious. Also, depending on the frequency and intensity of supports, the days a person is ineligible for Medicaid can vary month to month. Using other expanded eligibility options, the person is eligible for Medicaid every day of every month. The provider only has to collect the “excess income”, the amount that is above a set maintenance allowance. The provider’s claim is then offset by the amount collected.

Some states (such as Alaska) actually set the “maintenance amount” at the 300% level, thus they make no collection of excess income. Other states are more restrictive, collecting all income over the SSI Federal Benefit Level, while others collect everything except a small personal needs allowance. North Carolina permits individuals to keep up to the FPL, \$8,590 per year, which puts them in about the middle in terms of how much income states permit individuals to keep.

How high or low states choose to set the maintenance amount affects individuals’ incentives to work. As a means to address this type of potential work disincentive, some states (Colorado and Maryland) now exclude earned income (up to a total income of 300% SSI) as an added incentive to keep individuals employed. These states do not exempt *unearned* income (such as pension benefits or other unearned resources), thus they do collect unearned income that exceeds their established maintenance amount. See the Appendix for a paper written by Gary Smith that may be of help in understanding the interplay of work disincentives and the HCBS waivers.

While choosing the FPL standard for waiver recipients aligns with the North Carolina financial eligibility standard for all optional groups under the State plan, this is a narrower standard than adopted by some states, particularly for individuals enrolled in the HCBS waivers. The FPL is set at \$8,950 per year, while the 300% rule permits income up to \$19,116 per year before losing Medicaid eligibility. States may also choose an income standard that is lower than the 300%, but greater than just SSI.

States also have the option of using the new expanded eligibility criteria established under 1092(r)(2) of the Social Security Act. While these provisions are not specific to waiver recipients, they offer states flexibility in establishing financial eligibility requirements that allow individuals with higher income to retain Medicaid eligibility.¹⁸

It is important to remember that North Carolina could expand Medicaid eligibility and still assure that individuals with income above the FPL contribute to the cost of their care, offsetting a portion of the impact of expanded eligibility cost by applying the PETI rules.¹⁹

Because most individuals with developmental disabilities qualify for SSI, only a small number of individuals with developmental disabilities become eligible for Medicaid through the other options. While the inclusion of individuals with higher income levels expands eligibility for Medicaid, this inclusion would lessen the disincentive for individuals who are not SSI eligible to work. Given that this may only be a small number of individuals, it may not be too substantial in fiscal impact. Adopting these provisions also levels the field between SSI eligible and non-SSI eligible individuals for retaining Medicaid eligibility while working.

Expanding eligibility to either 300% of SSI, or using the 1902(r)(2) provisions, permits individuals who have higher income to access Medicaid without the problems associated with spend-down. Using the higher income standard levels the playing field between SSI recipients and non-SSI recipients. SSI recipients are permitted to earn additional income (up to \$700 per month) and still retain their Medicaid eligibility. For persons who do not qualify for SSI, using the FPL standard may be a disincentive to earning income. The

¹⁸ Some excellent resources on Medicaid eligibility options for working individuals can be found at: <http://www.disabilities.aphsa.org/> and <http://www.hcfa.gov/Medicaid/twwia/eligible.htm>

¹⁹ For a complete discussion of the interaction of work and Medicaid eligibility, please see Appendix, Smith, Gary, “*Disincentives for Employment and HCBS Waiver Participants with Developmental Disabilities: Eligibility Issues*”, NASDDDS, Inc., 2001.

complexity of tracking spend-down requirements and the fear of losing Medicaid benefits is a disincentive to employment.

Although North Carolina does not offer the TEFRA option under the State plan, the state does use the parental deeming option available under the HCBS waiver regulations. Thus children at risk of institutional placement whose family income exceeds the 100% FPL are eligible for Medicaid and for the waiver. This permits families that otherwise might face institutionalization of their children due to lack of medical or health services, or lack of other insurance coverage, to get Medicaid card and waiver services for their children. This has been of major importance to the families of children with disabilities, as the state does not offer other options for these children to qualify for Medicaid.

Recommendation

DMA and DMH/DD/SAS should consider expanding financial eligibility so that people who are not eligible for SSI can engage in employment and retain Medicaid eligibility on a more stable basis than under the spend-down requirements. This would include reviewing the options under the HCBS waiver as well as those available under 1902(r)(2).

“ Before we got on CAP we had to reduce our family income so we could qualify for Medicaid because our insurance didn’t cover my daughter...”

Parent

A second suggestion is to study the impact of raising the maintenance allowance, permitting individuals to keep more of their earned income. This should be reviewed in light of housing costs that the state may already subsidize. If individuals kept more of their income, they could potentially cover more of their housing costs.

Level of Care Eligibility

In order to qualify for the HCBS waiver, individuals must not only meet Medicaid eligibility, but must also qualify for institutional care in the absence of waiver services. This is known as meeting the level of care (LOC) needed to qualify someone for an institutional setting. In the case of CAP MR/DD, this means the person, in the absence of waiver services, would need and qualify for care in an ICF-MR.

HCBS regulations require that the LOC process for HCBS eligibility be either identical to or comparable to the process used for setting institutional LOC. While many states use an identical process, more and more states use streamlined LOC processes for determining waiver eligibility. These states found the ICF-MR LOC process cumbersome and more suited to the regulations and resources (physicians, psychologists and nurses) in institutional settings. Some states use a one or two page form (Oregon), typically filled out by a case manager. Other states use a comprehensive assessment at the initial LOC of care determination, and a simplified update in subsequent years (Wisconsin and Indiana). In these states, supporting documentation provides evidence of a developmental disability (such as already existing medical or school records) is permissible, as long as it is reasonably current.

Some states streamline the process even further, using a functional screen validated against the institutional process used for establishing ICF-MR eligibility. Kansas uses the Developmental Disabilities Profile (DDP), a functional screen developed by the state of New York originally used for establishing payment rates relative to functional status. Other states (South Dakota, Utah and Wyoming) use the Inventory of Client and Agency Planning (ICAP) that establishes a score indicating functional status. Maryland, Missouri, Nebraska and Ohio use variations on a functional screen derived from a tool developed by New Jersey.

These states decouple the LOC eligibility process from the in-depth assessment of the individual needed for person-centered planning. They make eligibility screening simple, focusing time and attention on the support planning process rather than the eligibility process. Two states (Ohio and Indiana) currently are in the

process of validating a functional screen (the DDP) against their existing process. Once the validation study is complete that establishes the range of scores that match the waiver eligible population (established using their current process), these states will use a functional screen for LOC eligibility.

Presently North Carolina requires completion of both the MR-2 (a form that requires a physician signature) and the NC-SNAP, a functional screen for determination of LOC. The MR-2 is identical to the process used for ICFs-MR and thus meets the federal requirement for comparability. This form is sent to Electronic Data Systems (EDS) for review and approval. The form must be sent in and approved within tight timeframes in order to remain valid. For example, the case manager must request EDS approval within 30 days of the physician signature or the form becomes invalid and must be signed again.

This tight timeframe seems unrealistic and may not really be necessary for persons with developmental disabilities. Developmental disabilities are typically fairly stable conditions, unlike medical conditions that can change rapidly and thus affect the level of care. The underlying condition, such as mental retardation, cerebral palsy or autism typically does not change radically in a short timeframe. Many states permit a longer timeline for the LOC validity, such as 90 days. This also comports with the regulations for Medicaid eligibility, that allow retroactive Medicaid eligibility up to 90 days prior to the date of application as long as all conditions of eligibility are met once billing is incurred for services.

Recommendation

If DMH/DD/SAS plans to continue using the MR-2, even for the near future, they should lengthen the timeframe in which the initial LOC form remains valid, given the stability of LOC in persons with developmental disabilities.

The present LOC determination process is cumbersome and time consuming. The MR-2 requires the person's physician to indicate habilitation goals. To be frank, it is unlikely that most community physicians would have a clear understanding of habilitation goals for persons with developmental disabilities. While these physicians can of course make a diagnosis and recommend medical treatment, they are not trained in supporting individuals with developmental disabilities in the community. Thus, the inclusion of these goals represents an institutional model and does not reflect the reality of community medical practitioners. To add to a physician's possible discomfort in filling out the form, the time taken to do this form is not Medicaid reimbursable according to the Manual (section 8.2.4.a, Medical Evaluation).

The form also includes certain medical information such as height, weight and bowel and bladder function, yet does not offer any in-depth medical information other than "diagnostic procedures". The form clearly is suited to an institutional setting where other records and access to medical information is readily available. It may make sense for individuals already institutionalized to use this form as the basis as the basis for their eligibility as it already exists in their records. For persons residing in the community, it may make sense to go to a simpler screening process for the establishment of LOC eligibility. If medical information is needed regarding the individual, this should be obtained from individual records or in-depth assessments if indicated by the person's needs.

Some states that use a functional screen recognize the limitations of these screens. They may not appropriately assess individuals with mental health problems. One state planning to use a functional screen requires additional supporting documentation on individuals who are dual-diagnosed. This is added assurance that these individuals do have developmental disabilities and meet the LOC. Given that the NC-SNAP is already required and is under extensive study to assure its validity, MH/MR/DD may want to consider moving to the use of the NC-SNAP, without requiring the MR-2. Because functional screens may not accurately assess individuals with dual diagnoses (mental health and developmental disabilities), some states require more supporting documentation for individuals with dual diagnosis to assure that the functional limitations are due to a developmental disability and not a function of mental health problems.

Recommendation: *MH/MR/DD should replace the MR-2 with the NC-SNAP. The state already utilizes the NC-SNAP, and requires that its completions for all recipients both initially and annually. The state should complete a validation study against the present LOC process to establish the scoring range for LOC eligibility. For individuals with dual diagnoses, MH/MR/DD should require supporting documentation regarding the developmental disability.*

As noted earlier, EDS reviews and approves all MR-2 forms. This type of external review follows the “utilization review” model used in institutional settings. It serves as a “check and balance” making sure that the case managers screen in appropriate individuals. At the waiver’s inception, this type of external review served the function of checking that only the eligible target group was screened in. State staff report that in the past, there were many denials of LOC eligibility from EDS. Most of these were persons with developmental disabilities, such as autism, who upon either secondary review or Fair Hearing were found to meet the LOC requirements.

It is worth reviewing EDS records to determine how many individuals are actually denied LOC eligibility truly due to not meeting the LOC requirements.²⁰ If this review indicates a low number of denials, it may indicate that the case managers are now experienced in who are appropriate candidates for the waiver. Reviewing the role of EDS in LOC determinations may be even more worthwhile if this activity entails significant expense. Again, if the denials are minimal, it may make programmatic and fiscal sense to check the LOC as a routine part of the plan approval. To assure proper compliance with the LOC requirements, the Medicaid agency or its designee could do sample oversight or monitoring. In many states, the state developmental disabilities authority (SDDA) approves the LOC and the Single State Medicaid Agency (SSMA) does a sample review to assure LOC guidelines are followed. This is often less costly, labor intensive and time consuming than using an external review such as EDS.

Recommendation: *Now that CAP MR/DD is a mature program in operation since 1983, the EDS external review may no longer be required. Regardless of what form used for LOC determinations, MH/MR/DD should evaluate the need for EDS review to determine if this adds value to the LOC determination process.*

Aside from the procedural concerns raised regarding LOC, concerns surfaced regarding interpretations of what eligibility for an ICF-MR LOC really entails. Some state personnel feel that that DMA (through it’s contractor EDS) utilizes too narrow a definition of who meets the ICF-MR level of care. As noted earlier, the state must use a LOC process that is either identical to or comparable to the ICF-MR LOC determination process used in institutional settings. This poses some problems. The heart of the problem is that the people admitted to ICFs-MR today (those meeting the current ICF-MR eligibility test) are quite different from individuals admitted to ICFs-MR in 1981, when the HCBS waivers came into being. Today, individuals are not even considered for institutional placement that in the past routinely lived in institutional settings. This is not due to failure to meet the ICF-MR LOC, but because states now have community-based supports and services that meet people’s needs. The very fact of operating an HCBS waiver changes whom we see as “appropriate” for ICF-MR placement. Many states no longer see ICFs-MR as viable for anyone. Eleven states closed all their state-operated ICFs-MR; sixteen more reduced the populations of their large facilities 50% over from 1990-2000.²¹

The University of Minnesota annual study on residential services notes that, “The proportion of MR/DD facility populations made up of the most severe cognitive impairments continues to grow.” Their findings indicate that in 1982, 56.2 % of residents of state facilities had profound mental retardation, while in as of June 30, 2000, 62.2% of residents were classified as having profound mental retardation. This holds true for other functional impairments. In 1977, 35.1% of facility residents had 2 or more functional impairments. In 2000,

²⁰ N.B. This review should not include those individuals denied LOC eligibility initially due to documentation or other procedural issues, who later were deemed eligible. The review should focus on only those who actually did not meet the LOC requirements.

²¹ Robert Prouty, Gary Smith and K. Charlie Lakin (eds.), “Residential Services for Persons with Developmental Disabilities: Status and Trends through 2000”, Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, June 2001, pp. iii-iv.

60% of residents had two or more functional impairments.²² These trends confound the process of determining ICF-MR eligibility. When reviewers compare those entering ICFs-MR today with the populations seeking waiver services, it can appear that individuals seeking community services do not meet the ICF-MR LOC. But if we apply the LOC test based on the standards in use at the inception of the waivers, these individuals *do* meet the LOC.

CMS is aware of this problem. In a March 6, 1997 Medicaid Letter, Dennis Gallagher, then HCFA Region III Chief of the Medicaid Operations Branch writes, "...the profile of individuals receiving home and community-based care may differ from those served in institutions. However, it would be a mistake to conclude that certain high-functioning individuals would not require ICF/MR services merely because their functional abilities exceed the levels ordinarily seen in ICFs/MR nowadays."²³ Thus CMS officials clearly recognize the disjunction between individuals currently placed in ICFs-MR and those seeking home and community-based services. Taking too narrow an interpretation of ICF-MR LOC criteria has significant fiscal impact. Individuals who actually could meet the LOC end up served using state funds only.

Recommendation: *DMA should carefully review waiver LOC criteria in light of the fiscal impact of serving individuals with purely state dollars when the state could claim FFP. This review must occur in the context that individuals currently placed and entering ICFs/MR may look significantly different from some individuals seeking waiver services.*

²² Ibid, pp. v-vi.

²³ Medicaid Letter Number: 97-10, "Subject: Guidelines Regarding What Constitutes an ICF/MR Level of Care Under a Home and Community-Based Services Waiver", March 6, 1997, Department of Health and Human Services, Region III, Health Care Financing Administration.

Service Configuration



Introduction

There is a disproportionate concentration of financial and human resources in the state operated Mental Retardation Centers and in the ICFs/MR in the community. The MR Centers are reported to have greater expertise in supporting individuals with severe problems. Indeed people with the most intense behavioral and/or medical challenges are supported in the MRCs in large part because the centers are the only places in the system that receive funding to provide intense supports or supervision. People cannot be discharged from state centers as they can be from the community if adequate supports are not available.

Policies determining how services are funded and configured through the area programs have a negative impact on the community's capacity to provide needed supports to people. Specifically, the absence of a system to fund and develop transportation, medical services, vocational and leisure opportunities militates against the community capacity to support people, even if additional waiver or non/ICF/MR living situations are created. Further, the area programs interviewed and reviewed do not appear to engage in a system wide planning process that facilitates planning so that people can be supported in the community. People going through the single portal are placed in available slots rather than experiencing a more person-centered plan resulting in. *Supports are not created to meet people's wants and needs.* There are caps and limits to funding in the community that do not apply to state MR Centers and community ICFs/MR, further impacting the community's ability to support people successfully.

Overview - State Operated ICFs/MR

The HSRI evaluation team visited the MR Centers over a period of four days. Common themes emerged from the visits to each center and although each center certainly had unique strengths and challenges this report will focus on the these themes framed within the context of their overarching definition of their mission and purpose.

Perception and Defined Mission:

- Provides a safe and healthful environment to individuals with severe medical and/or behavioral challenges.
- Provide technical expertise provided to the community, individuals and agencies.
- Provide individuals with choice and positive personal outcomes through person centered planning.

People Served and The Environment

The MRCs serve individuals experiencing a wide spectrum of disabilities. While some individuals could be defined as medically fragile, most observed both on-site and through facility reporting appear medically stable, and, with access to appropriate health care, could certainly be served in the community.

Medical services are available in the MRCs through a staff of physician and nurses. People have access to medical services at a higher rate than in the community since capacity outside of the MRCs has not been developed. However many people receive medical and therapeutic services that they probably don't need, given the structure of services and planning at the MRCs and North Carolina's interpretation of the ICF/MR certification requirements.

The MRCs do not provide an environment that is pleasant, or homelike in any way. Each MRC labels its buildings as neighborhoods, homes, cottages, etc., but the buildings are dreary and feel nothing like a home. (At O'Berry Center there has been some attempt to make the kitchens and dining areas more pleasant with individuals living there participating somewhat in food preparation and shopping.). There are few signs of individual choice other than a few posters and photographs at people's bedsides.

The bathrooms and bathing facilities in the MRC'S are cold and unpleasant, and staff reported that some people are bathed by being hosed down on slab tubs. Though the team did not observe such baths, staff reported that bathing in these tubs is extremely unpleasant.

Significant resources have been expended in certain program and therapy areas, designed to stimulate or relax individuals, expensive therapy equipment and well-appointed administration and medical areas.

Recommendations

- 1)** Through a viable person centered planning process (see Chapter 2) identify resources necessary to support individuals in the community and develop environments and supports necessary to facilitate the transition.
- 2)** Allocate capital resources for physical plant improvement to provide habitable and humane living environments (i.e., bathing, personal bedrooms and privacy)
- 3)** Divert resources for major renovations other than those mentioned above to the development of capacity in the community.
- 4)** Provide a more seamless sharing of services between the community and institution, with specific attention to medical care, transportation, workshops and other work and recreational opportunities, in order to facilitate people's opportunity to move into the community.

Individualized Planning Process and Outcomes and Day Programs

Staff at each MRC report that their planning process is person centered. This would mean that people are provided with an opportunity to make choices about how they spend their time, work, leisure, living situations etc. The 199w Comprehensive Plan for Services and Supports states that the system will recognize the uniqueness of each person and the right to person and family centered supports. "The life that the person wants is the outcome, not the plan." (DD Planning Document, 2001). The system in place in the MRCs, at least as evidenced by the plans reviewed by the review team, does not provide choice or individualization of services and outcomes.

Revised and streamlined planning processes will not make a significant difference to people at the Centers of in the community if there is not a significant change in services available. There is a need to balance resources utilized to train staff appropriately in more person focused planning processes with the need to assure that once people's needs and wants are identified there are resources and needed flexibility and creativity to begin to provide people with supports that more closely resemble what they want. This should not require additional resources just a reallocation of existing resources.

There is a template for an individual plan for all MRCs. Some utilize another person centered planning format such as essential lifestyles planning but plans developed still don't have personal outcomes that address what the person wants.

Analysis

People for the most part do not have choice about where they live, what they eat, or where they spend their time. Throughout the system the lack of transportation, workshop and work and leisure activities, and the configuration of the centers themselves do not allow for choice. Based on the HSRI team review, even when preferences are identified through the planning process the plans developed focus on isolated skill development areas. Further, those most directly involved with the person, the person themselves, family members, direct support staff, case management staff have limited ability to reallocate resources to provide people with what they want, so instead they are provided with programs and services that already exist. As a result:

- People from institutions rarely work in the community and are not exposed to opportunities that might be created or are already available. Neither the MRCs nor the area agencies appear to be planning for long term residential or vocational needs for people living in the MRCs.
- Staff responsible for planning often use forms and processes from various person centered planning curricula, but do not have experience in developing alternative services and supports for people. The plans that are developed for people are not person centered, meaning that they do not focus on what people want, or provide them with exposure to determine what they want. They focus on deficits and problems, not road maps for a better future life. (See example at right).
- There is an over-reliance on assessments from a range of traditional allied health disciplines, i.e. speech therapy, physical therapy, occupational therapy etc.
- Living situations do not provide even the most limited opportunities for choice and participation, such as choice of food, activities and work. (O'Berry Center does allow people to shop for and help prepare and choose food in their living units.)

Example of Individual Plan

What's important to me?

Living close to my family
A day placement doing home living skills such as cooking
Going on more home visits or receive more visits from my family
Cooking special meals
Going on trips

Goals worked on (sample)

Choosing work activities
Pet Therapy
Wash chest
Get housecoat
Once a month activities off campus
Fill 4 glasses with ice
Put on pillowcases

What's Left Out?

Development of alternative living situation close to family
Increasing visits with family
More opportunities to go into the community

Western Carolina Center

- Families and significant others are not meaningfully involved in the planning process. In some cases meetings are rescheduled to include family but in many the meetings are simply held at staff convenience.
- The format and structure of meetings or planning documents or plans themselves are not modified to better allow the person and/or family to understand them.

State surveyors appear satisfied with content of plans reflecting inconsistency with CMA's stated requirement for person centered planning. However, there are significant deficiencies related to outcomes and client rights and protection.

Day Programs and Work

While some people observed were engaged in activities or at workshops few appeared to be meaningfully engaged or interested. The workshops on the grounds of the MRCs are not available for use by community members. (Sometimes the absence of community work prevents people from leaving the institution)

The Bureau of Vocational Rehabilitation does not provide follow along services to people from the MRCs or the community once they are placed in a job. They also only place the most able people and do not assist with transportation.

Recommendations

- Realign organizational systems at MRCs so that planning can respond to individual needs and wants. Reallocate extensive resources expended on medical and therapeutic services.
- Revise planning systems, reduce paperwork, increase focus on analyzing and providing what people say they want, while assuring that health and safety needs are met.
- Increase flexibility of funding and creation of services and supports in order to begin to develop more of what people want.
- Reassess those aspects of the environment in which people could have choices that would increase their quality of life, choice of food, food preparation and other household activities, participation in community activities, personal shopping and decorating.
- Develop plans that are useful to staff and provide user-friendly information about how people want to spend their time.
- Provide needed transportation and resources so that people can engage in the community.
- Develop seamless flow of services between institutions and the community until greater community capacity is developed.

Regulatory and Survey Compliance

A review of ICF/MR deficiency reports indicates serious and repeated problems with services at the MRCs as evidenced by a review of the surveys conducted by the Division of Facilities and Licensure and Certification. One state operated facility had a survey with no deficiencies cited; however the other facilities had significant repeated deficiencies.

This summary of recent certification surveys is based on the following HSRI team activities

- All state-operated Mental Retardation Centers were visited by the review team.
- Administrative, direct support, case management and other supervisory and front line staff were interviewed.
- Individuals were observed in living units and work situations.
- Sampling of individual plans reviewed on site and after visits to facilities.
- Interviews – Division of Facility Services Mental Health Licensure and Certification Section
- Deficiency reports²⁴ were reviewed (see below)
- These findings are included in order to indicate that capacity issues regarding the needs of people with serious disabilities are not limited to the community system in North Carolina.
- **O’Berry Center**
Surveys reviewed:
August 4, 1999
August 10, 2000
Summary: The major patterns of deficiencies were in areas of program implementation. There did not seem to be a serious and systemic pattern of deficiencies.
Black Mountain Center
Surveys reviewed –
September 30, 1999
September 13, 2000
Summary – During the 1999 survey three deficiency areas were noted, protection of client rights, individual program plan and program implementation. During the 2000 survey no deficiencies were noted.
Caswell Center
Certification surveys reviewed:
March 4, 1999
March 8, 2000
April 20, 2000
September 14, 2000
January 30, 2001
Summary: Caswell Center had the most serious deficiencies noted. During two consecutive years individual clients died as a result of staff inability to assure their safety. The Condition of Participation related to client protections was cited during surveys held on March 8, 2000 and again during the death review on January 30, 2001. (Last survey report provided)
Examples: (Condition of Participation deficiencies – 2000 – Quotes from surveyors:)
Client Protections:
“The facility failed: to ensure that a client was provided adequate program structure, competent supervision and effective active treatment strategies to ensure client safety and to create a structure that prevented neglect.”
“The cumulative effect of these systemic practices resulted in the facility’s failure to provide statutorily mandated client protections”
“Based on record review and interviews, the facility failed to ensure that a clientreceived (A) competent supervision (B) appropriate program structure and (C) effective active treatment strategies to address well-documented behavioral problems that constituted a serious and immediate threat to that client’s health. As a consequence, client...died.
There are then detailed examples of how this client increased his problem behaviors and how staff was unable to adequately supervise him.
(Condition of Participation Deficiencies – 2001 - Quotes from surveyors:)

²⁴ ICF/MR Survey Information was secured from Jeff Horton, Division of Facility Services Mental Health Licensure and Certification Section

Client Protections:

"The facility failed to create a structure that prevented neglect. The cumulative effect of this practice resulted in the facility's failure to provide statutorily mandated client protections.

