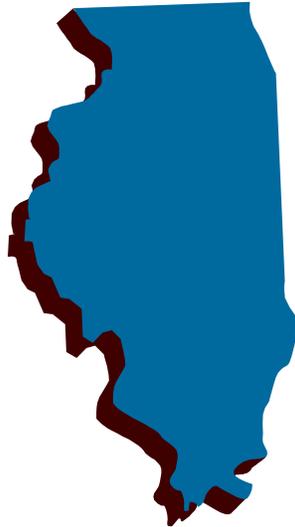


Financing Services to Individuals with Developmental Disabilities in the State of Illinois



BY

**Robert M. Gettings, Executive Director
Robin Cooper, Director of Technical Assistance
Max Chmura, Consultant**

September 2003

**National Association of State Directors
of Developmental Disabilities Services, Inc.**

**113 Oronoco Street
Alexandria, VA 22314
Tel: 703-683-4202
Fax: 703-683-8773 or 703-684-1395**

Developed in Partnership with the Illinois Council on Developmental Disabilities.

TABLE OF CONTENTS

Executive Summary.....	iii
Chapter I: INTRODUCTION	1
A. Project Objectives and Guiding Principles	2
B. Project Team Composition	4
C. Methodology	5
D. Contextual Considerations.....	6
Chapter II: DELIVERING SERVICES TO ILLINOIS CITIZENS WITH DEVELOPMENTAL DISABILITIES	8
A. Key Organizational Components	9
B. Service Eligibility	11
C. Covered Services	13
D. Scope and Composition of the Service System	15
E. Contracting Process.....	23
F. Illinois' Medicaid Program.....	23
G. Conclusion.....	24
Chapter III: IMPROVING THE COMMUNITY SERVICES INFRASTRUCTURE.....	26
A. Decentralized Management of State Services	27
B. Person-Centered Supports.....	33
C. Management Information Capabilities.....	36
D. Quality Assurance and Improvement Systems	38
E. System-wide Planning.....	41
F. Conclusion.....	43

Chapter IV: FINANCING STATE OPERATED DEVELOPMENTAL CENTERS	45
A. Analysis of Existing Rate Methodology and Reimbursement	46
B. Alternative Rate Methodology	49
C. Additional Revenue Issues	55
D. Conclusion.....	57
Chapter V: FINANCING COMMUNITY-BASED SERVICES.....	59
A. Claiming Additional FFP Under the State’s Existing DD Waiver Program.....	61
B. Expanding the Use of the Medicaid HCBS Waiver Authority	70
C. Medicaid Eligibility and HCB Waiver Services	85
D. Improving Medicaid Community Service Participation Levels.....	97
E. Claiming Medicaid Reimbursement for Case Management (Service Coordination) Services	102
F. Conclusion.....	108
Chapter VI: CLAIMING ADMINISTRATIVE COSTS.....	109
A. Administrative Claiming Strategies: State-Operated Services.....	110
B. Administrative Claiming Strategies: Community Provider Agencies...	114
C. Claiming MMIS-Related Costs.....	118
D. Conclusion.....	124
Chapter VII: MAPPING A PATHWAY TOWARD ENHANCED FEDERAL FINANCIAL PARTICIPATION	125

Executive Summary

INTRODUCTION

In the spring of 2002, the staff of the Illinois Council on Developmental Disabilities (ICDD) approached the National Association of State Directors of Developmental Disabilities Services (NASDDDS) about conducting an in-depth analysis of the state's existing methods of capturing federal revenue and other third party payments for services to persons with developmental disabilities. The ensuing discussions between ICDD and NASDDDS led the Council to award a grant to the Association that called for the completion of a study aimed at accomplishing the following objectives:

- ✓ Examine the existing methods used by the State of Illinois to finance services and supports to eligible children and adults with developmental disabilities.
- ✓ Develop a policy construct to guide future financing of public developmental disabilities services in the State of Illinois.
- ✓ Identify and evaluate potential new and expanded third party revenue sources that Illinois policymakers, administrators, and disability advocates might wish to explore.
- ✓ Analyze the alignment between Illinois' policy goals for people with developmental disabilities and the state's current and prospective methods of financing public services for this population.
- ✓ Prepare and submit a comprehensive report summarizing the principal findings of the project team's analysis as well as a detailed set of recommendations regarding new and expanded third party revenue sources the state should explore.

The NASDDDS project team gathered information and viewpoints from a variety of DD system stakeholders during the initial ten months of the project. In addition, budget documents, data reports and various other materials were reviewed during the course of the study in an effort to deconstruct and analyze the state's existing methods of financing and delivering long-term services and supports to children and adults with developmental disabilities. In reaching conclusions and formulating recommendations, the members of the project team drew upon their knowledge of federal-state Medicaid policy as well as the methods used by other states to finance specialized DD services.

This final project report summarizes the NASDDDS' project team's findings, conclusions, and recommendations. The report contains a compendium of proposed revenue enhancement strategies and related system management improvements. The concluding chapter includes advice on establishing targeted priorities for pursuing such enhancements and improvements.

Comparative Scope of Services and Spending

Comparative interstate data provides a useful backdrop for understanding the present status of specialized services to Illinois citizens with developmental disabilities and, in particular, where the state's existing service system may need improvements. Although Illinois furnished residential services to more individuals per 100,000 in FY 2000 than the national median for all states (147.2 v. 136.1), it did so by relying on larger, congregate care facilities (16+ people) to a greater extent than other states. That year, Illinois ranked 47th among the states in the proportion of dollars allocated for non-ICF/MR community services, with 57 percent of the state's total spending devoted to community services (compared to a national median of 75% for all states). The state's comparatively heavy reliance of congregate care services also was borne out by other statistical measures. According to researchers at the University of Colorado's Coleman Institute for Cognitive Disabilities, Illinois' level of fiscal effort (defined as state spending per \$1,000 of personal income) ranked as follows among the 50 states and the District of Columbia in FY 2000:

- ✓ 42nd in spending on community services;
- ✓ 13th in spending on institutional services; and
- ✓ 24th in overall MR/DD spending.

More to the point of the current study, the University of Colorado research team concluded that 24 percent of Illinois's general fund expenditures on behalf of people with developmental disabilities was unmatched during FY 2000, thus ranking the state 40th among the fifty states and the District of Columbia in the efficiency with which it claimed federal Medicaid reimbursements on behalf of this population. Vital steps have been taken over the past three years to improve the state's federal Medicaid recovery rate, but, as the report details, further work remains to be accomplished.

Effective Management of Third Party Revenues

Too often revenue enhancement is treated by state agencies as an isolated set of activities that are undertaken episodically to address budget shortfalls or take advantage of newly authorized funding options. In such an environment, efforts to identify new funding sources become an idiosyncratic process that depends almost entirely on the adequacy of existing data systems and analytical capabilities and, in the longer term, the effectiveness of reporting systems and oversight capabilities that are put in place to ensure ongoing compliance with applicable funding requirements. When any one of these key ingredients (timely, accurate data; knowledgeable/skilled staff; effective reporting and quality management systems; and a sound financial infrastructure) is missing, serious problems are likely to be encountered in qualifying for enhanced revenue and/or in sustaining such new revenue streams over time.

The potential pitfalls of attempting to obtain enhanced revenue "on the fly" are accentuated in the case of Medicaid financing options. Federal-state Medicaid policy is exceedingly complex, with multiple overlays of statutory, regulatory and administrative requirements that need to be thoroughly analyzed and applied in the context of the particular state's needs and capabilities before intelligent decisions can be made about accessing new or expanded funding options.

Often there are trade offs that have to be considered and administrative workload issues that must be addressed, plus new reporting and compliance mechanisms that have to be instituted in order to assure the continuity of new funding. In addition, the implications of any necessary administrative and managerial changes have to be examined from the perspective of all key components of the state's service delivery system, ranging from the single state Medicaid agency, the state DD program agency, the field office staffs of the two agencies, local single point-of-entry (county/regional/area) agencies (if such a mechanism exists within the particular state), local provider/vendor agencies/organizations, as well as individuals with disabilities and their families. Reaching agreement among all affected parties can be a complex, time-consuming undertaking, since perspectives on accessing new funding sources can and often do vary depending on one's vantage point within the service delivery system.

A state, therefore, must have in place an effective management structure in order to maximize third party revenues. Among the essential characteristics of this management structure are: (a) clearly delineated administrative roles and responsibilities throughout the service delivery system, beginning at the highest levels of state government and proceeding through the point at which publicly funded services are furnished to individuals and their families; (b) a policy/management environment in which revenue management is treated as an integral part of the overall policy development and implementation process, and in which the state maintains the analytical capacity to evaluate the potential effects of new and expanded revenue options on a routine basis; (c) a management information system that produces the utilization and expenditure data necessary to support existing third party revenue claims and investigate the possible impacts of new revenue generating strategies; and (d) a well-designed system for assuring the quality of community services and supports.

Improving the Community Services Infrastructure

Illinois, unlike most other states, has yet to establish a unified, single-point-of-entry system for managing state-funded developmental disabilities services in which a designated local entity within each catchment area of the state is responsible for eligibility determination, intake, individual program planning, service coordination and the purchase of needed services. One particularly problematic aspect of the existing organizational structure in Illinois is the bifurcation of local managerial responsibilities. Individual service planning and coordination responsibilities rest with Preadmission Screening/Individual Service Coordination (PAS/ISC) agencies operating under contract with DDD, while DDD, acting through its eight network teams, assumes direct responsibility for negotiating service contracts with local community provider organizations.

In addition to such organizational/structural issues, the NASDDDS study team identified a number of other key system management issues that need to be addressed in Illinois, including:

- ✓ *Creating a state/local management infrastructure to under gird person-centered support networks which afford individuals with developmental disabilities and their families true choices and control;*

- ✓ *Building a state-of-the-art management information system that gives state officials as well as program managers at all levels of the service delivery system the essential tools to manage resources more effectively and efficiently;*
- ✓ *Strengthening the components of the state's DD quality management system in light of the even-expanding scope of community-based services and the heightened expectations of state performance in this area that are being established by the federal Centers for Medicare and Medicaid Services;*
- ✓ *Improving the state's capacity to identify and track persons with unmet service needs and regulate access to state-funded developmental disabilities services on an equitable basis.*

An in-depth analysis and recommendations on restructuring and improving the state's DD service delivery infrastructure and processes was beyond the scope of the present study. Nonetheless, it is important to recognize that many of the past difficulties the state has encountered in accessing third party revenues can be traced back to the basic limitations imposed by the state's existing service delivery structure as well as the infrastructure that has been put in place to support it. For this reason, throughout its report the project team stresses the importance of re-investing a portion of General Fund savings associated with successful revenue enhancement strategies in strengthening system-wide management capabilities, especially in the areas identified above.

Due to the absence of critical data and the limited focus of the present study, it was not possible to quantify the costs of the proposed infrastructure improvements. The report also does not specify the proportion of GF savings that should be redeployed to expand and improve services to Illinois citizens with developmental disabilities. Nor does the report suggest the most effective approach to managing the redeployment process. Certainly a compelling argument can be advanced for applying any resulting GF savings to address the backlog in unmet needs among individuals with developmental disabilities and their families and to launch some of the broader system change initiatives identified in this report as well as in other analyses of the state's DD service system. Indeed, earlier in the year the Illinois General Assembly considered legislation (H.B. 75) which would mandate that all Medicaid revenues generated by community DD provider agencies be placed in a dedicated fund and used to compensate such provider agencies. Other states have demonstrated that "trust" funds and similar mechanisms can be an effective way of ensuring that new third-party revenues are reinvested in the service delivery system, rather than being return to the state treasury.

The unanswered question in Illinois, as far as the study team was able to ascertain, is: how should decisions regarding the redeployment of GF savings be made? Should such funds be used exclusively to compensate community provider agencies for shortcomings and inequities in the state's existing rate-setting policies (as appears to be the assumption underlying H.B. 75)? Or should these dollars be distributed among other systemic priority areas as well, such as: (a) extending services and supports to individuals and families who currently are un-served or under-served; or (b) improving the wages and benefits of direct contact workers, supervisors and other front line staff; or (c) financing some of the infrastructure improvements outlined above;

and/or (d) covering the from-end costs of broad, system change initiatives, such as reducing the state's reliance on large congregate care facilities or assisting adults to transition from shelter workshops to integrated jobs in the community? Obviously, determining the most appropriate distribution of available funds will be, in the final analysis, a political decision. Any views the project team might express on this subject, therefore, are not likely to be very helpful. We, however, would encourage Illinois policymakers and DD stakeholders to tie decisions regarding the investment of any GF savings to DDD's 3-Year Strategic Plan process, so that spending allocation decisions are linked directly to the state's planning and priority setting processes.

Near-Term and Longer Range Revenue Enhancement Strategies

As the Division of Developmental Disabilities prepares to update the agency's three-year strategic plan (to cover the period July 1, 2004 through June 30, 2007), in cooperation with the Statewide Advisory Council on Developmental Disabilities, consideration should be given to including a more detailed set of revenue enhancement objectives that are tied to accomplishing specific system change goals. With this general thought in mind, the project team offers the following observations regarding the establishment of revenue enhancement priorities as part of DDD's 3-Year Strategic Plan for FY 2004 through FY 2007:

1. Near-Term Revenue Enhancement Strategies. The team's report includes a number of comparatively straightforward, non-controversial steps that should result in increased federal Medicaid payments. Efforts to access a number of these new and expanded revenue options – particularly within the context of the state's existing HCBS waiver program for adults with developmental disabilities -- already have been initiated by DDD. Most notably, DDD officials over the past year have made administrative decisions or gained federal approval for a technical amendment that allows the state to claim reimbursement for “at home day programs”, “host family home services” and “home-based personal supports” (see additional discussion in Chapter V, Section A). In the team's judgment, the other proposals listed below could be completed relatively expeditiously. Among these steps are:
 - ✓ Take prompt actions to ensure that the state fully recovers the federal share of Medicaid costs associated with opening new facilities on or near the campus of Lincoln Developmental Center (see Section C-1, Chapter IV);
 - ✓ Institute actions to prevent the lost of certification status or eligibility on behalf of court-committed SODC residents with a history of violent, anti-social behaviors in combination with their developmental disabilities (see Section C-2, Chapter IV);
 - ✓ Convert all developmental training services to a fee-for-service methodology and begin claiming for such services under the state's adult DD services waiver program (see Section A-4, Chapter V);

- ✓ Review all other DDD grant-funded activities to pinpoint services (and recipients of such services) who could be converted to HCBS waiver funding (see Section A-5, Chapter V);
- ✓ Enroll in the state’s DD adult services waiver program Medicaid-eligible young adults with developmental disabilities, ages 18 to 22, who are currently receiving services funded by the Department of Children and Family Services, beginning with the 80 young people presently residing in Community Integrated Living Arrangements (CILAs; see Section A-6, Chapter V);
- ✓ Take steps to improve the efficiency of Medicaid claiming under the state’s adult DD services waiver program (see A-7, Chapter V);
- ✓ Explore the effects of adopting a special income standard for determining the financial eligibility of individuals to participate in the state’s adult DD services waiver program (i.e., as a substitute for the state’s existing spend-down policies; see B-2, Chapter V);
- ✓ Explore the effects of using federal Post Eligibility Treatment of Income policies (rather than spend-down policies) to determine the financial eligibility of persons with developmental disabilities to participate in the state’s DD adult services waiver program (see B-2, Chapter V);
- ✓ Streamline the existing process of determining ICF/MR level-of-care needs among applicants for adult DD home and community-based waiver services (see B-3, Chapter V);
- ✓ Monitor closely federal policy with respect to decoupling “active treatment” from eligibility to receive HCBS waiver services, with an eye toward removing “active treatment” as a condition of enrollment in the state’s adults DD services waiver program and replacing it with an ICAP-derived acuity of need measure (see B-3, Chapter V).
- ✓ Institute a requirement that all potentially eligible individuals who currently receive or request DDD-funded community services apply for Medicaid benefits and, if found eligible, enroll in the state’s adult DD services waiver program -- assuming they meet all program enrollment requirements (see E-3, Chapter V);
- ✓ Review the state’s present administrative claiming methodology for service coordination (ISSA) to determine whether it would be advantageous to switch to a targeted case management coverage option under the state’s Medicaid plan (see F-3, Chapter V);
- ✓ Revise the state’s existing methodology for claiming administrative costs in connection with CILA and Community Living Facility (CLF) services so that 100

percent, rather than 95 percent, of allowable costs are claimed (see Section B, Chapter VI);

- ✓ Compare the impact on billable Medicaid administrative costs if separate percentage rates are applied to the allowable cost centers of the Division of Developmental Disabilities and the Division of Mental Health (i.e., versus continuing to use a combined percentage; see Section B, Chapter VI); and
 - ✓ Complete an initial assessment of the state's existing DD-related management information capabilities and future needs, and use the results of this assessment to prepare, in collaboration with IDPA officials, a Planning – Advanced Planning Document, seeking CMS approval (and funding) to conduct an in-depth analysis of the principal components of an improved DD MIS module as part of the state's overall Medicaid Management Information System (see C-3, Chapter VI)
2. Intermediate and Longer Range Revenue Enhancement Strategies. In addition to the near-term revenue enhancement strategies outlined above, the report suggests other possibilities that will require a considerable amount of additional analysis and/or take much longer to bring on line. Among these options are the following:
- ✓ Explore the effects of switching from a cost-based methodology to a cost-related methodology of billing Medicaid for ICF/MR expenses incurred by the nine state-operated developmental centers, especially if DDD/IDHS elects to pursue an aggressive, multi-year plan to downsize the census of SODCs (see Section B, Chapter IV);
 - ✓ Analyze the merits of creating one or more HCBS waiver programs targeted to children with developmental disabilities, including the possibility of initiating a family supports waiver program and an children's intensive supports waiver program (see Section B-1, Chapter V);
 - ✓ Analyze the merits of establishing an intensive supports HCBS waiver program for adults with developmental disabilities as a mechanism to promote alternative community living opportunities for persons with severe, complex disabilities who currently reside in SODCs and other Title XIX-certified congregate settings (i.e., ICFs/DD and SNF/Peds.; see Section B-2, Chapter V);
 - ✓ Explore the feasibility of converting the funding of persons living in private ICFs/DD to the adult DD services waiver program, beginning with residents of small, community-based ICFs/DD (see Section B-3, Chapter V);
 - ✓ Consider creating an IDHS revenue budget that identifies the level of revenue that is expected to be associated with (or claimed as) administrative expenditure in each fiscal year (Section A, Chapter VI); and

- ✓ Study the effects of adding an IDHS administrative component to each rate or fee that is paid to community providers of adult DD waiver services before seeking federal Medicaid reimbursement (see Section B, Chapter VI).

As emphasized in Chapter III of this report, a state's ability to generate and effectively manage third party revenues is tied directly to the strength and agility of the underlying state/local infrastructure it puts in place to support such activities. Some components of this infrastructure are directly correlated with the performance of revenue management activities (e.g., ready access to complete, accurate and timely utilization and cost data), while the effects of other components may not be as readily apparent to the casual observer (e.g., the existence of clear lines of responsibility/accountability and clear, well defined roles throughout the service delivery system). As Illinois policymakers and disability stakeholders strive to generate additional third party dollars to finance services to children and adults with developmental disabilities, simultaneous improvements will need to be made in the following aspects of the state's DD service delivery infrastructure:

- Unifying responsibility for eligibility determination, intake, individual service planning, service coordination and the purchase of services within a single organizational entity in each designated catchment area of the state (see discussion under Section A, Chapter III);
- Improving the alignment between DDD's person-centered service delivery philosophy and the way in which services are planned and money is disbursed within the state's existing service system (see Section B, Chapter III);
- Improving IDHS' management information capabilities to produce the data necessary to: (a) enhance the efficiency of existing third party billing procedures; (b) analyze the potential impacts of proposed, new revenue raising strategies; and, most importantly (c) support individualized payment and accountability structures that allow services to be tailored to the unique needs and preferences of each person and family (see Section C, Chapter III);
- Reviewing the state's existing quality assurance and improvement program to ensure that it comports with CMS' new, heightened expectations (see Section D, Chapter III); and
- Developing statewide service access policies that: (a) afford individuals and families across the state equitable access to state-financed DD services and supports within the constraints of available public dollars; and (b) generate extensive data on unmet needs within the state's DD population that can be used to support requests for additional funding and map out plans for improving access to needed services.