Summary – During traffic accident an individual in a wheelchair was incorrectly secured in the van, which resulted in her death. The staff members did not secure wheelchairs in the manner described in a diagram provided, although staff had received training. When vans were inspected – six out of six vans did not have proper restraint
We have no information on follow up surveys after April 2001.

Murdoch Center:

Surveys reviewed:

April 28, 1999

April 28, 2000

March 7, 2001

Example:

"The facility must ensure that all allegations of mistreatment, neglect or abuse, as well as injuries of unknown source, are reported immediately to the administrator or to other officials in accordance with state law through established procedures." (Tag # W. 153)

1999 – 7 out of 14 cottages failed to report and follow through on allegations of neglect and abuse

2000 – 5 out of 13 cottages had significant incidences of late reporting, "**The evidence of pervasive, systemic late reporting was evident in 5 cottages...**"

2001 – Condition level citation cited due to failure to insure adequate policies related to reporting abuse and neglect, providing adequate supervision and specifically "Two distinct deficient practices were identified: failure to report allegations as required by state law, and failure to report allegations to the facility administrator or designee.

Summary – There are patterns of increasing serious deficiencies from 1999 to 2001. Problems noted all 3 years with the Condition of Participation involving client protections. Problems appeared to grow worse each year particularly in setting up structures to adequately report allegations of neglect and abuse. Surveyors noted continued patterns of failure to provide adequate supervision and to develop policies and implementation strategies to prohibit neglect of clients and to assure adequate reporting of incidents of neglect and abuse. Other areas of deficiencies include staff training and program implementation.

Western Carolina Center:

Surveys reviewed:

October 29, 1999

October 6, 2000

Summary – There were repeat standard level deficiencies in the areas of client protections and management of inappropriate behavior. Of particular concern were patterns of deficiencies related to failure to respect individual privacy: Other deficiencies in areas of program implementation and plan development.

Specific compliance areas:

Protection of client rights, example – Person can't carry money even if they want to and no rationale given.

Protection of client rights: "While observed nurse walked into a person's room while he was on the toilet with the door open and she gave him the medicine while he was on the toilet going to the bathroom." (This occurred on more than one occasion) (W. 130 – "The facility must ensure the rights of all clients. Therefore, the facility must ensure privacy during treatment and care of personal needs.")

"Privacy screens were not available for client use."

"Management of inappropriate behavior – "Use of arm pads, jump suits etc. as prevention and/or restraints rather than as directed in plan"

The above represent the most serious deficiencies cited, but, with the exception of one MRC, there was a pattern of deficiencies and problems throughout in the remaining four state operated MR Centers.

Community ICFs/MR

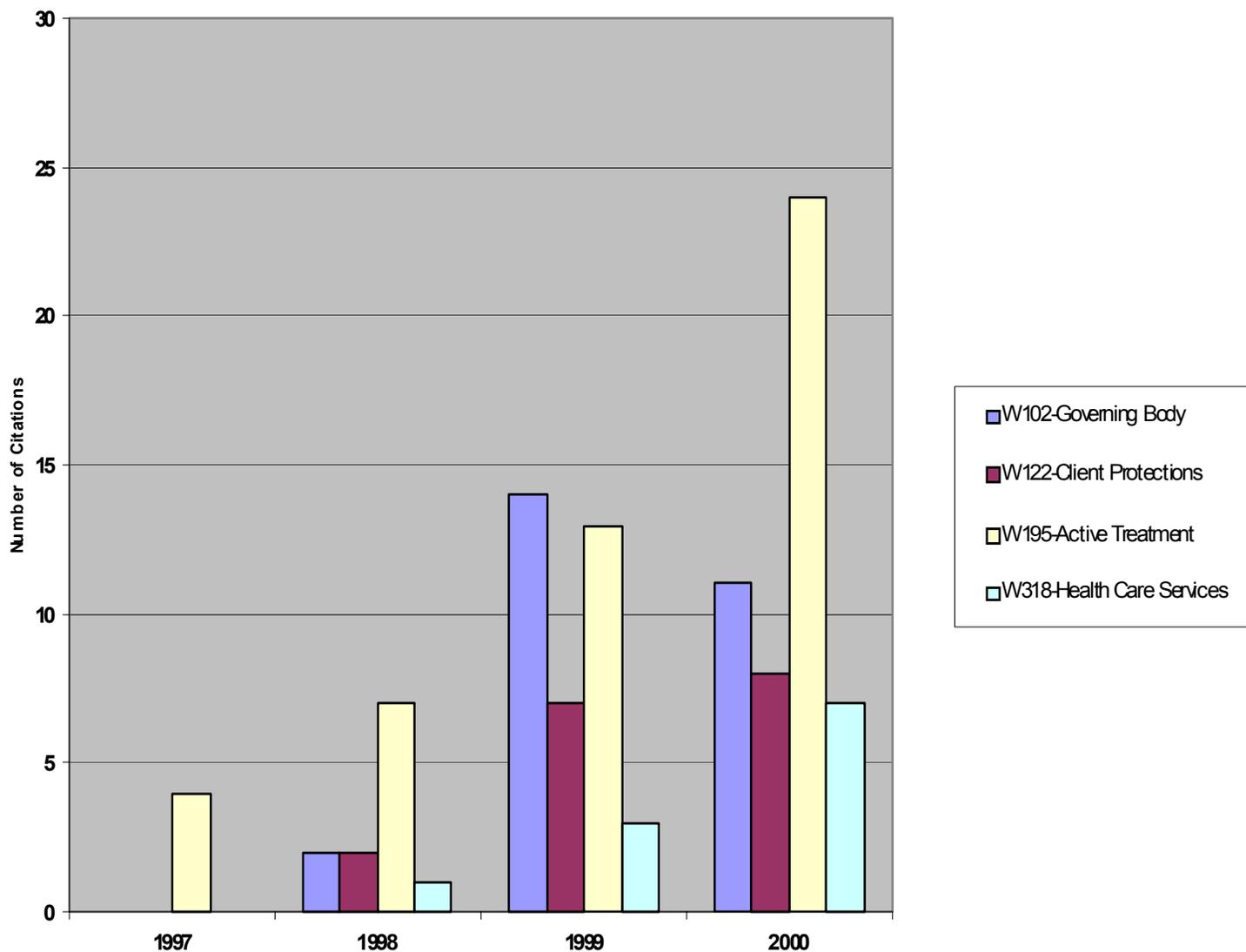
The community ICFs/MR visited on this review included a large residential program for children, several 6 and 8 bed ICFs/MR throughout the state operated by private providers, and an ICF/MR program serving people with autism. Of the 5000 people in North Carolina served in the ICF/MR program about half live in private ICFs/MR – both large and small.

They are surveyed under the same set of regulations as the state centers, but they are also licensed.

Since October 1, 2000 the private ICFs/MR can be fined because they are licensed. They are fined if there is a death or serious injury (except if the death is from natural causes.) A type B violation occurs if a condition of participation deficiency is not corrected at the time of the follow up survey. There have been several facilities fined and one facility closed since this procedure was implemented. The Division of Facilities and Licensure reports that there are more major deficiencies in the community ICFs/MR than in the state operated centers.

The total number of private ICFs/MR surveyed each year is 327. From January 2000 through August 2001, 34 facilities were cited under the Client Protections Condition of Participation (Tag# W122) and 37 facilities were cited for the Active Treatment Condition of Participation (Tag# W195). A total of 9 private ICFs/MR were cited for both conditions. During this same period, two MR Centers were cited for Client Protections and no state ICFs/MR were cited for Active Treatment.

According to staff at the Division of Facility Services, condition level citations are increasing in areas of client protections and active treatment overall among private and public ICFs/MR. The following chart is from a presentation made by the Director of the Division in May 2001.



ICF/MR Program: Condition Level Citations

It should, of course, be noted that there are significant funding and resource disparities between the funding available to private ICFs/MR and the state Mental Retardation Facilities (which receive higher reimbursement rates).

In one case reviewed, a facility was decertified and most of the people moved to the state operated center. There was no opportunity to reallocate those dollars to alternative, community living situations. Thus the assumption that institution was the only safe haven persisted since there was no opportunity to craft supports for the dislocated individuals in the community nor had the capacity been developed to make that possible.

In most cases the types of problems identified in person centered planning earlier in this report apply to the community ICFs/MR observed by the expert team. Plans still focus primarily on basic needs rather than on ways and means to expand the individual's ability to influence his or her own life.

Often people living in the community ICFs/MR are individuals who could receive fewer supports and live in a more flexible community alternative if such alternatives were available. The absence of viable work, transportation and leisure options is a critical barrier so people remain living in rigid, expensive programs.

When interviewed, the QMRP overseeing supports at four privately operated ICFs/MR had no experience or exposure to the concepts of person centered supports. When asked about training she indicated that the director of staff development did CPR, OSHA and each consumer is discussed over a three-day orientation. No training on self-determination or person centered planning. The area agency had provided some training on behavior management.

The large ICF/MR visited served primarily children. It is based on a medical model and few children attend school in the community.

Adult Care Homes

Approach

The scope of this evaluation included an examination of the situations of people living in nursing homes (skilled nursing facilities) and rest homes or “Adult Care Homes” as board and care homes are called in North Carolina. Based on interviews with key informants, reviews of pertinent long term care data available from the PASSAR²⁵ data base there are 161 people with developmental disabilities currently living in skilled nursing facilities and visits to individuals living in Skilled Nursing Facilities, the evaluation team determined that inappropriate utilization and over-utilization of Skilled Nursing Facilities (SNF) was not a concern in the North Carolina system.

The presence of people with developmental disabilities in nursing homes appears to be restricted to people who are older and who clearly need skilled nursing care. According to automated data available through PASAAR. Additionally, this federally mandated screening/annual review process provides for an annual review of all identified people to ensure that they have a continuing need for skilled nursing services. It also serves to notify the Division of DD-MH-SA of any specialized supports are needed to address the person’s developmental disability that are not provided through the nursing home.

Use of Adult Care Homes

It was determined, however, that this evaluation should explore the situation of people with developmental disabilities living in Adult Care Homes/Homes for the Aged (often referred to as Domiciliary Care, Rest Homes or Board & Care Homes in other states) that are not operated with funds from the Division of MH/DD/SA as DDA group homes but are licensed by the Division of Facility Services under the 131D licensing code. The term “Adult Care Home” is used to refer to a variety of supervised living arrangements that may house anywhere from 6 to 200 people. Although licensed by the Division of Facility Services, some Adult Care Homes or Family Care Homes are operated as group homes for people with developmental disabilities with state funds from DD-MH-SA. These tend to be smaller (6 to 8 bed group homes) with specialized services for people with developmental disabilities. There are many other Adult Care Homes whose residents have developmental disabilities but who do not provide supports specific to these needs and whose names and needs are not know to the DD Section. In the course of this study, advocates expressed strong concern for the unsatisfactory life conditions resulting from a lack of individualized support for these individuals

²⁵ PASSAR is a federally mandated screening and annual review activity intended to identify people with developmental disabilities or behavioral health needs before they enter nursing homes and to annually review all people with DD living in nursing homes to determine if nursing home level care is appropriate and whether needs for DD support are met.

To learn more about these people we requested that the Division of DD/MH/SA provide the study team with information regarding the number of people with developmental disabilities living in Adult Care Homes (Elderly type). The DD Section data indicate that there are approximately 1244 people known to the section who are living in supervised Adult Care Homes under the 131D code. (An additional 4622 people known to the Division live in supervised living situations under the 122C, a code that is specific to people with DD and behavioral health needs)

The number of people with DD known to the DD Section who live in 131D types of Adult Care Homes is inconsistent with the reported incidence of people with developmental disabilities living in Adult Care Homes reported in a fairly recent study (Hawes, 1995). In her *Study of North Carolina Domiciliary Care Home Residents*, Hawes found that 12% of the people living in Adult Care Homes not licensed by DD-MH-SA have a dual condition of mental retardation or developmental disabilities and a co-existing mental health problem and that another 12 % have mental retardation of developmental disabilities alone. Given the current population of North Carolina's adult care homes (25,000), The Hawes data suggests that there are 6000 people with developmental disabilities, half of whom have a co-occurring mental health condition, living in Adult Care Homes not licensed by the Division (thus excluding the 122C code homes). Of these, 1244 are known to the DD section and 4756 are not known and therefore not receiving support specific to their developmental disability.

It is likely that these people are not counted or known to the system because they do not receive any form of specialized support for their disability that is funded through state or Medicaid dollars. Therefore, they do not appear on databases, waiting lists, consumer surveys, single portal agenda or other measures of need throughout the system. They do, however, receive Special Assistance funds averaging about \$411 a month but these funds are available only to individuals living in a licensed facility.

North Carolinians have long faced significant barriers accessing services and supports in ordinary homes and small community residences. Few barriers have proved as tenacious as the statutory limits on the State's Special Assistance funds. North Carolina is one of only four states in which individuals are required to live in a licensed facility to receive Special Assistance, averaging some \$411 per month. Recently, the General Assembly authorized a demonstration project, allowing the use of Special Assistance funds for up to 400 eligible North Carolinians living at home, rather than in Adult Care Homes (the Special Assistance Demonstration). The Division of Social Services has 400 slots in the pilot located throughout the state. Key informants interviewed at the Area Program level indicated that enrollment in the program had been disappointingly low given anxiety about the long term stability of the supplement.

The pilots have kept the issue "front and center" for those committed to family support, home ownership, and tenancy. Advocacy has been strongly motivated by rapid growth in the Adult Care Home industry. Between the '80's and '90's, industry growth has resulted in the inappropriate placement in these settings of many people with DD. Legislation proposed in the 2001 Budget would allow full Special Assistance benefit eligibility to people with DD or MH needs who were living in their own homes or other non-licensed settings, in an amount equal to the benefit available to those in licensed settings.

Life in an Adult Care Home/ Elderly

To learn more about North Carolina's citizens with DD living in Adult Care Homes/ Elderly the study team asked the Division of DD-MH-SA to identify some individuals living in such arrangements who would talk with us about their situation. This request was consistently interpreted as a request to meet people in DD licensed Adult Care group homes and this made our case finding difficult. Ultimately, we did get to interview some people and here are their stories. The people depicted in these stories are people who do have case managers assigned by an Area Program, presumably they are among the 110 people who are known to the DD-MH-SA. Even with the advantage of an assigned case manager, several of the individuals we met did not have basic comforts of life. The names used in these stories have been changed for privacy reasons.

M.J. - Alone in a Crowd

M.J. is a 56 year old woman with moderate mental retardation who entered this suburban rest home of approximately 80 people with her mother who had Alzheimer's disease. They were roommates until her mother passed away last year. Mother and daughter had lived together in the family home until her mother was no longer able to care for her. M.J. came to the attention of the area program in 1997, prior to the adult care home admission through the intervention of the county's "Protective Services" Unit, which contacted the Area Program. The Area Program helped M.J.'S sister to become her legal guardian. Reportedly the guardian loves her sister but is resentful about providing money for clothing or personal needs. Through a special fund, the area program had purchased some clothes for M.J. the previous spring.

When we arrived in mid morning, M.J. was walking outside in the rest home parking lot. Her face was stained with tobacco juice as were her clothes

The case manager accompanied a member of the evaluation team to visit M.J. When we arrived in mid morning, M.J. was walking outside in the rest home parking lot. Her face was stained with tobacco juice as were her clothes

At some point since 1997, M.J. had been provided with a "retirement" program through the area program services. The DD case manager's knowledge of the mission and activities of this program was vague and she was not aware of why these services had been terminated.

According to the case manager, other problems through the course of M.J.'s stay at the Adult Care Home included that M.J.'s physical appearance was generally "unkempt" and her hair was a mess. The case manager reported that with her intervention, M.J.'s appearance had improved in recent months although this was certainly not the case on the day of our visit. The case manager told us that there are no efforts to seek an alternative living situation for M.J., such as a supervised DD funded apartment or home, because neither the guardian nor M.J. is asking for this. Current goals recorded described by the case manager are for 1) M.J. to remain in a safe and stable environment; and for, 2) M.J. to remain healthy as evidenced by receiving appropriate medical care

The case manager visits M.J. monthly and a typical visiting routine was to meet with M.J. in the common room rather than her bedroom. This may explain why the case manager was unaware that M.J.'s TV and radio are both broken. The common area was a dimly lit room with rows of people sitting in lounge chairs and rockers, between the two wings of the rest home. It was difficult to understand how a quality visit could take place in this common area which was filled with other residents who took a keen and relentless interest in any visitor. After our visit M.J. walked outside with us and was standing alone in the driveway when we left.

The goal of remaining healthy was adopted because there had been problems with M.J. seeing her physicians in a timely fashion at the Adult Care Home.

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Young Marrieds – Ricky and Lila

We visited Lila, a young woman in her early 20's with mild mental retardation who lives with her older husband, Ricky, who also has mild cognitive disabilities in an Adult Care Home in a small town. Lila has a case manager who accompanied us on the visit but Ricky does not. They have a room off a central corridor and eat in a common dining hall.

Ricky and Lila met and fell in love at a different Adult Care Home that was part of an enclave of seven homes. The couple told us they moved because they had no freedom in the previous home – it was pretty far out of town - and the food was cold. They also had lots of clothing stolen and there were few activities.

Their room was of a moderate size (12 x 12) lit with fluorescent lighting and linoleum flooring. It was crowded with their personal effects. We learned that Ricky loves to garden and tends many plants throughout the rest home on a voluntary basis. Lila helps with this and they gave us a tour of the home and yard to show us the plants they tend. Along the way they stopped to chat with several people. Ricky proudly explained that the obviously thriving plants were very unhealthy when he first arrived.

Ricky used to live in another town with his family – his parents died and he moved in with his uncle. His cousin had “power of attorney and “put him into a home.” Ricky said he was bored – he sat in his room all day. He does not have a case manager. Both Ricky and Lila said they would like to work but there is no transportation and they are not sure where to go for jobs.

Ricky and Lila are both quite outgoing and have a loving relationship. I couldn't help picturing them in their own home with their own garden. As things go, this was a good rest home but it's not a real home.

Ricky used to live in another town with his family – his parents died and he moved in with his uncle. His cousin had “power of attorney and “put him into a home.” Ricky said he was bored – he sat in his room all day. He does not have a case manager. Both Ricky and Lila said they would like to work but there is no transportation and they are not sure where to go for jobs.

Amy – Unnoticed and Unserved

... in the dining room we noticed a young woman with Down Syndrome who we will call Amy. She seemed to be in her early thirties. We were visiting with DD administrators from the Area Program and no one knew her.

We went to an Adult Care Home to meet Sarah but as we visited with her at lunch time, in the dining room we noticed a young woman with Down Syndrome who we will call Amy. She seemed to be in her early thirties. We were visiting with DD administrators from the Area Program and no one knew her. On the way out we spoke with the charge nurse about Amy. She told us that in recent years Amy had attended the main day program for people with developmental disabilities operated by the Area Program. The nurse said that they constantly received phone calls from the day program for Adult Care

Home staff to come and assist Amy with her self-help skills. This became too difficult for the Adult Care Home and Amy's brother withdrew her from the day program. We did not interview her because we did not have her brother's permission. During our visit we heard staff refer to people like Amy with Down Syndrome, as “mongoloid,” a term that knowledgeable people stopped using decades ago as a reference for people with Down Syndrome.

Jacqueline

The DD Area Program staff were asked by central office Division staff to bring our study team to meet Jacqueline. The DD Section of the Division identified Jacqueline as a woman with DD who lives in an Adult Care Home in a medium sized city. The Area Program DD staff did not know her however, she does have a primary therapist from the mental health section of the area program who accompanied us on our visit.

She also has a public guardian at the Area Program. The DD administrator who accompanied us said that when they received data on her from Division she was “shocked” to hear of her existence. – “How did they

We visited on a fairly warm day and Jacqueline complained that the sneakers she was wearing were too warm - she said she really wanted white sandals, size 10 as well as some stockings. Later at the area program we met with her public guardian and we conveyed this request to him. This guardian does not visit Jacqueline but obtains updates from her primary therapist who Jacqueline sees about once a month at the area program.

know and not us?" The administrator went on to say that an Adult Care Home is not inclined to report needs of people with developmental disabilities because they are afraid of losing the bed.

Jacqueline is an African American woman in late middle age who said she likes to go shopping and buy clothes. Sometimes she plays bingo at the rest home and told us that she won a "bar of soap." She's a large African American woman. She told us that she likes one of the staff, Mary, who does her hair. She had a manicure that was old. She appeared clean and well groomed.

Her room was half of a 12 x 12 room (shares with a room mate) Jacqueline's coloring book drawings decorated the walls but not much else. The furniture was shabby but she did have an operating television.

We visited on a fairly warm day and Jacqueline complained that the sneakers she was wearing were too warm - she said she really wanted white sandals, size 10 as well as some stockings. Later at the area program we met with her public guardian and we conveyed this request to him. This guardian does not visit Jacqueline but obtains updates from her primary therapist, whom Jacqueline sees about once a month at the area program.

Jacqueline had been married and when her husband died, DSS adult protective services placed her in the rest home. Staff referred to another patient at the facility as "mongoloid."

Mary

Mary is a short, dark haired woman with Down Syndrome who seemed to be in her late 50's. Before moving to the rest home she had lived with her mom and step-father. Her mother died 3 years ago and she continued to reside with her step-father who refused the area program efforts to place her in a group home.

The Adult Care Home was a one floor ranch style with 50-75 residents. The temperature was warm and we noticed several flies. It was very difficult to get in to see her. Her DSS representative had not shown up as they had agreed at 4:30. After numerous phone calls and about 30 minutes they faxed a release form for us to visit. Mary shares a 12 x 12 room with an older room-mate. She has visited Disney World with her family

Observations based on these visits:

Our visits with this limited sample of people suggest the following about the conditions of life for people with developmental disabilities living in adult care homes:

- Some (possibly many if you accept Hawes report data) are unknown to the system of support for people with developmental disabilities;
- Circumstances of neglect, lack of stimulation and exploitation occur even when case managers are assigned
- Service plans indicate that the tacit standard followed by some DD case managers for an acceptable quality of life is limited to the most basic requirements of health and safety
- Living conditions are characterized by institutional type of living and dining arrangements with little access to privacy or to maintain possessions
- Days stretch endlessly with little more to do than watch TV, lay on one's bed or sit with others in a day room
- People once identified in the system have a tendency to "disappear" when they live in adult care homes

- Public guardians have little direct contact with their wards
- People with developmental disabilities often come to Adult Care Homes because their families do not have access to other support resources

The Adult Care Home Industry has promoted legislation Section 21.54(a) of Senate Bill 1005 to use vacant rest home beds to meet the placement needs identified through Olmstead planning. The language of this legislation calls for the development of a “model program” established within a rest home that infuses additional services for people with Developmental Disabilities. It is the opinion of this study team that such an approach will only extend the deep-rooted and extensive problem of placing people with developmental disabilities in Adult Care Homes. Based on this exploratory study and the judgement of this team even best Adult Care Homes, are clearly inappropriate for people with developmental disabilities and infusing additional services into a place whose mission and base of expertise is not developmental disabilities will only throw good money after bad.

People with developmental disabilities do not typically thrive in domiciliary care arrangements. Given the limitations in communication and interpersonal skill experienced by many people with developmental disabilities, their needs, gifts and challenges often go unrecognized in large, congregate environments. These “homes” often house numerous people often with two to four people sharing a room limiting privacy and property to a half or third of a room and no choice over the persons who will share this meager space with you. Moreover, they do not offer specialized services and support that are common to programs whose mission is to support people with developmental disabilities. Such supports include assisting people to direct the course of their own lives through learning necessary life skills, finding work or meaningful daily activity within the community, assisting people with transportation and helping people make friends and become part of the neighborhood and community in which they live.

The primary mission of Adult Care Homes is to provide a home, it is not about teaching or helping people achieve their fullest potential – it is primarily a custodial mission. The DD field has struggled for 30 years to move beyond crowded living arrangements and custodial care to afford people with DD the dignity of a life of opportunity, privacy and support. Like many states, North Carolina has inherited a legacy of wholesale inappropriate placements of people with disabilities from public institutions to rest homes during the early years of deinstitutionalization. This initial problem appears to have been compounded in North Carolina by limited access to other community support arrangements and the relative unavailability of family support forcing even more placements to these inadequate settings.

Recommendations:

- 1) Conduct screening and outreach to identify people with developmental disabilities living in Adult Care Homes
- 2) Use the newly created ombudsman office to conduct an in-depth study of the life conditions and needs of people with DD
- 3) Ensure that those who seek or require alternative living arrangements are documented on waiting lists and resources are sought for them
- 4) Improve and expand the “special assistance” demonstration to scale to prevent inappropriate Adult Care Home placements
- 5) Expand the availability of other family supports and in-home supports to prevent inappropriate utilization of rest homes

DDA Group Homes

Group homes visited by the project team were operated by the area program and by private providers.