Chapter I

INTRODUCTION

The combined effects of a nationwide recession, the economic fallout from the events of September 11th and the continued, rapid growth in Medicaid expenditures have forced many states to reduce their budgets significantly over the past two years. A recent survey of state finances conducted by the National Governors' Association (NGA) and the National Association of State Budget Officers (NASBO) found that states face aggregate budget shortfalls of \$29 billion in FY 2003 and \$82 billion in FY 2004.¹ The capacity of states to address what NGA and NASBO have characterized as "the perfect [fiscal] storm" is complicated by the states' often antiquated, inefficient tax systems and the sharp decline in state reserve, or rainy day, funds over the past three fiscal years.

The present budget crisis in Illinois illustrates the grim fiscal realities facing many states today. Earlier this year, the Blagojevich Administration estimates that a \$4.8 billion gap had to be closed to produce a balanced budget for the fiscal year beginning on July 1, 2003. While the Governor and state legislature managed to craft an FY 2004 budget that is at least in nominal balance, they had to increase the state's long-term indebtedness substantially in order to achieve this end. Unless the state's economy rebounds sharply in the coming months, the state will face an equally serious budget crisis next fiscal year and, possibly, for several years to come.

Confronted with the prospect of major budgetary retrenchment, the options available to a state generally are to cut spending, raise taxes, or, more likely, employ a combination of these two strategies. But, there is another approach to closing revenue gaps – maximize revenue from third party sources.

Two years ago, the members and staff of the Illinois Council on Development Disabilities (ICDD) became concerned that the state was not taking full advantage of third party funding opportunities and, as a result, fewer children and adults with developmental disabilities were able to access publicly funded services and supports than otherwise might be the case. This conclusion was based to a considerable extent on the findings of a study conducted by the staff of the Coleman Institute for Cognitive Disabilities at the University of Colorado. The authors of the study concluded that 24 percent of the state's overall general fund expenditures were unmatched, thus ranking Illinois 40th among the fifty states and the District of Columbia in the efficiency with which it claimed federal Medicaid reimbursements during FY 2000.²

¹ National Governors' Association and the National Association of State Budget Officers, *The Fiscal Survey of the States*, June 2003.

² Braddock, David, Richard Hemp, Mary C. Rizzolo, Susan Parish and Amy Pomeranz, *The State of the States in Developmental Disabilities: 2002 State Summary*, Coleman Institute for Cognitive Disabilities, Department of Psychiatry, The University of Colorado, January 2002, p. 20.

In the spring of 2002, the ICDD staff approached the National Association of State Directors of Developmental Disabilities (NASDDDS) about conducting an in-depth analysis of the state's existing methods of capturing federal revenue and other third party payments for services to persons with developmental disabilities and preparing a comprehensive set of recommended revenue enhancement strategies. A proposal for completing such an analysis subsequently was prepared by the NASDDDS staff and approved by the full Council.

The purpose of this chapter is to outline the aims of the resulting study, explain the methods employed by the NASDDDS project team, and summarize several important contextual factors that impinge on current efforts in Illinois to identify additional sources of third party revenues for state-financed developmental disabilities services.

A. Project Objectives and Guiding Principles

The overarching goal of the study was to offer state policymakers and disability advocates a comprehensive set of options for generating additional federal revenue to finance services and support to Illinois citizens with developmental disabilities. More specifically, the project was designed to accomplish the following objectives:

- Examine the existing methods used by the State of Illinois to finance services and supports to eligible children and adults with developmental disabilities. The project team reviewed and summarized existing methods of financing state services and supports to individuals with developmental disabilities, with particular emphasis on documenting current approaches to claiming federal financial participation (FFP) in the costs of Medicaid reimbursable services. This review encompassed the methods used to establish billing rates, document payment claims and create a clear audit trail. It also included an examination of the revenue generating implications of possible modifications in Illinois' state Medicaid plan, service definitions, eligibility determination processes, and service delivery methods with respect to both state plan and home and community-based (HCB) waiver services.
- Develop a policy construct to guide the future financing of public services for people with developmental disabilities in the State of Illinois. The purpose of this policy construct was to lay out a proposed set of strategies and philosophies that state officials should employ in managing program revenues going forward. This policy construct will outline a general approach to revenue maximization and revenue management activities, rather than viewing such activities as a disconnected series of occasional initiatives.
- Analyze the alignment between Illinois' policy goals for people with developmental disabilities and the state's current and prospective methods of financing public services for this population. Throughout its review of existing and proposed revenue raising strategies, the project team attempted to compare the state's present methods of financing developmental disabilities services with strategic system reform goals articulated by state officials and non-governmental DD stakeholders. In keeping with the principle that new revenue initiatives should be driven by the state's strategic goals and not vice versa, the

aim was to identify changes in the state's developmental disabilities revenue management architecture that Illinois should consider as it strives to achieve its strategic goals.

- Identify and evaluate potential new and expanded third party revenue sources that Illinois policymakers, administrators, and disability advocates may wish to explore. The discussion of each revenue enhancement option includes: (a) information regarding the legal basis of the particular claiming option/strategy; (b) the steps involved in qualifying for such new/expanded revenue sources; (c) an exploration of any implications for developing improved information tracking systems and compliance assurance mechanisms that the state will need to avoid subsequent disallowances or compliance actions; (c) wherever feasible, a preliminary estimate of the range of additional third party revenues the state may be able to generate; and (d) other key factors that the state should take into account in evaluating whether to pursue the particular third party source of revenue. These explanations of proposed new or expanded revenue options are presented in non-technical language that is understandable to readers who are not steeped in the intricacies of state/federal fiscal policies and practices.
- Prepare and submit a comprehensive report summarizing the principal findings of the project team's analysis as well as a detailed set of recommendations regarding new and expanded third party revenue sources the state should explore. The aim of the project team was to offer interested Illinois stakeholders a user-friendly roadmap to the revenue options that should be explored as they consider future methods of financing public services to people with developmental disabilities in the years ahead. Again, the study team has attempted to present its findings and recommendations in non-technical language understandable to both government officials and citizen advocates.

Revenue streams and fund allocation practices are structured to support a set of approved service alternatives. The types and structure of the services a state finances should be based on the needs of people with disabilities, their desired role in society and the responsibilities of the state with respect to the provision of such services. State governments also have an overarching responsibility to ensure that scarce public resources are deployed in an efficient and effective manner. Faced with the choice of providing services to persons in alternative program settings, therefore, state policymakers are under an obligation to ensure that the most cost-effective and efficacious alternatives are emphasized. For this reason, it is vitally important that any study of current and potential future funding alternatives examine the full spectrum of a state's existing developmental disabilities budget as well as articulations of current system-wide values and goals.

In conducting the present study, the NASDDDS project team has been guided by the following general precepts:

- *The analysis is to be conducted within the framework of the state's overall strategic planning goals.*
- *The main focus of the analysis is on identifying new and expanded sources of federal Medicaid dollars to underwrite the costs of state services and supports to children and*

adults with developmental disabilities; but, other potential sources of third party revenue will be examined as well.

- ❑ *Consistent with the resources available, the project team will seek input from the widest possible range of system stakeholders, both within and outside of state government.*
- ❑ *The overall objective of the project is to lay out a comprehensive set of revenue enhancement strategies, along with the factors the state should weigh in determining whether to pursue each particular strategy.*
- ❑ *The project team will assess the state's existing infrastructure for managing third party revenues and offer recommendations regarding any additional investments that may be needed to ensure that revenues from existing and new/enhanced sources are effectively and efficiently managed.*

B. Project Team Composition

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) is a nonprofit, charitable organization that represents the chief state developmental disabilities officials in the 50 states and the District of Columbia. The mission of the Association is to assist member state agencies to build person-centered systems of services and support for people with developmental disabilities and their families. In pursuit of this mission, NASDDDS furnishes extensive on- and off-site consultation and technical assistance to member state agencies. Due to the staff's acknowledged expertise in the area of federal-state Medicaid policy, virtually every state turns to the Association – often on a recurring basis – or advice and assistance in designing and implementing home and community-based and institutional services targeted to individuals with developmental disabilities.

Robert Gettings, NASDDDS' Executive Director, has served as overall director of the present project. He has been ably assisted by Robin Cooper, the Association's Director of Technical Assistance Services, and Leyla Sargöl, NASDDDS' State Policy Analyst. In addition, Max Chmura, the President of PNP Associates, has served as a consultant to the project, contributing his specialized knowledge and expertise in financing public services for children and adults with developmental disabilities. PNP Associates, under Mr. Chmura's leadership, has helped developmental disabilities systems in a number of states to: (a) maximize Medicaid and other federal funding sources and, conversely, to minimize the state's reliance on state general revenues; (b) formulate strategies for reinvesting dollars presently committed to institutional/congregate services in person-centered community supports without destabilizing the state's finances; (c) create flexible payment mechanisms that promote the delivery of more community-based supports that are responsive to consumer choices and integrated into the mainstream of society; and (d) reengineer financing and service delivery processes to increase productivity and enhance consumer satisfaction.

C. Methodology

During the initial eight months of the project, the members of the project team visited the state on multiple occasions to meet with state officials, self-advocates, family members, provider agency administrators, and other knowledgeable individuals to gather information concerning the organization, financing, and delivery of specialized services and supports to Illinois citizens with developmental disabilities. During these visits, the project team conducted interviews with a wide range of state fiscal and program managers and collected information on various aspects of the operation and financing of developmental disabilities services in the State of Illinois. Between visits, members of the project team were in telephonic contact with a wide range of state officials and other knowledgeable stakeholders to clarify various points and obtain supplementary information. A considerable amount of time was spent analyzing budget documents, fiscal reports, claims management data, program policies, planning document, etc. in order gain a well-rounded picture of the state's current methods of financing and delivering publicly funded services to children and adults with developmental disabilities.

In late September 2002, with the assistance of the ICDD staff, the project team held a series of focus group meetings with various DD stakeholders groups. The purpose of these meetings was to obtain feedback regarding the perceived strengths and weaknesses of the state DD service delivery system – with special emphasis on financing of DD services – from the perspective of each, particular target audience. Focus group meetings were conducted with family members, self-advocates, service coordination agencies, and community provider agencies.

Later, the members of the project team participated in a special, one-day open forum, sponsored by ICDD, where potential, new DD revenue options were discussed. The purpose of this February 26, 2003 forum was to: (a) explain the fundamentals of Medicaid policy, including policies governing home and community-based waiver programs; (b) answer questions and clarify issues dealing with the Medicaid long-term services policy; and (c) outline the approach the NASDDDS project team was taking to analyzing potential new and expanded revenue options in Illinois. The forum also offered the project team another chance to obtain input from Illinois stakeholders on the strengths and weaknesses of the state's existing methods of financing public DD services, as well as the perceived opportunities and risks associated with the expanded use of federal/state Medicaid dollars.

On July 16, 2003, the project director briefed members of the Council's Community Inclusion and Housing Committee and invited guests on the study team's principal findings and conclusions. A similar briefing session was conducted for members of the Statewide Advisory Council on Developmental Disabilities on July 24, 2003 in Springfield. These sessions offered the study team an opportunity to obtain feedback concerning its key recommendations in advance of preparing the final report. It also gave key stakeholders a chance to learn more about the implications of the new revenue options and other recommendations that were being advanced by the study team.

This final project report summarizes the NASDDDS' project team's findings, conclusions, and recommendations. The report contains a compendium of proposed revenue enhancement strategies and related system management improvements. The concluding chapter contains

advice on establishing targeted priorities for pursuing particular revenue enhancements, but, with the completion of the study, responsibility for deciding how to proceed shifts to state officials working in tandem with other system stakeholders.

D. Contextual Considerations

Modifications in the financing of complex public service systems do not occur in a vacuum. It is important to understand the factors that are fueling the search for new and enhanced sources of third party revenue, as well as the forces that are likely to influence the success or failure of this venture. The closing section of this chapter, therefore, is devoted to an examination of several contextual issues that need to be taken into account in mapping out a near-term and longer-range revenue maximization strategy for developmental disabilities services in the State of Illinois.

The first and most obvious factor motivating the search for new and expanded sources of third party revenue is the serious budget shortfall presently facing the state. As noted above, the Governor and state legislature face an enormous challenge in balancing expenditures and revenues over the next few years.

To the extent that the state is able to access enhanced third party revenues, the overall impact of the budgetary shortfall will be cushioned and the dislocations often associated with deep spending reductions might be avoided or at least ameliorated. But, as will be discussed throughout the report, frequently state policymakers also have to consider the near-term and longer range managerial and systemic investments that are necessary to qualify for and ensure the ongoing stability of additional third party revenues. A tension exists between these two objectives (maximizing third party revenues vs. improving the state's service delivery infrastructure) that have to be resolved. There are numerous gaps and discontinuities in the state's existing system of financing services to persons with developmental disabilities. These issues will be enumerated in greater detail later in this report (see especially Chapter III). Determining whether and how these systemic issues are to be addressed and the net impact such actions may have on the state's budget are key considerations that must be weighed in evaluating the feasibility of new and expanded revenue options and deciding which of these options should be pursued. In subsequent chapters of the report, these tradeoffs will be discussed in additional detail. Suffice to say for present purposes that finding the proper balance point is one of the critical challenges of analyzing the feasibility of alternative revenue enhancement options.

Second, the fact that a new governor took office in January has altered the decision-making dynamic in Springfield to a considerable extent. Rod Blagojevich became the first Democratic Governor of the State of Illinois in 26 years, following his victory in last November's election. Accompanying the new governor is an entirely new, top-level management team within state executive branch agencies and a significantly modified set of policy goals and priorities. Democrats also gained control of both chambers of the Illinois State Legislature in last fall's election.

The effects of changes in the state's political leadership were still unfolding as this report was being prepared. However, with respect to accessing new sources of revenue for publicly funded developmental disabilities services, it was clear that these changes were likely to have two

contrasting effects. Certainly, a new executive management team and a revised legislative leadership, unburdened by past decisions and precedents, will be in a position to take a fresh look at the financing of state DD services and potentially adopt a significantly revised set of strategies. On the other hand, given the learning curve every new administration faces as it puts its management team in place and attempts advance its policy agenda, it is likely to be a difficult environment within which to gain (and hold) the attention of top level administrators and key legislators. The details of a revised revenue management plan can be worked out by permanent civil servants, working in tandem with other DD system stakeholders. But, the plan is unlikely to be instituted unless it has the strong backing of key political appointees within the Blagojevich Administration and elected leaders in the legislature.

Finally, last year, the Ryan Administration offered state civil servants an early retirement option as part of its approach to filling a projected budget gap during FY 2003. While this initiative may have helped to address the near-term fiscal shortfall, the resulting loss of senior personnel has significantly eroded the institutional memory of many state agencies. This problem has been exacerbated by the hiring freezes that state executive branch agencies currently are operating under, thus making it very difficult to recruit and hire replacement personnel in all but the most essential positions.

The project team observed, in microcosm, some of the consequences of the state's "early out" program as it gathered information for this report. During an early phase of the project, highly knowledgeable state officials were contacted and provided very helpful materials and insights into the financing of relevant services in Illinois; however, when we called with follow-up questions several months later, we learned that these officials had retired and their positions had yet to be filled. The recent "brain drain" within Illinois state government – especially within the state departments of Human Services and Public Aid – will make the task of developing and implementing a coherent, long range plan for financing public developmental disabilities services in the State of Illinois more difficult than it otherwise might have been.

Chapter II

DELIVERING SERVICES TO ILLINOIS CITIZENS WITH DEVELOPMENTAL DISABILITIES

A number of agencies of Illinois State Government play a part in furnishing services and supports to individuals with developmental disabilities. Four executive branch agencies, however, exercise primary responsibility for organizing and delivering services to children and adults in Illinois:

- The Board of Education is responsible for overseeing and improving the quality of educational services throughout the state, including special education services for children and adolescents with physical, mental, sensory and developmental disabilities.
- The Department of Children and Family Services provides child welfare and child protection services to abandoned, neglect or abused youngsters statewide, including services to children with disabilities who reside with their families or in foster family homes.
- The Department of Public Aid administers the state's medical assistance (Medicaid) program, which purchases acute health care and long-term supports for thousands of children and adults with developmental disabilities, statewide.
- The Department of Human Services administers early intervention services for more than 10,000 infants and toddlers with developmental delays and disabilities, and also oversees the delivery of long-term services and supports to nearly 45,000 children and adults with developmental disabilities and their families. In addition, the department furnishes vocational rehabilitation services to adolescents and adults with disabilities of all types, manages the state's mental health service system, the Food Stamp program and other low-income cash and food assistance programs. IDHS also oversees the Medicaid eligibility determination process.

The aim of this chapter is to offer readers a concise overview of the state/local service system as it impacts on persons with developmental disabilities. The summary information below is intended to serve as a foundation for the analysis of policy issues and revenue options that follows. Since the overarching purpose of the report is to pinpoint viable, new and expanded third party financing alternatives – principally in the area of long-term services and support – the succeeding sections of this chapter concentrate mainly on programs administered by the Illinois Department of Human Services (IDHS) and, in particular, IDHS' Division of Developmental Disabilities (DDD). For this same reason, the project team has included a brief overview of relevant features of the state's medical assistance program, in recognition of the fact that

Medicaid is the primary financing source for specialized services and supports to children and adults with mental retardation and other developmental disabilities.

A. Key Organizational Components

The Illinois Department of Human Services (IDHS) is the largest agency of state government, with over 19,000 employees and a nearly \$5 billion annual operating budget. IDHS furnishes services to Illinois citizens through seven major programs:

- Alcoholism and substance abuse treatment and prevention services;
- Developmental disabilities services and supports;
- Health services to pregnant women and mothers, infants, children and adolescents;
- Services to prevent domestic violence and assist at-risk youth;
- Mental health services to children, adolescents and adults;
- Vocational rehabilitation services for adolescents and adults with disabilities; and
- Public assistance programs, including Temporary Assistance for Needy Families, Food Stamps, Aid to the Aged, Blind and Disabled and other food and cash assistance programs, and child care services.

One out of every five Illinois citizens receives IDHS assistance each year. This assistance is furnished through a statewide network of over 200 local offices, operating in partnership with networks of local service providers.

Developmental Disabilities Services. IDHS' Division of Developmental Disabilities (DDD)¹ oversees the Illinois system of specialized services and long-term supports for children and adults with lifelong disabilities. In addition to furnishing direct services to approximately 2,800 individuals who reside in nine state-operated developmental centers (SODCs), DDD establishes policies, provides technical assistance and oversees the provision of services furnished by over 300 private intermediate care facilities for persons with developmental disabilities (ICFs/DD) and pediatric skilled nursing facilities (SNF/Ped's), as well as some 340 providers of a wide range of community residential, day and support services.

The estimated FY 2003 budget for DDD totaled approximately \$1.2 billion. Of this amount, about \$533 million, or roughly 44 percent, was spent for community services and supports. The remaining funds are being used to support individuals residing in SODCs, privately operated ICFs/DD, pediatric skilled nursing facilities, and childcare institutions.² Embedded within these figures are expenditures charged to the state's Medicaid home and community-based waiver program for adults with mental retardation and related conditions. During fiscal year that just ended (FY 2003), DDD claimed Medicaid for 9,471 adults enrolled in HCB waiver services, with the Medicaid claim totaling \$271.5 million. (The total waiver enrollment was 10,390 individuals with a total expenditure of almost \$333 million but DDD was unable to claim FFP

¹ Until earlier this year, DDD was a component of the Division of Mental Health and Developmental Disabilities Services and known as the Office of Developmental Disabilities (ODD). But, during a recent departmental reorganization, DMHDDS was abolished and ODD was elevated to divisional status.

² Unpublished FY 2003 data as of July 2003 supplied by DDD/IDHS Data Support Unit.

for all enrollees and all billed services.) Thus, the HCBS waiver Medicaid claim presently accounts for about 40 percent of all community services spending in the state of Illinois (excluding expenditures on community-based ICFs-DD).

According to Division officials, 44,640 children and adults received DDD-funded services during FY 2002. Of this number, 34,301, or more than three quarters of the total, lived in non-institutional settings. The overwhelming majority of individuals receiving DDD-financed services are adults. Only 6,695 children and adolescents under 18 years of age received services provided or funded by the Division during FY 2002. This figure represented about 15 percent of DDD's total fiscal year caseload.

A statewide advisory council was created in October 2000 to provide feedback to DDD officials on a wide range of issues, including the development and implementation of the agency's three-year strategic plan. This council is composed of individuals with developmental disabilities, family members, service providers, and other interested professionals. Most members of the statewide advisory council are selected by their local network advisory councils.

The state has been divided into eight geographic areas, called "networks" – four in the greater Chicago metropolitan area and four in the other quadrants of the state – to facilitate the management of DDD-funded services. Each network is assigned a DDD team and maintains a local advisory council. Network facilitators: (a) manage the state's financial agreements with private ICFs/DD and community provider agencies; and (b) coordinate community services with SODCs.

Independent Service Coordination Agencies (ISCA) are the principal entry point to state-funded specialized developmental disabilities services. There are eighteen Pre-Admission Screening and Independent Service Coordination Agencies across the state that provide service coordinators to people with developmental disabilities. The responsibilities of these agencies include: (a) ensuring the completion of comprehensive assessments; (b) developing and monitoring individual service plans; (c) helping individuals/families establish linkages to providers of needed services and supports; and (d) providing on-going service monitoring and advocacy.

Early Intervention Services. Since January 1998, the Illinois Department of Human Services has served as the lead agency for early intervention services authorized under Part C of the federal Individuals with Disabilities Education Act (IDEA). The department's Bureau of Early Intervention (BEI) oversees the development of a coordinated, comprehensive, interagency and interdisciplinary system of early intervention services for infants and toddlers, ages 0-3, with developmental disabilities and delays. BEI/IDHS is assisted in carrying out its responsibilities by the Illinois Interagency Council on Early Intervention. Eligible children and families access early intervention services through a statewide network of 25 Child and Family Connections (CFCs). These CFCs are funded by IDHS and serve as the "front door" to the program. When a referral is received, the CFC assists the family through the developmental evaluations necessary to establish a child's eligibility. Each eligible youngster is assigned a service coordinator who is responsible for: (a) facilitating the development of an Individual Family Services Plan (IFSP); (b) assisting the family and the child to access needed services identified in his/her IFSP; and

(c) monitoring the implementation of the IFSP and completing all necessary modifications to the plan and related services.

In recent years, BEI officials have been attempting to enroll as many EI participants in Medicaid as possible in order to minimize state general revenue outlays. During federal fiscal year 2002 (October 1, 2001 – September 20, 2002), 58 percent of children enrolled in the state’s EI program were Medicaid eligible and 52 percent of total EI program costs were being recovered through Medicaid payments (i.e., 26% FFP and 26% state matching dollars). As of early this calendar year, efforts were underway to add transportation and assistive technology costs to roster of Medicaid-reimbursable EI services. The financing of service coordinator costs also was being converted to a target management coverage under the state plan, and state officials were attempting to improve Illinois’ administrative recovery rate for EI services under the state’s Medicaid plan.³

Licensing, Certification and Oversight. IDHS’ Bureau of Accreditation, Licensure, and Certification (BALC) is responsible for assuring that community agencies providing state-funded services conform to established operating standards. Among the duties of BALC is to conduct licensure surveys of Community Integrated Living Arrangements (CILAs), the principal type of community residence serving persons with developmental disabilities in the State of Illinois, and complete certification reviews of developmental training programs, the primary daytime service option for individuals with developmental disabilities.

The Office of Health Care Regulation (OHCR) within the Illinois Department of Public Health is responsible for certifying Medicaid long-term care facilities, including state-operated developmental centers (as ICFs/MR), privately run ICFs/DD, and pediatric skilled nursing facilities. OHCR/DPH serves as the Medicaid state survey agency under an agreement with the federal Centers for Medicare and Medicaid Services (CMS).

B. Service Eligibility

Eligibility Definition. To be found eligible for specialized services and supports funded through the IDHS Division of Developmental Disabilities, an individual must meet the state’s statutory definition of a person with “mental retardation” or a “related condition.” Mental retardation (MR) is defined in state law as “significantly sub-average intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 22 years old.” The term “significantly sub-average intellectual functioning” is defined as an intelligence quotient (IQ) of 70 or below on standardized measures of intelligence.

A related condition is defined as a “severe, chronic disability that meets all of the following conditions:

- a. It is attributable to:
 1. cerebral palsy or epilepsy; or

³ Illinois Interagency Council on Early Intervention, **Annual Report: FY 2002 (October 1, 2001 – September 30, 2002**, Year 15 Annual Report of Illinois.

2. any other condition other than mental illness found to be closely related to mental retardation because this condition results in an impairment of intellectual functioning or adaptive behavior similar to that of persons with mental retardation
- b. It is manifested before the person reaches age of 22;
 - c. It is likely to continue indefinitely;
 - d. It results in substantial functional limitations in three or more of the following areas of major life activity:
 1. Self care;
 2. Understanding and use of language;
 3. Learning;
 4. Mobility;
 5. Self-direction; and
 6. Capacity for independent living.

The state's definition of "related conditions" parallels, almost word for word, the federal definition of the term, as contained in 42 CFR 435.1009. By limiting eligibility to persons with mental retardation and related conditions, Illinois has adopted an approach used by many states. One effect is to exclude persons with substantial, chronic disabilities who meet neither the specific etiological categories (MR, CP and epilepsy) nor the functional criteria of a "related condition." At least in theory, such individuals may qualify for DD services in states that have adopted a fully functional definition similar (or identical) to the definition contained in the federal Developmental Disabilities Assistance and Bill of Rights Act. In practice, however, whether the service applications of such individuals are accepted or rejected often has as much to do with how the state's definition is operationalized and applied as it does with the particulars of the statutory definition itself.

To be eligible for Medicaid-reimbursable services under the state's home and community-based waiver program for persons with mental retardation and related conditions, an applicant must meet the above statutory definition, be found to require institutional (ICF/MR) services in the absence of the requested HCB waiver services,⁴ meet the following criteria, and fall within priority or target population criteria applicable to particular elements of covered services (see discussion below under "Covered Services"):

- The individual is at least eighteen of age or older;
- The individual is a resident of Illinois living in Illinois;
- The individual is eligible for Medicaid services in Illinois;
- The individual has a developmental disability, either mental retardation or a related condition;
- The disability was manifested before the individual reached age 22 and is likely to continue indefinitely;

⁴ The process the state uses to make such Level of Care (LOC) determinations are reviewed and discussed in Chapter V of this report.

- If the individual has a “related condition, he or she must have substantial functional deficits in three out of six major life areas;
- The individual has been determined to need active treatment to address his/her developmental disabilities;
- The individual is **not** in need of nursing facility level of care;
- The individual is **not** receiving services in a nursing facility, a skilled nursing facility, an intermediate care facility, an intermediate care facility for persons with developmental disabilities, a state-operated facility, a skilled nursing facility for pediatrics (SNF/Ped), a hospice facility, a sheltered care facility, an assisted living facility, or a hospital at the time adult DD-funded waiver services are delivered; and
- The individual is **not** receiving services funded through another Medicaid waiver program at the time adult DD-funded waiver services are delivered (including services provided as a part of the Office of Rehabilitation Services’ Home Services Program or the Department on Aging’ Community Care Program).

Similar to all other states, Illinois uses separate criteria to determine if a child is eligible to receive state-funded early intervention services. Infants and toddlers, ages 0 to 3, are eligible to receive early intervention if they: (a) have a medical diagnosis that typically results in a developmental delay; or (b) are presently experiencing a developmental delay of 30 percent or greater in one or more area of development.

C. Covered Services

IDHS/DDD offers a wide range of residential, daytime and support services for children and adults with developmental disabilities. The Division’s “Program Manual” for the current fiscal year identifies over 30 separate programs, with several of these programs further divided into one or more sub-categories (sub-program codes).⁵ The services provided by the Division can be grouped into the following general categories:

Services Coordination. As noted above, independent service coordination is furnished by 18 pre-admission screening/service coordination agencies across the state. These agencies act as the “front door” to the state’s specialized developmental disabilities service system (see additional discussion and commentary on the role, functions and financing of PAS/ISC agencies in Chapters III and V of the report).

Residential Services. DDD underwrites the cost of out-of-home residential services in various settings, including in both institutional and community-based facilities and programs. The licensed categories of institutional providers of residential services include: State-Operated Developmental Centers (SODCs); Intermediate Care Facilities for Persons with Developmental Disabilities (ICFs/DD); Specialized Living Centers; and Skilled Nursing Facilities – Pediatric (SNF/Ped). These facilities are operated as Medicaid-certified, long-term care facilities. DDD also supports a wide range of privately operated community residential alternatives for individuals (primarily adults) with developmental disabilities, including individual apartment-

⁵ Illinois Department of Human Services, Division of Disability and Behavioral Health, Office of Developmental Disabilities, *Program Manual: FY 2003*.

like settings (Supported Living Arrangements), foster homes (Special Home Placements), two-person homes (Home Individual Programs) and community group facilities (Community Integrated Living Arrangements), residential schools, adolescent group homes and Community Living Facilities. Generally, the latter settings are funded with a mixture of state general revenue dollars and Medicaid reimbursements obtained through the states DD home and community-based waiver program. Chapter IV includes an extended discussion and commentary on the methods the state uses to finance services in state-operated developmental centers, while Chapter V reviews the methods the state used to finance community residential services.

As in most states, residential services represent the single largest expenditure category in DDD's budget. Data reported as of July 23, 2003 for FY 2003, indicate outlays for Community Integrated Living Arrangements (CILA) services, Illinois' primary licensing category of community residential services for adults with developmental disabilities, totaled \$235.4 million on behalf of roughly 6,900 individuals. That same fiscal year, DDD expended \$8.7 million on residential services for 491 adults residing in Community Living Facilities, congregate living facilities typically located on campus-like settings. Meanwhile, \$22 million dollars was expended on 392 individuals age 21 and younger living in childcare institutions and children's group homes.⁶

Daytime Services. DDD finances a variety of daytime services designed to enhance the skill levels of persons with developmental disabilities in work-related and other major area of life activity. Among these services are: Developmental Training; Sheltered Employment; Supported Employment; Vocational Development; and Other Day and Adult Day Care. The implications of existing day service coverage and related financing arrangements are discussed in Chapter V of the report.

Day and vocational services represent the second largest category of DDD expenditures, accounting for about \$160 million to provide services to approximately 30,000 individuals during FY 2003.

Individual and Family Support Services. DDD funds various types of services aimed at allowing individuals to remain in their own home or the home of a family member(s) while receiving essential supports. The third largest spending category is supportive services to families, including: Respite Care; Client and Family Support; Family Assistance; Home-Based Support Services; and Other Related In-Home Support Services. These programs account for about \$58.9 million in expenditures during FY 2003. Roughly, 15,000 individuals received such services last fiscal year.

The remainder of DDD's expenditures are for smaller programs, such as case coordination, dental services, epilepsy services, diagnosis and evaluation services and leisure programs.

⁶ Unpublished data on FY 2003 expenditures as of July 21, 2003, as furnished by the DDD/IDHS Data Support Unit.

D. Scope and Composition of the Service System

The size and make-up of a state's DD service system can yield valuable information about the utilization of state resources and potentially where there may be gaps in the types and volume of services offered as well as in the individuals being served. System size also may be used as a benchmark in estimating and understanding unmet needs within a state's service system. As Gary Smith has pointed out, "...there is an inverse relationship between relative system size and the relative size of a state's waiting list. The larger the system, the smaller the waiting list."⁷ Knowing the scope and size of a state's DD service system, therefore, is a vital step toward planning where and how to target existing and future resources. As Illinois captures more third party payments by leveraging federal Medicaid financial participation, understanding the scope and size of the service system will help decision makers target new resources and rebalance existing expenditures.

Adding community service utilization figures to occupancy rates in public and private ICFs/MR plus other institutional facilities serving individuals with developmental disabilities, DDD provided services to 44,640 persons during FY 2002. Based on service utilization data furnished by DDD, 7,681 of these individuals were 17 years of age or under.⁸ These figures do not include persons with developmental disabilities who are receiving:

- Early interventions services for infants and toddlers, ages birth through three, which included 20,993 children during FY 2002;
- Services under the state's medically fragile/technology dependent children's waiver program operated by the University of Illinois at Chicago, which furnished services to 415 children during FY 2002;
- Services provided under the state's brain injury waiver program operated by the IDHS Office of Rehabilitation Services, which served 953 individuals during FY 2002; and,
- Services furnished under the HCBS waiver program for non-elderly persons with physical disabilities, operated by the IDHS/ORS, which served 17,592 persons during FY 2002 (a small but undocumented number of whom had developmental disabilities).⁹

Thus, it seems reasonable to conclude that the total number of individuals with developmental disabilities served through state-financed programs in Illinois is somewhat larger than the 45,000 who receive services through the state Division of Developmental Disabilities, plus the 20,000+ infants and toddlers who are enrolled in early intervention services; but, beyond these 65,000

⁷ Smith, Gary, "*Serving and Waiting: The Question of System Size*", NASDDDS, April 1999.

⁸ Unduplicated utilization data by age, provided by IDHS/DDD Data Support Unit.

⁹ ORS staff told the NASDDDS study team that individuals with cerebral palsy without significant cognitive impairments are likely to represent the largest number of individuals with developmental disabilities served through the state's disability waiver program, but that there may also be some individuals who would qualify for DDD-funded services, including ICF/MR level of care, as well.

individuals, it is not possible, using existing data sources, to determine how many additional persons with developmental disabilities receive services and supports funded by the State of Illinois.

Interstate Comparisons. Comparative interstate data provides a useful backdrop for understanding the present status of specialized services to Illinois citizens with developmental disabilities and, in particular, where the state’s existing service system may need improvements. As will be detailed below, existing national data as well as direct comparisons with states that have similar demographic characteristics generally indicate that Illinois lags behind other states when examined along several critical dimensions.

When making interstate comparisons it is important to remember that eligibility criteria may differ, economic conditions may dictate variations in the scope of publicly funded services, and political considerations as well as program practices may influence the selection of service target populations. With these caveats in mind, we offer states that provide illustrative parallels, rather than direct comparisons with Illinois. The following table compares Illinois’ demographic and service delivery data with identical data elements from three other populous states (New York, Ohio, and Pennsylvania). The statistics in Table 2.1 are for FY 2002, as this was the most complete data set available at the time the analysis was performed.

Table 2.1: Census, Income, and Service System Data from Four, Selected States

	Illinois	New York	Ohio	Pennsylvania
Census (2000)	12,419,213	18,976,457	11,353,140	12,281,054
Median Income	\$46,136	\$40,838	\$43,079	\$42,348
Number in poverty	1,288,000	2,530,000	1,190,000	1,013,000
% in poverty	10.26	13.8	10.00	8.6
Total served	44,640	119,923	68,768	62,845

*Sources: US Census Bureau; State utilization data: personal communications with officials in the following state agencies: PA Office of Mental Retardation; Ohio Department of Mental Retardation and Developmental Disabilities; New York: Office of Mental Retardation and Developmental Disabilities; and the Illinois Division of Developmental Disabilities. The totals in Table 2.1 include services to children funded by the references state/local developmental disabilities service system that are **not** part of early intervention programs.*

Illinois is the fifth most populous state in the nation. Ohio and Pennsylvania are, respectively, the 6th and 7th most populous states. Not only are these states similar in population to Illinois, they are similar demographically (i.e., median incomes and incidences of poverty are similar in the three states). New York, as the third most populous state, provides an interesting “benchmark” comparison to Illinois. The Empire State has a highly developed DD services system that utilizes Medicaid financing extensively.¹⁰ New York operates the largest HCBS waiver program in the nation for persons with developmental disabilities, based on utilization rates per 100,000 in the general population.

¹⁰ Braddock indicates that New York State leverages 100 percent of its state general funds budget (see D. Braddock (Ed.), *Disability at the Dawn of the 21st Century and the State of State*, American Association on Mental Retardation: Washington, D.C., 2002). New York officials agree that they strive hard to use federal funds wherever possible but note that 100% leveraged is an overstatement.

Illinois, compared to the three other states, serves fewer individuals overall through its DD service delivery system (Table 2.1). Other data shown on Table 2.2 indicates that the number of individuals served in the Illinois' community DD service system (excluding SODC and ICF/DD residents) represents only 276 per 100,000 in the general population. By comparison, Ohio serves 450 individual per 100,000, Pennsylvania serves 474 per 100,000, and New York serves 580 per 100,000. Even when ICF/MR residents are taken into account, Illinois lags behind these comparison states.

Table 2.2: Comparison of Numbers Served per 100,000 Population

	No. served per 100,000/general population (minus ICF/MR)	No. served per 100,000/general population (with ICF/MR)
Illinois	276	359
New York	580	620
Ohio	450	610
Pennsylvania	474	510

The New York community service system (excluding ICFs/MR) serves twice the number of persons with developmental disabilities as the Illinois system. Even though New York and Illinois have approximately the same number of ICF/MR beds (New York at 9,923 and Illinois at 10,267),¹¹ New York's level of community effort is double that of Illinois in relation to total population.

It is also interesting to note that when the four previously referenced states are compared in terms of the proportional number of persons served in large versus small residential settings, Illinois demonstrates a much greater reliance on larger congregate care facilities than the comparison states. Table 2.3 compares utilization rates per 100,000 for all residential service settings (ICF/DD, HCBS and others).

Table 2.3: Comparison of 2001 Utilization per 100,000 Population and Size of Home

	No. of Persons Per 100,000 by Size of Residential Setting ¹²			
	1-6	7-15	16+	Total
Illinois	42.9	43.2	61.2	147.2
New York	109.4	96.0	18.9	224.3
Ohio	80.2	23.0	47.9	151.0
Pennsylvania	141.6	3.9	31.4	176.9

¹¹ Prouty, Robert, Smith, Gary and Lakin, K. Charlie, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*, Rehabilitation Research and Training Center on Community Living, University of Minnesota, June, 2002, Table 3.3, p. 61.

¹² Ibid, p.78

Table 2.3 on the preceding page shows that, although Illinois serves more people per 100,000 than the national median (147.2 v. 136.1) it does so by relying on larger facilities (16+ people) to a greater extent than other states with similar demographic characteristics. This finding, when combined with the fact that Illinois serves a lower number of individuals per 100,000 overall (see previous tables), suggests an even greater reliance on larger residential facilities. This reliance on larger residential facilities is in marked contrast to recent national trends and provide a context for future decisions regarding the redeployment of dollars within the Illinois state DD service system as well as possible options for utilizing newly obtained federal financial participation.

Spending Patterns. A careful analysis of service delivery and spending patterns can offer insights into the strengths and shortcomings of a state's DD service system. Although Illinois' effort is slightly above the median for all states in overall residential placements, perhaps the more interesting statistic is that the proportion of total MR/DD spending allocated to community services, as opposed to ICF/MR and other institutional services, is much lower in Illinois than in most other states. In FY 2000, Illinois ranked 47th among the states in the proportion of dollars allocated for non-ICF/MR community services, with only 57 percent of the state's total spending devoted to community services. According to data compiled by Braddock, in FY 2000 the median state set aside 75 percent of its MR/DD budget for non-ICF/MR community services.¹³ Alaska and Vermont dedicated 100 percent of their DD service budgets to community services. Meanwhile, twelve additional states expended 90 percent or more of funds appropriated for specialized DD services in community program settings. Thus, while Illinois has an overall residential placement rate that is somewhat above the national average, compared to most other states Illinois' fiscal commitment is heavily weighted toward larger, congregate care, mainly in ICF/MR-certified, residential settings.