In one home, we spent time with two individuals who were in their twenties. One had recently moved there from an ICF/MR. The two individuals attend the day program operated through the county since it provides transportation. There was no transportation available for other activities such as recreation. One individual has experience with and would like to work in food service but there is no transportation to take him to a job. According to those interviewed, the state Bureau of Vocational Rehabilitation works only with people easily placed in jobs. They also receive CAP Waiver services in the group home, but, based on plan reviews, these supports were directed toward the basic skill development such as housekeeping, medical appointment etc. The supports did not focus on increasing exposure to community alternatives. There was little understanding of the person centered planning process on the part of staff interviewed.

In Home Supports Family

Families interviewed report receiving some supports through the CAP MR Waiver although they expressed the same frustration with the lack of flexibility and “all or nothing” approach noted in other sections of this report. Some families also noted that they felt constrained to accept the minimal amount of family support available outside the waiver for fear that they would miss out on a waiver slot.

Families also reported that they are dissatisfied with staff available to provide CAP services, especially since area programs can no longer employ staff and when families hire them the pay rates are much lower than for those working for the area program. As a consequence, there is a shortage of qualified staff to provide in home supports to people. Further, limited transportation, medical and dental and behavioral supports in the community also pose problems for families.

Vocational and Day Services

The study team did not have sufficient time to visit and observe people being supported in day and vocational programs. HSRI did, however, have an opportunity to interview and spend time with a broad range of day and vocational providers from all over the state. Based on these encounters, the following issues confronting such providers emerged:

- Approximately 75 – 85% of people receiving services in the state are receiving Adult Day/Vocational Program services. For many of these individuals, it is the only service that they receive. Only a few live in group homes and receive multiple services.
- Vocational and day providers are not being paid the full cost for all of the individuals they are serving and consequently must raise funds elsewhere in the community (e.g., one ADVP provider noted that he receives \$275 per month for a 5 day a week, 8 hour a day program). For this reason, they appeared loath to take on additional individuals from the waiting list unless adequate funds were made available.
- Unlike ICF/MR and, more recently, waiver providers, non-waiver and day and vocational providers (94% of those served are non CAP waiver recipients) must craft agreements directly with the area programs. Further, there is no set rate for their services so fees can vary widely from county to county (NCARF developed an accurate cost finding instrument which was accepted by the Division, but state has failed to embrace it).
- There is also no way of tracing the funds that come from the Legislature for day and vocational services since, according to day and vocational providers, the Area Programs have no accurate data on how much is set aside for such services, how many people are served and how much has been spent.

- Regulatory requirements and paperwork are significant and the intensity of enforcement varies from Area Program to Area Program (one administrator noted that the Pioneer system required reporting service provision in 15 minute intervals).
- Those providers interviewed felt marginalized by the system and were concerned that their issues were no longer of high priority within the Division.
- There was concern among those providers that seek accreditation from CARF that they were also being asked to undergo the Council on Accreditation process – a duplication of effort. The providers contacted also felt that state monitoring was duplicative, that Area Program monitoring was inconsistent and that no resources (TA or otherwise) were available to upgrade day and vocational services
- There is growing concern that funds for day and vocational services will be diverted to other Area Program priorities since there is no accountability for how they are spent and there is not mandate to provide day and vocational services.
- Though not all providers of day services are receiving waiver funding, the impact of the “medical” orientation on such services is being felt.

Recommendations

- A more systematic and consistent cost finding instrument should be implemented for ADVP Services
- A means for tracking the deployment of day and vocational funds should be developed
- There should be a statewide policy on the role of day and vocational services and a workgroup should be developed to identify best practice, to develop statewide priorities, to explore a stable funding stream, to standardize contract requirements and to explore uniform performance expectations and accreditation requirements; the workgroup should be comprised of people with disabilities, their families, providers and advocates.

Summary

A review of those aspects of the system discussed here reinforces the same key conclusion. The state operated MR Centers received the major portion of resources and attention from the system in North Carolina. The community cobbles a system together without:

- Coherent and forward thinking statewide and area agency planning.
- Adequate resources or support
- Flexibility and consistent messages from the state and regulatory agencies.

The result is that people throughout the system:

- Often live in places that offer more intensive and restrictive services and supports than may be necessary
- Receive extensive training in self-care and skill development but not the supports they need to experience the lives that they want.
- Are unable to move about throughout the community due to the serious lack of transportation and work and recreational services.

Further, in the MRCs:

- The state centers describe themselves as centers of excellence, however a review of their programs and survey results suggests that there is room for improvement.
- The environment in many MRC units is cold and dreary.
- People are not actively engaged in interesting or meaningful activities.
- The planning process is heavily dependent on paperwork and documentation but does not provide tools to implement individual wishes and desires.

Financing



CAP MR/DD Waiver

Covered Services

As can be seen from the accompanying chart, the CAP MR-DD waiver offers a reasonably broad array of services. DMH/DD/SAS deserves recognition for including services such as Family Training and Developmental Day Care for children that are supportive of families with children with disabilities. The inclusion of Adult Day Health programs offers supports to seniors and those with medical needs who otherwise might not receive appropriate services through the traditional developmental disabilities system. The waiver offers extensive benefits in terms of individuals who experience communication and/or physical limitations, allowing for vehicle and home modifications, adaptive equipment, and communication assistance in the form of equipment and interpreter services.

General Impressions

Consumer, case manager and provider concerns about the service array mainly revolved around detailed and restrictive regulations for some of the services, *not* the specific array of services. A review of the CAP MR/DD Manual reveals complex regulations, restrictions and paperwork requirements for many of the services.

Based on the manual review and the observations of case managers, state staff and providers, many of the rules regarding specific services are in place to exert cost containment. Restricting the amount (frequency of service) or capping payment for services are typical cost containment approaches used for State plan services. Since the State plan is an open-ended entitlement to all people who are eligible, states cannot limit access to services. Thus, utilization controls on specific services are one of the only ways a state can exert cost controls under the State plan. This is not necessarily the case under the HCBS waivers. Although the state must assure that the array of supports and services an individuals receives are adequate to assure health and safety, states have other options than utilization controls to exert cost containment, making tight utilization control on specific services unnecessary.

CAP MR/DD Covered Services

- ✓ Adult Day Health
- ✓ Augmentative Communication Devices
- ✓ Case Management
- ✓ Crisis Stabilization
- ✓ Day Habilitation
- ✓ Developmental Day Care
- ✓ Environmental Accessibility Adaptations
- ✓ Family Training
- ✓ In-home Aid Service
- ✓ Interpreter Services
- ✓ Live-in Caregiver
- ✓ MR Waiver Equipment and Supplies
- ✓ MR Personal Care
- ✓ Personal Emergency Response Systems
- ✓ Respite Care
- ✓ Supported Employment
- ✓ Supported Living
- ✓ Therapeutic Case Consultation
- ✓ Transportation
- ✓ Vehicle Adaptations

A growing number of states are using alternatives to tight controls on individual services. They achieve budget control through individual budgets that permit flexibility in service design. They also manage their waivers as a global budget, using the average aggregate expenditures per person, rather than an individual cap, as a means to assure flexibility and cost containment.²⁶

The issue in North Carolina is that there are neither practice guidelines nor an overarching understanding about how to manage the costs under the waiver. State staff and other individual service plan reviewers report wide variability in the resources made available to individuals with similar needs. Because there is no guidance as to how to relate spending to assessed needs, nor a person-centered planning process that has integrity on a statewide basis, case managers characterize individual costs as “all over the map.” One state staff person reported that initial cost reports for the current waiver year show costs rising rapidly toward the caps. The DD Section reports that in FY 2001, waiver expenditures exceeded their budget by about \$1 million, added evidence that the present approach to cost control is ineffective. Case managers report that, “everyone wants everything” and that they have no effective, equitable way to negotiate a budget with an individual. This lack of a coordinated approach to establishing overall management of waiver expenditures and an effective equitable manner to allocate resources makes for restrictive service definitions that still do not result in cost containment.

Fundamentally, there are two approaches to the distribution of individual funding resources:

- 1) The actual amount of funding for an individual is determined through the person-centered planning process and is based on the costs of the supports and services the person needs and prefers as determined through the planning process, or
- 2) Funding is determined through an assessment that sets a budget or individual resource allocation amount within which the individual can purchase supports and services (with the specific mix of services determined through the person-centered planning process).

The first approach takes a mature system with well-trained case managers. It also requires a system that has enough capacity to respond to individuals’ changing needs and that cannot be compromised by political pressures. A system that rests on resource allocation through person-centered planning must demonstrate responsiveness to changing needs. This means that if someone’s situation requires additional supports, those supports are readily available. If a system has a good history of responding to changing needs, this goes a long way in driving out fears that a people cannot or will not get what they require if their needs increase. In a system that readily responds to changing needs, individuals and families no longer feel the need to “load up” on services as soon as they enter the system as insurance against future needs. Vermont, Wisconsin, Colorado and Maine are examples of systems that use person-centered planning as the basis for setting individual resources.

A number of states now tie individual budgets to some type of functional assessment. South Dakota and Wyoming have fairly sophisticated approaches to constructing individual budgets based on analysis of functional needs and costs for support services. Other states use a functional assessment to broadly determine a “planning budget” within which the individual has considerable flexibility in choosing services. Kansas uses this approach.

Recommendation

DMH/DD/SAS needs to establish a management framework for assuring cost containment that does not rely on strictures on individual services. This approach has clearly not proven to be effective. Approaches such

²⁶ The issue of managing the budget in aggregate is covered in detail in the “Report to the Senate Appropriations Committee on Human Resources and the House of Representatives Appropriations Sub-Committee on Human Resources”, May 1, 1999, Section V.A. Flexible Funding, pp. 14-18.

as tying individual budgets to functional status or a well-developed person-centered planning process are two alternatives in setting individual budgets.

Other strictures on services relate to certain Medicaid regulations. For example, Medicaid regulations require that states give assurances that services do not “duplicate” each other. This means that the state must have a means to assure that providers do not bill for similar services at the same time. For example, a provider could not bill for Adult Day Health services and Day Habilitation during the same hour. This is also in place to assure that a provider does not bill a person’s Medicaid card at the same time a provider bills the waiver for a similar service. One example is personal care. Providers may not bill for both MA card funded personal care and MR personal care under the waiver at the same time. Medicaid regulations do permit billing of similar services serially. An example could be using up an MA card personal care benefit and then accessing a waiver personal care benefit.

Under CAP MR /DD, a number of services are exclusionary, meaning you cannot get them on the same day. While this certainly addresses concern with compliance with Medicaid’s non-duplication requirement, this also constrains creativity and may not result in a support plan that is what an individual needs and prefers. The Medicaid non-duplication clause means providers cannot bill at the same time of day, but does not require that providers cannot deliver similar services consecutively on the same day. Thus someone could attend two different types of habilitation programs within the same day, say a day habilitation service and supported employment, if this is an appropriate plan. These restrictions constrain individualization and as noted in the Lewin Group report, “The inability of the claims processing system to support these policies renders them effectively meaningless...”²⁷

CAPMR/DD requires some service delivery in “blocks”, such as a minimum of four hours. While this may make it easier for payment purposes, again this may not be the amount of service someone needs or wants. Certainly the regulations must be clear regarding violation of Medicaid regulations, but the rules also need to permit more flexibility in designing supports. This is an issue with a number of services, but was most problematic in Supported Living Services, detailed below.

Case managers noted that any change in services, whether affecting the overall budget or not, require extensive paperwork, review and approval. They note that they have little flexibility in moving funds around for consumers and voiced concerns about the many constraints on certain services. Providers noted that the documentation requirements are very intensive and sometimes difficult to complete. Providers said they spend enormous amounts of time making sure their documentation is in order in fear of generating paybacks, not due to actual improper activities, but due to improper documentation of allowable costs and services. The cycle of requiring more paperwork to assure compliance actually creates the issue it was originally intended to prevent. Again, the Lewin Group report noted a further problem with this approach, “...it is easy for providers to ignore the rules, and difficult for DMA to detect or correct abuse.”²⁸ Thus the documentation requirements add to the problem of compliance without assuring compliance. This is explored further in the section on case management.

Although the waiver covers a reasonably comprehensive array of services, there are gaps. For example, the waiver does not cover family support type services. This is a surprising gap in that CAP MR/DD overwhelmingly serves individuals living at home with their families. The waiver also does not offer any particular mechanisms for self-determination. The section on service gaps below covers this topic.

It appears that some services are underutilized. A review of the FY 2000 HCFA 372 report reveals that no one used environmental accessibility adaptations. Supported employment does not even appear as a separate category on the HCFA 372 (although it is an approved waiver service), so it is impossible to determine if this service has been use at all. In fact, there is some difficulty assessing waiver utilization

²⁷ The Lewin Group, “North Carolina Medicaid Benefit Study: Final Report” May 1, 2001, p. III-26.

²⁸ Ibid., p. III-26.

patterns as the HCFA 372 does not use the same service categories listed in the approved waiver application and the CAP MR/DD Manual. The HCFA 372 reflects no data on supported employment, therapeutic case consultation, interpreter services and live-in caregiver.

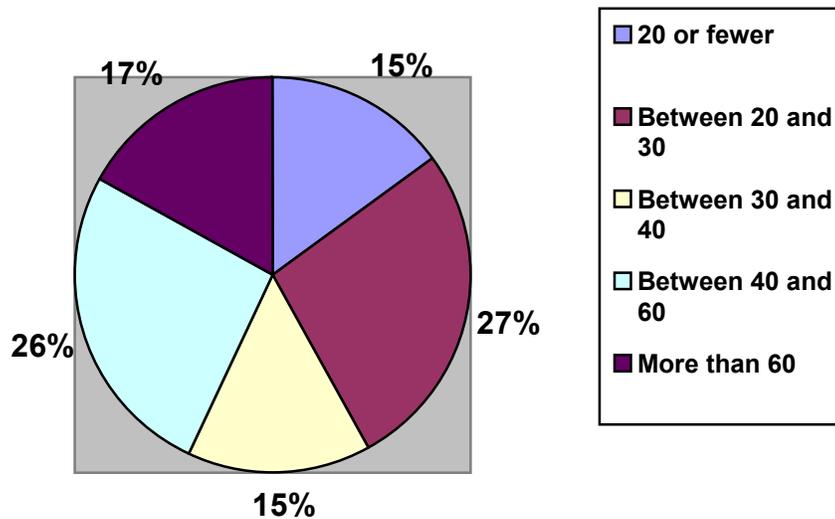
Recommendation

DMH/DD/SAS should work with DMA to align the HCFA 372 reporting categories with the list of approved services. This would result in better information on cost and utilization patterns and would conform to the waiver application and CAP MR/DD manual.

Case management

The approved definition of case management is comprehensive and reasonably flexible. The definition focuses on tailoring the amount of case management time to the needs of the person. The intensity and frequency of this contact is specified in the person’s plan of care. Case managers are required to make a face-to-face contact at least monthly. North Carolina case managers have small caseloads at least in comparison to national averages. The case managers interviewed reported caseloads from 1:10 (one case manager to ten consumers), to a maximum of 1:20 individuals. This compares very favorably with the national caseload average that is about a 1:40 ratio. In a recent survey, NASDDDS staff found that only 15%

Caseload Ratios



responding to the survey (N 48) had caseloads of 20 or less.²⁹ Only seven of the 48 states responding had caseloads of less than 1:20. Thus, North Carolina's case managers are in a unique position in terms of their caseload size.

Given these small caseloads, one might surmise that the case managers are able to be in very close contact with the consumers and families on their caseloads. Unfortunately, case managers and families report that this is not completely the case. While case managers, consumers and families do report that they have frequent contact, the intensity of their contact is not as great as might be as case managers report that approximately 50% of their time is spent on paperwork. This paperwork includes the typical responsibilities of developing the Plan of Care, keeping case notes and updating materials as changes occur in the person's situation or supports. Beyond these specific tasks tied to documenting the individual's situation, case managers must review all documentation for every claim made on behalf of consumers on their caseloads. They review these claims to assure that they are filled out properly, and are for only allowable, approved services. The claims are "hand-reviewed" as the automated claims system has no mechanism to "kick-out" claims that exceed allowable cost limits, either on specific services or in aggregate.

Case managers noted they do these intensive reviews in order to prevent paybacks to Medicaid for failures in documentation or due to incorrect billings. Payback was actually a theme heard throughout the interviews with providers, case managers and state staff. There is a recent history of large paybacks due to improper billing and documentation. Everyone in the system is highly sensitized to this possibility and engages in intensive scrutiny and oversight of documentation to assure no paybacks will occur.

For case managers, this focus drains attention from person-centered planning and assuring individuals outcomes and quality for waiver participants. Some Area Programs report 100% turnover in case managers on an annual basis. This is quite surprising given the small caseloads, as usually case manager turnover bears a relationship to caseload size—high caseloads lead to high turnover. The case managers and their supervisors report one of the reasons turnover is high is job content. They say they have difficulty finding and retaining individuals with the required mix of paperwork and people skills. As one case manager noted, "You can be a good case manager or a good auditor, but you can't be both." The case managers and their supervisors actually saw these skills as almost antithetical—individuals were either good at one or the other, rarely both.

"We're not so much case managers, as auditors..."

CAP case manager

Case managers report that they must do a complete update to the individual service plan whenever there is any type of change in the plan, even those that do not have any fiscal impact. This is particularly time-consuming, as the budgets must be managed to a monthly cap, rather than an annual cap. This means that if service needs increase temporarily, the case manager must redesign the entire service plan, perhaps reducing services in one area to fund increased services in another, in order to stay within the monthly cap. This is required even if the temporarily increased cost will not cause the plan to exceed the annual cap. A review of the CAP MR/DD Manual revealed no specific description of the monthly or annual caps on the total cost of services, other than references in Appendix L. Although this information appears in official correspondence between DMH/DD/SAS and the area programs and counties, it does not appear in the manual.

Although one case manager reported she thought there was a process to apply for an exception to the monthly cap, she did not know the process. Information as to how to apply for exceptions to caps on *specific services* appears in the manual, but no information was located regarding any process to apply for exceptions to the annual or monthly cap.

²⁹ Gettings, Robert M. and Smith, Gary, "Managing Medicaid Home and Community-Based Waiver Services: An Analysis of State Policymaking and Operational responsibilities for waiver Programs Serving People with Developmental Disabilities, A Special Studies Initiative Report", NASDDDS, Inc., June, 2000, pp.19-20.

In calculating the annual cap, case managers are responsible for including the cost of certain Medicaid card services. This means case managers must research the costs of planned Medicaid services and add those into their calculations. The intent of this approach is to assure that the cost of waiver plus MA card services does not exceed the average annual cost of ICF-MR services plus card services. This of course comports with the fundamental requirement of the HCBS waiver, cost neutrality. According to the HCFA 372, North Carolina's Medicaid card costs for waiver participants in FY 2000 was \$6,099 per person per year. These costs are comparable to other states expenditures for State plan services. Waiver costs were \$30,283 bringing the total to \$36,382 per person per year. On the institutional side, the HFA 372 indicates card costs of about \$3,000 per participant.³⁰ Institutional services accounted for \$84,692, for an average per person total of about \$88,000 per person per year. Thus, in FY 2000, the waiver was very cost-effective, compared against institutional costs.

Tracking Medicaid card costs is time-consuming and difficult to predict as individuals are entitled to all medically necessary Medicaid services. While assuring cost neutrality is of course important, North Carolina is the only state these reviewers are aware of that takes this approach with persons with developmental disabilities. This type of management forces individuals to "trade-off" waiver services to gain access to Medicaid card services. This may actually put individuals in the position of not having enough waiver supports and services to meet their needs, thus violating a basic waiver assurance. Most states factor in the card costs in setting a cap on the waiver services. In a sense, they permit the card costs to "float" and assure cost containment though managing the waiver services expenditures. Using historical data from the 17 years of operating the waiver should suffice for managing State plan costs.

An alternative approach is managing the card costs to an aggregate average, while maintaining a cap on the waiver services. Based on historical and current data, DMH/DD/SAS could establish that an average annual card cost of say, \$3,500 would assure cost-effectiveness. As a means to assure the overall cost-effectiveness DMH/DD/SAS could lower the cap on the waiver services side to accommodate managing the card costs in aggregate. This would reduce the paperwork burdens of the case managers, alleviate any issues regarding access to State plan services and still provide a mechanism to track cost-effectiveness.

The salary structure was another cause for turnover. Because the case managers salaries relate to county civil service, the pay can vary significantly from county to county. This is despite the reimbursement rate of \$509/month/person served.³¹ Case management supervisors report this variability also can compromise case manager competency. Because some areas have low salaries, they can only attract individuals with limited experience. They report that these individuals move on to other better paying counties as soon as they have some experience. Supervisors report the average length of employment for case managers is about 1-1 ½ years.

Based on our interviews, there may be alternatives to using costly case management time to assure compliance with documentation requirements. If DMH/DD/SAS deems it important to continue these reviews, this could be separated from case management. While it may be appropriate to have a case manager look at claims that seem anomalous or that exceed allowable limits, having the case manager do the actual review of every claim seems a misuse of professional case management time better spent on assuring the quality and outcomes for consumers.

Again, fear of payback drives the fiscal reviews. This fear seems misplaced given that the paybacks mainly occurred with "Y" code services, not waiver billings. Case managers report problems with the claims they review, but these are *documentation* issues. They report that they do not find significant issues around

³⁰ The HCFA 372 actually shows the card costs as \$29,569 per person. This number appears to be a decimal point error.

³¹ Given the salaries, it is apparent that the case management rate funds other than the direct costs of case management. The rate supports other MA administrative costs and functions not otherwise captured under MA administrative costs.

fraudulent or otherwise improper billings. It seems that the extensive documentation requirements are, in some cases, actually the source of errors.

Recommendations

While of course the state must manage the cost-effectiveness of the waiver, a simpler approach is to lower the cap on waiver services and manage the card services in aggregate. The state could review card expenditures on an aggregate basis regularly to ascertain if card costs will cause the waiver to be cost-ineffective.

As a first step to revamping the fiscal management of the waiver, DMH/DD/SAS should allow case managers to manage within an annual cost cap. This allows greater flexibility for consumers and case managers.

DMH/DD/SAS should not require an entire new cost summary for changes to the plan that have no effect on cost.

More specific information as to monthly and annual cost caps should appear in the main body of the CAP MR/DD Manual. If the actual amounts of the caps do not appear in the Manual, the Manual should note where the cost caps are published and how they are administered.

If there is a process for an exception to the overall or monthly cost cap (not just exceptions to caps on specific services), this also should appear in the Manual.

DMH/DD/SAS should consider alternatives to using case managers as the main assurors of fiscal integrity. Clerical support, auditors and automated systems with appropriate edits can accomplish much of what the case managers do. Additionally, the many restrictions and requirements around individual services actually may generate documentation problems, thus a review of the efficacy of these restrictions is in order. Finding alternatives to case manager review of all claims would free them to work more closely with individuals on service quality and outcomes.

Adult Day Health

As noted earlier, the inclusion of this service is very positive. Seniors, or individuals with medical support needs have an opportunity to get assistance as well as opportunities for socialization or pursuing other activities through these programs. Unfortunately, the definition of services requires that an individual attend these services four or more hours per day, *and* the person may not receive Day Habilitation Services on the same day as Adult Day Health services.

While it is legitimate to monitor and prevent the possibility of duplication of services (that is, billing for the same or similar services at the same time), this constraint does not allow for designing highly individualized supports. Perhaps an individual can only tolerate a short outing to an Adult Day Health setting; perhaps the person may want to attend a few hours at one setting and pursue other activities available under Day Habilitation (such as supporting the person to volunteer, or teaching them to shop for groceries.) The types of restrictions placed on these services seem to be artifacts of earlier program models, where people attended facility-based settings for blocks of time (during which their residential settings were not staffed, typically, Monday through Friday from 9 AM to 3 PM). Designing truly person-centered plans requires service regulations that permit unusual combinations of services, which are idiosyncratic to each individual. Rather than making the person conform to the service category or the payment process, the service definitions and regulations must be flexible enough to accommodate individual needs and preferences without seeking exceptions or “bending” the rules.

Recommendations

*Remove the requirement that Adult Day Health be delivered in four hour blocks; permit an individual to receive as much or as little of this service as is appropriate and practical for their needs. Remove the constraint on receiving both Adult Day Health and Day Habilitation on the same day, permitting individual combinations of services. (*This conforms with the non-duplication requirements under Developmental Day Services, which state that similar services cannot be delivered at the same time of day as noted in the Manual, Section 6.6). As a part of the quarterly documentation reviews done by DMH/DD/SAS, review a sample of claims on a random basis to assure non-duplication. Since this service is used by only a small fraction of waiver enrollees, this should not pose undue burden.*

Augmentative Communication Devices

While the augmentative communication devices benefit is very comprehensive, even covering the costs of computers (which some states choose not to offer), the process to develop the request and seek approval is very detailed. Requests under a certain amount require one type of professional assessment, while requests over another amount require a multi-disciplinary team review including a Occupational Therapist or Speech Pathologist plus a professional qualified to assess cognitive capacity. Any request requires a physician's order demonstrating the "medical necessity" of the equipment. For any purchase over \$500, there are detailed instructions regarding rental versus purchase and bid requirements to establish the lowest bid. Requests under a certain amount per year go to one the Local Lead Agency, with other types of requests sent to the DMH/DD/SAS Waiver Office. The description of the process by which to even put in the request for these devices has its own Appendix that encompasses six pages of the manual.

Clearly the purchase of these items should be carefully assessed, tied to the individual's needs and capabilities, and of course be fiscally responsible. While appropriate cost and programmatic controls are reasonable, the level of detail for approval of just the items that fall under this category is actually staggering.

Documentation of involvement of a qualified professional (OT/Speech Pathologist) should suffice. The addition of a physician's signature, while in keeping with typical Medicaid practices, most likely does not add benefit as most community physicians have little knowledge or understanding of these types of needs. The signature is really just a formality and likely a source of delay in getting the requests processed.

Items that cost more than \$500 require three bids and a justification as to why purchase, not rental is justified. The "three bid" requirement seems onerous, particularly in areas where there are limited vendors of equipment. This type of bidding requires the case manager or other professionals to find vendors, seek bids, and wait to get the written bids before submitting their requests. Again, in service of prudent buying, perhaps the bid requirement could be used only for truly expensive items say, over \$5,000.

It also might be worth reviewing the history of these requests. If a lot of requests have been denied based on being unnecessary or having out-of-line costs, this would indicate that there are serious misunderstandings of the benefit. If this is the case, then certainly more intensive oversight, and actually more technical assistance and training on the benefit is warranted. If historically requests meet the needs of the individuals and the costs are within acceptable levels, perhaps approval could be delegated to the local level, again except for items that are very costly. This would eliminate some of the time lag in getting approvals.

Recommendation:

DMH/DD/SAS may want to consider streamlining the requirements for request and approval of Augmentative Communication Devices. This could be done by eliminating the physician's signature, moving most approvals to the local level and requiring more extensive review only of items that exceed a certain threshold that is higher than the \$500 threshold now in place.

MR Waiver Equipment and Supplies

Consumers and families are pleased that the waiver covers a broad array of equipment and supplies not available under the State plan. This is of enormous help to individuals and families who otherwise would face substantial out-of-pocket expenses for these items. Although the allowable services are comprehensive, families and case managers reported extensive delays in getting the equipment due to the documentation requirements and the approval processes. Coordinating the purchase of equipment with

“My kid outgrew the wheelchair from the time it was ordered until it was authorized and delivered...”

the CSHS coverage (children’s health program in North Carolina) is quite complicated and results in significant delays in getting equipment and supplies to children. In the interviews conducted for this report, two parents reported such extensive delays in getting a wheelchair approved that their children outgrew the chair before it even arrived.

Excerpt from the CAP MR/DD Manual Instructions Re: MR Waiver Equipment and Supplies

Including Information about Nutritional Supplements on the Cost Summary

To determine the Medicaid allowable for Nutritional Supplements, the following procedure is followed:

- Find the number of calories per can (total number of calories per can);
- Determine the number of units in the can. There are 100 calories in a unit so divide the total number of calories per can by 100;
- Locate the allowable Medicaid rate on the DME list; and
- Multiply the units per can times the allowable Medicaid rate for the supplement. If the cost of the can of the supplement is the same or lower than this calculation, the price per can is within the Medicaid allowable.

Note: Always indicate by mouth or by tube when reflecting nutritional supplements on the Cost

Case managers must provide highly detailed documentation on the cost summary that again seems to be an issue related to cost containment. It is worth looking at the cost of the effort expended to assure cost containment, versus just paying for the service without the extensive calculations, reviews, and physician signatures. A review of the FY 2000 HCFA 372 report indicates that MR Waiver Equipment and Supplies accounted for .85% of the total dollars spent.³² According to the report, 1,267 people used this service at an average cost per person of \$1,289 per person. This is not a costly service and as such tight controls over utilization and expenditures are misplaced.

Much like with Augmentative Communication devices, the cost or utilization patterns do not warrant the intensive documentation and approval processes. If cost containment is at issue, expending extraordinary effort to contain costs for items that account for such a small portion of the total waiver costs is misplaced. It makes more sense to put extensive oversight and review on services that account for more of the costs.

Recommendation

If cost containment is truly at issue, a more reasonable approach might be to set a dollar amount that requires no prior approval and does not require extensive documentation. Once the person’s need for MR Equipment and Supplies exceeds this amount, then more extensive review and some type of additional approval could be required. This allows timely approval of routine requests that do not have much effect on the overall waiver costs. It makes more sense to subject only high-cost requests to intensive review..

Environmental Accessibility Adaptations

Environmental accessibility modifications are limited to a total cost of \$2,500 per year. This limit may pose problems for individuals requiring extensive modifications. This amount could easily be exhausted for modifying just a bathroom, leaving all other rooms inaccessible. Rather than setting an annual cap, perhaps

³² Smith, Gary, “Today’s Choice, Tomorrow’s Path: Gauging North Carolina’s Effort in Support of Its Citizens with Developmental Disabilities”, HSRI, August 2001, p. 25.

a lifetime cap would permit more flexibility. Although the manual is not completely clear, it appears that the cost of housing modifications are included in calculating the monthly and annual cap. This could be very problematic for an individual with costly on-going support needs. Many states exclude “one-time” services such as housing modifications from other caps. Funding for these one-time items is set aside in a “pool” that individuals enrolled in the waiver draw from. Again, because DMH/DD/SAS does not have a sound approach to cost containment, nor a flexible system to manage the waiver costs, tight caps are in place on the individual service. There is some evidence that environmental modifications are cost-effective. In some instances, making rooms accessible allows for greater independence (persons can cook for themselves because the stove is in reach). Some environmental modifications such as a lift can substitute for staff assistance.

Environmental modifications are not permitted in a rental property. This means that unless individuals live with family, or own their own homes, they cannot benefit from environmental modifications. Perhaps this limitation explains why, according to the HCFA 372, in FY 2000 no one utilized this service. Lack of accessible housing is a significant barrier to community life for individuals with disabilities. Allowing modification in rental property can actually benefit the community of individuals with disabilities, creating more choice of where to live. Many states find that allowing modification of rental property benefits the individuals they serve by providing more housing options. Although it seems that the property owner gets something for free, modifying rental property is actually an investment in housing choices for people with disabilities.

It is noteworthy that the FY 2000 HCFA 372 report indicates that no one used this service. While this might mean that no one actually needed the service, it may be that the restrictions on the service contribute to individuals not using it.

Recommendations

Consider moving to a lifetime cap, rather than an annual cap on environmental accessibility adaptations. In light of the low utilization and thus, minuscule impact on cost-effectiveness, consider excluding this service from the monthly or annual caps.

Remove the restriction on modifying rental property as a means to open up housing options and increase choice for consumers.

MR Personal Care

The inclusion of MR personal care under the waiver is clearly a valued service. Fully one quarter of waiver participants use this service at close to \$10,000 per person per year. The service definition makes sense and permits a mix of hands-on support and incidental homemaker activities.

There are some exclusions on the services that are both confusing and bear review. The CAP MR/DD manual reads:

The Personal Care direct service employee may function in a supportive role accompanying and facilitating the person's participation in day services and travel in the community.

This seems a sensible approach as personal care may very well be needed for an individual to participate in community life—the need for care with ADLs is not limited to an individual's home. Unfortunately, other limitations on the service appear to contradict this statement. Of particular concern is the limitation that an individual may not receive personal care at the same time of day as he or she receives supported employment. It is understandable that in traditional day habilitation settings such as a day program or pre-

vocational setting, the staff are expected to provide personal care as part of the daily program. This service is usually integrated into the day program and is part of the compensation offered to the provider. This may not be the case in a supported employment situation or in the workplace. It is not usually the responsibility of job coaches or paid co-workers to provide personal care. In fact, the need for personal care services can be a barrier to employment, either supported or competitive. Employers typically are not responsible for personal care. Realizing this, the CMS rules for State plan personal care permit the provision of personal care in the workplace and in other community settings beyond someone's home.

Recommendation

Remove the prohibition on providing personal care in supported employment and any other employment setting in order to reduce barriers to employment.

Supported Employment

Supported employment appears both in the approved waiver application and the CAP MR/DD Manual as a covered service. Although the official report of waiver utilization and expenditures the HCFA 372 does not show any data on supported employment, DD Division records show 461 individuals receiving supported employment services in FY 2001 an increase of 115 individuals over the previous year. Supported employment is a significant service that will continue to grow as more individuals graduate from school programs oriented to employment.

The manual defines supported employment as:

“...paid employment for persons with developmental disabilities for whom competitive employment at or above minimum wage is unlikely and who, because of the severity of their disabilities, need intensive ongoing support to perform in a work setting.”

While a fairly standard definition (this mirrors the CMS suggested definition), the implied restricting of supported employment to individuals for whom competitive employment at or above minimum wage is unlikely may inadvertently prohibit the delivery of supported employment services to appropriate individuals. In some instances, individuals are able to earn at or above minimum wage while still requiring on-going supports to retain employment. As an example, an individual worked for a state agency as a clerical support person with a starting salary of \$8.50 per hour. Based on her productivity in the job, her wages were \$6.00 an hour, which exceeds the minimum wage. Although she earned above minimum wage, she could not continue her employment without the support of a job coach funded through the waiver as she had already exhausted other benefits available under vocational rehabilitation. Using the definition above it is unclear whether she would be able to use supported employment services.

As more individuals move into employment, offering the on-going support to retain employment seems a valuable investment, even when earnings exceed minimum wage. The same logic applies to the “intensive” support. Some individuals may only need a few minutes a day of support to retain their employment—this certainly is a cost-effective investment.

Recommendation

Remove the language regarding minimum wage and the need for intensive supports from the definition of supported employment.

Respite

The most recent set of waiver amendments included a substantive change to the respite definition. This change stemmed from DMA's directive to attempt to "regularize" the respite definitions across all of the state's HCBS waivers. Unfortunately, in the estimation of the individuals interviewed for this report, this change was a step backward. The CAP MR/DD Manual new respite definition states:

"Respite Care is a service that provides periodic relief for a family or primary caregiver on an interim basis. It may not be used as a daily service in treatment planning. It must be used at irregular intervals if used as a periodic service. In order to be considered a primary caregiver, the person must be principally responsible for the care and supervision of the individual and must maintain his/her primary residence at the same address as the individual."

This restrictive definition does not meet the needs of families and individuals caring for persons with disabilities. Regular, *planned* respite may be exactly what some caregivers need to continue to offer care. The requirement of "irregular intervals" does not allow families and caregivers to plan their activities. In fact, case managers and families report in some situations they now use personal care as a substitute for respite, as at least they can schedule this on a routine basis. Since personal care is a more costly service than respite, the change in definition had an unintended effect in driving costs under the waiver.

Respite services over 720 hours per year require special authorization. This limit harks back to the 1990 suggested definition of respite on the waiver format. This no longer appears in even the CMS suggested definition on the official waiver format, which defines respite as:

"Services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care."

Recommendation

Amend the waiver to reinstate the original definition of respite or substitute the suggested CMS definition. Remove the cap on respite and determine the amount of respite through the planning process.

Supported Living

The most recent amendment to the waiver redefines supported living to focus on habilitation and eliminates a service called Community Integration. The change in supported living also includes tying the number of hours authorized, and the provider reimbursement for this service, to NC-SNAP scores. The intent is to equalize funding across individuals with similar needs and provide a functionally based framework for determining the level of support an individual receives. Given the issues noted above regarding resource allocation, these could prove important and necessary changes to decision-making about individual resources.

Unfortunately, of all the services, those interviewed report supported living poses the most significant problems. The new definition is more explicit as to the content of the service and reinforces the habilitative nature of this service, noting

Supported Living provides flexible, individually tailored supports and assistance to meet the person's habilitation needs and to facilitate adequate functioning in their home and community. This habilitation service works towards meeting habilitative goals and objectives throughout the person's day and provides personal assistance that is *incidental* [italics added] in nature.

The habilitative focus of this service does not offer enough flexibility either to the individuals providing the service or to those receiving it. This service is one of the primary supportive services delivered in individual's homes as well as in group living arrangements. The habilitative focus forces providers into detailed record keeping. If, throughout the day, the provider does personal care activities that are not "incidental" to the delivery of supported living, this requires documentation and billing as another service, such as MR personal care. This makes little sense, particularly if it is the same agency and same direct service worker providing the supports. Provider and families report confusion as to what is incidental personal care and what they should report as actual personal care.

Supported living as presently defined, "just isn't how life happens..."

Parent

For individuals with intensive support needs, the definition of the service provides for structured skill building and training for up to 12 hours a day. While other services may be more appropriate, consumers and case managers report that the reimbursement for supported living makes it more attractive to providers than other services, thus there is a push for this service. Families of children (and adults) with severe medical disabilities report that the intense habilitative focus of the service just does not work for their children. Although some goal-oriented teaching and training is appropriate, the individuals need "down time" that allows for just support or rest, or to go for a walk that has no particular goal. These children require extensive supports from qualified individuals, paid commensurate with the training needed to support and supervise severely disabled individuals. It seems that providers perceive the only way to cover the costs of serving these individuals is through supported living, although the individual actually may not want or be able to tolerate habilitation hour after hour.

The intensity of supported living services is tied to the NC-SNAP, which then ties back to payment rates. Although it seems logical that the most severely disabled individuals would need the most supported living services, in some instances the reverse is actually true. Individuals with less intensive cognitive and medical disabilities want and can respond to more hours of teaching and training. Case managers and families report that individuals with behavioral challenges and "high functioning" individuals get low NC-SNAP scores and thus qualify for lesser amounts of habilitation than those who actually cannot tolerate hour after hour of habilitation.

The attempt to correlate NC-SNAP scores with hours of service and provider reimbursement has some merit. Both Utah and New York take this approach, using a functional screen to establish needs and reimbursement rates. Unfortunately, in North Carolina this has not played out as intended due to the two issues noted above. The NC-SNAP doesn't seem to work as well for individuals with behavioral challenges and those who are more capable, actually offering them less teaching and training time than they can benefit from. Second, the definition of supported living does not offer enough flexibility to deliver what individuals need in a "seamless" manner. This affects both the individual receiving the service and the provider who is required to document their activities.

Many states offer supported living as a "wrap-around" service that combines support, supervision and training in whatever combination and amount (from an hour to a full day) that makes sense given the individual support needs. Payment rates tie to the intensity of the support that is combination of the hours of support, the staffing ratio and the specific specialized needs of the individual. Please see the Appendix for approved definitions of supported living that permit an individualized mix of services that include both training and personal care.

Some states offer a comprehensive definition and provide the option of offering selected components by continuing inclusion of “stand-alone” personal care or skill training. This permits an individual to get whatever mix of services, in whatever degree of intensity that is appropriate to their needs and preferences. If someone just needs specifically targeted skill training then that is covered under a specific skills training service (much like Community Integration previously covered under the waiver). If all that’s needed is some personal care, then that is the service utilized, but if the person needs support throughout the day that is a combination of habilitation, personal care and supervision, then supported living as a broad-based definition makes sense.

Recommendations:

Redefine supported living as a “wrap-around” service that includes an individualized mixture of habilitation, personal care and supervision that more closely aligns with the rhythms of daily life.

Reinstitute a habilitation-only service that specifically provides skill development.

In the DMHMRSA continues to use the NC-SNAP to determine hours of services and/or rate-setting, further refinements are needed to assure that the scores reflect the actual needs of individuals, particularly those with behavioral challenges.

Gaps in Covered Services

As noted earlier, CAP MR/DD offers an array of services that generally seemed to cover most of the needs of individuals served. Despite this, some additional services are of interest particularly to families and consumers. The first service is family support. Although the waiver covers some key family support services such as respite or MR personal Care, many families prefer a separate, more flexible family support option within which they can tailor the mix of supports to their own situation. This can be modeled along the lines of North Carolina’s existing First in Families program. Using a family-centered model, this program offers families support and flexibility in finding resources and supports. The waiver could cover supports and services that are waiver allowable, supplementing the small stipends from First in Families that could then be used for non-waiver allowable services. Planning and supports to families could link into the existing networks, which, according to those interviewed are well received. The Appendix includes some approved definitions of Family Support for consideration.

CAP MR/DD offers no specific means to support self-determination. Some states include support to individuals to exercise choice and control over their own lives. Self-determination services often include support to the individual in exercising civic duties, educating individual as to their rights, learning self-advocacy, choosing supports and services, and hiring, supervising and firing the individuals providing supports. Given the limited progress in the development of the self-determination pilots, including a self-determination option under the existing waiver would enhance the opportunity for individuals to have choice and control. While components of this service are likely available through other existing services (such as supported living), much like with family support services, it often helps make these options a reality when they are set aside as separate services. This highlights the state’s commitment to offering these types of supports and may offer alternative approaches that do not fit within the traditional service definitions, providers and payment practices.

Another service worth consideration is educational services that fall outside of those covered by P.L.94-142 or the Rehabilitation Act. Covering educational services allows states to pay for community college courses or educational tutoring outside of school settings. The Appendix offers one state’s approved definition of educational services.

Recommendations

DMH/DD/SAS should consider adding family support, self-determination and educational services to the CAP MR/DD waiver.

Services to Individuals with Traumatic Brain Injury (TBI)

North Carolina serves many citizens who have experienced a traumatic brain injury in nursing facilities (both intermediate and skilled care), in state psychiatric facilities and in out-of-state specialized neurobehavioral treatment centers. DD Section staff report that nursing facilities admit over 300 people with a brain injury. State psychiatric facilities admit about 100 individuals annually. Although the state no longer sends individuals out-of-state for Medicaid-financed long-term care, North Carolina still utilizes out-of-state settings for acute rehabilitation. In the 1999-2000 session, the Legislature funded development of a neurobehavioral unit for persons with TBI. The intent of the unit, housed in one of the Regional Mental Retardation Centers, was prevention of out-of-state placements and use of in-state psychiatric facilities.³³ Budget issues (the flood of 2000 and the current deficits) resulted in cutting of all funds appropriated for this project. Thus, pressures are again mounting to send individuals out of state. DD Section staff report that there are presently two pending requests for out-of-state placement (funded with pure state dollars) for individuals with intensive behavioral support needs. The cost of these placements is \$600 per day per person.

Without highly specialized services tailored to the specific needs of persons with brain injury, people remain institutionalized. This is particularly devastating as TBI occurs more frequently in younger individuals (particularly young adults) who have many potentially productive and satisfying years ahead of them. In addition, with growing pressure on nursing homes due to the aging of the general population, community alternatives for persons with TBI can result in less pressure for growth in nursing home beds.

At present, 16 states operate specialized HCBS waivers that serve individuals with TBI. States develop TBI-specific waivers for several reasons. Typically, many persons with TBI do not qualify for ICF-MR waivers due to the age of onset of their disability. Although they may qualify for nursing facility waivers, the cost of their continued care in the community is more comparable to the costs of neuro-behavioral or rehabilitation hospitals that offer specialized treatment and care, rather than nursing home care. Another rationale for separate TBI waivers is to set up programs, services and provider qualifications that specifically address the unique needs of individuals with TBI.

North Carolina has tracked the needs of individuals with TBI since 1993. The DD Section Single Portal Q&A Newsletter found in the Appendix details the efforts to develop a TBI waiver. Each year since then the DD Section reopened the discussions on seeking permission and financing for a TBI waiver. Under the direction of the General Assembly, in FY 1999-00 the DD Section contracted with a NC Institute for Public Health to prepare a cost study exploring the cost-effectiveness of a TBI waiver. Although the DD Section presented this study to the General Assembly in May 2000, no budget or legislative action materialized. In 2001, the DD Section earmarked \$400,000 to serve as match for a TBI waiver that would serve approximately 25 individuals and \$200,000 for a TBI group home. Unfortunately, enabling legislation permitting the Section to actually apply for a waiver never passed. The waiver process is completely stalled. Individuals continue to be admitted to costly institutional settings, and the state continues to spend money for services that could be covered under a Medicaid waiver.

In 2001, retaining a person in a skilled nursing facility costs Medicaid \$122.14 per day, an intermediate care facility \$93.11 per day. While about 62% of these costs are federal funds for those who are eligible for

³³ While this unit could initially generate cost-savings, if there are no community services to receive people from this inpatient setting, individuals will remain in what is still a costly setting. Additionally, with no community resources, and the special unit full, North Carolina will have to continue to place people in the state psychiatric settings and nursing homes, neither of which is equipped to effectively serve individuals with TBI. Thus, even with an in-state inpatient unit, North Carolina would continue to see costs and waiting lists increase.

Medicaid, any adults (over age 22) served in state psychiatric facilities are funded purely by state dollars at a cost of \$363 per day. In addition to persons with TBI served in institutional settings approximately \$1.5 million in state funds are in use for people with TBI who are ineligible for CAP MR/DD.³⁴ If any of these individuals meet the eligibility requirements for a TBI waiver, federal funds become available to support their services. In effect, the state funds already being spent could serve as match to “draw down” federal funds for services. This would in turn free state funds to serve new individuals.

The TBI waiver is a key resource to assure that persons can move into the community once inpatient treatment is completed. Without a stable, viable source of funding—and the appropriate specialized providers—these individuals remain in institutional settings. This is very detrimental to persons with TBI as rapid community reintegration is critical to long-term success in the community. The longer persons remain disconnected from their families and communities, the harder the transition. A TBI waiver will provide critical resources to assure return to as productive, self-sufficient life as is possible as well as make better use of state funds already expended for this population.

Recommendations

Given growing pressures for out-of-state placements and the continued use of these placements for short-term services, DMH/DD/SAS should revisit the cost impact to determine if an in-state unit is more cost-effective.

The state should seek the Legislative authority to move forward on the TBI waiver initially utilizing the \$400,000 set aside specifically for this purpose. Additionally, DMH/DD/SAS should refinance all waiver eligible individuals currently using state funds for services. Funds generated from refinancing should be available for expansion of services to individuals with TBI on the waiting list.

³⁴ Eligibility requires that the brain injury occur before age 22 in order to meet the federal definition of having a developmental disability. These data were provided by the DD Division.

System Performance and Oversight



Introduction

A public mental retardation/developmental agency must recognize six important quality assurance responsibilities in its state quality assurance plan³⁵:

- To assure that individuals are free from abuse, neglect, and exploitation;
- To protect the rights of individuals and families;
- To assure accountability in the use of public dollars;
- To assure that individuals have access to necessary services;
- To evaluate the effectiveness of service and supports;
- To assess the performance of service providers;
- To ensure that the voices of people with disabilities and their families are heard and responded to

In addition to these basic responsibilities, the public systems of support should also be committed to the enhancement of services and supports through assertive quality improvement strategies including training, consultation, and dissemination of information on best practices. Finally, it is understood that the primary means of understanding the quality of services and supports should be through the lens of the person receiving services and his or her family.

Quality assurance is a responsibility shared by everyone. Although the focus of this study is on the public system for people with developmental disabilities in North Carolina, all providers of supports and services, individuals receiving services, their families, guardians, advocates, state and federal government have a role in defining expectations and ensuring those expectations are met and exceeded. The focal point of a responsive system is the quality of life for the customer.

A comprehensive quality assurance system consists of multiple components responsive to public quality assurance responsibilities including:

³⁵ Gettings, Robert M., "Building a Comprehensive Quality Management Program for Public Developmental Disabilities Services Systems, NASDDDS, 2001, p. 6-10.

- 1) **Consumer Protections** – The capacity to effectively monitor the physical safety and security of individuals with disabilities who are enrolled in publicly funded programs
- 2) **Service Planning** – the capacity to develop comprehensive, individualized service/support plans and assure that all prescribed services and support are delivered in a timely, effective manner, in accordance with the terms of each individual’s service plan.;
- 3) **Safeguarding Rights** – the capacity to protect the rights of all individuals applying for or enrolled in publicly funded developmental disabilities programs and services
- 4) **Provider Oversight** – the capacity to ensure that all providers of community services and supports meet the qualifications and other operating standards/requirements established by the state.
- 5) **On-Site Monitoring** – the capacity to monitor the overall performance of the service delivery system.
- 6) **Financial Integrity** – the capacity to ensure that public funds are disbursed and managed in an accountable manner and fraudulent transactions are detected, investigated and the responsible parties are punished.
- 7) **Health and Behavioral Health Surveillance** – the capacity to monitor the health status of all individuals with developmental disabilities who receive publicly funded long-term community supports and assure that these individuals have access to appropriate, high quality health and mental health prevention and treatment services.
- 8) **Consumer Satisfaction and Outcomes** – the capacity to obtain structured feedback from individuals and families, as well as comparative data on system-wide performance (both longitudinally and across jurisdictions) in areas deemed critical to achieving overriding systemic goals
- 9) **Quality Improvement** – the capacity to initiate a continuous cycle of activities designed to address weaknesses in the service delivery process and improve service outcomes.