Illinois' comparatively heavy reliance on institutional/congregate care services is borne out by other statistical measures as well. Braddock defines fiscal effort as, "...a state's spending for MR/DD services per \$1,000 of total state personal income." In terms of overall fiscal effort, Illinois ranked as follows among the 50 states and the District of Columbia:

- ✓ 42nd in spending on community services,
- ✓ 13th in spending on institutional services, and
- ✓ 24th in overall MR/DD spending.

These rankings clearly show that, although Illinois commits proportionally more dollars to specialized MR/DD services than the average state, the state is heavily invested in ICF/MR services. As of June 2001, only 212 individuals in Illinois resided in ICFs/MR with 6 or fewer beds – i.e., facilities that are more akin to community residences. At the time, a total of 3,171 individuals were residing in ICFs/MR with 7-15 beds and 3,736 individuals lived in privately operated ICF/MR facilities with 16 or more beds.¹⁴

The state's comparatively heavy reliance on ICFs/MR and other congregate residential care settings has restricted efforts in Illinois to move toward more flexible community spending on

¹³ Statistics cited in this paragraph are from Braddock, *Ibid*, pp. 111-123.

¹⁴ *Ibid*, Prouty, et al., p. 58.

alternative residential and home-based service options that afford individuals and families enhanced choice and control. Even well-run ICFs/MR afford residents and their loved ones limited opportunities to exercise choice and control over their lives and few options for self-directing their services. An over-emphasis on 24-hour residential services (both institutional and community-based), rather than home-based supports, also drives up costs, thus restricting the dollars available to address unmet community service needs. When the options for home and family-based supports are limited, individuals are driven to choose costly out-of-home placements. In Illinois, the lack of individual and family-based services is particularly evident in the pattern of spending on children's services.

Children's Services. With regard to services to children, Illinois lags behind many other states. If early intervention utilization figures are excluded from the comparison, Illinois served about 6,961 children, 17 years of age or younger, during FY 2002. Comparatively, Pennsylvania served about 21,179 children, ages 0-17, including 3,400 infants, toddlers, and their families through a specialized HCBS waiver program targeted to this population. [N.B., Pennsylvania also serves about 22,000 infants and toddlers through the state's regular Part C, IDEA program, or a number roughly comparable to Illinois' early intervention program for infants and toddlers.] Ohio officials told the NASDDDS study team that about half the individuals they serve (30,530) through the state's developmental disabilities service system are children.

According to the FY 2003 appropriations of the Illinois Division of Developmental Disabilities, approximately \$47 million was to be expended on providing services to 720 individuals living in pediatric skilled nursing facilities (SNF/Peds), 319 of whom were 17 years of age or younger. This age split suggests that about one-half of the \$47 million was spent on SNF/Peds services and was attributable to children. An additional \$28.1 million was earmarked in the DDD budget for children's services, but fully half of this amount – or approximately \$16 million – was expected to be used to fund voluntary out-of-home residential placements for an estimated 309 children.¹⁵ [N.B., Preliminary FY 2003 data as of July, 2003 show an expenditure of \$22 million for out-of-home residential services on behalf of 398 children.] The remaining \$16 million was set aside to finance services to approximately 3,000 children. As with adult services, spending is weighted toward costly out-of-home residential services. Heavy reliance on out-of-home placements affect the capacity of a state to develop additional home and community-based supports since residential placements are expensive and, inevitably, divert a significant amount of funds from other community service options.

If Illinois is committed to increasing self-directed service options and enhancing home-based supports to families as indicated in DDD's the three-year strategic plan, current spending patterns do not support these aims. Present patterns of resource distribution provide a strong rationale for reducing the state's reliance on out-of-home placements over time and increasing investments in family and individual support services. Such steps would bring Illinois more in line with the aims of DDD's strategic plan and closer to national program and financing trends.

¹⁵ Estimate of Selected Non-Medicaid Expenditures for Children's Services, derived from DDD Data provided by IDHS/DDD Data Support Unit.

HCBS Waiver Claims. In terms of federal financing of home and community-based services, the Section 1915(c) waiver authority is the key to garnering additional federal funds for services to individuals with mental retardation and related conditions. Prouty, Smith and Lakin report that all fifty states and the District of Columbia presently operate HCBS waiver programs targeted to persons with mental retardation and/or developmental disabilities.¹⁶ In aggregate, these waiver programs served over than 327,000 individuals in FY 2001, with total waiver expenditures exceeding \$10.9 billion in federal/state dollars.¹⁷ The HCBS waiver authority is the single most important source of federal financing for community developmental disabilities services. Between 1996 and 2000, inflation-adjusted growth in waiver spending increased by 77 percent nationally, as states aggressively sought to capture additional federal funds for services previously underwritten by state and local dollars.

HCBS waiver outlays, as a percentage of total state DD expenditures, are another useful measure of a state's fiscal effort – particularly its efforts to increase the claiming of federal Medicaid funds for community services. Braddock indicates that, as of 2001, 33 percent of total national spending on developmental disabilities services was attributable to federal/state HCBS waiver payments. Rhode Island ranks first with 68 percent of its overall state expenditures attributable to federal/state HCBS waiver payments.

Illinois' use of the HCBS waiver authority has not kept pace with national trends. After 17 years of operating a specialized HCBS waiver program for persons with mental retardation and related conditions, Illinois ranked 48th among the states in terms of the percentage of total community service costs recovered through HCBS waiver claims, with only 13 percent of its expenditures tied to the HCBS waiver program. Since 2001, Illinois has added over 3,000 individuals to its DD waiver program, thus its ranking surely has changed over the past two years; but even so, Illinois lags considerably behind other states in utilizing the HCBS authority to under gird the financing of community DD services.¹⁸ Steps Illinois might take to make better use of the Section 1915(c) waiver authority are discussed in Chapter V of this report.

Within the existing DD waiver program, Illinois relies heavily on out-of-home placement as its major service modality. In FY 2002, the Illinois waiver enrolled 8,815 adults. Of this number, 6,749 individuals received residential habilitation services – either in a Community Integrated Living Arrangement (CILA) or in a Community Living Facility (CLF). A total of 387 individuals received supported living and/or home based-supports services.¹⁹ While the number of individuals receiving home-based supports and in-home supports grew to 1,352 during FY 2003 – a significant improvement – the state's DD waiver program still remains heavily slanted

¹⁶ Ibid, Prouty, et al., p. 65.

¹⁷ Ibid, Table 3.5b and 3.7, pp. 67 and 71.

¹⁸ Braddock's Analysis is based on FY 2002 expenditure date and, thus, reports a lower percentage of DDD community funding claimed as HCBS waiver-reimbursable services than the FY 2003 percentage cited in this chapter.

¹⁹ Data from July 2003 report on FY 2002 enrolled client data, DDD Data Support. These numbers are the individuals enrolled in the waiver receiving the service, not the number for an actual waiver claim was paid. The paid claim numbers are less than the enrolled numbers receiving the service.

toward out-of-home placements for adults, while offering limited in-home and family-based support services to eligible adults.

The net effect of this policy is that Illinois serves fewer people through its HCBS waiver program than comparable states and relies on ICFs/MR as a residential service modality to a greater extent than most states. By limiting the HCBS waiver program largely to financing out-of-home residential services, Illinois constrains access to other, less costly home and community-based services.

Although significant improvements were made in the state's DD home and community-based waiver program during FY 2003, there remains ample room to expand family support services under the waiver program to both adults and children living with their families. Chapter V will sketch out some of the steps that Illinois officials might take to improve access to such services while at the same time drawing down additional federal revenue.

Unmet Service Needs. DDD historically has not gathered systematic information on the number of un-served or under-served individuals with developmental disabilities statewide. If an individual was not enrolled in the state's DD waiver program or receiving state-funded residential services, the local PAS/ISC agency referred the individual to community service providers in its catchment area or to generic service resources. No central list of these referrals and other information regarding requested services and supports was maintained by PAS/ISC agencies or by DDD. Some individual provider agencies maintained information about persons waiting for services. Anecdotal reports from such provider agencies indicate that there is a sizable backlog of unmet needs, but since the state had no uniform policies governing the maintenance of waiting list information, there is no way of ascertaining the nature and scope of unmet service needs, statewide.

IDHS, with legislative support, now is focused on the creation of a "cross-disability database" that will record data on all individuals with a disability who "are potentially in need of disability services funded by the Department." This database will include people with mental illness, physical disabilities, and developmental disabilities. It will include demographic and service need information on young adults transitioning from special education programs as well as children and adults living in existing residential facilities, such as state operated developmental centers, private nursing and residential facilities and community integrated living arrangements. Information also will be included in the database on the services each person potentially may need as well as a fairly broad range of individual-specific profile and diagnostic information. This database is to be in place by July 2004 and will be used by the DDD as it develops cost-effective and appropriate services for individuals with developmental disabilities (see additional discussion in Chapter III, Section E).

In light of the historic absence of the type of database contemplated in the newly enacted legislation (which is somewhat similar to the waiting list data collected by other states), it has been difficult to assess unmet needs system-wide. The best analysis that can be made at present is once more to draw comparisons with the experiences of other states. Again, valid comparisons are difficult to draw since demand for services varies from state-to-state as a result of a number of factors that are difficult to quantify. The waiting list data cited below is for residential

services; while the exact mix of consumers on these lists is unknown, residential services waiting lists tend to serve as a reasonable proxy for overall unmet services need among adults with developmental disabilities. Since the overwhelming majority of recipients of services in Illinois are adults, the waiting list data should have even greater validity than other types of state-to-state waiting list comparisons. Table 2.3 provides comparative waiting list data from three states (NY, OH, and PA).

Table 2.3: Residential Services Unmet Need FY 2001

	New York	Ohio	Pennsylvania
# of residential service recipients	42,650	17,176	21,741
# on waiting lists	4,395	9,486	1,123

*Source: Prouty, Robert, Smith, Gary and Lakin, K. Charlie, **Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001**, Research and Training Center for Community Living, Institute on Community Integration, University of Minnesota, June 2002*

During FY 2003, New York reported that its residential services waiting list increased to 7,400 individuals despite new funding intended to reduce waiting lists. [N.B., New York’s HCBS wavier enrollment grew from 40,165 in FY 2001 to 47,700 in FY 2003.]

Pennsylvania has gathered extensive waiting list information over the past few years. The Commonwealth’s Office of Mental Retardation has developed a data based system, called Prioritization of Unmet Needs for Services (PUNS). Through the PUNS system, Pennsylvania officials collect information on individuals requesting services, assigning each person to one of three priority-of-need categories. While Pennsylvania does not segregate waiting list data by the type of service requested at present, during the most recent reporting period 1,500 persons were reported to have emergency service needs, 5,653 individuals had critical service needs, and an additional 7,276 individuals had planning needs. PUNS is one of the more sophisticated waiting list data collection systems in the country, thus the Pennsylvania figures probably are more representative of actual unmet needs than the statistics gathered by many other state MR/DD service systems. If so, the Pennsylvania figures suggest that the overall universe of unmet needs among persons with mental retardation in the Commonwealth encompasses some 14,000 individuals.

While the extent of unmet needs in Illinois is not known, the relatively modest level of effort in serving children plus the comparatively low number of adults who receive specialized, state-funded DD services suggests that, in all likelihood, there is a considerable backlog of un-served and under-served individuals across the state. In keeping with Smith’s observation that the size of a state’s service system is predictive of the extent of unmet needs, it seems fair to conclude that addressing the needs of un-served and under-served individuals and families represents a major service delivery challenge facing Illinois state policy-makers (additional discussion of managing unmet service needs can be found in Chapter III of this report).

E. Contracting Process

With the exception of the services provided by state-operated developmental centers, ICFs/DD and SNF/Peds, all DDD-funded services are furnished through individual contractual agreements between IDHS/DDD and private providers of service. (IDPA has provider agreements governing the operation of over 300 providers of ICF/DD and SNF/Ped services) IDHS/DDD has contractual agreements governing the operation of more than 340 providers of community day, residential and support services. These contracts, generally referred to as agreements, consist of the following:

- Standard contract language that is included in all departmental contracts;
- A contact sheet, including information on how to reach the contractor, the type of service to be provided, the method of payment, the method of reconciliation, and the contract deliverables; and
- Requirements related to funded programs, including applicable federal and state laws, rules, policies, and procedures.

The department initiates the agreement, sends it to the provider for review and signature. Then the Secretary's signature is obtained and a copy of the executed agreement is returned to the provider. Contract amendments are initiated when: (a) the contract is extended beyond the original expiration date; and/or (b) the department adds services to the provider's program beyond the scope initially spelled out in the agreement.

F. Illinois' Medicaid Program

Over 1.5 million citizens of Illinois are enrolled in the state's Medicaid program, making the program the largest health insurer in the state. Illinois spends over \$8 billion a year on Medicaid services and, therefore, the program has a major impact on the state's overall budget.

As the designated single state Medicaid agency, the Illinois Department of Public Aid (IDPA) is responsible for overseeing the program. But, seven other Cabinet-level agencies of state government, plus scores of local governmental units and sub-units of state government, play critical roles in administering Title XIX-funded services under a series of interagency agreements with IDPA.²⁰ Besides IDPA, the state agency that plays the most prominent role in administering Medicaid programs and services is the Illinois Department of Human Services.

The functions of several Cabinet-level agencies were combined in 1997 to form IDHS, including the Department of Mental Health and Developmental Disabilities as well as the Department of Rehabilitation. As part of this reorganization, responsibility for managing a variety of low-income assistance programs, including the state's Food Stamp program, Aid to the Aged, Blind or Disabled and other food and cash assistance programs, were transferred from IDPA to the new

²⁰ For an analysis of these interagency roles and more complete description of the state's Medicaid program, see *Medical Assistance Action Plan (the MAP): Illinois Medical Programs Outline and Blue Print for Action*, Chicago: Health and Disability Advocates, April 2003.

department. IDHS also assumed responsibility for operating a network of over 200 local welfare offices, where Illinois citizens can apply for and receive a determination of their eligibility to receive Medicaid, SCHIP, and other medical benefits and well, as other types of social services and cash assistance.

Illinois' Medicaid program has a pervasive impact on the availability of services and supports for low-income citizens with disabilities. While 16 percent of enrollees in the state's Medicaid program in FY 2002 were non-elderly blind or disabled individuals, the costs of services to these individuals consumed 44 percent of state's overall Medicaid outlays.²¹ In the current policy environment, where sagging revenues are necessitating deep budget cuts, Illinois policy-makers, like their colleagues in other states, face the enormous challenge of limiting the growth rate of Medicaid spending while assuring that program beneficiaries still gain access to the services they need and are entitled to receive.

According to an analysis completed by researchers at the Coleman Institute for Cognitive Disabilities at the University of Colorado, during fiscal year 2000, the State of Illinois expended \$1.2 billion on specialized services and supports for individuals with developmental disabilities and received \$426 million in federal Medicaid payments – primarily in the form of payments to public and private ICF/MR facilities (\$309.7 million) and private vendors of home and community-based waiver services (\$74.4 million). Roughly three-quarters (76%) of the state's total general revenue expenditures at the time were being matched by federal Medicaid payments, according to the CICD/UC team's analysis. Illinois ranked 41st among the states in federal Medicaid recovery rates for specialized DD long-term services and supports (i.e., the overall percentage of matched state/local dollars).²²

As will be pointed out later in the report, DDD/IDHS has taken steps over the past few years to increase the number of recipients of state-funded services who are enrolled in Illinois' DD home and community-based waiver program, thereby generating additional Medicaid FFP. It is likely, therefore, that the state's federal Medicaid recovery rate will improve to some degree by the time the next CICD/UC analysis is completed. Nonetheless, Medicaid remains the state's primary vehicle for recovering DD service and support costs and, as will be pointed out in subsequent chapters of this report, the Medicaid program represents by far the best opportunity available to the state to draw down additional third party revenues. For this reason, the team's analysis of potential new and expanded revenue options focuses primarily on untapped or under-utilized Medicaid funding avenues.

G. Conclusion

The purpose of this chapter has been to provide readers with a brief overview of the organizational structure and programs of Illinois State Government as they impact on the delivery of publicly financed services and supports to individuals with developmental disabilities. It should be obvious even from this concise, admittedly broad-brush analysis that the

²¹ Illinois Department of Public Aid, *Illinois Medical Programs: A Primer*, IDPA, 2003, p. 2.

²² Braddock, David (Ed.), *Disability at the Dawn of the 21st Century and The State of the States*. Washington, D.C.: American Association on Mental Retardation, 2002, p. 104; 195-96.

state's DD service system encompassed many organizational entities and actors as well as a complex web of programmatic and financial relationships.

Subsequent chapters of the report will analyze in much greater detail some of the topics discussed above. But, based on the concept that it is important to gain a sense of the "forest" before examining particular "trees" – i.e., to understand the broader context within which the state's developmental disabilities service system operates – the project team decided to begin by sketching out for readers the principal features and components of Illinois' approach to serving people with lifelong disabilities. Our hope is that, having read this chapter, readers will find it somewhat easier to grasp the team's findings and conclusions regarding specific aspects of the state's existing methods of financing specialized developmental disabilities services as well as possible future financing options that might be considered by the state.

Chapter III

IMPROVING THE COMMUNITY SERVICES INFRASTRUCTURE

Too often revenue enhancement is treated by state agencies as an isolated set of activities that are undertaken episodically to address budget shortfalls or to take advantage of newly authorized funding options. In such an environment, efforts to identify new funding sources become an idiosyncratic process that depends almost entirely on the adequacy of existing data systems and analytical capabilities and, in the longer term, the effectiveness of reporting systems and oversight capabilities that are put in place to ensure ongoing compliance with applicable funding requirements. When any one of these key ingredients (timely, accurate data; knowledgeable/skilled staff; effective reporting and quality management systems; and a sound financial infrastructure) is missing, serious problems are likely to be encountered in qualifying for enhanced revenue and/or in sustaining such new revenue sources over time.

The potential pitfalls of attempting to obtain enhanced revenue “on the fly” are accentuated in the case of Medicaid financing options. Federal-state Medicaid policy is exceedingly complex, with multiple overlays of statutory, regulatory and administrative requirements that need to be thoroughly analyzed and applied in the context of the particular state’s needs and capabilities before intelligent decisions can be made about accessing new or expanded funding options. Often there are trade offs that have to be considered and administrative workload issues that must be addressed, plus new reporting and compliance mechanisms that have to be instituted in order to assure the continuity of new funding. In addition, the implications of any necessary administrative and managerial changes have to be examined from the perspective of all key components of the state’s service delivery system, ranging from the single state Medicaid agency, the state DD program agency, the field office staffs of the two agencies, local single point-of-entry (county/regional/area) agencies (if such a mechanism exist within the particular state), local provider/vendor agencies/organizations, as well as individuals with disabilities and their families. Reaching agreement among all affected parties can be a complex, time-consuming undertaking, since perspectives on accessing new funding sources can and often do vary depending on one’s vantage point within the service delivery system.

A state, therefore, must have in place an effective management structure in order to maximize third party revenues. Among the essential characteristics of this management structure are: (a) clearly delineated administrative roles and responsibilities throughout the service delivery system, beginning at the highest levels of state government and proceeding through the point at which publicly funded services are furnished to individuals and their families; (b) revenue management is treated as an integral part of the overall policy development and implementation process, and the state maintains the analytical capacity to evaluate the potential effects of new and expanded revenue options on a routine basis; (c) the state’s management information system produces the utilization and expenditure data necessary to support existing third party revenue

claims and investigate the possible impacts of new revenue generating strategies; and (d) the state has a well-designed system for assuring the quality of community services and supports.