Recent Efforts

In North Carolina, important initiatives are underway to link the various components noted above into comprehensive quality assurance and quality enhancement approach. According to those interviewed, the impetus for the current activities is the quality imperatives laid out in the Quality Protocol released by the Center for Medicare and Medicaid Services in January (to govern federal reviews of the Medicaid Home and Community-Based Waiver), the framework articulated by Robert Gettings above, and a concern for the well-being of individuals receiving services funded by un-matched, state dollars.

As part of these recent activities mounted by the DD Section, planners are working on the outlines of an internal “Quality Management Committee” that would be constituted to review trends apparent in quality assurance data. In addition, after a review of the protocol and the Gettings framework, the DD Section has established six working committees looking at the existing capacity in each of the following areas:

- 1) Health and behavioral health
- 2) On-site monitoring, consumer satisfaction, and consumer outcomes
- 3) Protections and rights

- 4) Service planning
- 5) Area program and provider monitoring
- 6) Financial integrity

These categories coincide with the categories of quality assurance laid out in the recent protocol developed by the U.S. Center for Medicare and Medicaid Services and with a framework devised by Robert Gettings, Executive Director of the National Association of State Directors of Developmental Disabilities Services. A copy of the framework is included in the Appendix. According to key informant interviews, the process of rationalizing the quality assurance components has made headway but is constrained by the fragmentation of quality assurance and the difficulty of getting all necessary policy makers and administrators around the table. This is in part because of reductions in force and the time demands on staff involved in the subcommittee.

As part of their explorations, staff in the DD Section are putting together the outlines of a Quality Management Committee that would be responsible for identifying trends including data from the Core Indicators Project, data from the Division of Facility Services, information from performance agreements, data from Program Accountability, Client Advocacy and Quality, and DMA Program integrity.

The group is also reviewing mortality monitoring and there is increasing concern that provisions of the Mental Health Reform bill will eliminate the current comprehensive review of Thomas S. class members. Currently the Division of Facility Services conducts death reviews in licensed facilities and does a report within 3 days. There is no follow up and the reviews appear to only be aimed at obvious criminal or abuse neglect issues. No information is collected systematically regarding cause of death and trend data is rarely analyzed.

With respect to the review of providers (outside of licensing), the extent of monitoring has in fact diminished for waiver providers now that they have a direct billing relationship with DMA. As a consequence, Area Programs are no longer involved in such monitoring. While DMA does do a sample record review, this can no substitute for systematic monitoring and observation.

Recommendations

- The Secretary and the new Division director should ensure that all parties critical to the development of a quality management activity participate in the process on a regular basis and make relevant data available
- The DD Section should deploy resources on a regional level to conduct provider monitoring and to provide technical assistance to the LME regarding quality assurance components of local business plans. The DD Section should consider using family members and people with disabilities as part of external provider monitoring teams.
- Business plans for the LME should include specific provisions for the oversight of the well being of people with developmental disabilities receiving services in those communities.
- Abuse and neglect investigators should be trained and certified; and assistance should be sought from the State Police help in this process.
- The quality management activity should include both an internal as well as external process for reviewing relevant information. The external group should include people with disabilities and their families as well as providers and other interested constituencies.

- The Division and the DD Section should take steps to replace the mortality review process that was established as part of Thomas S. Such a process should include both an investigation of the circumstances of those deaths deemed to be “untimely” or suspicious as well as a review of the causes of death. Such causes should form the basis for trend analyses. Aggregate trends should be reviewed by the Quality Management Committee.
- The use of the Council on Accreditation process should be reconsidered as a quality assurance approach for people with developmental disabilities. The expense and lack of concentration on outcomes relevant to people with developmental disabilities and their families suggests that the COA approach is an inefficient use of scarce resources.

Provider and Area Program Responses

System Performance and Oversight

Based on the results of the electronic surveys, DD System oversight is seen as adequate in terms of assuring health and well being, but area program directors and service providers generally agree that the system does not adequately monitor outcomes. Directors report that monitoring expectations of Area Programs constantly change, without adequate notice and funding support. They requested more on-site technical assistance and training prior to implementation of new rules and regulations. There was some disagreement among respondents on whether the responsibility of local monitoring providers should rest with the Area Programs or with the Division.

According to providers, the system lacks consideration of the whole person, understanding values of minority cultures, and a quality improvement/training component. Many providers conduct their own consumer surveys and other types of feedback activities. They feel that the system should be standardized across areas and should focus more on encouraging improvement through training, mentoring, and corrective action plans, rather than a punitive approach.

Area Program Directors and Providers were asked to characterize the state requirements for QA:

Response option:	AP Directors Number (%) of Responses			Providers Number (%) of Responses		
	Always	Sometimes	Never	Always	Some-times	Never
QA provides an comprehensive picture of individual well-being	1 (9%)	8 (73%)	2 (18%)	1 (4%)	20 (74%)	6 (22%)
QA provides us with information that is useful in individual planning	2 (18%)	7 (67%)	2 (18%)	3 (11%)	16 (59%)	8 (30%)
QA ensures the health and well-being of people with developmental disabilities	3 (30%)	1 (10%)	6 (60%)	1 (4%)	23 (85%)	3 (11%)

“QA has become only a stopgap measure to prevent extreme cases of neglect. It is not current on achieving personal outcomes and offers no support in the improvement of services, only in the maintenance [of] minimal quality.” - DD Provider

System Financing

All respondents were asked to rate the adequacy of funding for various administrative functions including monitoring quality assurance, management of information, etc. The categories were slightly different, depending on the respondent group. Categories that overlap both groups are shaded for comparison purposes.

Area Program/DD Program Component:	Number (%) of Responses (n=25)	
	Adequate or Sometimes Adequate Funding	Not Adequate Funding
Case Management	22 (88%)	3 (12%)
Information systems	15 (60%)	10 (40%)
Quality assurance	15 (60%)	10 (40%)
Contract Monitoring	13 (52%)	12 (48%)
Training	19 (76%)	6 (24%)
Outreach	16 (64%)	9 (36%)
Accounting	22 (88%)	3 (12%)
Human Resources	19 (76%)	6 (24%)

Provider Agency Administrative Operation:	Number (%) of Responses (n=28)	
	Adequate or Sometimes Adequate Funding	Not Adequate Funding
Promptness of reimbursement	19 (67%)	9 (32%)
Information systems	14 (50%)	14 (50%)
Quality assurance	23 (82%)	5 (18%)
Training	16 (57%)	12 (43%)
Staff Salaries	13 (47%)	15 (54%)
Accounting	10 (62%)	6 (38%)
Non-traditional services (e.g., recreational support)	13 (46%)	15 (53%)

Provider Standards and Privileging

The required provider qualifications under CAP MR/DD are generally reasonable for agency-based, traditional providers. The standards require all providers to meet a set of Core Competencies as well as any applicable licensing or certification. For example, providers of day habilitation are licensed under GS-122C and all direct care workers must have training in the Core Competencies as well as any “client-specific competencies identified by the client’s treatment team.” The licensing requirements are typical, laying out agency structure, minimum staffing requirements or in the case of living arrangements, floor space and other physical plant requirements. The process for privileging these providers (deeming them qualified) requires submission of documentation and various agreement to the Program Accountability Section for review and approval. Again, this is standard practice for qualifying agency-based providers.

Generally, agency-based providers did not report these standards as particularly difficult to meet. What is problematic is the requirement of Core Competencies for all providers, including family members, neighbors and friends providing services such as respite or personal care. The impetus behind—and the content of—the core competencies is well-meaning. They cover key training areas that affect the well being of consumers. Direct service workers must complete training in the following areas *before* commencing work with the individual:

- Client Rights
- Abuse
- Neglect
- Confidentiality
- BBP/Universal Precautions
- Interaction and Communication Strategies
- Incident/Accident Reporting
- Role/Purpose/Philosophy of services
- CPR/First Aid (unless other trained person always available)

- Type of Service and required documentation

The following training must be complete within 90 days:

- Overview of Developmental Disabilities
- Person-Centered Planning Orientation

It is of course difficult to argue with the items on these lists. Competencies in these areas can only improve the skills of the individual providing support. For agency direct care staff that may work with a variety of individuals, these afford a basic skill level that is of use to whomever the direct care worker supports.

The problem arises when the individual provider is a friend or neighbor supporting only one individual and not employed through an agency. Many states, rather than requiring the same type of training as agency personnel, allow specific experience or skills to substitute for the generic “core competencies.” The planning team reviews the person’s experience and qualifications on a case-by-case basis. The team, with approval perhaps from a higher authority (such as the AP), “deems” the individual competent based on a combination of training and experience. If the individual needs specific skills to support the person, then training in these selected areas must be completed before the person is deemed qualified.³⁶ Rather than a “one size fits all” approach, individual providers are qualified based on the match between the needs and preferences of the consumer and the provider skills and experience. Background checks are still required as is the healthcare registry check and medical statement. This works very well for a number of services such as respite, personal care, or homemaker-type services. Colorado uses this process under their supported living waiver; Wisconsin qualifies their supportive home care workers (individual providing in-home support, supervision and training) by matching experience to the needs of the person.

If the DD Section is serious about moving toward more self-determined services, then opening up the provider pool to non-agency (and other non-traditional) providers is crucial. Of course, opening up the provider pool is not a license to permit unqualified, untrained individuals to provide services. However, the use of independent practitioners does require a more flexible approach that still assures they are qualified.

Recommendation: *Allow non-agency-based, independent practitioners to become qualified providers through an alternative to the Core Competencies. These providers can substitute other training and experience germane to the individual they support that is reviewed and approved by the treatment team and AP. These providers would still be subject to background and healthcare registry checks as well as a medical statement.*

Additionally, the process to qualify independent providers does not lend itself to paperwork review by the Program Accountability Section. Approval of independent providers should move to the local level with sample monitoring and oversight performed by Program Accountability.

³⁶ Actually this requirement is already in place as CPA MR/DD providers must also meet any client-specific competencies required by the treatment team.

Today's Choices



Strategic Concerns

What are the critical strategic issues and challenges with which North Carolina must grapple if it is to improve its supports of citizens with developmental disabilities? A clear understanding of these issues is absolutely vital for North Carolina to chart “Tomorrow’s Path” – the near and long-term strategies that the state must pursue in order to configure its developmental disabilities service system to meet the needs of individuals and families economically and effectively. Here, we identify what we regard to be the sentinel strategic issues that must command serious attention going forward.

North Carolina lacks a clear vision for its system of services and supports for people with developmental disabilities. As a consequence, there is no consensus and frequent disagreement concerning the system’s fundamental mission and how it will be pursued in the near and long-term.

In order to chart “Tomorrow’s Path,” there must be broad-based consensus concerning the service delivery system’s fundamental, essential mission – what the system is striving to achieve on behalf of individuals and families. At present, such consensus is noticeably lacking in North Carolina. The shop-worn cliché that “if you don’t know where you are going, any road will get you there” fits North Carolina all too well. Because there is no clear, shared vision regarding the essential aims and purposes of the service delivery system, the present system lacks coherency and is not goal-driven. Issues and problems are debated and reacted to item-by-item rather than dealt with in the larger context of system mission and shared goals.

In part, this lack of a clear vision stems from North Carolina’s tendency to create funding/program silos that pose enormous obstacles to putting into place a coherent, unified system of services and supports. We discuss this silo problem in more detail below. The problem also arises as a result of the considerable fragmentation in system management responsibilities and accountability at both the state and local levels. This situation is exacerbated by the competition for resources and attention within DMHDDSAS and at the local level in meeting the needs of varied target populations.

We know of no state where substantial, ongoing progress in meeting the needs of people with developmental disabilities has taken place in the absence of a shared, clear and coherent vision of system mission and goals. When there is a lack of consensus among state officials, policy makers, advocates, individuals and families, and providers, it is virtually impossible to agree on the near and long-term steps necessary to improve performance and outcomes. Where such consensus has been achieved (e.g., Vermont’s System Unification Plan, Pennsylvania’s Multi-year Plan for mental retardation services, Michigan’s restructuring of its mental health/developmental disabilities system based on person-centered principles), such consensus continuously informs strategic planning and decision-making (e.g., “Is this step on the path we have chosen?” or “What obstacles stand in our way of achieving a desired outcome?”).

For example, Vermont committed to building an entirely community-centered system that would provide people with developmental disabilities access to person-centered supports to promote community integration and membership. This commitment (a) led to identifying and ramping up critical community capabilities (e.g.,

a community-centered crisis response system and a durable, continuous commitment to community worker training) that were vital in order to proceed with the closure of Brandon State Hospital (the state's only public institution), (b) resulted in the state's selecting the Medicaid HCBS waiver program as its principal avenue for financing its system because the parameters of the waiver program were most congruent with the plan's goals (including emphasizing person-centered and highly integrated support strategies), and (c) centered attention on individualized living arrangements and integrated employment opportunities for people with developmental disabilities. The commitment also animated key structural reforms and gave Vermont a solid basis for measuring and improving system performance.

The absence of consensus concerning the fundamental mission and goals of North Carolina's service system has led to and continues to cause the system to drift, results in too many short-sighted "make do" decisions and has spawned numerous initiatives (e.g., family support and self-determination) that are implemented in only a very limited fashion.

Going forward, it is absolutely vital that North Carolinians arrive at consensus concerning the central aims of its services and supports for its citizens with developmental disabilities. This consensus must span the entire system and all people who receive publicly funded services.

Today, North Carolina is unable to serve all people and families who need services and supports. Absent action to expand system capacity substantially, there is every prospect that this situation will worsen.

In July, there were 7,000 North Carolinians with developmental disabilities waiting for services and supports. More than half of these individuals receive no services at all. Most are waiting for basic, essential services – in-home supports in the case of children, work and residential supports in the case of adults. The lack of supports for these individuals causes serious degradation in the quality of their and their families' lives. In North Carolina, there is no guarantee that individuals or families will receive services. For example, youth with disabilities who leave school where they may have acquired important life and work skills are not assured of continuing services and supports. By the time services become available, they face starting all over again.

When basic services and supports are not available to individuals and families, a service system becomes beset by a rising tide of crises as personal and family situations unravel. The service system shifts to a "triage" mode where services are furnished to persons who have the most urgent needs and addressing the needs of other individuals and families is postponed, setting the stage for more crises in the future. Triage frequently results in stopgap "solutions" to resolve the problem at hand rather than working out the best solution for each individual. Too often, the "stop-gap" is to institutionalize the person.

Moreover, the sheer size of North Carolina's waiting list places the state increasingly at risk of litigation that could result in federal court intervention to force the state to expand or guarantee access to services. Federal lawsuits already have been filed in seventeen states challenging the practice of wait listing individuals for services.³⁷

The fact that North Carolina's system today cannot meet the needs of a very substantial proportion of its citizens with developmental disabilities is a critical, overarching strategic issue. This problem has persisted for many years, although there was some – albeit short-lived – progress in reducing the waiting list two years ago as a result of special appropriations and the expansion of the CAP/MR-DD program. Looking ahead, the demand for services and supports in North Carolina is certain to grow at a brisk pace for the foreseeable future. The demand for developmental disabilities services is increasing rapidly nationwide, as a result of demographic and other factors. There is no reason to believe that the situation will be any different in North Carolina.

³⁷ Gary Smith (September 2001). "Status Report: Litigation Concerning Medicaid Services for Persons with Developmental Disabilities." Salem Oregon: Human Services Research Institute.

Our assessment³⁸ of North Carolina's present level of effort in support of its citizens with developmental disabilities revealed that – relative to population – the state presently supports fewer individuals than is the rule in other states. The dimensions of the present waiting list are not surprising given this situation. Indeed, all that is surprising about the size of the current waiting list is that it is not larger. So far as we are able to determine, the present waiting list by no means overstates the extent of unmet demand in North Carolina and more likely understates demand.

During the 1990s, North Carolina considerably stepped up its financial support of developmental disabilities services. Absent this increase in funding, today's situation would be substantially worse. However, despite these efforts, North Carolina's financial effort in support of developmental disabilities services is not appreciably different than the nation at large and well below that of many other states.

From a "top-line" perspective, in light of North Carolina's present level of financial effort and the sheer size of the gap between present system capacity and expressed demand for services and supports, "closing the gap" – catching up with the present backlog in meeting service demand and keeping pace with the likely growth in demand going forward – cannot be accomplished solely by redeploying current dollars, although there are some opportunities that merit attention along these and other lines that can contribute to expanding system capacity. There is no zero-cost solution.

From a strategic perspective, there is no more important or critical challenge facing North Carolina than charting a course to ensure that all its citizens with developmental disabilities who need services and supports receive them promptly. Individuals and families should not be divided into "haves" and "have nots." A healthy service system provides universal, equitable and prompt access to services and supports.

North Carolina's present budget problems obviously cannot be ignored when considering steps to expand system capacity. For the time being, it would be unrealistic to expect that new state dollars can be infused into the system, although certainly more will be required in the future. Hence, any near-term strategies must revolve around redeploying current dollars, improving efficiency and/or securing more federal dollars.

Even if the state's budgetary circumstances were better, the necessary expansion in system capacity necessarily would be a multi-year enterprise. It will take time to build out system capacity. Every state that has launched a serious initiative to reduce or eliminate a large waiting list is pursuing a multi-year strategy employing three-to-five year time horizons. Moreover, simply scaling up the availability of current services and supports will not necessarily be the best path for North Carolina to follow. Concurrently, there must be fundamental changes in how North Carolina supports people with developmental disabilities and families in order to reconfigure services and supports to promote the use of cost-effective person and family-centered supports.

Going forward, North Carolina must answer a very fundamental question: **"What actions will contribute to closing the gap between system capacity and service demand so that all North Carolina citizens with developmental disabilities who have legitimate needs for services and supports receive them promptly?"**

North Carolina has especially high utilization of and reliance on costly legacy institutional, ICF/MR and other congregate services. North Carolina has not developed or implemented the strategies to move forward in supporting all individuals in the community.

North Carolina's utilization of legacy services – large state-run facilities and ICFs/MR – is abnormally high and distinguishes North Carolina from most other states.³⁹ Relative to population, North Carolina serves more individuals in its large state-run facilities and in ICFs/MR than is the case nationwide and in the substantial

³⁸ Human Services Research Institute (August 2001). "Gauging North Carolina's Level of Effort in Support of Its Citizens with Developmental Disabilities."

³⁹ Ibid.

majority of states. Still more individuals are served in congregate adult care homes. Elsewhere, states have significantly cutback the use of these services in favor of promoting everyday living in the community and the provision of more flexible, person-centered services and supports. Scaling back legacy services also had contributed to improved cost effectiveness in most states.

One outcome of North Carolina's high utilization of these services is that people with developmental disabilities are served in larger settings than is common in other states, a result that appreciably detracts from their quality of life. High ICF/MR utilization – whether the MR Centers or non-state facilities – also elevates North Carolina's per beneficiary cost of furnishing Medicaid long-term services well above the nationwide average. Elsewhere, states rely more heavily on the Medicaid HCBS waiver program to support individuals and far less on legacy services.

Continued high utilization of legacy services is a costly proposition for North Carolina. Over the past decade, MR Center per resident costs have spiraled upward, even after adjusting for inflation. Center spending has not dropped appreciably even though the number of Center residents declined significantly during the 1990s. North Carolina devotes a higher proportion of its budget to “congregate services” than is typical nationwide or the majority of states.

In North Carolina, legacy services have come to be regarded as “necessary” due to real and perceived shortcomings of community capabilities. Individuals are described as “requiring” MR Center or ICF/MR services because it is believed that they cannot be otherwise supported in the community or due to the severity of their disability. In point of fact, there are very few people who cannot be supported in the community. Several states have closed down their large state facilities entirely and make little or no use of non-state ICFs/MR or settings like adult care homes. The experiences of these states demonstrates that operating an entirely community-centered system is feasible, from either a programmatic or a financial standpoint.

It is important to recognize that whatever “necessity” there is to legacy services stems principally from the lack of key capabilities or is the byproduct of policies that bias service selection and resource allocation. For example, North Carolina has decided to operate its CAP/MR-DD waiver program in a fashion that effectively prevents individuals who require especially extensive supports from being supported in the community.

North Carolina finds itself caught up in a “chicken-and-the-egg” problem with respect to legacy services. Substantially cutting back on the number of individuals served at the MR Centers is regarded as infeasible due to the lack of or weaknesses in critical community capabilities. But, dollars that could contribute to strengthening community capabilities continue to be tied up in operating the Centers.

At the end of the day, unless North Carolina significantly reduces its utilization of and reliance on legacy services, the result will be that: (a) North Carolina will continue to devote a disproportionate share of system resources to these services; (b) the per beneficiary costs of furnishing Medicaid long-term services will remain high; and, (c) the overarching aim of ensuring that all individuals have access to appropriate, person-centered supports in the community will be undermined.

North Carolina's service system for people with developmental disabilities is built around funding/program “silos.” These silos are the source of inefficiency, pose substantial barriers to system unification and fundamentally undermine the principle that the services and supports individuals receive be based on their individual needs and preferences.

When dollars are cordoned off into categorical programs and the services/dollars available to support individuals with similar needs differ markedly program-to-program, the result is funding/program “silos.” Silos cause the inefficient use of resources and dollars not to be portable. They pose substantial barriers to framing the provision of services and supports employing person-centered principles. Silos also seriously undermine the underlying, essential aims of a single-portal system because the types of services individuals receive

frequently hinge on the availability of an empty “slot” or “bed” in one silo or another rather than the specific needs of each person.

We count at least six program/funding silos in North Carolina:

- The Mental Retardation Centers;
- Non-state ICFs/MR;
- CAP/MR-DD Waiver Program;
- The pool of dollars earmarked for MR/MI services;
- Services underwritten with state-only dollars; and,
- Adult care homes

Within each silo, people with similar needs receive different services and supports. It is inordinately difficult in North Carolina for people to move from one of these silos to another. For example, it is believed that there are numerous individuals in non-state ICFs/MR who could be readily and more satisfactorily supported in the community through the CAP/MR-DD waiver program. But waiver slots are not available. Or, if these people were enrolled in the waiver, the net result would be to reduce the number of individuals on the waiting list who might be offered CAP/MR-DD services.

The provisions of S.B. 1395 nominally cross-link the MR Centers and non-state ICFs/MR under the single ICF/MR bed cap but, for all practical purposes, each sector operates independent of the other. The CAP/MR-DD waiver program is operated as a distinct program/funding sector. It has its own slot/funding limits as well as distinct programmatic rules and operational requirements. Even though CAP/MR-DD and ICF/MR eligibility are the same, utilization caps on both programs and other policies result in walling one program off from the other.

There have been ongoing efforts to integrate services and funding of persons with mental retardation and mental illness into the mainstream of community services. However, progress has been slow, in part because many of the needs of these individuals cannot be satisfactorily addressed in the CAP/MR-DD program as presently constituted. Due to issues in supporting these individuals in the community, proposals have surfaced to create special units at the MR Centers to serve these individuals, a step backwards.

North Carolina also has not fully integrated its state-funded community and Medicaid-funded services, even though this step is critical in order to maximize federal Medicaid dollars and afford individuals and families equal access to a common, unified set of services and supports. Similarly situated individuals are treated differently, depending on whether they qualify for Medicaid services (and a CAP/MR-DD slot is available).

The adult care (rest) home silo is especially problematic. There are very serious questions concerning the appropriateness of rest homes as living arrangements for people with developmental and other mental disabilities. The especially large number of persons served in adult care homes is not an intentional result (i.e., the result of an assessment that a rest home placement will most appropriately meet the needs of an individual) so much as it is the outgrowth of funding silos. Rest home funding is outside the developmental disabilities system. The dollars that support individuals in rest homes (the adult care home supplement and Medicaid personal care dollars) are not available to support individuals who prefer or would benefit from other alternatives. The high utilization of rest homes is the unintentional consequence of North Carolina’s cost containment of its developmental disabilities programs. This result is no different than what occurred in several other states when large numbers of individuals were inappropriately admitted to nursing and similar

facilities due to the lack of specialized developmental disabilities services and supports. Service demand flows to what's available when specialized services and supports are rationed or unavailable.

In order to unify the funding of services and supports and reposition the service system so that people with developmental disabilities can be supported based on their unique needs and preferences by providing equal access to a common package of services and supports, North Carolina must tear down these silos. Unless and until this happens, North Carolina's system will not function in the best interests of individuals and families. Operating programs in isolation from one another is counterproductive, inefficient and costly.

North Carolina's present system is an especially weak platform for furnishing person-centered supports. North Carolina faces many challenges in repositioning its system around the principles of person-centered supports.

In order for a service system to serve as a sound platform for the provision of person-centered supports, it must have certain structural features and capabilities. For example, funding and purchase of service mechanisms must embrace flexibility and portability. Dollars must be decoupled from specific service categories or service providers in favor of open-contracting, open-panel approaches. Service systems must tie dollars to the individual. The system must be structured so that decisions concerning dollars are driven by person-centered plans rather than fitting individuals into predefined programs/models. There must be solid service/support coordination capabilities and ongoing engagement with and support of individuals and families in realizing the outcomes expressed in their person-centered plans.

North Carolina's program/funding silos clearly are antithetical to person-centered supports. Individual needs and preferences cannot be easily accommodated because of these silos. The program that in theory should be guided by person-centered principles – the CAP/MR-DD waiver program – is very rule bound and prescriptive and therefore makes it extremely difficult to pursue person-centered support strategies. Although person-centered planning has been mandated in the CAP/MR-DD program, the program's rules and requirements work at cross-purposes with furnishing person-centered supports. Service/support coordination resources have been diverted to auditing provider billings and records and enforcing program requirements rather than devoted to assisting individuals to achieve their preferred outcomes.

A central element of person-centered supports is supporting families. Historically, North Carolina has not devoted significant dollars to family-centered, family support services. Even though such supports are exactly what many families want, only a few families are able to receive very limited, flexible supports.

Although North Carolina has made some progress in aiding people with developmental disabilities to obtain real, meaningful jobs in the community, the state's performance along these lines remains lackluster. There are large numbers of individuals who want community jobs but are backed up on the waiting list. North Carolina also has performed poorly in supporting people with developmental disabilities to live in a home of their own. In North Carolina, "supported living" has become synonymous with family living rather than aiding individuals to live on their own in the community in homes of their own.

Nationwide, states are working diligently to offer individuals and families expanded opportunities to manage their own supports employing the principles of self-determination. Many states and localities have made considerable progress over the past four years in this regard. In North Carolina, however, little progress has been made so far in offering individuals and families direct control over resources and the authority to manage their own services and supports.

North Carolina's present system falls substantially short as a platform for person-centered supports. Consequently, a central strategic issue facing the state is how it will restructure its system to adopt a "one person at a time" orientation to supporting people with developmental disabilities.

There are material defects in the CAP/MR-DD waiver program. As a consequence, North Carolina is not able to realize the benefits afforded by the HCBS waiver program to serve as a solid vehicle for the provision of person-centered supports or as the centerpiece of a system unification strategy.

Nationwide, the HCBS waiver program now serves as the primary vehicle for states to acquire federal dollars to underwrite diverse community services and supports for people with developmental disabilities. The HCBS waiver program affords states considerable flexibility and latitude. It can underwrite a wide-range of services, including family supports, person-centered supports (including employment) and traditional services (e.g., group homes and facility-based day services). In many states (e.g., New Hampshire, Vermont and Wyoming), the HCBS waiver program has enabled unifying the funding for community services under a single stream and thereby assisted in putting into place a unified package of benefits and a coherent approach to supporting individuals.

In contrast, there is considerable dissatisfaction in North Carolina with the operation of the CAP/MR-DD program. The program is widely regarded as “rule-bound” and inordinately complex. Its complexity causes numerous headaches. For example, by some estimates, case managers devote half or more of their workday to ensuring that all the “i’s are dotted and the “t’s” crossed. Preparing service plans or accommodating even simple changes in plans triggers considerable paperwork. As observed by the Lewin Group study of North Carolina’s Medicaid program, CAP/MR-DD services have been defined in such an intricate fashion that makes it virtually impossible to screen claims to determine if they are allowable as they pass through the state’s Medicaid payment system because of the large number of conditions placed on service authorization/provision. As a result, a heavy burden falls on case managers to conduct pre-review of the claims. For providers, “pay backs” are a constant concern. Many families remark that the services individuals receive are not exactly what they want or need. For many years, there have been complaints that CAP/MR-DD rules and requirements result in higher costs than need be and that program reform would enable more individuals to be served.

The CAP/MR-DD program is structured so that the greater a person’s needs for specialized services (in the form of “Y-code” services), the less other basic supports a person can receive, a perverse outcome that contributes to continuing reliance on legacy services. The program is not well designed to support individuals who no longer live with their families. This defect, in turn, leads to the view in North Carolina that the state must maintain or even expand ICF/MR services.

Going forward, the HCBS waiver program affords North Carolina its best and most powerful opportunity to acquire federal dollars to expand services and supports. It can play an enormously important role in assisting the state to work out of the problems caused by the funding silos. Hence, it is absolutely critical that North Carolina seriously consider revamping the CAP/MR-DD program.

In North Carolina, critical collective system capabilities need to be strengthened. Weaknesses in these capabilities undermine confidence in community services and causes continued over reliance on legacy services.

In order for a service system to function effectively in support of people with developmental disabilities, it must have certain capabilities that buttress the provision of individual services and supports. When such capabilities are not in place, the end result is a system that falls short of effectively and adequately supporting individuals and families and/or causes the over utilization of very costly legacy services.

For example, in North Carolina, a prime rationale for the continued operation of the MR Centers is that the community does not have the capability to serve individuals who have especially serious health or behavioral problems. It is said that the Centers possess expertise that the community at large does not have and, hence, the Centers have to be maintained.

So long as North Carolina fails to recognize that it must have certain system-wide capabilities in place to address critical dimensions of supporting people and families in the community, there will be continued pressures to maintain the present capacity of the MR Centers or develop more ICFs/MR. These “solutions”

are too costly and too limited in their scope. If North Carolina's system is to become resolutely community-centered, then these capabilities must be developed and available throughout North Carolina.

The critical system-wide capabilities that North Carolina must develop include:

- Putting into place an effective approach to ensuring that the health care needs of North Carolinians with developmental disabilities are addressed effectively and continuously in the community. North Carolina has not devoted adequate attention to health care for people with developmental disabilities. Attention to health care is essential for quality of life and avoiding institutionalization. Access to effective health care services also holds costs down over the long-term. Proactive steps are necessary not only to ensure access to basic health care services but also to develop networks of expertise around North Carolina that are specifically designed to meet the health care needs of people with developmental disabilities in the community.
- In a parallel vein, North Carolina must develop system-wide capabilities to respond effectively in support of people who have behavioral challenges so that they can continue in – rather than face being removed from – the community. At present there is no comprehensive strategy to address the needs of these individuals even though the lack of such capabilities is regularly cited as a shortcoming of community services.
- North Carolina also must develop an effective, broad-based and continuous capacity to train its community developmental disabilities work force and upgrade its skill/competency level. The lack of this capability seriously diminishes the quality, value and effectiveness of services and supports. Concerns about the stability and competence of the community workforce have been voiced from many quarters. The community work force is the system's linchpin – services and supports will only be as good as the workforce is capable of furnishing.
- North Carolina must embrace and invest in systematic and broad-based continuous quality improvement. Today, "quality" in North Carolina means determining conformity and compliance to rules and regulations. Certainly, it is important that baseline standards be met and that people with developmental disabilities are afforded essential, fundamental protections. However, there must be strong emphasis on quality improvement in order to move the system forward by creating a climate that supports change in support of better performance and improved outcomes for people with developmental disabilities. In North Carolina there is too much attention paid to rote compliance and too little to quality improvement.
- Finally, there is little doubt that North Carolina must rethink its present approach to the operation of the single portal and service/support coordination. Single portal's conceptual basis is sound enough. However, its functioning is hamstrung by North Carolina's funding silos and other systemic problems. In a similar vein, there are material defects in service/support coordination, not only in the CAP/MR-DD program but more broadly as well. Service/support coordination in North Carolina must be revamped to provide not only more direct and relevant assistance to people with developmental disabilities in accessing specialized services but also effective help in enabling access to non-specialized services along and more direct assistance to individuals and families.

Often, these capabilities can be too costly for community service organizations or Area Programs to create on their own. They are best thought of as "collective" capabilities that are implemented most effectively employing system-wide approaches. Absent the development of these collective capabilities, North Carolina's service system will continue to struggle in supporting individuals with developmental disabilities in the community.

Summary

Each of these seven critical issues is daunting in its own right. Moreover, in many respects, none can be addressed in isolation from the others. They are interconnected. For example, community workforce problems cause reluctance to cut back the use of legacy services and create uncertainty about North Carolina's commitment to person-centered supports, because such supports hinge on a skilled workforce. The most economical and effective way for North Carolina to meet the needs of people waiting for services is to expand HCBS waiver services but the CAP/MR-DD program itself needs reform. Expanding the program in its present form is not necessarily the best strategy to secure reductions in the waiting list as cost effectively as possible.

In many respects, the central strategic issues facing North Carolina parallel issues in other states. Some of these issues (e.g., over utilization of legacy services) are more pronounced in North Carolina than elsewhere. However, it would be too facile to simply describe the present situation in North Carolina as "like other states." Broadly, North Carolina's present situation is unique and of its own making. Particularly lacking in North Carolina is the lack of agreement and commitment to address these issues in a comprehensive, systematic and holistic fashion going forward. Instead, there is an inclination to address problems in isolation or avoid making fundamental changes that would address the root causes of these strategic problems and issues.

Tomorrow's Path



Introduction

Clearly, it is vital to have a clear grasp of the central problems that confront a state's service system. However, the greater challenge is to identify effective strategies to address such problems singly or in combination. The issues with which North Carolina must grapple are complex. They are not amenable to quick fixes. In order to address these problems, the state must embark on system change over a multi-year period. All North Carolina stakeholders must collaborate in this system change.

Here we offer our suggestions and recommendations concerning the steps we believe North Carolina should seriously consider in addressing the challenges it faces. These recommendations have been formulated with two main considerations in mind:

- System change in North Carolina must firmly embrace the principles of person-centered supports. These principles have been articulated in various ways but most powerfully and simply in *Person-Centered Supports – They're for Everyone*, a document that emerged from a consensus conference sponsored by the National Association of State Directors of Developmental Disabilities Services, Inc. These principles call for public systems to "... empower and support all people with developmental disabilities to realize their own vision for their lives." These principles envision the restructuring of public systems to support each and every person and family "one-at-time" in the community. Services and supports must match the unique needs and expressed preferences of every individual. Individuals and families must have real authority over services and supports. The principles of person-centered supports define the contemporary standard of excellence in supporting people with developmental disabilities.

"Tomorrow's path" in North Carolina should concentrate on manifesting the principles of person-centered supports throughout its public system of services and supports for people with developmental disabilities. There is no reason why North Carolina should not set its sights high. North Carolina is every bit as capable as any other state of achieving excellence. There are thousands of individuals in North Carolina who are enormously committed to supporting people with developmental disabilities. What has been lacking in North Carolina is a shared vision of the future that will enable harnessing this commitment in pursuit of excellence. The principles of person-centered supports will provide North Carolina a cohesive framework in charting an effective multi-year plan for system change.

- At the same time, our recommendations are leavened by present realities and capabilities in North Carolina. It would serve no purpose for us to make recommendations based on overly optimistic assumptions. For example, eliminating North Carolina's waiting list will require more state tax dollars. There is no rearrangement of current dollars that reasonably can be expected to free up sufficient money to eliminate the waiting list entirely. As elsewhere, North Carolina's budget has been sorely battered by recession and other factors. Hence, we do not include a recommendation that the legislature simply solve the waiting list problem by appropriating more state tax dollars. Instead, we offer recommendations

that in the near to mid-term offer the potential will to expand the availability of services by changing how dollars are used today and/or acquiring more federal Medicaid dollars.

Similarly, fully embracing the principles of person-centered supports should cause North Carolina to seriously contemplate closing down long-term residential operations at all its MR Centers. However, this cannot realistically be accomplished within a three-five year time horizon or, if attempted, could cause more harm than good. Instead, our recommendation concerning the Centers sets a more modest objective – one that we believe is feasible even though it will require North Carolina to arrange for more community placements within a five-year period than it ever has in the past.

North Carolina cannot solve all its problems overnight. No state ever has. States that have positive reputations in supporting people with developmental disabilities engaged in system change over multi-year periods, not all at once. But, it is vital that North Carolina launch system change right away.

Over the near to mid-term, North Carolina’s framework for system change should emphasize the following themes:

- **Support all people in the community.** North Carolina should substantially reduce its use of congregate living arrangements, including its MR Centers.
- **Embrace person and family-centered supports as the state’s “primary care system.”** North Carolina must restructure its system so that it is capable of responding to the unique needs and preferences of each and every person.
- **Create a unified benefits package and a system of funding that promotes flexibility while containing costs.** This means that North Carolina must deconstruct its funding/program silos and revamp its funding of community services.
- **Strengthen key capabilities in the community and system-wide.** North Carolina must strive to ensure that critical capabilities are in place throughout the state to meet the needs of people and improve quality.
- **Use the HCBS waiver program to serve as the state’s primary financing mechanism.** The HCBS waiver program affords North Carolina its best opportunity to finance services and supports in a way that is compatible with the principles of person and family-centered supports.
- **Redeploy dollars and maximize federal Medicaid dollars.** North Carolina must seize on all opportunities to shift dollars to the community and acquire additional federal dollars to expand services to close the waiting list gap and underwrite improved system-wide capabilities.

In the main, our recommendations concern actions that principally must be initiated and conducted out by the executive branch. **However, we also are mindful of the Legislative Oversight Committee’s strong interest in system reform and point out areas legislative and executive collaboration.**

Recommendations

Organizing for System Change

At the outset, it is enormously important that North Carolina recognize that it will be engaged in complex system change over a multi-year period. An important question to address right away is: “How can we best organize ourselves to conduct system change?” One model for organizing system change is for the executive branch (i.e., the Department of Health and Human Services) to prepare a multi-year plan and then

seek feedback before finalizing the plan. This model is appropriate in many cases and often necessary when there are tight deadlines.

However, there is an alternative model that we believe would serve North Carolina better in conducting multi-year system change. This model posits that system change should be conducted as a collaborative enterprise that engages stakeholders (people with disabilities, families, advocates, community service organizations, and state officials) as active and valued participants in arriving at shared goals, setting objectives and identifying strategies to accomplish them. This way of conducting system change engages stakeholders themselves in setting priorities and shaping solutions. The multi-year plan is the product of active engagement with and problem solving by stakeholders rather than a document to which stakeholders react. This approach to system change builds cohesion.

This collaborative model has been employed successfully in other states. For example, stakeholders were engaged early on and have been involved ever since in the development and implementation of Pennsylvania's multi-year plan to reform services for individuals with mental retardation. The Office of Mental Retardation's Planning Advisory Committee played a central role in the development of the multi-year plan and key strategies (e.g., the State's waiting list plan). As a consequence, Pennsylvania's plan enjoys broad support. In Oregon, a similar approach was used to develop of the state's Universal Access Plan and map out implementation strategies following the Oregon Legislature's agreement to underwrite the costs of implementing the plan.

North Carolina has not had a good track record in engaging stakeholders as active collaborators. Where planning groups have been formed up, they frequently have not included adequate representation of all stakeholder constituencies or often have been put in the position of reacting to proposals rather than engaged in actively developing solutions. This lack of collaboration has caused mistrust.

Therefore, we recommend that right away:

The Secretary of DHHS appoint a Developmental Disabilities System Change Advisory Committee composed of a cross-section of stakeholders and charge this Committee with developing and overseeing the implementation of a multi-year plan for the developmental disabilities system.

We further recommend that the majority of the Committee's membership be composed of individuals with developmental disabilities and family members so that "end-users" play a central role in shaping the multi-year plan. In the past, North Carolina has not done as good a job as it could in directly including people with developmental disabilities and families as partners in system shaping activities. This has bred mistrust by raising questions about whether decisions have been made with the best interests of end-users in mind. System change in North Carolina should rigorously adhere to the "nothing about us without us" rule. Successful system change must include individuals and families as central and valued allies.⁴⁰

Obviously, the Committee also must include other key stakeholders (e.g., advocacy organization representatives, local authority leaders, providers, direct support and other professionals, and state officials). Secretarial sponsorship of this Committee will send a strong message that its recommendations will be seriously considered. In addition, many of the issues with which the Committee likely will grapple will extend beyond the present span of responsibilities of DMH/DD/SAS to programs administered by other DHHS divisions.

⁴⁰ In order for individuals and families to participate on this Committee, many likely will require assistance in one form or another. Such assistance certainly will include reimbursement for travel expenses, paying for personal assistants and advisors to accompany individuals, and, in the case of families, providing respite or financial stipends to provide for the care of the family member with the disability. The Department must commit to covering these costs and/or secure dollars from other sources (e.g., the Developmental Disabilities Planning Council) if possible.

We also strongly encourage the Secretary and Legislative Oversight Committee to explore the appointment of two or more legislators to this Committee. Active legislative participation would contribute to creating a bridge between the executive and legislative branches in support of system change. Alternatively, legislative staffers from key committees might be assigned to serve on the Committee in an *ex officio* capacity.

The enactment of H.B. 381 – the landmark Mental Health System Reform Legislation – also provides another important reason to establish this Committee. The Committee can advise the Secretary concerning aspects of H.B. 381 implementation that affect developmental disabilities services. H.B. 381 will trigger many changes in North Carolina’s service delivery system over the near and long-term. It is absolutely vital that the Secretary continuously seek the advice of stakeholders concerning these changes. For example, under the provisions of the legislation, local authorities must develop business plans. This Committee should play an important and continuing role in advising the Secretary concerning the topics these business plans should address. Moreover, we believe that this Committee also should provide input to the Secretary concerning potential uses for the dollars in the Mental Health Trust Fund. The Trust Fund dollars offer many opportunities to address key issues and concerns, albeit obviously they must be carefully husbanded.

There is a second change that we believe will aid in moving system change along in North Carolina. We recommend that:

The Secretary of DHHS should consolidate administrative responsibility and authority for developmental disabilities services within a single administrative unit.

Presently, authority over developmental disabilities services is split between DMH/DD/SAS and the Division of Medical Assistance (DMA). DMA is directly involved in the administration of the CAP/MR-DD waiver and ICF/MR services. DMH/DD/SAS – and the DD Section in particular – administers non-Medicaid services, has responsibility for the operation of the “single portal system” and some aspects of the administration of the CAP/MR-DD program. Going forward, there should be clear lines of authority, responsibility and accountability for developmental disabilities services. North Carolina faces the task of reforming its service system to eliminate funding/program silos, develop a unified package of benefits, and ensure that individuals and families are treated consistently regardless of the types of dollars that underwrite their services and supports. These objectives will be more readily accomplished if state administration of developmental disabilities services itself is unified. In states where there has been the greatest success in unifying the provision of developmental disabilities services, typically a single state-administering agency has the responsibility and authority to manage services.

During our interviews, DMA officials expressed willingness to shift responsibility for the administration of the CAP/MR-DD waiver program and other Medicaid services to DMH/DD/SAS. Since the HCBS waiver program will play a central role going forward in North Carolina’s system, we urge that right away responsibility for its operation be moved to DMH/DD/SAS. As North Carolina’s multi-year plan unfolds, administration of other Medicaid-funded services also should be shifted to and consolidated within DMH/DD/SAS.⁴¹

Finally, in light of the changes that will occur as a result of the Mental Health Reform legislation and the subsequent “business plans” that will be written, it will be important for the North Carolina Legislature to review existing statutes to ensure that person-centered practice is the governing construct for the delivery of services and supports to people with developmental disabilities. Such language will provide a framework for the emerging county programs and will provide a foundation upon which to build the multi-year plan.

⁴¹ In the past, there have been proposals to establish a standalone DHHS administrative division that would be responsible for services for individuals with developmental and certain other disabilities. This division would have been formed out of the current DMH/DD/SAS DD Section and possibly other DHHS offices and/or units. This approach has been rejected in the past. This recommendation is not an attempt to revive the proposal of creating a separate Disabilities Division. While the proposal is not without merit for programmatic and managerial reasons, creating a new Division at this juncture would pose other problems, most notably vis-à-vis the restructuring of the Area Programs under the provisions of S.B. 381. So long as the Area Programs (or the LMEs that are formed under the provisions of S.B. 381) have crosscutting MH/DD/SAS responsibilities, splitting up the current Division likely could cause new problems.

It is therefore recommended that:

The North Carolina Legislature should revamp states statutes to explicitly embed person-centered principles into state law as states such as Michigan have done in the last few years.

State Mental Retardation Centers

We have characterized the Mental Retardation (MR) Centers as “legacy services.” Institutional services once dominated state developmental disabilities systems. They were the principal way that states furnished “care and treatment” to individuals. However, today, institutional services are outside the mainstream. As community services have expanded and evolved, the “necessity” of removing individuals from their communities in order to serve them has faded. Twenty percent of the states no longer operate these facilities; in many others, only a handful of individuals are still served in institutions. The contemporary standard of excellence is supporting all individuals in the community regardless of the severity of their disabilities or the challenges their disabilities pose. This standard was embraced in the U.S. Supreme Court’s Olmstead decision.

Relative to state population, the number of individuals served in North Carolina’s Mental Retardation Centers is 43% above the nationwide average. While North Carolina has scaled back its institutional census over the past decade, it has done so at an appreciably slower rate than has been the case nationwide. North Carolina’s present rate of utilization of institutional services is abnormally high.

North Carolina has not put into motion effective strategies to substantially reduce its high reliance on institutional services. In part, this stems from legitimate concerns that there are significant weaknesses in community services and capabilities. Understandably, there has been reluctance to cut back on institutional services until these problems are corrected. Consequently, the Centers are viewed as serving a “safety net” role. In addition, the Centers have stepped forward to fill some gaps in North Carolina’s service system by sharing expertise with community programs.

But, there is no doubt that maintaining a large institutional service sector is a very costly proposition for North Carolina. Institutional services are very costly in their own right. Because North Carolina has elected to continue to operate five Centers while continuing to slowly reduce the institutional census, there has been an upward spiral in per resident costs. As a consequence, census reduction has not translated into freeing up significant dollars that could be used to expand community services. At the end of the day, the cost of maintaining five Centers competes with securing the dollars that are needed to expand and strengthen community services. So long as North Carolina persists in operating five centers, the amount of dollars they claim will become increasingly disproportionate to the number of individuals they serve.

Going forward, North Carolina should keep separate and distinct two dimensions of Center operations: (a) the role the Centers play in furnishing long-term residential services to individuals on a permanent basis, and (b) the role that the Centers play or might play in support of community services and meeting the needs of individuals throughout North Carolina. This distinction is important. Clearly, the first role should be scaled back. There is no inherent programmatic reason why the overwhelming majority of individuals presently served in the Centers cannot be supported in the community. There are some structural issues that need to be addressed and other steps that need to be taken so that individuals can return to the community.

The role that the Centers play as valued partners in supporting people in the community and statewide is a separate matter and should be addressed in the context of North Carolina’s strengthening or creating capabilities that are directly tied to making sure that all people with developmental disabilities have access to services and supports that will enable them to enjoy everyday lives in the communities. The expertise and capabilities that the Centers possess should not be discarded. It should be amplified through the participation of Centers in the operation of networks designed to address critical needs system-wide. In this role, the

Centers might continue to furnish direct services to a few individuals but on a more time-limited basis. We will return to this topic in a subsequent section. Sustaining current Center capabilities, however, does not mean that the Centers themselves must continue to furnish residential services to large numbers of individuals.

There are two rationales for North Carolina to substantially scale back residential operations at its Centers. The first is “programmatically” – every Center resident should have the opportunity to enjoy community living. Absent an overriding reason that justifies continued institutionalization, every effort must be made to support individuals in the most integrated setting, as provided by the Olmstead decision. The second rationale is economic – the need for North Carolina to re-deploy dollars from very costly service settings to less costly alternatives in order to free up dollars to strengthen and expand community services, especially in order to meet the needs of people who are waiting for services.

There are two aspects to the economic dimension. The first is that, in order to maximize the amount of dollars that can be redeployed from institutional to community services, North Carolina must consolidate institutional operations by closing one or more facilities. Absent closure, per resident costs will continue to rise. During the 1990s, North Carolina’s institutional census declined appreciably. This decline was sufficiently large that it alone should have triggered the closure of at least one facility. Going forward, if North Carolina merely adheres to its objective of reducing Center census at the rate of 4% per annum, by 2007 the number of Center residents will drop to approximately 1,450 individuals. This decline by all rights should trigger the closure of at least one center. If closures do not take place, per resident costs will continue to spiral upward.

The second aspect is the amount of money that can be gained through community placement itself. Even if the cost of supporting Center residents in the community is as high as 85% of current Center per resident costs (or about \$100,000 per person), significant dollars will become available to strengthen and expand community services. If experiences elsewhere are any guide, this 85% benchmark likely overstates the average outlays that North Carolina will have to incur in order to secure community placements for Center residents.

We therefore recommend that:

North Carolina should reduce the long-term residential census of its Mental Retardation Centers by 50% by 2007 and close out the residential services operations at two Centers.