Chapters IV, V, and VI of this report zero in on possible new and expanded revenue streams that Illinois DD stakeholders may wish to consider accessing. In each case, the authors of the report review current financing methods being used by the state, identify the statutory and regulatory basis for proposed new/enhanced revenue options, and explore potential barriers that may be encountered in accessing each new/expanded revenue source. This chapter, by contrast, will focus on the underlying strengths and weaknesses of Illinois' existing infrastructure for delivering developmental disabilities services as they impact on the state's capacity to qualify for new and expanded revenue sources and manage such revenue effectively over the long haul. The premise underlying this chapter is that a revenue management structure with serious flaws will undermine a state's efforts to maximize third party revenues.

A. Decentralized Management of State Services

Two interrelated trends that began in late 1970s and gathered momentum through the 80s and 90s – the development of dispersed community-based services and the privatization of the service delivery process – led to the creation of a service delivery structure in many states that emphasized decentralized management of state-funded community services.¹ While the particulars of these decentralization initiatives varied considerably from state to state, one common theme was the need to create a single point of entry to state-financed services and fix responsibility and accountability for overseeing the management of state-funded services within each, defined geographic catchment area of the state. Some states assigned these functions to a local governmental (usually county) unit (e.g., OH, WI, MO, PA, etc.). Other states created a separate, statewide network of regional/area, non-profit agencies to perform these functions (e.g., CA, KS, CO, NH, etc.); while still others set up area or field offices of the state program agency to orchestrate the deliver of state-financed services within assigned geographic regions (e.g., NY, NJ, MA, ME, etc.).

During the late 1970s, the Illinois Department of Mental Health (which later was renamed the Department of Mental Health and Developmental Disabilities),² established a statewide network of field offices to oversee the delivery of community mental health and developmental disabilities services in localities across the state. These field offices, however, were eliminated in FY 1987 due to a combination of budget pressures and concerns about the quality and accessibility of the community services being financed by the department. The management of community MH and DD services was re-centralized following the elimination of DMHDD's field offices.

¹ The Research and Training Center on Community Living reports that, of the 270,141 persons who entered a state-funded community residential setting between 1977 and 2001, 258,617, or 95.7 percent, were, or are being, served in a non-state operated residential setting, and 235,816 of these individuals, or 87.3 percent were placed in a residential setting with six or fewer beds (*Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*, RTCCL/UMN, June 2002, p. 46).

² DMHDD was later folded into the Department of Human Services as part of a reorganization proposed by then Governor Jim Edgar, subsequently approved by the Illinois Legislature in 1996, and implemented as of July 1, 1997.

Over the succeeding fifteen years, several new program initiatives were launched to address emergent issues in the management of state-funded community DD services. These new initiatives included the establishment of statewide networks of Preadmission Screening (PAS) agents, the creation of Individual Service and Support Advocacy (ISSA) services, and the initiation of Independent Service Coordination (ISC) agencies across the state. In addition, a separate program was established to cover the cost of service coordination for selected members of the *Bogard* class, former skilled nursing or intermediate care facility residents with developmental disabilities now living in alternative institutional or non-Medicaid-funded community settings.³

DMHDD began contracting with a statewide network of Preadmission Screening (PAS) agents in the late 1980s, as part of an agreement with the Chicago Regional Office of the federal Health Care Financing Administration (HCFA)⁴ that called for reducing over a multi-year period the number of individuals with developmental disabilities inappropriately placed in geriatric nursing facilities. These PAS agents initially were responsible for: (a) screening all applicants for admission to Medicaid-certified nursing facilities and determining whether such placements were appropriate in the case of persons known or suspected to be mentally ill or mentally retarded; and (b) reviewing all existing NF residents with an “MI or MR/DD” diagnosis and determining the most appropriate placement for each affected individual. Subsequently, the role of PAS agents was expanded to include reviewing and determining the eligibility of all applicants for admission to state-operated developmental centers, privately operated ICFs/DD as well as eligibility to receive services furnished through the state’s Medicaid home and community-based waiver program.

As the number of persons participating in the state’s DD home and community-based waiver program increased during the 1990s, DMHDD created a statewide network of Independent Service Coordination (ISC) agencies to ensure that services were being provided in accordance with the provisions of the participants’ individual service plans (ISPs) and that assistance was furnished to persons unable to access appropriate services. One key reason for the establishment of ISC agencies was to avoid potential conflicts of interest, where providers of community DD services were responsible for assessing the effectiveness of ISP implementation activities on behalf of persons enrolled in a service program(s) they operated.⁵

Following an August 1998 federal review that criticized numerous aspects of the state’s management of its home and community-based waiver program for people with developmental disabilities, including the appropriateness of the contents of ISPs and the state’s oversight of ISP implementation, DHS and DPA officials agreed, as part of a six-step corrective action plan, to

³ This special appropriation covers *Bogard* class members residing in nursing facilities, non-traditional DD settings, and state-operated developmental centers. Class members who are enrolled in HCB waiver services, reside in an ICF/DD, or live in settings funded through the Home/Individual Program or the Host Home program receive Individual Service and Support Advocacy Services.

⁴ Subsequently renamed the Centers for Medicare and Medicaid Services (CMS).

⁵ DDD contracts with PAS/ISC agencies specify that no more than ten (10) percent of the membership of the agency’s board of directors may be persons affiliated with community provider agencies.

assign an “individual service and support advocacy” coordinator to every waiver participant. As a result, each person enrolled in the waiver program was to receive at least four visits annually by a qualified mental retardation professional (QMRP) employed by a PAS/ISSA agency. ISSA services currently are furnished to all HCBS waiver participants as well as adults in host family living arrangements, including those served through the Home/Individual Program and the Special Home placement program.

Beginning in 1996, Illinois’ developmental disabilities service system was divided into eight geographic areas, called networks. These networks are divided into two groups – the four networks serving the greater Chicago metropolitan area and the four networks that serve other geographic areas of the state. Network facilitators, employed by DHS/DDD and operating out of the agency’s Springfield and Chicago offices, manage financial agreements with community provider agencies as well as privately operated ICFs/DD and coordinate the delivery of community services with state-operated developmental centers. Each of the 340 community provider agencies and the over 300 private ICFs/DD and pediatric skilled nursing facilities (SNF/Peds) that furnish services to persons with developmental disabilities under contract with the state, in turn, is assigned to one of the networks.⁶

In 1990, NASDDDS was asked by the Illinois Council on Developmental Disabilities⁷ to conduct an assessment of the state’s use of Medicaid funding to support services to citizens with developmental disabilities. One of the key findings of the resulting study was that Illinois lacked a coherent organizational structure for managing a decentralized service delivery system. Drawing upon his knowledge of the experiences of other states, the author of the report noted that:

One central lesson that can be drawn from the states’ collective experiences over the past two decades with Medicaid funding of services to persons with developmental disabilities is that the ability to access and effectively use federal entitlement dollars is closely tied to the general manner in which a state is organized to finance and deliver services. Where responsibility and accountability for managing Medicaid dollars is divided among several autonomous ... agencies, ... it is far more difficult to develop and implement a holistic strategy that takes full advantage of financing opportunities presented by the Medicaid program, without compromising the basic programmatic directions which state policymakers have elected to pursue on behalf of the DD population.⁸

⁶ SNF/Peds facilities operate under provider agreements with the Illinois Department of Public Aid.

⁷ Known at the time as the Illinois Planning Council on Developmental Disabilities.

⁸ Gettings, Robert M., *Utilizing Medicaid Dollars to Finance Services to Illinois Citizens with Developmental Disabilities: A Technical Assistance Report*, prepared for the Illinois Planning Council on Developmental Disabilities and the Illinois Department of Mental Health and Developmental Disabilities, National Association of State Directors of Developmental Disabilities Services, January 1991.

Since this report was prepared over a decade ago, the State of Illinois has taken a number of positive steps to rectify some the major problems that were identified at the time. Specifically:

- ❑ The Illinois Legislature enacted a measure in 1992 (Public Act 87-996) that transferred responsibility for overseeing the day-to-day management of Medicaid-funded services for persons with mental illness and developmental disabilities to the Department of Human Services⁹, working in close cooperation with the Department of Public Aid (DPA). DHS and DPA subsequently entered into a detailed interagency agreement spelling out the specific, mutually reinforcing roles and responsibilities of the two agencies for managing Medicaid-funded developmental disabilities services. From all of the evidence the project team was able to gather during the course of the current study, the 1992 legislation, along with the implementing administrative agreements, has led to substantial improvements in the working relationship between the two departments.
- ❑ A statewide network of independent agencies has been established to: (a) determine the eligibility of applicants for Medicaid-funded DD services and develop individual service plans for new entrants to the service system (PAS agents); and (b) furnish conflict-free service coordination services to such individuals on an ongoing basis (ISC/ISSA agencies).
- ❑ Services coordination services for HCB waiver participants and certain other recipients of state-funded DD services have been intensified through the establishment of specific requirements governing the interactions between service coordinators and participants in Medicaid-funded services (ISSA services).
- ❑ The state has been divided into eight geographic “networks” to improve the coordination of services within each specified catchment area of the state.

Despite these commendable efforts to strengthen the community service infrastructure, Illinois still lacks a true single point of accountability to oversee the delivery of specialized DD services within local communities across the state. The ISC agency, which doubles as the PAS agent, acts as the “front door” to the state’s DD service system. This agency determines the eligibility of all applicants for Medicaid-funded services, assures that a service plan tailored to the needs of each new eligible is prepared; in addition, PAS/ISC agencies see to it that such individuals are assigned a service coordinator and receive assistance in locating a service agency(ies) capable of meeting their needs in the least restrictive environment.¹⁰

PAS/ISC agencies, however, have no formal role in determining how community services funds are deployed and, thus, are not in a position to function as a local single-point-of-entry (SPE) to

⁹The legislation originally vested this responsibility in the Department of Mental Health and Developmental Disabilities; but, when DMHDD was folded into the Department of Human Services in 1997, the delegation of responsibility was shifted to DHS.

¹⁰ In an attempt to minimize the number of unnecessary state facility admissions, within the past year DDD has instituted a uniform statewide protocol to review the eligibility of candidates for admission to state-operated developmental centers (SODCs). A Clinical and Administrative Review Team (CART) has been created in each network area to administer this new protocol.

the service system in the same sense as SPE entities function in most other states. Decisions regarding the distribution of the state's community service dollars are the result of individual negotiations between DDD and each community provider agency. An eligible individual, with the assistance of family members and his/her service coordinator, therefore, is left to "shop" for an appropriate service agency, knowing that the likelihood he/she will be enrolled rests almost entirely on whether the community agency has available an appropriate program "slot" at the time the application is submitted (or subsequently if they are wait listed). This approach to managing community services contrasts sharply with states where the SPE agency, in addition to being responsible for eligibility determination, intake, support planning and service coordination, also controls state purchase-of-service dollars and, therefore, is in a much stronger position to negotiate program placements with providers of community services.

Furthermore, the responsibilities of PAS/ISC agencies are limited to individuals who are applying for or receiving Medicaid-funded services. But, under a number of existing state programs, DDD also awards grants to assist community services agencies in furnishing developmental training, supported employment, family assistance, diagnostic and evaluation and other services to persons with developmental disabilities. Individuals participating in such grant-funded service programs may receive information and referral services from a PAS agent but are not subject to pre-admission screening, the ISP process, and are assigned an individual service coordinator on an as-needed basis only. Indeed, until recently, very little statewide information was available on the participants in these grant-supported programs and, as will be discussed in much greater detail in Chapter V, over the past two years the absence of such information has proven to be a major impediment to converting the funding of selected grant-supported activities to Medicaid financing and thereby qualify the state for additional FFP.

Two primary barriers have been encountered. First, the absence of accurate, person-specific utilization and cost data has made it difficult for state officials to estimate the effects of converting from a grant-funded to a fee-for-service payment mechanism and instituting procedures to gather the data necessary to justify Medicaid payment claims on an ongoing basis. And, second, many community provider agencies have been fearful that the conversion to fee-for-service funding would erode their financial flexibility significantly, thus leaving them in an even more vulnerable cash flow position.

The split between grant and fee-for-service funding also affects the capacity of PAS/ISC agencies to perform their functions. These agencies, as noted above, are funded by DDD through multiple program authorities. They are reimbursed for services to recipients of ISSA services on a fee-for-service basis¹¹ and for PAS functions and service coordination furnished to individuals who are ineligible for PAS and ISSA services on a grant basis.

On several occasions over the past decade, the state has selectively increased the ISC (Program 500) grant allotments of PAS/ISC agencies which have been heavily impacted by population and service growth. But, there remains no direct relation between the number of persons receiving service coordination and the amount of grant assistance PAS/ISC agencies receive from the state.

¹¹ Medicaid reimbursement for such services, in turn, is claimed as an administrative cost as part of the state's administrative recovery plan.

In addition, several PAS/ISC agency directors told the NASDDDS project team that a considerable amount of overlap exists between the contractual functions and activities of PAS agents and Program 50 ISC agencies in the areas of intake, eligibility determination, referrals, selection, linkage and placement, initial follow-up monitoring of new program placements, and the completion of necessary assessments and service arrangements. However, recommendations to create a unified service coordination process and to consolidate the funding of PAS and service coordination services, the team was told, thus far have not been acted upon by state officials.¹²

DDD's network facilitators, as noted above, are involved in managing the state's contracts and agreements with community provider agencies, but, according to the community agency administrators and PAS/ISC executives who the NASDDDS project team spoke to during the course of the present project, all of the critical decisions concerning the distribution and use of community services dollars continue to be made by DDD central office personnel in Springfield. In a confined budget environment, centralized decision-making has permitted DHS/DDD officials to pursue important program initiatives and fulfill legislative mandates, such as downsizing the population of state developmental centers and assuring that the state meets its obligations under court-approved settlement agreements in the *Bogard* case and other class action lawsuits. But, it also has generated a high level of tension and distrust within the state's DD service delivery system.

A certain degree of tension in the relationship between the funding agency and the provider community can be expected, given the competing financial interests of the two parties. The NASDDDS project team, however, found a higher level of animosity and mistrust in Illinois than team members have encountered in most other states in which they have worked. The causes of this ill will and misunderstanding are, no doubt, multitudinous. But, one major underlying factor seems to be the fragmented process by which financial and program management decisions are made within the state's DD service delivery system.

In summary, viewed from a financial management perspective, the bifurcation of responsibility for service planning and coordination on the one hand and contract negotiations/funding on the other erects numerous barriers to effective local management of the service delivery process. First, it makes it far more difficult to shift from traditional "slot managed" funding to an approach that tailors financing to the individual needs and aspirations of the person and his/her family, an essential pre-condition to promoting self-directed/self-determined services and supports (see additional discussion below). Second, the development and implementation of local plans and funding priorities becomes far more problematic when financial control is separated from the eligibility determination and service coordination functions. And, third, when the financing of services is managed separately from eligibility/intake/service coordination, it becomes virtually impossible to achieve the level of systems integration necessary to efficiently manage resources and, more to the point of the present study, to take maximum advantage of available third party funding opportunities.

¹² See undated paper, entitled "Consolidation of Individual Service Coordination Activities Concept Paper," prepared by the Illinois Association of Independent Service Coordination Agencies.

Numerous considerations need to be taken into account in determining the most effective approach to unifying responsibility and accountability for area-wide eligibility determination/individual service planning/coordination on the one hand and contract negotiations/financing functions on the other. Analyzing such factors and weighing the pros and cons of alternative administrative approaches was beyond the scope of the present study. Nonetheless, it became clear to the authors of the report that resolving this long-standing issue is a key to improving the management of available resources system-wide, including the capacity of the state to access and manage third party payments more effectively.

B. Person-Centered Supports

One of the primary strategic goals of the Division of Developmental Disabilities is to adopt "... a person-centered philosophy in determining the appropriate services needed" by citizens with developmental disabilities.¹³ DDD's current three-year strategic plan contains an impressive array of objectives and action steps designed to make community DD services more person-centered and assure that state funding "follows the individual."¹⁴ These are laudable goals, very much in keeping with contemporary thinking within the developmental disabilities field. The problem is that the state's existing infrastructure for managing resources and developing supports is incompatible with a person-centered approach to delivering services.

In 1998, after completing a review of the state's home and community-based waiver program for people with developmental disabilities, a team from the federal Centers for Medicare and Medicaid Services concluded that "[t]he design of the waiver is provider-centered, rather than consumer oriented." The team's final January 1999 report continued:

Although the waiver, in theory, allows individuals freedom of choice in the delivery of services, the procedures used for enrolling and assessing as well as managing services and service delivery, place providers in control of the service delivery structure.¹⁵

To rectify the waiver program deficiencies cited by the federal review team, DPA, working in close collaboration with DDD/DHS, filed a plan of correction (POC) with the Chicago Regional Office of CMS. As part of its POC, the state took a number constructive steps to improve service coordination services, prevent abuse and neglect, and intensify program oversight. But, none of these actions altered in any substantive manner the state's fundamental approach to financing and delivering home and community-based services to Illinois citizens with developmental disabilities.

¹³ *Report of Progress as of the Second Quarter FY '02: 3-Year Strategic Plan*, July 1, 2001 through June 30, 2004, Office of Developmental Disabilities, Illinois Department of Human Services.

¹⁴ *Ibid.*

¹⁵ Health Care Financing Administration, "Management Review of the Illinois Home and Community-Based Services Waiver Program for Persons with Mental Retardation and Developmental Disabilities," Control No. 0205.90, Chicago Regional Office of HCFA, January 1999.

One principal element of managing resources on a person-centered basis is the methods a state uses to allocate and use state dollars. The study team heard conflicting versions of how such decisions are made within Illinois' community DD service delivery system. Family members and advocates expressed concern that decisions often are the product of negotiations between DDD and individual community provider agencies. They did not feel that the applicant and his/her family/guardian are a party to these negotiations and, consequently, their needs and preference become, at best, one of many factors that are taken into account in arriving at state payment rate. Representatives of community provider agencies reinforced this view, adding that state payment rates frequently under-compensate provider agencies and allow them limited flexibility in tailoring supports to the needs of each individual/family.

DDD officials on the other hand were adamant in their contention that important strides have been made over the past few years in shifting the focus away from provider-based negotiations toward a system that is much more person-centered, not only in particularizing service/support packages to the needs of each individual but also in promoting consumer choice among available provider agencies. They said that great pains have been taken in recalibrating community provider payment rates in ways that allow providers greater flexibility in meeting consumer needs and preferences. DDD managers did acknowledge that they were struggling against historical inertia within the system and that consumers and families still may be encountering less than optimal conditions as plans of care are developed and service/support choices are made.

Moreover, once initial program placement and rate-setting decisions are made, family members and consumer advocates contend that formidable hurdles still exist to modifying the setting in which an individual receives services as well as the types/intensity of services provided. In other words, although the Department has worked hard to make dollars more portable within the service system, it remains difficult for many individuals/families to select a new service provider or alter the mix of services received. Due to this historical lack of dollar portability, the Illinois DD service system has evolved over time into a multi-layered array of service settings and providers in which individuals and families have limited opportunities to choose new services, service settings and providers as their needs and preferences change.

DDD's current efforts are making inroads into the way in which service and resource allocation decisions are being made. However, the consequences of years of tying dollars to providers rather than to individuals and families receiving state-funded services are evident in comparative national program data. While Illinois furnishes residential services to more individuals with developmental disabilities per 100,000 in the general population than the national median, a disproportionate number of these individuals are served in large congregate settings in comparison to other states. According to statistics compiled by the Research and Training Center on Community Living at the University of Minnesota, 147.2 Illinois citizens with developmental disabilities per 100,000 in the general population were receiving state-funded out-of-home residential services as of June 30, 2001, compared to a national median figure of 136.1/100,000. At the same time, the state's per capita rate of placements in large congregate care facilities (16+ beds) was more than double the median for all states (IL: 61.2/100,000 vs. U.S. median: 26.8/100,000), while the proportion served in small (1-6 bed) community residences was less than half the national median (IL: 42.9/100,000 vs. U.S. median: 88.9/100,000).¹⁶

¹⁶ Ibid, *Residential Services for Persons with Developmental Disabilities...*, RTCCL/ICI/UMN, p. 35.

In recent years, a number of states have adopted resource allocation methods that link service expenditures to each recipient of state funded services in an attempt to increase the portability of public dollars and afford individuals and families expanded opportunities to tailor paid supports to their unique needs and aspirations. NASDDDS is in the process of completing a study of the individual budgeting methods employed by state mental retardation/developmental disabilities agencies across the nation. A report summarizing the findings of this study, which is scheduled to be released in the fall of 2003, will include an in-depth comparison of the individual budget methods used by nine, selected states.¹⁷

Suffice it to say for present purposes that state/local service systems in which money, in fact, follows the individual exhibit certain common characteristics, including:

- ✓ system-wide acceptance of a set of values that emphasizes person-centered services and supports and full community integration;
- ✓ statewide access to person/family centered service coordination/support brokerage services;
- ✓ a well-articulated and widely accepted system for developing and managing individual budgets, including methods of responding to the changing needs and preferences of individuals and families;
- ✓ effective channels of communications and a problem-solving ethic that cuts across all levels of the service system and encompasses all stakeholder groups; and
- ✓ quality oversight and improvement activities that are properly aligned with the state's systemic goals and the underlying values which they reflect.

In mapping out future revenue management strategies, Illinois policymakers, service providers and disability advocates will have to consider the steps necessary to manage state-financed services on an individualized, person-centered basis. Given the fiscal constraints under which the state's DD services system presently operates and, in all likelihood, will continue to operate for the foreseeable future, change strategies that rely on substantial infusions of new dollars are likely to prove highly problematic. Instead, state policymakers and disability advocates will need to develop initiatives aimed at transitioning existing dollars from congregate care settings to integrated, community-based settings and simultaneously managing community service funds in a manner that comport with the person-centered goals embraced by DDD's three-year strategic plan. Chapter IV and V outline several targeted strategies the state might pursue to downsize large, congregate care facilities and, thereby, create a more conducive environment to developing person-centered community support strategies, without a sizeable investment of new General Fund (GF) dollars. However, it is worth emphasizing here that, if these initiatives are to result in sustainable, system-wide changes, it will be necessary to re-invest a portion of the GF savings

¹⁷ Moseley, Charles R. *A Study of Individual Budgeting Practices*, NASDDDS, Alexandria, Va., in press.

associated with proposed revenue enhancements in creating a state/local management infrastructure to undergird person-centered support networks which afford individuals and families true choice and control.

C. Management Information Capabilities

The Department of Human Services has taken a number of steps in recent years to improve data reporting systems related to developmental disabilities programs. For example, in phases over a multi-year period, all in-state fee-for-service community providers have been converted to a paperless billing process, called ROCS (Reporting of Community Services). In addition, within the past year, DDD has gathered survey data from over 7,400 families and more than 300 provider agencies in an attempt to identify existing service gaps, including getting a handle on the number of individuals in need of particular elements of services and supports. Yet, despite these advances, there are a number of noteworthy gaps in the state's existing approach to gathering, analyzing, storing and retrieving data on individuals and families currently receiving state-funded DD services and supports.

During the course of its study, the NASDDDS project team encountered numerous problems in accessing the data necessary to evaluate the effects of employing new third party funding options.¹⁸ These problems will be detailed in Chapters IV, V, and VI of the report. Suffice to note for present purposes that the main source of the problem was the inconsistency of the data gathered across DD program categories. In particular, until recently, virtually no client-based information was collected by DDD on participants in grant-funded community programs. Individuals receiving grant-funded services are not required under present state policy to go through a preadmission screening in order to be enrolled in such programs, and, while many service providers, no doubt, have gathered a considerable amount of information concerning the characteristics and needs of the individuals they serve, it cannot be translated into a reliable, statewide data set. In fact, until recently, DHS/DDD had limited capacity to determine the total number of individuals enrolled in these programs, by service agency and the types of services furnished. But, for purposes of the present study, the most significant limitation in the state's data system was the absence of information on the Medicaid eligibility status of participants in DDD grant-funded programs.

Providers of grant-funded services are required to report certain elements of participant-specific information to DDD. However, because these required data elements are not extensive and community provider agencies do not always comply with these requirements, frequently the information available to public policy-makers and state administrators is inadequate. Without an adequate database, it is difficult to determine key demographic and administrative characteristics of persons receiving services, including their age, Medicaid eligibility/enrollment status, and enrollment/non-enrollment in other DDD-funded activities. The absence of such person-specific

¹⁸ The difficulties the project team ran into, it should be noted, were entirely systemic in nature. The staff of DHS and DDD proved to be very cooperative, giving team members complete access to available information and data as well as their experience and insights – even on occasions initiating special data runs at the team's requests.

information greatly complicates the task of completing accurate revenue analyses.¹⁹ As will be detailed in Chapter V, the project team in a number of instances found it necessary to rely on informed judgments rather than hard data in arriving at estimates of the revenue implications of potential, new third party funding options.

Comparable, statewide expenditure and utilization data on grant-funded services also is lacking, thus further complicating the task of completing accurate revenue analyses. For example, although the project team was told that a significant number of children receive services through grant-funded programs, we were unable to determine the Medicaid eligibility status of individuals under age 18 who are enrolled in services, by service category, or the amounts expended on their behalf. Consequently, the team had to base its potential Medicaid revenue estimates on a series of assumptions that may not be supported by the facts once they are fully revealed.

Clearly, claiming federal financial participation in the cost of these grant-funded programs would be highly advantageous to the state, especially in light of the serious revenue shortfall that presently confounds Illinois state government. However, in order to claim Medicaid reimbursement on behalf of grant-funded recipients of developmental training, supported employment and other services that currently are being funded entirely with state grant-in-aid dollars, it will be necessary to move to a fee-for-service method of paying for such service providers. Why? Because Medicaid is a vendor payment program in which states are required by federal law to establish that a given reimbursable service has been furnished to a particular Title XIX-eligible beneficiary, at a specified date and time, at a specified location and in accordance with state established requirements. Thus, in order to claim reimbursement on behalf of Medicaid-eligible individuals presently being served through state grant-in-aid programs, it will be necessary to establish and maintain a far more robust state/local management information system. Furthermore, such data systems needs to be dovetailed with the state's Medicaid Management Information System (MMIS) in order to file FFP claims with the federal Centers for Medicare and Medicaid Services (CMS).

Looking beyond the immediate tasks of, first, evaluating the merits of particular Medicaid claiming strategies and, second, establishing a sound data collection/reporting/claiming system, there are other, sound reasons why the State of Illinois needs to upgrade its information technology capabilities over the next few years. First, CMS is in the process of "raising the bar" with respect to state oversight of the quality and accountability of providers of Medicaid-funded home and community-based services and, consequently, it would be advisable to review the state's existing quality management capabilities to ensure that they comport with CMS' expectations (see additional discussion below in Section D of this chapter).

Second, as the size and diversity of community DD service systems have grown, it has become more and more difficult for states to manage such systems effectively without employing advanced IT applications. Quite aside from the initiatives CMS has launched, more and more states – especially large, populous states like Illinois – have come to recognize that information can be a powerful management tool if properly employed. That is why you see states like

¹⁹ The recently enacted legislation directing IDHS to develop a cross-disability database should help to fill this information void (see discussion below under Section E of this chapter).

Pennsylvania, California, New York, Connecticut, and Massachusetts making significant investments in upgrading their management information systems.

Third, as states transition from their traditional role as a direct providers of DD services to managers of increasingly large and complex service delivery systems, the need for complete, accurate and timely data upon which to base management decisions becomes more and more acute. The continuing decline in the number of state employees – a longstanding, nationwide trend that is being accentuated by the states’ current budget woes – also is a contributing factor to the emerging emphasis on developing “data-driven” management systems. CMS, for its part, is encouraging states to upgrade their information technology capabilities.²⁰

Improving DDD’s information technology capabilities is not simply a function of adding more sophisticated hardware and software. Effective revenue management requires human resources with the capacity, skill levels, and authority to analyze related information, inform fiscal and programmatic policy decisions, and hold other parts of the system accountable for performance related to generating additional third-party revenues. Completing an in-depth analysis of IDHS/DDD’s current analytical capabilities and recommending specific actions that should be taken to improve the department’s performance in this area is beyond the scope of the present study. Nonetheless, it seemed clear to the project team that, in order to create a first class DD revenue management program, IDHS/DDD managers need to reorganize and expand the agency’s current capacity to collect and analyze related data as well as its capacity to manage revenue-related administrative and programmatic functions.

Investing scarce dollars to improve management information systems may seem unrealistic during a period when the state faces the worst budget crisis since World War II. But, as will be pointed out in Chapter VI, if the initiative is properly structured, the federal government will assume 90 percent of the costs of designing new MIS applications and 75 percent of the cost of implementing them, provided they are to be an integral part of the state’s Medicaid Management Information System.

D. Quality Assurance and Improvement Systems

Over the past few years, CMS has invested millions of dollars in discretionary grant and contract-funded activities aimed at: (a) helping states to strengthen basis elements of the infrastructure necessary to effectively oversee the delivery and ensure the quality of HCB services; and (b) improve the federal government’s own, internal capacity to monitor state performance in this area. Among these activities are:

- ✓ *The preparation and promulgation of a new regional office protocol for conducting reviews of state HCBS waiver programs.* Developed with the assistance of an outside contractor (Medstat) and effective with federal waiver assessments conducted after

²⁰ CMS is in the process of releasing a series of “data readiness” reports prepared a contractor (Medstat) that was asked by federal officials to complete a systematic examination of the efforts underway in seven states that are at the forefront in attempting to apply IT technology to improving the quality and appropriateness of Medicaid-financed home and community-based services.

January 1, 2001, the purpose of this new protocol is to improve the scope and consistency of federal waiver reviews, thereby assuring that waiver participants receive high quality services and supports.²¹

- ✓ *The creation of a “Quality Framework”* that offers states guidance regarding the principal components of a comprehensive, statewide quality assurance/quality improvement system, including CMS’ expectations regarding the performance of such systems.
- ✓ *The completion of a national Quality Inventory*, a comprehensive survey of the states’ capabilities to monitor and improve the quality and accessibility of Medicaid home and community-based waiver services for persons with mental retardation/developmental disabilities as well as frail elderly and physically disabled individuals. CMS plans to use the results of this survey, scheduled to be released in the fall of 2003, to target future waiver-related quality improvement initiatives.
- ✓ *The preparation of new quality monitoring and improvement tools*, including a “Participant Experience Survey,” designed to elicit structured feedback from participants in Medicaid-financed HCB services, and a HCBS Work Book, a step-by-step guide to designing a comprehensive statewide or local quality management program.
- ✓ *The retention of a national technical assistance contractor* to assist CMS regional office staff and individual states to upgrade their quality oversight and improvement capabilities.

In addition to these activities, work is underway within CMS on a new streamlined Section 1915(c) waiver application format that is expected to embed the agency’s heightened expectations regarding quality monitoring and improvement into the basic HCBS waiver application/approval process. Among the changes that are anticipated in the new waiver submission format is a requirement that states submitting new or renewal waiver applications after a specified date include with their submission a detailed quality management plan. In this plan, which already is a feature of the Independence Plus, self-directed waiver template which CMS promulgated last year in draft form, states will be expected to spell out the detailed procedures and processes it will use to ensure the quality and appropriateness of the home and community-based services it intends to provide to the targeted group of waiver beneficiaries.

CMS also plans to issue a revised Form 372, the form states use to report annually on the status of HCBS waiver services, and simultaneously improve its own, internal waiver tracking capabilities. One aim of the Form 372 revisions will be to add specific data elements that furnish CMS with feedback on the performance of the state’s quality management and improvement system.

²¹ Additional information concerning the following CMS-funded QA/QI activities can be found on the agency’s Web site at <http://cms.hhs.gov/medicaid/waivers/quality.asp>.

The U.S. General Accounting Office (GAO) recently issued a report criticizing CMS' oversight of the quality of home and community-based waiver services.²² The agency's response to the report suggests that CMS will be redoubling its attempts to complete and implement the changes in policy and practice outlined above.²³

Following CMS' 1998 review of Illinois' HCBS waiver program for persons with mental retardation and related conditions, IDPA and IDHS agreed to take the following steps to improve state oversight of services furnished through the program:

- ✓ Require community provider agencies to conduct pre-employment background checks on all applicants for employment through a newly established, centralized state registry.
- ✓ Hire ten additional IDHS/DDD staff members to carry out enhanced quality assurance and monitoring activities involving participants in the state's MR/DD waiver program;
- ✓ Follow-up on all substantiated cases of abuse and neglect reported by the IDHS Office of the Inspector General;
- ✓ Monitor a random, two percent sample of all waiver participants to determine the quality and appropriateness of the care they are receiving;
- ✓ Follow-up on all IDPA monitoring findings; and
- ✓ Follow-up on all quality assurance referrals filed by Individual Services and Supports Agencies, waiver provider agencies, and the IDPH Office of Accreditation, Licensure and Certification.

These and other steps initiated in the wake of CMS' 1998 assessment of the state's MR/DD waiver program, no doubt, have addressed the deficiencies identified by the federal review team and placed the state in a better position to avoid similar problems in the future. Nonetheless, in light of CMS' heightened expectations of state performance in this area, prudence would seem to dictate the initiation of an in-depth review of the state's quality management system for MR/DD waiver services.²⁴ CMS' new Quality Framework in combination with the state's own response to the national Quality Inventory survey should be used as the basis for this review.

²² U.S. General Accounting Office, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should be Strengthened*, GAO-03-576, June 2003.

²³ The department's response to the GAO report is summarized in separate letters which HHS Secretary Tommy G. Thompson sent to Senators Charles E. Grassley (R-IA) and John B. Breaux (D-LA), the chairperson and ranking minority member, respectively, of the Senate Finance Committee, on July 28, 2003.

²⁴ A detailed review and analysis of the state's quality management capabilities was beyond the scope of the current study. This recommendation, therefore, is not intended as a criticism of the performance of Illinois' current quality management system. Rather, it is an attempt to highlight an area of potential vulnerability. Indeed, in view of the attention CMS is giving to the area of quality oversight and improvement at the present time, the project team would make the same recommendation to virtually any state MR/DD agency in the country.

E. System-wide Planning

The state Division of Developmental Disabilities has created several mechanisms to obtain input from self-advocates, parents, community service providers and other system stakeholders. A Statewide Advisory Council on Developmental Disabilities, composed of representatives of these and other key stakeholder groups, has been established to offer DDD guidance on current and emerging policy issues. In addition, each of the eight DDD networks maintains its own area-wide advisory council.

During 2000-01, DDD, with the assistance of the Strategic Planning Standing Committee of the Statewide Advisory Council, developed a three-year strategic plan that identifies a series of broad goals and specific, time-sequenced implementation activities aimed at improving system-wide access to appropriate services. One of the objectives of this plan is to furnish community residential services to an additional 1,150 individuals with developmental disabilities, including a mixture of former state developmental center residents and un-served individuals residing with their families or in other, non-funded community settings.

Some of the initial community expansion benchmarks of the DDD's Strategic Plan were achieved. Progress on many of the objectives, however, has slowed because of the constraints imposed by the state's budget crisis. Of greater significance from the perspective of long range system-wide planning, however, the state lacks accurate, up-to-date information on the needs of un-served and under-served citizens with developmental disabilities. At present, lists of persons in need of service are maintained by individual community provider agencies, but this information is not aggregated into a statewide list that contains comparable data on individuals in need of DDD-funded services and supports. Nor has the state articulated a clear set of priorities for managing access to services as new resources become available. The family and provider survey data which DDD gathered during the past year should help to narrow this information gap. But, information derived from special, one-time surveys is not a substitute for a well-designed management information system that generates data on a recurring basis.

As the project team's report was being finalized, the Illinois General Assembly completed action on a measure directing the Department of Human Services to "... compile and maintain a cross-disability database of Illinois residents with a disability who are potentially in need of services funded by the Department."²⁵ This database must be operational by July 1, 2004 and include detailed demographic and needs-based information on individuals with mental illnesses, physical disabilities, and developmental disabilities.

The absence of accurate, timely, comparable, system-wide data on unmet service needs has far reaching implications for managing access to state-funded services. Without such data, regulating entry to the service system becomes a continuing triaging process, where system administrators and community provider agencies respond, as best they can, to presenting crises as they arise. In addition, it is not possible to develop new resources in anticipation of predictable future needs or to adopt and enforce statewide (or area-wide) program placement priorities that are grounded in equity principles and tied to the deployment of scarce fiscal resources.

²⁵ Public Act 93-0503, effective August 11, 2003.

A class action lawsuit was filed in the U.S. district court serving northern Illinois in September 2000, accusing Illinois officials of failing to furnish Medicaid services with “reasonable promptness” to eligible individuals with developmental disabilities in accordance with the requirements of federal Medicaid law (*Boudreau v. Ryan*). The plaintiffs’ petition also alleged that the state was denying individuals their right under federal Medicaid law to choose between institutional (ICF/MR) and HCB services as well as their rights under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act to receive services in the “most integrated setting appropriate to their needs.”²⁶

In May 2001, Senior District Judge John F. Grady, the presiding judge in the *Boudreau* case, dismissed the plaintiffs ADA claims because the case was filed against state officials acting in their official capacity, rather than against a “public entity.” Later, he also dismissed the remaining grounds for the suit, ruling that: (a) federal law contains no requirement that a state arrange for Medicaid services on the basis of the proximity of the service to the family of a recipient; and (b) the services the plaintiffs sought (placement in an ICF/MR) might be available elsewhere in Illinois. The plaintiffs filed an appeal with the 7th U.S. Circuit Court of Appeals in March, 2002. The circuit court upheld Judge Grady’s dismissal of the plaintiffs’ claims under Medicaid law indicating that federal law does not mandate that services be located near the familial home of an individual. But, the appellate court remanded the case to the district court for a ruling on the validity of the plaintiffs’ claims under the ADA and the Rehabilitation Act, indicating that its earlier ruling that suits against public officials acting in their official capacity are invalid was not in keeping with precedents set by rulings in other judicial circuits. As of this writing, the district court has not acted on the issues remanded by the circuit court.

Regardless of the ultimate disposition of the *Boudreau (Bruggeman)* lawsuit, the “waiting list question” is almost certain to remain a major unresolved policy issue in Illinois for the foreseeable future. In the absence of accurate statewide data, the number of individuals and families who are in need of specialized DD services will be subject to dispute. Hopefully, as a result the passage of PA 93-0503, IDHS will be able to close this information gap.

States that have completed in-depth studies of service demand have found that persons with unmet needs include a small percentage of individuals who are in urgent need of services, a larger, second tier of individuals who will require services within the near term (one to two years), and a third, even larger tier of individuals who will require services at some point, but probably not within the immediate future. These states also have discovered that, while requests for out-of-home placements tend to predominate, the needs of many individuals and families can be met through other, less costly interventions and supports if the service system is prepared to offer persons with disabilities and their families viable, flexible alternatives to out-of-home placement.²⁷

²⁶ *Edward Boudreau, et al. v. George H. Ryan, et al.* (subsequently redesignated *Bruggeman, et al. v. Blagojevich, et al.*, Civil Action No. 00-C-5392, United States District Court, Northern District of Illinois, filed September 2000.

²⁷ For an analysis of the waiting list phenomenon and how states are attempting to address it, see Smith, Gary, *Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports*, NASDDDS, May 1999.

Armed with robust service need data, these states have been able to formulate waiting list management policies that establish a clear order of priority in responding to unmet needs within the resources made available by the legislature. In addition, once emergency needs are addressed, the state is able to initiate strategies intended to meet the most pressing needs of other un-served or under-served individuals and families.²⁸

This approach to regulating access to state-financed services does not eliminate the problems associated with an under-resourced service system. But, it does offer all system stakeholders assurance that, within the constraints of available dollars, public funds are being deployed in an equitable and defensible manner. It also provides public policymakers with an accurate portrayal of the consequences of under-funding – right down to the names, locations and presenting needs of individuals awaiting services – and, thereby, permits state officials to design and implement strategies for minimizing the negative effects on such individuals and families.