This recommendation translates into North Carolina’s targeting a 2007 Center long-term residential census of approximately 950 individuals or about 500 fewer than would result if the state adhered to its present objective of reducing the census by 4% per annum. This census target in combination with the recommendation that two Centers be closed would mean that the remaining three Centers would serve about 316 individuals on average or about the same average census if all five centers stayed in operation but the target census was 1,450. A census of 950 individuals will bring institutional utilization in North Carolina into proximate alignment with the projected 2007 nationwide population-indexed utilization rate.

Securing a 50% reduction in Center census will require North Carolina to accelerate its pace of community placement. Attrition alone likely will result in Center census declining by about 200 to 250 individuals by 2007. In order to secure the 50% reduction, North Carolina will have to place 700 to 750 individuals over the five-year period. This is an appreciably more rapid pace of community placement than North Carolina has achieved in the past. In our view, this volume of community placements is entirely feasible and manageable. However, North Carolina will need to employ different strategies than it has in the past in securing community placements.

Before turning to the community placement strategies that North Carolina should entertain, it is important to discuss some key elements of this recommendation. In particular:

- **Selection of facilities for closure.** We make no specific recommendation concerning which of the five Centers should be closed.⁴² Key considerations should include the status of Center physical plants. Centers where there is a high likelihood that significant capital expenditures will have to be made in the next five years are the most likely candidates for closure. Similarly, facilities that have especially high operating costs also should be considered. The scope of our investigations did not include delving into these questions. Finally, some consideration should be given to the level of deficiencies noted by the health surveyors as part of the ICF/MR reviews.
- **Early identification of facilities.** However, the Centers that will be closed should be identified as soon as possible for three reasons. First, it will be important to close off new admissions at these Centers. Closure must proceed as quickly but prudently as possible. Continuing to accept admissions at Centers slated for closure will elongate the closure process. Second, the Centers slated for closure obviously should dictate where efforts to arrange for community placements must be concentrated. Early identification will aid in organizing placement activities. Finally, early identification is vital in managing Center workforce, especially in order to put into motion steps to secure new jobs for affected employees. Effective workforce planning will maximize opportunities for affected employees to transfer to facilities that will continue in operation or find other job opportunities within the Department or elsewhere in state service. While turnover rates at the Centers are relatively low in comparison to community programs, they are significant and strongly suggest that it will be possible to avoid outright lay-offs as the closures proceed.
- **Sequencing Closure.** In order to hold down costs, the closures should be sequenced. In other words, the effort should be made to secure the closure of one facility early on and the second later in the process instead of scaling back both facilities concurrently.
- **Trans-institutionalization.** North Carolina obviously could close one facility right away by transferring individuals from one Center to the other four. We strongly recommend against such transfers. Trans-institutionalization causes enormous disruption in the lives of affected individuals. It also potentially will put many individuals through two moves within a relatively short period of time (i.e., transfer to a new facility and then placement in the community). In the end, it may be necessary for a few individuals to move from one Center to another in order to effect a closure. However, only individuals who are most likely to remain in the Centers should be transferred. North Carolina should adopt the “one move rule” – no Center resident will experience more than one move as a result of closure.
- **Managing Institutional Spending.** Finally and especially with respect to the facilities that will close, it will be important to carefully manage institutional spending. The Centers that are closing will need to chart a financial management plan wherein their expenditures will be reduced as census reduction benchmarks are achieved. Tight financial management is necessary to reduce as much as possible the amount of dollars consumed by “double budgeting” – paying for community services while also having to pay for the continued operation of the Centers.

In short, there are a variety of considerations that must be addressed in managing the institutional side of the closure process.

Above, we noted that North Carolina should adopt new strategies with respect to the actual community placement of Center residents. Several changes merit consideration:

- **Financing.** In general, the strategy that North Carolina has followed for accomplishing community placement has been to: (a) shift MR Center beds to the private ICF/MR sector under the provisions of S.B. 1395 or (b) place Center residents in private sector ICF/MR beds that have been vacated by persons who transfer to the CAP/MR-DD waiver program. Basically, community placement has been

⁴² H.B. 381 gives the Secretary of DHHS the authority to close a Center, subject to the review of the Governor and the Executive Council.

confined to working out the movement of individuals from one type of ICF/MR (a state-run Center) to another type of ICF/MR (a private sector facility). For various reasons, North Carolina has made little use of the HCBS waiver program as a vehicle for facilitating community placement. One reason is the silo problem: S.B. 1395 enables dollars to move between the two ICF/MR sectors but not across to the CAP/MR-DD program, which is subject to its own participant cap.⁴³

Community placement itself must embrace person-centered principles. While it might be the case that a non-state ICF/MR is an appropriate placement alternative for some individuals, limiting individual choice to such facilities is not appropriate and fundamentally at odds with person-centered principles and the “most integrated setting” mandate.

The HCBS waiver program offers greater opportunities to link community placement to person-centered principles in developing community placement strategies. States that have been most successful in securing community placement have relied almost exclusively or entirely on the HCBS waiver program to facilitate such placements. The HCBS waiver program provides the ability to tailor services and supports to meet the needs of each person.

We therefore recommend that North Carolina develop and launch a new HCBS waiver to pay for community placement and to in turn create the opportunity to craft one-person-at-a-time community placement strategies. At present, the CAP/MR-DD waiver is not well suited to facilitate community placement. In the case of some individuals, the program’s cost limit is problematic. There are other structural defects as well. As we will discuss later, reforming the CAP/MR-DD waiver program demands attention in North Carolina. In the meantime, however, North Carolina should work around these problems by launching a new HCBS waiver program so that community placement can proceed. A state may operate multiple HCBS waiver programs, including programs specifically designed to facilitate community placement from state facilities. Georgia developed a program specifically to facilitate the closure of its Brook Run facility. Tennessee has implemented a stand-alone program for people moving from its state facilities to the community. Idaho has operated a “deinstitutionalization” waiver program for several years.

We have come to this recommendation reluctantly. It would be better if the needs of Center residents could be accommodated readily within the CAP/MR-DD program. However, it is important that North Carolina not hamstring community placement by making it contingent on reforming the CAP/MR-DD program. Launching up a new HCBS waiver program will provide North Carolina with an important opportunity to make a fresh start on how it employs the HCBS waiver program, including embracing the principles of person-centered supports into community placements. The development of this new program also will aid in informing CAP/MR-DD waiver reform.

- **Placement Planning.** Historically, the identification of candidates for community placement has chiefly been the responsibility of the Centers. This practice must be replaced by a new process that effectively engages the Centers, community agencies, the person and his/her allies as partners in developing community placement strategies. “Best practice” with respect to community placement does not begin with “readiness” assessment. Instead, it starts with the presumption that community placement is feasible for every individual and the central tasks are to: (a) identify the needs and preferences of the person and (b) develop person-centered strategies that will ensure the person will have the services and supports s/he requires in the community. Such placement planning employs person-centered planning methods

⁴³ We note that the plan that DHHS has circulated concerning H.B. 381 implementation includes various proposals concerning the MR Centers, including arranging for the community placement of individuals under Olmstead principles. This plan continues the practice of principally employing the development of additional private ICFs/MR and/or placement of facility residents to ICF/MR beds vacated by individuals who would be served in the CAP/MR-DD program. The plan also identifies the potential for the Centers themselves to operate community ICF/MR residences and start-up “MR/MI” units. Lastly, the plan would “close” Black Mountain Center by reconfiguring it as a skilled nursing facility for aged individuals with developmental disabilities. This plan should be carefully scrutinized. It is premature to launch new Center-operated programs absent broader consideration of the underlying problems such programs might address.

(e.g., essential lifestyle planning) and enlists facility personnel who know the person, community agency staff, family members and others to build highly personalized support plans. Center personnel cannot perform this type of planning alone or in isolation from community agencies. This type of planning process has been employed with great success in several states, including Kansas (through its Community Integration Initiative), Pennsylvania and elsewhere. However, such planning only is practicable when there is considerable flexibility in arranging for community services and supports. This is why it is important that North Carolina switch to the HCBS waiver program to finance community placements.

The missing link in North Carolina with respect to community placement has been the continuous and active engagement of community personnel with Center residents. Center residents are only weakly tied back to the Area Programs. Stronger ties must be established. Consequently, we recommend that every Center resident be put on active case management status with the appropriate Area Program and that Area Programs receive additional funding so that they can assign personnel who will become familiar with each resident and participate in placement planning in collaboration with Center personnel.⁴⁴ These area program personnel would be responsible for arranging for services and continue to be involved with person post-placement.

- **Area Program Responsibilities.** In order to move community placement along, each Area Program also should be assigned numeric targets for community placements. Moreover, every Area Program/LME H.B. 381 business plan should spell out the steps that will be taken to meet these targets.
- **DHHS Responsibilities.** The Department also must play a very active role if these community placement targets are to be achieved. We recommend detailing two or more state personnel to this task. These personnel should monitor progress in placement planning and also function as “trouble shooters” who will intercede when problems arise. It also is absolutely vital for the Department to underwrite training and technical assistance throughout the duration of the community placement initiative.
- **Legislative Involvement.** Clearly, the North Carolina Legislature must exercise its oversight responsibilities in making sure that community placements are on target and individuals are receiving appropriate services and supports in the community. One way of exercising this oversight would be for the Legislature itself or in tandem with DHHS to engage an independent a third-party to monitor placements and make an independent assessment of the community placement parties. Third parties have been employed in several states for exactly this purpose. However, we do not advocate that this contract be structured as a “study” of the effects of community placement on individuals. There have been many such studies conducted over the years in several states. We see no value in North Carolina’s conducting yet another such study. Instead the third-party should be engaged to evaluate the effectiveness of service planning, plan implementation, and consumer/family satisfaction post-placement as well as identify any major problems/barriers that are encountered in securing community placements.

Another point of legislative-executive intersection is the appropriation process. An important benefit of substantially reducing institutional census is that it will free up dollars that can be employed to strengthen and expand community services even after accounting for the cost of community placements. In order to realize this benefit, it will be vital that the Legislature itself commit to keeping institutional cost savings within the system. While present budget exigencies pose serious problems in substantially boosting appropriations, institutional downsizing and facility closure must not have the net result of draining dollars out of the service system. **We therefore recommend that the Legislature and the executive explore the creation of a “community services enhancement” fund into which institutional cost savings will be directed and remain available to support community services expansion or underwriting**

⁴⁴ These costs are eligible for federal Medicaid reimbursement, either as an administrative expense or as a service expense in the case of individuals who are actually placed in the community.

the costs of establishing or strengthening systemwide capabilities, subject to legislative review and approval.

In summary, North Carolina should embark on a proactive initiative to substantially scale back the role that the MR Centers play in furnishing long-term residential services to people with developmental disabilities. This will best be accomplished by embracing a person-centered approach to community placement and employing the HCBS waiver program in order to underwrite the costs of community placements.

Adult Care Homes

Inadvertently, North Carolina has spawned a residential services sector that is serving – so far as we can determine – almost 5,000 individuals in settings that were not designed with the needs of people with developmental disabilities in mind. This high use of adult care homes in part is the result of limitations on the availability of services and supports in the developmental disabilities system. Adult care homes have become the outlet valve for service demand. Service demand inevitably seeks out funding silos that have openings. Much the same phenomenon took place in other states (e.g., Georgia) where excess demand led to the inappropriate admission of numerous individuals into general purpose nursing facilities where their needs were not well met.

Adult care homes receive two types of funding – a special state supplement that is available only for people who reside in adult care homes and Medicaid personal care funding. People with developmental disabilities and other mental disabilities in adult care homes have not been tied into the community developmental disabilities system, although DHHS has begun efforts to establish such a linkage. Entry to adult care homes falls outside the purview of the single portal system. This means that individuals are entering adult care homes without an evaluation of whether such facilities are appropriate.

Based on our investigation, the placement of people with developmental disabilities in adult care homes is enormously problematic. Adult care homes provide very minimal services. They are a way to house people with mental disabilities but fall well short of meeting their needs except for custodial services. While it may be the case that adult care homes are acceptable settings for some individuals, it is very likely that they generally are inappropriate settings for most individuals.

Obviously, North Carolina will not be able to effect a large-scale transfer of people with developmental disabilities out of adult care homes in the near-term. Appropriately meeting the needs of adult care home residents likely will require more dollars. How much more cannot be determined absent learning more about individuals who reside in adult care homes, a step that will necessitate adding adult care home residents to the active caseload of the Area Programs/LMEs.

For the near-term, we recommend that:

DHHS take steps immediately to expand the scope of single portal to include reviewing new admissions of individuals to adult care homes, identify people with developmental disabilities in adult care, link them to Area Programs via furnishing case management services to these persons and conduct assessments to determine their needs and add individuals whose needs are not well met in adult care homes to the waiting list.

In the near-term, the Department should proceed quickly to make sure that it has solid information available about people served in the adult care homes and establish a continuous linkage between adult care home residents and Area Programs. The additional case management costs of establishing this linkage will be eligible for federal Medicaid funding under the targeted case management option.

We further recommend that the Department direct that H.B. 381 county business plans include the requirement that localities affirmatively address how they will address the needs of people with developmental and other disabilities who are served in adult care homes.

In addition, the Department should – to the extent feasible – examine opportunities to reprogram on a case-by-case basis the dollars that support individuals in adult care homes to enable individuals where possible to transition to more appropriate community alternatives. In at least a few cases, current adult care home dollars – if used differently – may be sufficient to assist individuals to leave the facilities.

Until there is a clearer understanding of the individuals presently served in adult care homes and there is assurance that future admissions to such facilities will be properly evaluated, we further recommend that North Carolina not embark on initiatives to expand the use of adult care home services for people with developmental disabilities, including putting into place “enhanced” adult care home programs. Adult care homes are congregate settings. North Carolina already is too highly invested in the use of such settings for people with developmental disabilities. Embedding adult care homes in North Carolina’s service system as a permanent residential services sector is at odds with the principles of person-centered supports and best practice. A central task facing North Carolina is to eliminate its funding/program silos, not harden them.

As a final matter, going forward the Legislature should revisit the policy of limiting supplement payments to adult care homes. The effect of current policy in North Carolina is to subsidize one type of housing – adult care homes – but not others. This policy has the effect of locking people with disabilities into facilities and thereby creates barriers to their securing homes of their own. Dollars available to them in adult care homes disappear if they leave. Correctly, a pilot program has been launched that enables care home dollars to follow the person.

This issue needs to be kept on the front burner. At the end of the day, people with developmental and other disabilities should be able to make real choices between receiving services in settings like group homes and having supports in living arrangements of their own. In most cases, individuals will not have this choice unless they receive financial assistance to help in meeting their housing and other living expenses. SSI payments alone usually are insufficient. This causes a bias toward the use of congregate facilities (adult care homes and ICFs/MR) where government subsidizes housing costs. As we have observed, relatively few CAP/MR-DD participants who do not live with their families are receiving supports in homes of their own. There are several states that have taken action to correct this bias. For example, Connecticut and New York make available supplements to individuals that enable them to secure their own community housing.

Non-state ICFs/MR

We have observed that North Carolina’s utilization of ICF/MR services is abnormally high in comparison to the nation at large. In part, this is a byproduct of the large number of individuals served at the MR Centers, which, of course, are ICF/MR certified. But, it also stems from North Carolina’s spawning a relatively large non-state ICF/MR service sector that has continued to grow through the transfer of beds from the Centers under the provisions of S.B. 1395.

ICF/MR services are legacy services. Their use once was commonplace and today they by and large are not regarded as being in the mainstream of best practice. Until the advent of the HCBS waiver program, the ICF/MR program was the only practical alternative available to states to acquire federal Medicaid dollars to underwrite the costs of residential services whether in large state facilities or elsewhere in the community. ICF/MR services expanded as a byproduct of the “institutional bias” in federal Medicaid policy rather than any inherent superiority of the ICF/MR “model” in supporting people with developmental disabilities. After the HCBS waiver program began to take hold, ICF/MR utilization nationwide stabilized. Since approximately 1993, the rapid expansion of HCBS waiver services caused the utilization of ICF/MR services to decline appreciably. When once the vast majority of people with developmental disabilities who received Medicaid-

funded long-term services were served in public and non-state ICFs/MR, today ICFs/MR serve only 30% of all recipients. In almost all states, ICF/MR utilization has dropped steadily and significantly. There are many states where only a handful of individuals are served in ICFs/MR outside public institutions. But, in North Carolina, ICF/MR utilization has not changed appreciably over the past several years.

ICF/MR services in North Carolina are a distinct funding/program silo. People served in ICFs/MR cannot readily opt for other alternatives. There is no guarantee, for example, that a person who leaves an ICF/MR will be able to obtain a CAP/MR-DD “slot” because the number of individuals who can participate in the CAP/MR-DD program is subject to its own independently determined numeric limit. Even though people served in both programs must meet essentially the same eligibility criteria, individuals cannot readily move between programs.

We do not regard ICF/MR group homes to be inherently inappropriate settings for people with developmental disabilities, although we regard large ICFs/MR – whether operated by the state or the private sector – as very problematic. North Carolina by and large has concentrated on developing smaller scale ICFs/MR. The main issue that arises out of North Carolina’s high reliance on ICF/MR services is that it causes deviation from the principles of person-centered supports. The services individuals receive are determined by availability rather than based on the person’s own preferences or as the result of efforts to develop alternative supports. There is no doubt that many individuals require intensive services and supports like those furnished in ICFs/MR. However, ICFs/MR are not the only way to address such needs. Service supply rather than service demand is driving ICF/MR utilization in North Carolina.

Ideally, North Carolina should merge ICF/MR group home services into the HCBS waiver program. If such a merger were to take place, an enormous stride would be made in addressing the problems caused by funding silos. Person-centered principles could be followed more readily. Individuals served in ICFs/MR would have wider choices and group home placement could be more tightly regulated based on individual needs. Lastly, the single portal system would function more effectively if funding were unified under the HCBS waiver program.

Some states (e.g., Massachusetts) have merged ICF/MR group home services into their HCBS waiver program. Elsewhere, states (e.g., Pennsylvania) have worked with non-state ICF/MR operators to “convert” their facilities to HCBS waiver funding on a voluntary basis.

For better or worse, however, North Carolina cannot by simple fiat merge the ICF/MR group homes into the HCBS waiver program and, in fact, cannot today because the CAP/MR-DD waiver program itself lacks appropriate payment mechanisms for group home services in any case. At the end of the day, shifting ICF/MR group homes to the waiver program can and should only take place as the result of North Carolina stakeholders working out a sound strategy for transitioning these services. Hence, we recommend:

The Secretary of DHHS designate the conversion of non-state ICF/MR group homes to HCBS waiver funding as a distinct topic that will be addressed through the development of the multi-year plan.

In order to convert the present group homes, numerous questions will need to be addressed, including ensuring that conversion does not result in a degradation in funding, the development of new payment rate methods under the HCBS waiver program, and an assessment of non-ICF/MR group home regulations to determine if alterations are required. Obviously, non-state ICF/MR providers – along with other stakeholders – must be active participants in developing a workable plan for ICF/MR conversion. We believe that, properly conducted, conversion will enable the more economical delivery of group home services.

Meantime, we urge that North Carolina not proceed with the development of new non-state ICFs/MR. We believe that the state is “over-bedded” and new development should not be sanctioned. Instead, in near-term North Carolina should concentrate on implementing our recommendation to launch a community placement

HCBS waiver program and expanding the CAP/MR-DD program to accommodate as many current ICF/MR residents as possible in order to create bed openings in current facilities for individuals who at present cannot be accommodated through CAP/MR-DD.

One step North Carolina might well consider in order to capture additional federal Medicaid dollars is the enactment of an ICF/MR “provider tax.” This device is sanctioned in federal law and regulations, albeit its use was circumscribed in the early 1990s. Without delving into all details, such a provider tax does not cause a net loss of revenue to facilities and broadly has the effect of securing additional federal Medicaid dollars without increasing state expenditures. The dollars garnered through the use of a bed tax can be applied to underwrite other services and supports. Various states have implemented such bed taxes. ICF/MR services are apt candidates for the use of such bed taxes because all individuals served in such facilities are Medicaid recipients. Employing a bed tax in other long-term care settings (e.g., nursing facilities) is more problematic because of the large number of private pay recipients.

Legislative action will be necessary to establish such a bed tax. We recommend proceeding with the creation of such a bed tax. It likely will generate about \$10 million that can be used to meet the needs of other individuals in the community. The conversion of ICF/MR group homes to the HCBS waiver program would reduce the amount of revenue generated from such a tax.

Priority Populations

One of the topics with which North Carolina has been grappling is “priority populations” – e.g., the promotion of certain groups of individuals to receive services through the public system. In general, this topic most often has been discussed in the context of mental health services and has revolved around placing greater emphasis on serving people with severe and persistent mental illness through community programs.

In the context of services for people with developmental disabilities, North Carolina’s fundamental eligibility criteria already have pointed the service system toward serving individuals with significant, life-long disabilities. Eligibility criteria for Medicaid-funded services – whether via the CAP/MR-DD waiver program or ICF/MR services – add an additional overlay with respect to the severity of the disabilities of individuals who are eligible to receive these services. We have found no evidence that the developmental disabilities service system has promoted the needs of individuals with less serious disabilities over those with more significant disabilities.

North Carolina’s development of its NC-SNAP assessment tool provides additional assurance to policy makers that publicly funded services are being directed to individuals who have bona fide needs for services and supports.

To the extent that there are “priority population” issues extant in North Carolina’s developmental disabilities system, they principally are of two types:

- First, it is by no means certain that individuals who receive services are receiving the proper mix of services. Some people likely are “over-served” and some underserved. For example, there likely are individuals served in ICFs/MR who likely could be supported elsewhere in less costly settings. Most assuredly, many individuals served in adult care homes need more services than they presently are receiving. In part, under and over-service are byproducts of the funding silo problem. Individuals receive what’s available rather than tailored services and supports. The funding silos also impede changes in service. People who could be supported through the CAP/MR-DD waiver program but presently reside in ICFs/MR cannot move along because openings are not available in the CAP/MR-DD program.
- By and large, the Area Programs have leeway in selecting individuals from the waiting list to receive services when they become available. While undoubtedly most Area Programs give priority consideration

to individuals and families with the most urgent needs, it is likely that there is inconsistency from locality to locality in this regard.

The extent of the first problem is unclear. There is no doubt that broad application of the NC-SNAP tool across all individuals receiving services will aid in North Carolina's obtaining a firmer grasp of the extent to which over or under-service may be present and, thus, inform strategic planning going forward at both the state and local levels. However, at the end of the day, addressing the root cause of the over- and under-service problem – to the extent it exists – will require deconstruction of the funding silos.

The DD Section is developing an approach that will aid in sorting out the waiting list. Essentially, this tool will enable distinguishing among individuals with respect to the urgency of their needs and the types of services they need based on NC-SNAP and other information. While this approach to sorting out the waiting list undoubtedly will require additional discussions with stakeholders, we regard it as fundamentally sound. Information concerning urgency of need is important for strategic planning purposes. In addition, DHHS should develop and implement a statewide policy concerning the order of selection that Area Programs need to follow in offering services to people who are on the waiting list. In this regard, people regardless of where they reside should be able to access services under consistent criteria.

The Legislature has expressed concerns about whether resources are distributed equitably across North Carolina, including CAP/MR-DD waiver "slots." The scope of our work in North Carolina did not permit us to examine this question in any detail. One concern is that some Area Programs have been allocated CAP/MR-DD slots they are not using while other Area Programs have individuals backed up waiting for a "slot." The current moratorium on the admission of additional individuals to the program moots this issue, at least for the time being – there are no slots that can be redistributed in any case. We suspect that the distribution of people participating in the CAP/MR-DD program probably is uneven. Over the program's history, some Area Programs have been more aggressive than others in employing the program. We believe this issue merits investigation and would benefit if it were conducted from a demand analysis perspective (e.g., the number of people receiving or waiting for CAP/MR-DD services relative to each Area Program's general population). To the extent that this analysis reveals that slots are distributed unevenly relative to demand, then clearly priority should be given to allocating any new slots that might become available to Area Programs where there are the greatest deficits relative to overall demand.

A New Funding Framework

One of the problems spawned by North Carolina's funding/program silos is that individuals who have similar needs do not have the same amount of dollars available to meet their needs. In addition, absent sound funding methods, "cost containment" takes the form of rationing services (e.g., capping the number of individuals served) or attempting to control the use of certain types of services (through "utilization management" and elaborate prior authorization processes). At the end of the day, these cost containment methods are shortsighted and frequently ineffective in any case. They often lead to inefficiency or do not work well in practice. Still, cost containment is vital. If costs are not appropriately contained, a state's ability to accommodate service demand is foreshortened.