From the point of view of revenue management, the principal advantage of maintaining a statewide information on unmet needs and operating under a clearly delineated set of service initiation policies is that system managers are in a much better position to design financing strategies that take into account not only existing recipients of services but those whose needs are not currently being addressed by the service system. As will be discussed in greater detail in Chapter V of this report, in recent years a number of states have initiated specialized HCB waiver programs that are specifically aimed at allowing un-served and under-served individuals and their families to gain access to services and supports that they would not have received had pre-existing service initiation policies been followed.

F. Conclusion

Too often, accessing additional third party revenues is viewed as a discrete set of activities, unrelated to the basic organization and delivery of services. But, as this chapter has demonstrated, revenue management needs to be treated as an integral component of service planning and implementation. Discontinuities in the service delivery process and weaknesses in the infrastructure necessary to effectively manage the service system erode the capacity of a state to take advantage of new and expanded sources of third party revenue.

Illinois, unlike most other states, has yet to establish a unified, single-point-of-entry system for accessing state-funded developmental disabilities services in which a designated local entity in each catchment area of the state is responsible for eligibility determination, intake, individual program planning, service coordination and the purchase of needed services. In addition, as this chapter has demonstrated, there are a number of other key system management issues that need to be addressed in Illinois. An in-depth analysis and recommendations on restructuring the state's DD service delivery system and improving the state's service delivery infrastructure is beyond the scope of the present study. Nonetheless, it is important for readers of this report to recognize, as they examine the revenue options discussed in the subsequent chapters, that many of the

²⁸ See Smith, Gary, *A Supplement to Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports*, November 1999.

difficulties in accessing third party revenues that have been encountered in the past can be traced back to the basic limitations imposed by the existing state/local organizational delivery system and the infrastructure that has been put in place to support it.

Chapter IV

FINANCING STATE OPERATED DEVELOPMENTAL CENTERS

The federal government reimburses states for Medicaid service costs incurred in certified intermediate care facilities for people with mental retardation and related conditions (ICFs/MR). The ICF/MR Program was established in 1971 when legislation was enacted by Congress authorizing federal financial participation (FFP) in the cost of providing ICF/MR services. Congressional authorization of ICF/MR services as a state plan option under Medicaid allowed states to receive federal matching funds for institutional services that previously had been funded entirely with state or local government money. Section 1905(d) of the Social Security Act establishes this benefit to fund "institutions" (four or more beds) for people with mental retardation or other related conditions and specifies that these institutions must provide "active treatment," as defined by the Secretary.

To qualify for Medicaid reimbursement, an ICF/MR must be certified and comply with federal standards (referred to as Conditions of Participation and found in 42 CFR Part 483, Subpart I, Sections 483.400-483.480) These regulatory requirements are divided into eight areas or conditions, including facility management, client protections, facility staffing, active treatment services, client behavior and facility practices, health care services, the physical environment and dietetic services.

Illinois currently has nine state-operated developmental centers (SODCs) that are administered by the Division of Developmental Disabilities (DDD), a unit of the state Department of Human Services (IDHS). These developmental centers are comprehensive residential programs serving persons whose developmental disabilities are complicated by severe medical or behavioral needs. The population of these centers has declined steadily over the past decade as new community living alternatives have been developed. As of June 30, 1991, a total of 4,340 individuals were residing in SODCs.¹ Twelve years later, the aggregate SODC census had dropped to 2,811 residents.

The Lincoln Developmental Center, which was closed during the final year (2002) of the Ryan Administration, is being reopened by the new Blagojevich Administration. Current information suggests that Lincoln DC will not be reopened as a large congregate care facility (developmental center). A committee has been formed to develop recommendations for the use of resources available from the Lincoln Developmental Center. It is expected that these recommendations will result in the development of residential capacity for approximately 40 individuals on or in close proximity to the Lincoln campus. Pending final policy decisions, these new homes are expected

¹ Prouty Robert, Smith, Gary, and Lakin, K. Charlie (Eds.), *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, May 2002, p. 103.

to be certified as ICFs/DD (which is Illinois' equivalent of the federal ICF/MR designation). The proposed budget to develop and operate these new homes has been included as part of this analysis.

There are current discussions underway concerning expanding the capacity of Choate Developmental Center to accommodate additional court-committed youth with developmental disabilities. This proposed expansion is not included in the present analysis since there was insufficient information regarding the final form that this program expansion might take at the time the report was prepared. General thoughts on the revenue implications of this pending action, however, will be presented in this chapter.

A. Analysis of Existing Rate Methodology and Reimbursement

Determining the efficiency of the existing billing rate methodology and reimbursement experience focuses on two primary elements. The first is how the rate methodology is articulated, especially how it defines allowable expenditures. The second focuses on how efficient a state is in claiming federal Medicaid reimbursement for the care days provided in a developmental center.

Table 4.1 displays census and expenditure data from the nine existing state-operated developmental centers, as of July 1, 2003. Although the net census is not expected to increase, the FY 2004 budget for SODC operations totals \$307.16 million, which represents an increase of

Table 4.1: Resident Census and Budgets: State Operated Developmental Centers

Developmental Center	Location	Projected Census on Beginning FY 04	FY 04 Budget
Choate Center*	Anna	195	\$23,898,800
Fox Center	Dwight	171	\$17,867,800
Howe Center	Tinley Park	425	\$51,059,600
Jacksonville Center	Jacksonville	265	\$29,298,000
Kiley Center	Waukeegan	250	\$26,290,700
Ludeman Center	Park Forest	408	\$36,298,800
Mabley Center	Dixon	112	\$10,457,900
Murray Center	Centralia	330	\$31,025,400
Shapiro Center	Kankakee	655	\$69,226,700
TOTAL ALL CENTERS		2,811	\$295,423,700
Lincoln Center	Lincoln	40 (June 2004)	\$0**

• Represents DD Census Only- Budget \$\$ Pro-rated @ 67.346%

** The FY 2004 budget includes no operating funds for Lincoln Center, but does contain \$7 million in capital development funds.

4.83 percent compared to DDD's FY 2003 budget for SODC operations. It should be noted that in Table 4.1 the census and FY 2004 budget figures for the Choate Developmental Center reflect

only the “DD portion” of this jointly certified mental health and developmental disabilities facility. This adjustment was made to focus the analysis solely on services delivered to people in developmental centers who, if eligible, may qualify for Medicaid-funded ICF/DD services. Table 4.1 also presents the projected census and FY 2004 budget for development of facilities on the Lincoln Developmental Center campus.

1. Developmental Center Rate Methodology

Illinois has chosen to use facility-specific, cost-based billing rates for its state-operated developmental centers. In a general sense, facility reimbursement rates are calculated for each fiscal year by dividing the projected operating expenditures of each facility by the projected number of “care days”. This approach creates a baseline to which facility-specific capital expenditures and a pro-rated allocation of developmental center and central office administrative costs can be added to create the prospective billing rate for each fiscal year. The Illinois Department of Human Services (IDHS) then bills each payer periodically throughout the year for each day of service (care day) recorded over the course of the fiscal year. At the end of the fiscal year, the “actual” expenditures and actual recorded care days then are used to reconcile billings and payments with each developmental center’s documented expenditures and utilization for the year. This approach to rate-setting is commonly referred to as a “cost-based” or “cost-settlement” methodology.

Each of Illinois’ nine existing state-operated developmental centers currently has a facility-specific billing rate structure. Each has a separate billing rate for Medicaid, Medicare, Private Pay, and Veterans benefits. It is expected that, pending final policy decisions, the homes developed on the campus of Lincoln Developmental Center will have a similar billing rate structure.

The methodology used to calculate the billing rate for each developmental center was reviewed in some detail. It appears that the calculation includes an appropriate range of allowable expenditures at each developmental center. It also appears that all direct expenditures related to program administration by the staff of the Division of Developmental Disabilities are similarly included in the state’s rate calculations. This finding suggests that there are few if any significant opportunities to increase the types of direct expenditures that are used in calculating the state billing rate.

Information supplied by managers in the departments of Public Aids and Human Services suggest that actual Medicaid billing rates for state developmental centers at times are restrained by the “Medicare Upper Payment Limit”. This federal regulatory requirement (42 CFR 447.272) restricts Medicaid payment for each class of long-term care facility to 112 percent of the state’s approved Medicare upper payment limit. DPA had experienced occasions when the billing rate for a developmental center exceeded that limit. In such instances the Department was able to claim FFP only in an amount equal to the Medicare upper payment limit. This practice has resulted in claims that are lower than actual costs, as calculated using the state’s existing methodology. In such instances the state gets no federal reimbursement for expenditures about the limit. Data was not available to identify the revenue impact of this factor.

2. Developmental Center Billing Efficiency

The \$307 million FY 2004 operating budget for the state developmental centers² is funded predominantly by a General Fund Appropriation, with Medicaid reimbursements claimed later for billable care days. Other revenue is generated through Medicare and Veterans benefits plus private insurance and other private payments. However, at the present time, such payments comprise less than 4 percent of total SODC operating revenues. Anecdotal information indicates that IDHS has predicted that, during FY 2004, 93 percent of the care days delivered in the nine state-operated developmental centers will be reimbursed by Medicaid. Those care days that are not expected to be reimbursed by Medicaid involve facility residents who are not eligible for Medicaid benefits (due to excess assets or their immigration status), those who are eligible for Medicaid but not currently enrolled (which is considered to be a negligible number of residents), or those whose care is reimbursed by other payers. The Department has what appears to be an effective method of collecting payments from these other payers, although it was not possible to identify exactly how much revenue or how many care days were billed and paid for through this method. When all payers are taken into account, it appears that IDHS/DDD has maximized the number of care days that are actually billed to the various legally liable funding sources.

It should be noted, however, that this anecdotal data suggests that three percent of total care days cannot be claimed or billed to any funding source. This finding indicates that, during FY 2003, \$8.87 million in developmental center expenditures (\$4.43 million in third party revenue) cannot be reimbursed by any funding source.

3. Revenue Potential

Given the current rate setting methodology, there is little room for increasing revenue associated with DDD's developmental center operations. It is possible that, through aggressive measures to maximize enrollment in Medicaid and to minimize the number of people in developmental centers who do not qualify for active treatment, DDD could increase its Medicaid revenue for this program by a comparatively modest amount. However, for reasons explained later in this chapter, it is unlikely that such action would generate significant revenue.

The impact of the Medicare upper payment limit on federal reimbursement for developmental center expenditures has a real, if uncalculated, revenue impact. Expenditures that cannot be reimbursed are funded through 100 percent state general funds. A thorough analysis of the recent and projected revenue losses due to this federal constraint should be conducted. If the proposed analysis concludes that the loss of federal revenue is significant (more than \$100,000/year), the Department should engage outside experts to determine whether there are tactical options available that would allow it to legitimately increase its billing rates. While the experience of DPA and IDHS has let state officials to be skeptical, a number of states have federal reimbursement rates for developmental centers that far exceed

² This figure includes the entire budget of Choate Center, which is why the total SODC appropriation shown here is larger than the amount displayed in Table 4.1 on page 46.

those calculated for these nine developmental centers. It is likely that there are CMS-approved methods that would allow the state to claim federal reimbursement for a higher proportion of expenditures than are currently allowed through its approved rate methodology.

B. Alternative Rate Methodology

While the existing “cost-based” or “cost-settlement” methodology does not appear to offer any noteworthy opportunities for enhancing Medicaid revenue, there is one option that merits consideration. The Center for Medicare and Medicaid Services (CMS) allows states to use another methodology to determine reimbursement levels. This methodology, which is generally referred to as “cost-related” payments, requires a state to establish and “certify” a base year for institutional expenditures that is satisfactory to CMS. Then, certain assumptions regarding the manner in which base expenditures can be modified each year are also agreed upon by the state and CMS. These assumptions must be tied to actual historical expenditure experience or to industry standards acceptable to CMS. Thus, federal reimbursement is triggered by the impact of the interplay between changes in a facility’s census (or utilization) and these agreed-upon modifiers (i.e., fixed v. variable expenditure factors, trend factors, etc.), rather than expenditures recorded each year.³

This “cost-related” methodology is conceptually similar to the reimbursement rate methodology used by IDHS/DDD to create the “fee for service” payment methodology now being used to establish payment rates for providers of developmental training services under the state’s DD home and community-based waiver program, where payment levels are not directly tied to annual expenditures. This cost-related approach can be quite advantageous in states involved in significant downsizing and/or closure initiatives within their institutional service sectors.

The revenue impact of shifting from a “cost-based” or “cost-settlement” method of determining institutional reimbursement levels to a “cost-related” method requires a much different policy approach than any others anticipated in this revenue generating project. To be of maximum benefit to the state, a number of policy and operational decisions should be in place. The Department should:

- ❖ Create a developmental center fiscal analysis and/or business plan that, with a high degree of accuracy and predictability, identifies the fiscal year when expenditures and utilization in the developmental centers are or will be at their realistic maximum. Ideally both expenditures and the aggregate facility census will be “cresting” or reaching a peak during the selected base year. This analysis should include staffing and “other than personal service” expenditures as well as the number of residents being served in the developmental centers. This approach will allow the state to identify and certify a base year for expenditures that creates the optimal revenue foundation for future years. [N.B.,

³ It should be noted that prior to 1986 the Department of Public Aid used a similar cost-related methodology to calculate SODC reimbursement claims. They were instructed by HCFA (now CMS) at that time to switch to the cost-reconciliation method that the state now uses. It is the opinion of the project team that it is still possible for the Department to pursue this alternative rate methodology, although its historical experience may require additional justification to demonstrate how this approach becomes a “cost-containment” strategy as the developmental center population decreases.

The state's analysis should incorporate any expansion anticipated within the developmental center system – including any projected increase in the census at Choate DC, as well as the four, 10-bed facilities that are to be developed on the campus of Lincoln Developmental Center.]

- ❖ Create a developmental center fiscal plan that establishes a single, system-wide per diem. This figure would encompass current and projected operational expenses at the nine state-operated developmental centers. Moving to a system-wide per diem would offer the state maximum flexibility and predictability in claiming federal payments. [N.B., It is possible to include any new, smaller state-operated facilities (i.e. the four, 10-bed facilities planned for development on the campus of the Lincoln Developmental Center). This approach could enhance the third party revenue generated by these new facilities.]
- ❖ Develop realistic and predictable facility census or utilization targets to reflect significant overall decreases in the total developmental center population or the closure of specific developmental centers.
- ❖ Create a “cost containment” strategy for reconfiguring the size, structure, and service capacity of state-operated developmental centers. The switch to a cost-related methodology is best conceptualized as a means of containing expenditure growth in the developmental center system, especially while experiencing the fiscal volatility often associated with significant downsizing or reconfiguration within the system. Historically, CMS has been willing to entertain state requests to contain expenditure growth by creating a base year and agreeing to allow annual increases based on specific growth factors. These considerations include trend factors, utilization factors (the interplay between fixed costs, variable costs and utilization), and other predictable cost factors.

Projecting the revenue impact of switching to a “cost-related” reimbursement methodology is difficult without knowing the “base year” expenditure levels and cost adjustment factors (that will be negotiated with CMS) or anticipated changes in developmental center utilization. However, it is possible to create a hypothetical fiscal analysis that demonstrates the potential value of converting to a cost-related reimbursement methodology.

Using the FY 2004 projected census and budget for SODC operations and assumptions provided by the IDHS/DDD staff regarding the percentage of overall costs that can be billed to Medicaid (93% of all care days), it is possible to develop a hypothetical scenario that demonstrates the revenue impact of the shift from a “cost-based” or “cost-settlement” methodology to a “cost-related” approach.

For the purposes of this analysis it was assumed that FY 2004 will be chosen as the new base year, with an average developmental center population of 2,810. This figure was chosen to be similar to the census figure included in the FY 2004 budget. It includes the MH consumers residing at Choate DC and excludes the 40 new beds being planned for the campus of the Lincoln Developmental Center. The projected FY 2004 budget of \$307,122,100 will also be used. (Please note that for this hypothetical example we are using the operational budget – not the total revenue generated by the developmental centers.)

For the purposes of this analysis, it was assumed that 100 percent of the care days in the developmental centers involved people who were receiving ICF/MR services that qualified for Medicaid reimbursement. This, again, does not accurately represent the information that suggests that only 93% of the care days in developmental centers can be claimed for Medicaid reimbursement. But it does allow the example to be much simpler and tied more closely to budget data that will be recognizable to a broader audience.

Using these figures, we can assume that the average per capita expenditures for the 2,810 SODC residents was approximately \$106,640 for this hypothetical base year.

To estimate the revenue impact of switching to a “cost-related” methodology, the analysis uses the following policy and fiscal assumptions:

- The “base year” for developmental center ICF/MR expenditures and utilization will include an average census of 2,810 people, an average per capita expenditure level of \$106,640, and a total expenditure level of \$307,122.100.
- IDHS/DDD should be able to demonstrate a fixed cost versus variable cost ratio of 65/35. For revenue purposes, this ratio means that for every net reduction of one person on the developmental center census, 65 percent of the \$106,640 remains in the developmental center budget and 35 percent is removed (ostensibly to be transferred to support community placements). [N.B., It should be pointed out that, as the variable costs are moved with transitioning SODC residents to the community, the ratio will change based on the increased proportion of total expenditures that are fixed. But the actual dollar amount for the variable portion will remain constant, as demonstrated in the table below.]
- The net average decreases in the developmental center population were set by the projections included in DDD’s current 3-Year Strategic Plan. This plan calls for reductions of 150, 150, and 200 over a three-year period. These figures were assumed to represent the first three of the five years immediately following the base year. This analysis then simply projected two more years with 150 person decreases in the overall developmental center census. This outplacement rate would result in average end-of-the-year populations of 2,660, 2,510, 2,310, 2,160, and 2,010 during the period of this hypothetical analysis.
- A COLA of 3.0 percent will be applied to developmental center base costs in each of the five years covered by this hypothetical analysis. This COLA will represent an actual Medicaid trend factor that will be negotiated with CMS. It is typical for this trend factor to be tied to some nationally recognized health care industry cost index.
- Any increases in expenditures due to growing programmatic needs or certification problems will be excluded from this analysis. Should the Department elect to pursue this option, the agreement with CMS should specify that such increased expenditures will be accommodated by adding them to the “base year” calculations.

Through this simple exercise, it is apparent that DDD can maintain a predictable aggregate level of revenue that increases slightly in the first year of the hypothetical example and then remains remarkably consistent over the next five fiscal years, even while the overall developmental center population is reduced by almost 30 percent.

At first blush, this approach does not appear to be tremendously advantageous, especially if IDHS/DDD is able to get all of its actual expenditures reimbursed each year through its “cost-settlement” process. It would be reasonable to assume that, unlike the assumptions used in Table 4.2, DDD received budget authority that decreased its DD Operations appropriation by \$65,000 for every one-person dropped from the developmental center census (roughly 65% of the Base Year per capita of \$106,640). Therefore, still assuming a 3 percent annual COLA on remaining base-year expenditures, the DD Operations budget could grow in the way projected in the “Cost-Settlement Methodology” column shown in Table 4.3 on the following page.