In North Carolina, the present funding/program silos in fact operate as "cost-containment" devices. Absent other strategies, the state attempts to control utilization through recipient caps and other schemes. Most recently, in the CAP/MR-DD program, the upward spiral in the cost per participant has caused DHHS to close down the program to new admissions. CAP/MR-DD costs are subject to a per participant dollar ceiling. However, the ceiling is quite high (about \$88,000). Service plans and authorizations have ratcheted upward toward this ceiling. The state's only tool – short of eliminating services, cutting payment rates or reducing the cost ceiling (all of which would cause other problems) – to address this problem is to cut off new enrollments, an especially devastating step in the face of the state's large waiting list.

Going forward, it will be absolutely critical for North Carolina to develop new service funding methods that will enable it to do away with the funding silos while also providing for cost containment. The main alternative to the state's present cost containment methods is developing a funding scheme wherein dollars are allocated by person based on their assessed needs and other factors. Such a funding scheme would ensure that the total dollars available to support individuals with similar needs and circumstances are equalized. This type of funding scheme also is compatible with the principles of person-centered supports: if there are reasonable controls on total spending, then individuals and families can be afforded greater control and authority over how dollars are employed without the fear that costs will spiral out of control. In addition, going forward, it will be important to put into place a sound system of allocating dollars across North Carolina as H.B. 381 implementation unfolds.

Thereby, we recommend that:

DHHS proceed to develop a new community services funding system that is designed to ensure that the total dollars available to individuals and families are based principally on consumer need and other relevant factors.

The Department has been exploring the potential of employing its NC-SNAP assessment/eligibility instrument to serve as the basis of such a funding system. For a variety of technical reasons, we do not believe that the NC-SNAP instrument is well suited to this task.⁴⁵ This does not mean that North Carolina should discard NC-SNAP (it appears to work well enough as an eligibility tool) but instead it probably will be necessary to supplement NC-SNAP with other information and conduct more in-depth analysis in order to arrive at an acceptable and reliable funding method. At the end of the day, we believe North Carolina should direct its energies toward seeking to develop a funding model that is roughly similar to the matrix employed in Utah that integrates information about consumer support needs and living arrangements. While there are flaws in the Utah approach, we believe it is an apt framework.⁴⁶ Utah's matrix sets fund allocation amounts that are graduated to assessed need and further adjusted to take into account whether the individual is an adult or a child and lives with his or family.

The development of a new funding system is a very challenging undertaking. It requires the intensive data analysis and sometimes the acquisition of additional data. In order to move this development along, it may be advisable for the Department to consider contracting some elements of the work out rather than attempt to develop the new system entirely on its own.

At the end of the day, we believe that North Carolina will continue to struggle in its management of community dollars and funding until it develops funding methods that enable allocating dollars at the "person-level" rather than continuing to attempt to manage utilization or use other cost containment devices. Person-level funding methods are absolutely necessary in order to promote flexibility and provide for portability. For sure, new funding methods are absolutely critical in order to disentangle the present problems in the CAP/MR-DD waiver.

⁴⁵ We do not believe that the NC-SNAP instrument is sufficiently robust to support the statistical analysis that is necessary in order to develop reasonably sound funding allocations. We do not question the reliability and validity of NC-SNAP per se and regard it as an acceptable tool for eligibility determination and other purposes. However, with respect to the design of funding methods, NC-SNAP scores likely will not prove to be sufficiently predictive of resource requirements.

⁴⁶ There are other states that have switched to funding methods that allocate dollars at the "person-level." These include Kansas (which adopted a "tiered" funding approach several years ago) and Wyoming (which has developed a very sophisticated method for making individualized budget allocations). Each of these approaches has merit. We believe that the Utah approach holds more promise for North Carolina since its structure seems most compatible with the role of Area Programs (LMEs) in managing dollars. Our reservations about the Utah model is that we believe it is overly reliant on higher-level assessment scores (from the ICAP tool) and may not adequately take into account important factors that are not well measured by the assessment tool (e.g., health status and maladaptive behaviors).

Creating and Strengthening System-wide Capabilities

In order to support all individuals in the community and assure that they receive high quality services, a service system must have various capabilities. For example, a common reason why individuals “fail” in community placement is that the community system lacks the requisite expertise and capabilities to address serious behavior problems. Individuals with such problems often bounce from placement to placement and, as a last resort, are placed in state facilities. Indeed, these “failures” are frequently cited as a reason why institutions cannot be closed because the community “cannot” meet the needs of such individuals. In North Carolina, there have many such “failures”, especially among dually diagnosed individuals. When the appropriate capabilities are not in place, the costs of supporting these individuals escalate rapidly. Where capabilities are in place, costs are lower in both the near and long-term.

Similarly, many people with developmental disabilities have significant health challenges. Addressing these challenges requires various expertise and skills that may not be readily available through the generic health care system for a variety of reasons. Even routine care can be difficult to obtain (in North Carolina, this is especially the case with respect to dental care.) The lack of capabilities to address these challenges and promote wellness undermines confidence in community services and, frequently, causes actual harm to people with developmental disabilities. To a limited extent, the North Carolina’s MR Centers have attempted to fill some of these gaps by providing outpatient services and technical assistance. However, the ability of the Centers to play this role is limited, both in terms of resources and by virtue of geography.

It also is true that meeting the needs of people with developmental disabilities requires a workforce that has a solid skill set. In most states, training and skill development falls to provider agencies individually but often agencies lack the resources to build the skills of their workers. As a consequence, the community workforce in North Carolina often is regarded as insufficiently skilled to meet the needs of individuals. This problem is exacerbated by the fact that the rate of turnover in the community workforce is very high, due to low wages and other factors. Because there is less workforce turnover and a greater investment in skill set building at the MR Centers, they are regarded as “better” at supporting people with developmental disabilities than community agencies. Here again, the Centers have stepped forward to play an active role in offering training.

The simple fact is that there are gaps in community capabilities in North Carolina. And the simple truth is that unless and until North Carolina confronts these gaps and addresses them proactively it will not be able to support all people in the community as well as possible.

At a very basic level, it is important for stakeholders to acknowledge that these gaps exist and recognize that none of them will be addressed effectively and appropriately except by making targeted investments to build the necessary capacities and capabilities system-wide. These gaps will not be adequately addressed if they are regarded as problems that every provider agency must solve on their own or each Area Program must address in isolation. And certainly, these are problems that will not cure themselves.

Consequently, we recommend:

DHHS actively promote and underwrite the costs of network-based approaches to creating and strengthening system-wide capabilities along multiple dimensions. The dimensions that demand attention right away are: (a) behavioral services; (b) health care; and, (c) workforce.

By network-based approaches, we mean clearly identifying the capabilities that are required, buying or building the expertise needed to create or strengthen these capabilities in the public sector and/or in partnership with the private sector, and organizing these networks so that expertise is readily accessible systemwide in North Carolina. The Department must take the lead in building these networks.

For example, in Vermont it was recognized early on that closing Brandon Training School (the state's only large public facility) potentially would create a hole in the state's "safety net" for individuals who have severe behavior crises. Moreover, absent building the capability to effectively and quickly address the needs of these individuals in the community, the closure of Brandon could trigger increased admissions to the state's mental health hospital or private psychiatric facilities. Vermont's solution to this problem was to develop the Vermont Crisis Network (VCN). VCN possesses the capability to furnish off-site consultation to community agencies, put behaviorists on site as needed, and furnish – as necessary – short-stay residential services. Vermonters recognized that it would be very expensive for each provider agency or locality to acquire and fund this type of capability, which includes the costs of maintaining a stand-by capability. Moreover, skilled behaviorists are in short supply. Building VCN as a statewide capability was more economical and effective. This network was funded through premium charges to service agencies (which permitted obtaining federal Medicaid dollars to partly underwrite its costs). Obviously, Vermont is a small state – this approach worked well there. In North Carolina, putting such capabilities into place might well proceed differently – building standalone capabilities in more populous areas and multi-area networks in other parts of the state.

In Kansas, community worker training was not left to chance. The state partnered with the university system to develop a core curriculum underwrote the costs of training to this core curriculum. Providers could buy training through the university system or create their own training capabilities. Either way, provider rates were adjusted to cover these costs. In Pennsylvania, the Office of Mental Retardation took the lead to create a network of Health Care Coordinating Units that provide area-wide access by provider agencies to assistance in meeting the health care needs of individuals along with liaison to managed health care providers.

There are many different ways to build capabilities. In North Carolina, it will be important to think about building capabilities in a network framework and system-wide rather than provider-by-provider or area-by-area. Where expertise exists, the task is to amplify it by making it available via the network. Where expertise needs to be developed, it will be least costly to do so on a wide-area basis. Especially with respect to training, behavior and health care services, building networks will hold costs down on a system-wide basis and usually result in more effective solutions.

With respect to creating or expanding capabilities, our view is that the MR Centers can and should play a pivotal role by virtue of their well-recognized expertise and current capabilities. The Centers might furnish some "outpatient" services along with "dispersed" services in the form of dispatching Center staff to community agencies on an on-call basis. The Centers might also operate short-stay residential services more or less along the lines of the respite services the Centers presently furnish. However, we do not believe that the Centers should be positioned as sole suppliers. Networks should include "suppliers" located throughout North Carolina and where possible and economically feasible be locally based and accessible. Networks should be structured in a fashion that amplifies expertise wherever it exists.

One of the main challenges in building such networks is underwriting their costs. By definition, gaps arise because dollars have not been devoted to a task in the first place. There are at least three ways North Carolina might underwrite the costs of these networks: (a) devoting a portion of the savings from institutional closure and downsizing; (b) earmarking dollars from the Mental Health Trust Fund; and/or, (c) capturing federal Medicaid reimbursement by vendorizing the services that the networks furnish or, when appropriate, claiming some costs as Medicaid administrative expenses. An example of vendorization is the step Nebraska took to amend its HCBS waiver program to create a crisis intervention service to cover the costs of furnishing dispersed behavior services furnished by the Beatrice Developmental Center. In general, acquiring federal Medicaid dollars for networked services can be accomplished in a variety of ways.

Networks are potentially powerful solutions to the capabilities problem. However, they are not the only strategy that merits consideration. For example, no amount of networking will overcome a fundamental lack of expertise. For example, there are few physicians and psychiatrists in North Carolina who possess the skill sets to effectively address the needs of some individuals with developmental disabilities. Building these skill sets might include partnering with the university system and the state medical society to develop curricula

and create continuing education opportunities as well as possibly creating fellowships to encourage medical students to specialize (including possibly the requirement that students make a commitment to work with people with developmental disabilities post-graduation).

In other cases, the underlying problems can be addressed in different ways. For example, frequently individuals have difficulty accessing dental care because state payments for dental services do not account for the additional time and expenses involved in dental care for people with cognitive impairments. Adjusting payment rates can aid in resolving this problem.

As a final element of the capacity building agenda, it will be important for North Carolina to recognize that embracing person-centered principles is not a “task” but a continuous process of acculturation and training. We know of no state that has achieved a solid reputation in furnishing person-centered services and supports that has not invested enormous energy and considerable resources year-over-year in training about person-centered planning and promoting other active learning opportunities concerning putting person-centered principles to work.

There are a myriad of possibilities in creating and strengthening the requisite community capabilities by “thinking outside the box.” We believe that North Carolina can proceed most quickly in building these capabilities if the Department exercises strong leadership. We would urge that the Department set up task forces along each of the three main dimensions and charge these task forces with develop proposals to guide capability/capacity development. These task forces should include not only developmental disabilities stakeholders but also other potential network partners from the university system, health care, and others.

HCBS Waiver Program

The HCBS waiver program provides each state with enormous opportunities to acquire federal Medicaid dollars to underwrite diverse, person-centered supports for people with developmental disabilities. States have tremendous flexibility in how they structure their programs. Nationwide, states have seized on this opportunity and rapidly expanded their HCBS waiver programs. As a result, there now are many states where the HCBS waiver program is paying for services and supports for the substantial majority of individuals who receive publicly funded services.

Until 1995, North Carolina’s CAP/MR-DD waiver program was quite limited in its scope and served relatively few individuals. In 1995, North Carolina made major alterations in the program and expanded it considerably. Even so, the number of people participating in the program (relative to population) considerably lags the nationwide utilization rate.

Going forward, it is absolutely vital that North Carolina maximize the role that the HCBS waiver program plays in underwriting services and supports for people with developmental disabilities. Growing the waiver program will be central to North Carolina’s attacking its waiting list problem at the least cost in North Carolina state tax dollars. The program’s design flexibility allows it to be operated in a fashion that is congruent with the principles of person-centered supports.

However, the present CAP/MR-DD waiver program has several serious problems. The most pressing current problem is that its per participant costs have shot upward, causing DHHS to shut down new enrollments to the program. Historically, North Carolina’s per person costs have not been appreciably different than the nationwide average and more or less changed year-or-year in a predictable fashion. The present problem appears to changes that were made in the program when it was last renewed and other changes made thereafter (in particular, boosting the participant cost limit by approximately one-third).

However, there are other serious problems as well in the program, including the costliness of its administration and in its basic design. In other chapters, we have provided a detailed analysis of many of

these issues and these problems also have been the subject of previous reports prepared by outside consultants. As we have observed previously, these problems are not the by-product of federal policy but instead by and large have arisen as a result of how North Carolina has designed its program.

In the end, we believe that it will be necessary for North Carolina to scrap the CAP/MR-DD program and replace it with two standalone programs. We discuss this redesign in more detail below. However, until the redesign can be completed and receives federal approval, the CAP/MR-DD waiver program must continue to operate. Thousands of individuals depend on it. But some short-term changes should be considered to deal with some of the current problems and issues. Therefore we recommend:

The Secretary instruct DMHDDSAS and DMA to convene a stakeholder work group and charge the work group to identify within 90-days specific, actionable changes to the CAP/MR-DD waiver program that can be rapidly implemented with or without federal approval to address the program's most serious problems.

This work group should identify changes that: (a) will streamline the program's administration; (b) fix programmatic defects; and, (c) put the program on a more predictable and stable financial footing. We urge that this work group include stakeholders. There have been too many instances in the past when the CAP/MR-DD program has been altered without sufficient involvement and participation by key stakeholders. We leave it to this work group to sort through our analysis and recommendations concerning the program to identify the most beneficial and actionable changes. However, we believe that strong consideration must be given to rolling back "supported living" to its *status quo ante* prior to the last federal waiver renewal.⁴⁷ We also believe that the decision to boost the participant-spending limit by one-third also must be revisited. There were legitimate problems that needed to be addressed that sparked the decision to boost the limit. However, it may be possible to address the most serious of these problems in an alternative fashion while better containing overall costs.⁴⁸

Going forward, we believe that the CAP/MR-DD waiver program should be replaced by three new waiver programs.⁴⁹ In recent years, a growing number of states have redesigned their waiver programs to operate two waiver programs: (a) a "comprehensive" waiver program principally designed to serve individuals who require out-of-home services and/or who have especially intensive needs and (b) a "supports" waiver that makes a more limited package of benefits available to individuals who live with their families and/or have less intensive needs, (c) a waiver aimed at the needs of people with traumatic brain injury (an initiative that has been in the planning stage for some time). States have taken this step for a variety of reasons, including seeking to divert demand from high cost residential services by furnishing more robust in-home and other supports to families. This design also aids in cost-containment. The "supports waiver" usually has a significantly lower per participant cost cap than the "comprehensive waiver." For technical reasons, it is generally not possible to operate a single HCBS waiver program that employs differential cost caps. Operating three HCBS waiver programs permits the use of differential cost limits and avoids several

⁴⁷ Previously, "supported living" was a more flexible benefit. As presently defined, supported living appears to cause the over-provision of "habilitation" services when individuals and families would prefer personal assistance and similar supports.

⁴⁸ We have suggested decoupling "Y-code" service costs from the overall cost limit. The principal reason why the cost limit was boosted was to accommodate individuals who require considerable Medicaid state plan services. Under the previous limit, high consumption of state plan services caused not many dollars to be left to purchase other services. If "Y-code" service costs are allowed to float, then a separate but lower limit can be placed on CAP/MR-DD waiver services themselves and, thereby, potentially stabilize overall spending. Splitting "Y-code" services out will allow furnishing these services as needed but still enable access to waiver supports. If past experience is any guide, there is not high utilization of "Y-code" services among the vast majority of CAP/MR-DD waiver participants.

⁴⁹ This step would be in addition to launching a new HCBS waiver program to support community placement of MR Center residents, which should proceed on its own. The recommended CAP/MR-DD redesign – once completed – may permit terminating the "deinstitutionalization waiver" and serving those individuals in the community.

problems, including problems similar to those that North Carolina has experienced recently with respect to the CAP/MR-DD waiver program.⁵⁰

For example, about three-years ago, Pennsylvania launched its Person/Family Directed Supports waiver program. Under this program, upwards of \$20,000 in benefits are provided. Because this program operates under a fixed dollar limitation, Pennsylvania also is able to give individuals and families considerable authority in selecting supports. This program operates under a consumer-directed model and has incorporated many of the features of self-determination. Pennsylvania also operates its longer-standing “Consolidated Waiver” program, which is chiefly devoted to underwriting services and supports for individuals with more intensive needs who live outside the family home. Launching the P/FDS waiver program enabled Pennsylvania to expand the number of waiver participants, strengthen its services to people living with their families and leverage more federal dollars (which are assisting the Commonwealth in reducing its waiting list). The same fundamental design is mirrored in Oregon’s Universal Access Plan, which guarantees all eligible individuals a basic package of services up to \$20,000, gives them considerable control in selecting and managing services and supports. In order to implement the Universal Access Plan, Oregon also will be operating two waiver programs – a supports and a comprehensive waiver program. Other states that have adopted much the same strategy include Colorado, Montana and Oklahoma.

We believe this strategy merits serious consideration in North Carolina. Even if the most serious design flaws in the CAP/MR-DD waiver program are addressed, the state is likely to have continuing problems in managing the program financially. Operating under a single-fixed cost limit across all consumers will be especially problematic. One of the steps that North Carolina needs to take is to use the HCBS waiver program more aggressively in funding residential services and supports of all types. Under a single-fixed cost limit, it will be very difficult to do this given cost differentials in serving people in the family home versus other living arrangements. Merging the ICF/MR group homes into the CAP/MR-DD waiver program could not be accomplished under the previous cost-limit, which was at a level below group home payment levels). However, raising the cost limit to accommodate more residential services and supports poses the danger that participant costs will ratchet upward toward the new limit. Splitting the program as recommended would allow services and cost limits to be structured more appropriately to meet the needs of each group.⁵¹

We believe that this strategy potentially will have another important benefit – namely it may position North Carolina to leverage more of the state dollars it presently expends on community services and supports. That result has been achieved in other states that adopted this strategy. However, to fully leverage as many dollars as possible, North Carolina likely will need to entertain making changes in its HCBS Medicaid financial eligibility rules. A contributing factor to low utilization of HCBS waiver services in North Carolina is that the state’s financial eligibility rules are more stringent than in many other states.

HCBS waiver redesign, however, should be broader than merely mechanically re-arranging the CAP/MR-DD program. Redesign also should be regarded as presenting many opportunities to adopt new approaches to

⁵⁰ Present federal policy requires that a state must provide for access by all participants to any services offered in an HCBS waiver program. This means that a state may not restrict individuals to the receipt of a limited package of in-home/family supports but also must provide for access to other services as well, including out-of-home residential services. This aspect of federal policy causes various problems for states, especially with regard to cost-containment. It causes states to limit participation in the HCBS waiver program for fear that costs will rise once individuals enter the program. On the other hand, it serves the state’s interest and consumer interests when the state is able to offer some benefits, even if less than “comprehensive.” As a consequence, the only sure-handed way that a state may offer a more limited package of benefits is to offer them through a separate distinct program.

⁵¹ In the past, some have advocated that, instead of using a single-fixed cost limit, North Carolina manage its HCBS waiver program on an “aggregate” basis – e.g., off-setting the costs of individuals who require intensive services by those who need more limited supports and target at an average cost per participant. Managing an HCBS waiver program on this basis is feasible. However, we do not believe that approach necessarily will resolve any of the underlying cost issues in the CAP/MR-DD waiver program. We believe redesign to create two waiver programs is the more satisfactory approach, especially in light of recent problems.

supporting individuals, including embracing consumer-directed services and self-determination.⁵² This does not mean starting from scratch. However, redesign should be seized upon as an opportunity to embark on new directions. Ideally, this redesign also will be closely linked with revamping funding methods as described above.

Consequently, we recommend that:

The Secretary also charge the stakeholder work group established to make short-term changes in the CAP/MR-DD waiver program to prepare a preliminary redesign along the lines described above by March 31, 2002.

We believe this time line is short but nonetheless feasible, especially because there are many examples of this approach that can be used to inform this redesign. By “preliminary redesign”, we mean a proposed approach that is sufficiently fleshed out to permit broader stakeholder input that can aid in informing the development of final waiver submissions to the federal government.

Performance/Outcome Monitoring

System change and quality improvement must be continuously informed by information concerning system performance and gathering and evaluating data about consumer outcomes. Certainly, the enactment of H.B. 381 underscored the Legislature’s expectation that the performance of Area Programs (LMEs) must be continuously scrutinized and evaluated. As the implementation of H.B. 381 unfolds, it obviously will be important for DHHS to identify the elements of performance that will be tracked continuously. Present approaches (e.g., the contract with COA) do not strike us as adequate or sufficiently reflective of the service and support environment in developmental disabilities. Undoubtedly, there will be elements of performance that will cut across all three-population groups that the LMEs serve. We believe it will be especially important to define and implement performance and outcome measures that are population specific, including measures that are directly relevant to services for people with developmental disabilities.

We note that North Carolina is participating in the national Core Indicators Project, which is co-sponsored by the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. The project has developed tools and instruments that are directly relevant to measuring consumer outcomes and satisfaction with services. North Carolina should seriously consider expanding its use of CIP consumer interviews and family surveys so that statistically reliable information is acquired for each Area Program/LME rather than on a statewide basis. Pennsylvania, which also participates in CIP, adopted this approach with respect to its county-based administering agencies. The information that North Carolina can garner through its participation in CIP will well serve the objective of measuring Area Program/LME performance along important dimensions.

However, broader scale performance and outcome measurement also must be implemented along various lines, especially related to Area Program/LME spheres of responsibility, including core services (e.g., case management/service coordination and crisis/emergency response). Along these lines, distinct performance measures should be developed. We note, for example, that Washington State has been particularly energetic in compiling performance data concerning case management services for people with developmental disabilities.

In the main, it will be important for the Department to establish a minimum data set to inform Area Programs/LME information system development and the type of data that will be reported to DHHS. While

⁵² We are aware that the Division of Medical Assistance is developing a proposal to operate a Section 1115 waiver program that would enable CAP/MR-DD participants to direct their own services. We support this step. We believe that such a demonstration waiver will move North Carolina along in affording individuals and families more authority and control over their services and supports and will aid in informing CAP/MR-DD redesign in many ways. But, we do not regard such a waiver as a substitute for embarking on a more fundamental redesign.

issues with the provision of mental health services certainly were a central imperative behind the enactment of H.B. 381, we note that there are different emphases (but also some areas of overlap – e.g., employment outcomes) in performance tracking and monitoring between mental health and developmental disabilities services. As a consequence, we recommend that:

Implementation of H.B. 381 should include the specification of performance and outcome measures that are directly relevant to services for people with developmental disabilities so that legislators and stakeholders are able to gauge performance and engage in quality improvement activities.

This activity should be directly tied to the development of the multi-year and engage system stakeholders as active participants in defining these performance and outcome measures.

Further, the DD Section also should have the capacity to monitor outcomes in the aggregate and to analyze and act on trends that can be gleaned from a range of QA data. Given the increasing decentralization of the system, it will be important for the Section to concentrate on key aspects of service performance including the important areas of health and safety. To this end, we recommend that:

The DD Section should continue its efforts to develop a quality management committee with the charge of reviewing serious injury reports and investigations, abuse and neglect investigations, mortality reviews, ICF/MR deficiency reports, licensing exceptions and other notable indices of the well-being of people served in the system.

Finally, in order to provide another check on the quality of services in the state, the DD Section should explore the development of an external monitoring entity comprised of family members, people with disabilities and other interested citizens. Such a system is currently being implemented at the county level in Pennsylvania and by the Arc in the State of Maryland.

Conclusion

The preceding recommendations reflect an ambitious but practical agenda for the State of North Carolina. There is nothing in the above action steps that has not been implemented successfully in a number of states around the country. The challenge for those concerned about the future of services and supports to people with developmental disabilities is to put aside many of the parochial issues that have tended to divide the DD constituency and that ultimately have stalled the movement of North Carolina to a more person centered, effective and efficient system of supports. Until this logjam is broken, the system will continue to be fragmented, lacking in flexible options, and unable to muster the consensus necessary to move forward. Our conversations around the State during the course of this project suggest that there is a critical mass of individuals who are ready and willing to take up the challenge. What is needed is the will to take the first step.