Table 4.2: Federal Revenue Generated By “Cost-related” Methodology

	A. Census	B. Fixed \$\$\$ Per Capita (base year \$)	C. Variable \$\$\$ Per Capita (base year \$)	D. Total \$\$\$ (AxB)+(AxC) x1.03	E. Federal Medicaid (D x .50)
Base Year	2,810	\$71,042	\$38,254	\$307,122,100	\$153,561,050
Year 1	2,660	\$77,300	\$39,401	\$310,425,575	\$155,212,788
Year 2	2,510	\$84,377	\$40,583	\$313,650,849	\$156,825,425
Year 3	2,310	\$94,433	\$41,801	\$314,700,217	\$157,350,109
Year 4	2,160	\$104,021	\$43,055	\$317,683,002	\$158,841,501
Year 5	2,010	\$115,137	\$44,346	\$320,561,524	\$160,280,762

Table 4.3: Comparison of Cost-Related vs. Cost Settlement Methodologies

	A. Census	Cost-Related Methodology	Cost-Settlement Methodology	Difference in Medicaid Revenue
Base Year	2,810	\$307,122,100	\$307,122,100	\$0
Year 1	2,660	\$310,425,575	\$306,293,263	-\$2,066,156
Year 2	2,510	\$313,650,849	\$305,138,286	-\$4,256,282
Year 3	2,310	\$314,700,217	\$300,086,983	-\$7,306,617
Year 4	2,160	\$317,683,002	\$298,115,882	-\$9,783,560
Year 5	2,010	\$320,561,524	\$295,756,436	-\$12,402,544

Table 4.3 on the preceding page shows that, with a simple change in the assumption regarding the dollar amount that is removed from DD Operations for each one-person drop in the overall developmental center census, the existing methodology can result in significantly less federal Medicaid revenue than a “cost-related” methodology. However, it can be assumed that there are additional ways to make this difference more advantageous to DDD. Here are some elements of a cost-related reimbursement methodology that may create an enhanced revenue picture for DDD:

- Once a base year is established and the fixed and variable cost ratios are determined, reimbursement to each related cost (the fixed and variable per capita in the above example) increase in accordance with the agreed upon factors (here only the 3.0% COLA and changes in utilization). The Department may be able to manage actual expenditures in ways that generate additional savings.
- Any structural changes in expenditures that are of significance, if the new methodology is properly articulated in the state Medicaid plan, can be accommodated by increasing the base to make sure that such increases are adequately covered by reimbursement without disrupting other elements of the methodology. This approach eliminates the major vulnerability to using a “cost-related” methodology – unanticipated and uncontrollable increases in expenditures that are not accommodated by the original methodology or calculation.
- All revenue generated through this reimbursement methodology becomes available for general fund appropriation back to the developmental centers or to fund services in the community, should the developmental centers’ annual operating budget exceed the amount required to run the facilities.
- It should also be noted that CMS currently allows states to increase their billing rate for developmental centers to reflect the “transition costs” of operating the developmental centers at less than optimal capacity while transitioning large numbers of facility residents to community-based living arrangements. This option is available to states now and will be significantly enhanced should Congress adopt President Bush’s proposed Money Follows the Individual Rebalancing initiative.⁴ Congressional approval of the President’s proposed initiative could further enhance the revenue impact of using a cost-related reimbursement methodology.

1. Revenue Potential

The actual revenue potential associated with shifting to a cost-related reimbursement methodology depends on too many policy decisions to be predictable at this time. The Department will have to identify its base year, its developmental center population targets, and the cost adjustment factors that it intends to incorporate in the new methodology. At the same

⁴ This initiative was announced by HHS Secretary Tommy Thompson on January 23, 2003 as part of President Bush’s proposed FY 2004 budget. As this report was being prepared, legislation was pending in the U.S. Senate to adopt the President’s Money Follows the Individual initiative as part of the Prescription Drug and Medicare Improvement Act of 2003 (S. 1).

time Illinois officials will have to weigh the level of expenditure savings they wish to achieve against the state's ability to leverage new, more predictable revenues to accomplish its policy goals. It is important to point out that the state will realize the savings projected above only if it adopts a developmental center out-placement policy geared toward reducing the overall SODC census by approximately 200 persons per year. A significantly lower net annual out-placement rate will negate the positive revenue effects of shifting to a cost-related reimbursement methodology. Conversely, a more aggressive census reduction policy could enhance the revenue impact of using a cost-related methodology.

One attractive feature of using a cost-related reimbursement methodology is the high degree of control it affords the state in managing expenditures within the cost factors used to set annual reimbursement levels. Since many states accept a provider's ability to generate a 3-5 percent "fund balance" for not-for-profit vendors and similar or even larger gross profit margins among for-profit vendors, it would be reasonable to expect similar efficiencies to be achieved through IDHS/DDD's management of this new methodology. Three percent efficiencies could generate upwards to \$9 million in savings, which would enhance the general fund and allow reinvestment in the community system.

This additional revenue would not be available until the base year has been certified and the population census begins to decrease in predictable ways. It would not be possible to impact on FY 2004 revenues. It also is unlikely that all of the necessary policy decisions will be in place (especially policy decisions regarding any significant decreases in the SODC census) in time to impact on FY 2005 revenues. In other words, the advantages of moving to a cost-based reimbursement methodology will not begin to kick in until FY 2006 under any reasonable scenario. IDHS/DDD officials, therefore, should have sufficient lead-time to institute the necessary policy changes and align the fiscal management structure within DDD and within each of the developmental centers to manage in a cost-containment mode.

Again, we need to emphasize that the advantages of a cost-related reimbursement methodology will be realized only to the extent the Department chooses to pursue a policy of achieving sustained and significant decreases in the net developmental center population. The state need not close any existing developmental centers. Nor does it have to reduce the overall SODC census to minimal levels. But the opportunity to enhance revenue is tied to the state ability to achieve a sufficient numbers of outplacements on a sustained basis.

2. Action Steps

In order to institute a new SODC rate-setting methodology, Illinois officials will have to take the following steps:

- IDHS, in cooperation with IDPA, should begin a fiscal and operational analysis of its developmental center system that allows it to predict the point in time when center expenditures as currently configured will be maximized. This analysis will allow agency officials to determine the most advantageous "base year."

- IDHS/DDD officials also should begin to determine the point in time where either agency policy or customer demand will result in sustained and significant decreases in the overall SODC census. Again, a cost-related methodology works best during periods of significant downsizing and/or the closure of specific SODC campuses.
- IDHS/DDD officials should begin discussing with their IDPA counterparts cost adjustment factors that are both credible and advantageous that might be incorporated into any new cost-related reimbursement methodology.
- A detailed revenue analysis should be completed that is based on projections of SODC census levels, a proposed base year, and an agreed upon list of cost adjustment factors. This analysis should predict annual and total revenue and expenditures for a five-year period, using the existing cost-based methodology, and comparing it to a prediction based on the proposed cost-related methodology. This analysis also should include an assessment of the impact of the “Medicare Upper Payment Limit” on any tactical plan the Department develops related to this alternative rate methodology.

This initiative will require extensive analytic capability to ensure that the selection of a base year, utilization targets and cost adjustment factors give the department a reasonable opportunity to generate the savings that are projected. At the same time, this initiative necessitates a public policy that embraces significant and sustained decreases in the SODC census over a multi-year period. Finally, the Department must create a new cost-related methodology and supporting analysis that CMS finds reasonable and credible.

C. Additional Revenue Issues

1. New Lincoln Campus Capacity

The hypothetical analysis presented above makes no assumptions regarding state-operated services in the community. However, if the Department decides to establish 40 new beds on or near the property of the Lincoln Developmental Center and those beds are certified as ICFs/DD and operated by state staff, the inclusion of related expenditures as part of DD Operations will increase the revenue impact of any change to a cost-related methodology. DDD will need to make policy decisions quickly to ensure that these new homes are accepted as part of the developmental center system, should that be DDD’s intent. Likewise, if these new homes are operated by state staff, it could set a precedent for developing additional community-based capacity that is operated by state staff. While this is often a controversial policy decision that states make, it does not impact on the revenue opportunity created by the shift to a new cost-related methodology. States that have done this have concluded that it would provide some stability for the workforce and minimize the reduction in revenue that is associated with the transition of developmental center residents to community supports and services provided by private providers.

2. Forensic Services

The majority of people who experience developmental disabilities are law abiding and productive. However, as is the case with the general population, a small percentage engages in unlawful activities and/or in behavior that poses a risk to their community. The latter group of individuals creates special policy and operational challenges as states strive to balance their rights and needs with the responsibility to provide adequate protection for the community.

Over the past few years states have created appropriate residential and daytime services for adults and adolescents with development disabilities in combination with anti-social behaviors outside of the criminal justice system. Initiatives exist in many states that provide community-based education, behavioral services, and treatment designed to respond to the needs of such individuals while minimizing the risks in the community. States also have created institutional programs that provide the needed services while offering the structure and security that is either demanded by law or assumed to be necessary for the protection of the public. These public policy decisions typically recognize that people with developmental disabilities are not criminally responsible for their actions. However, some states do not require formal court orders to place people with significant behavioral needs in these “forensic” programs.

Historically, the Centers for Medicare and Medicaid Services (CMS) has agreed that many such “forensic” or “behavioral” treatment units meet the certification requirements of an Intermediate Care Facility for Persons with Mental Retardation (ICF/MR). As a result, these special unit/facilities have been classified as Medicaid long-term care facilities, thus allowing states to claim federal Medicaid reimbursement on behalf of unit/facility residents at the same rate as their Federal Medical Assistance Percentage (FMAP). Over the past two years, however, CMS, as part of an intensive series of federal validation, or “look behind,” surveys, has begun to operationally re-examine how it views regulatory compliance issues within these forensic or behavioral treatment facilities. Among CMS’ primary concerns are: the need for “individualized” programming; informed consent regarding the use of restrictive interventions; safeguarding individual rights and their expression; and the application of prescribed functional analyses and positive interventions. These issues are central to the treatment that CMS expects from ICFs/MR. There also has been an increasing focus on whether persons with developmental disabilities who are placed in developmental centers by the courts are in need of active treatment. In a number of individual cases CMS is concluding that many of these individuals do not need active treatment because they are able to perform most Activities of Daily Living without assistance.

CMS’ recent series of intensive look behind reviews has resulted in the withdrawal of ICF/MR certification from units/facilities serving dually diagnosed individuals in some states that had been certified for years. Furthermore, states that have successfully gained recertification of such “forensic” units/facilities have been experiencing continuing difficulty retaining certifications in the face of CMS follow-up reviews.

These developments suggest that it will remain difficult for IDHS/DDD to bill Medicaid for services currently provided to individuals living in specialized behavioral treatment/forensic units. Furthermore, as the department considers expanding the capacity to serve additional court-

committed individuals in SODCs (such as the proposed expansion of the Choate Developmental Center capacity), it should consider taking the following actions:

- Assess its policies governing admission to forensic programs to minimize the number of people who require placement and, if necessary, develop a plan to educate key actors within the judicial system about other placement/treatment alternatives that may be available for some people placed through the courts;
- Assess the department’s program and administrative policies governing the operation of forensic and behavior-oriented facilities or programs to ensure that they comply with CMS requirements governing the provision of active treatment, individualized program planning and implementation, and protection of individual rights;
- Develop a program initiative aimed at minimizing the “correctional environment” of any affected units/facilities serving dually diagnosed SODC residents to ensure that the resultant physical plants fully reflect federal ICF/MR Conditions of Participation;
- Assess the staffing needs of forensic units/facilities within the SODC system to ensure that they operate in compliance with all applicable federal requirements governing active treatment, individualized program planning and implementation, and protection of individual rights, including the substitution of level of care or non-level of care staff for some of the security staff and security-related technology;
- Provide appropriate training and supervision for staff to succeed at any newly defined tasks and responsibilities; and
- Enhance the management capacity at headquarters and within each forensic unit/facility to maintain certification once it is achieved.

D. Conclusion

IDHS/DDD has an existing reimbursement methodology for its developmental center that generates claims for federal Medicaid reimbursement based upon projected annual expenditures and an annual reconciliation process. It establishes rates for each facility and reconciles them individually. All indications are that this process, as designed, is efficiently implemented.

CMS allows states to use an alternative reimbursement methodology that is cost-related. This approach allows states, especially those with significant institutional downsizing objectives similar to that of IDHS/DDD, to create a more stable and predictable level of federal financial participation while it transforms its system and assists large numbers of people with developmental disabilities to move into the community. It is likely that moving to that alternative reimbursement methodology could increase revenue significantly. The actual revenue impact cannot be predicted until key policy decisions have been made.

As IDHS/DDD officials approach any policy decisions related to its operation of the developmental centers, it should consider the revenue implications related to expanding the

number of SODC resident with forensic service needs, and developing new residences on the campus of the Lincoln Developmental Center.

Chapter V

FINANCING COMMUNITY-BASED SERVICES

Enacted in 1965, the Medicaid program initially was conceived of as a federal-state partnership primarily aimed at furnishing medical and other health and health-related services to low-income individuals and families. The original Medicaid program authorized states to pay for care in qualified skilled nursing facilities and for services to elderly residents of public mental hospitals. Later, other institutional coverage options were added to the program (e.g., the coverage of intermediate care facility services as well as specialized intermediate care facility services for persons with mental retardation (ICF/MR) in 1971; and inpatient psychiatric services for children in 1972).

States also were permitted under the original legislation to cover certain health-related services to eligible individuals living in non-institutional settings, such as home health services and physical and occupational therapy). But, it was not until 1981, with the enactment of the home and community-based waiver authority, that states gained broad authority to claim federal Medicaid reimbursement for community-based long-term services and supports on behalf of qualified individuals with chronic illnesses and disabilities, including persons with developmental disabilities. Although prior to the 1980s the federal Social Services Block Grant program channeled limited financial assistance to states, for the most part state and local governments were the predominant funders of home and community-based long-term supports for persons with physical, mental, developmental and sensory disabilities.

The enactment of the HCBS waiver authority in 1981 represented a major breakthrough in federal policy because, for the first time, it gave states a way of equalizing the financial incentives to serve low-income individuals with chronic disabilities in home and community-based versus institutional settings. Furthermore, this legislation was passed at a time when many states were searching for ways to emphasis HCB service options.

The fundamental aim of the HCBS waiver authority is to remove the “institutional bias” of Medicaid financing. Section 1915(c) of the Social Security Act, as implemented by regulations contained in 42 CFR Parts 431, 435.440 and 441, permits states to offer Medicaid-funded community care to individuals who otherwise would be eligible for care in a Title XIX-certified nursing facility, hospital or other long-term care institution, including an ICF/MR-certified facility. In effect, a state requests permission to waive statutory requirements that restrict Medicaid funding to congregate, institutional settings. The waiver permitted states to use federal dollars that otherwise would have supported institutional services for eligible individuals, provided the home and community-based supports to be furnished cost no more on average that the cost of furnish institutional services to the same recipient target group. Using an application format provided by the federal Center for Medicaid and Medicare Services (CMS), the state applies for permission to operate a HCBS waiver program, initially for a period of three years. The state subsequently may request renewals for an unlimited number of five-year periods.

In 1982, two states initiated HCBS waiver programs targeted to persons with developmental disabilities. By 2003, all fifty states and the District of Columbia were operating waiver programs for persons with mental retardation and other developmental disabilities (a total of 80 different waiver programs). The HCBS waiver authority has provided the funding which has fueled the rapid expansion of community services for persons with developmental disabilities over the past two decades. Data for FY 2001 indicate that states served 327,713 individuals with developmental disabilities through Section 1915(c) waiver programs that year. State and federal outlays under the waiver authority on behalf of persons with developmental disabilities exceeded \$10.9 *billion* in FY 2001.¹ Clearly, the HCBS waiver authority has become the predominant avenue for financing home and community-based services for persons with developmental disabilities. Indeed, federal Medicaid payments now account for approximately half of all public spending on community services for persons with developmental disabilities nationwide.

The availability of the waiver authority has had an enormous impact on the configuration of public services to persons with developmental disabilities. In 1977, 154,638 individuals were living in state-operated MR institutions, while 40,424 were receiving state-funded community residential services. By 2002, the state institutional population had plummeted to 43,249. Meanwhile, the number of individuals receiving community residential services had skyrocketed to 323,028.² HCBS waiver funding has been instrumental in funding the vast majority of these community residential alternatives. In fact, between 1992 and 2001, the number of HCBS waiver recipients grew by 287,875.³

While the national deinstitutionalization movement contributed to the early growth in waiver utilization, much of the recent expansion in the number of waiver participants has resulted from the extension of services to persons already residing in the community. Particularly during the 1990s, states used the waiver authority extensively to refinance services once paid for exclusively with state and/or local dollars. Through this refinancing, states were able to claim federal Medicaid matching funds for services that otherwise would have been financed purely with state and local dollars. This leveraging of federal funds has allowed states to greatly expand the numbers of individuals receiving community MR/DD services without a comparable rate of growth in state general revenue outlays.

The purpose of this chapter is to review the options available to Illinois stakeholders as they consider possible ways of expanding federal financial participation in the cost of providing community services to persons with developmental disabilities. Within this analysis, particular emphasis will be given to identifying alternative approaches to expanding participation in, as well as the coverages available under, the Medicaid home and community-based waiver authority. Expanded utilization of the HCBS waiver authority is emphasized for two reasons. First, as noted above, the Section 1915(c) waiver authority has proven to be the predominant

¹ Lakin, K. Charlie, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*, RTCCCL/UMN, June 2002, p. 70, p.72.

² Lakin, K. Charlie, Prouty, Robert, Polister, B., and Coucouvanis, K., "Selected Changes in Residential Service Systems Over a Quarter of a Century, 1977-2002, in *Mental Retardation*, Vol. 41, No. 4, pp. 303-306.

³ Lakin, K. Charlie, *Residential Services for Persons with Developmental Disabilities...*, pp. 66-67.

vehicle that states use to capture Medicaid reimbursement for community DD services, because it affords states maximum flexibility in tailoring approaches that meet both their program and fiscal objectives. And, second, as pointed out in Chapter II (see especially Section D of that chapter), Illinois, historically, has lagged considerably behind most states in using the HCBS waiver authority to expand federal financial participation in the cost of delivering community DD services. Over the past two years, however, steps have been taken to expand and improve the recovery rate under the state's existing HCBS waiver program for adults with developmental disabilities. The subsequent analysis, therefore, will acknowledge and comment on waiver-related revenue enhancement strategies that have been initiated recently in Illinois as well as outline additional action steps that might be considered.

A. Claiming Additional FFP Under the State's Existing DD Waiver Program

States have broad latitude in determining the services they choose to cover as part of their HCBS waiver requests. According to Section 4442.3 of the *State Medicaid Manual*, "Home and community-based services" means services that are furnished under a waiver granted under the provisions of Part 441, Subpart G of 42 CFR. The services may consist of any of the following services, as defined by the agency, that meet the standards specified in §4442.4:

- Case management services;
- Homemaker services;
- Personal care services;
- Adult day health services;
- Habilitation services;
- Respite care services;
- Day treatment or other partial hospitalization services, psychosocial rehabilitation services and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness; and

Other services requested by the Medicaid agency and approved by HCFA as cost effective and necessary to avoid institutionalization (*emphasis added*)

While CMS offers states suggested services definitions as part of its waiver template (application form), states can propose alternative definitions to the listed services as well as include definitions of services not expressly listed on the template. Given the fiscal impact of federal financial participation, most states cover all allowable services to persons with developmental disabilities under their HCBS waiver requests. At present, Illinois has a number of DDD-funded community services that are paid for exclusively with state funds, such as developmental training, in-home supports, and non-medical transportation that certainly can be covered under a state's HCBS waiver program. Additionally through improvements in claiming methods and fiscal management practices, DDD has opportunities to increase revenues for certain services

already covered its exiting DD home and community-based waiver program. These options and opportunities will be discussed in this section of the chapter.

1. Include Host Family Homes as an Approved HCBS Waiver Service. DDD (then the Office of Developmental Disabilities) removed host family homes (including foster homes and shared living arrangements) as a coverage option under its DD waiver program in 1999. Prior to that time, the expenditures of private host home providers was reimbursable as a sub-category of Community Integrated Living Arrangements (CILA) services under the waiver program. It was removed as part of an agreement with the Chicago Regional Office of CMS in recognition of health and safety problems that were documented by a CMS (then HCFA) review team in the summer of 1998.

The Division has submitted, in collaboration with the IDPA, a technical amendment that will qualify family host homes once again for Medicaid reimbursement as a sub-category of CILA services under the state's existing HCBS waiver program. This action represents an acknowledgement of the importance of federal reimbursement. Prior to deciding to develop and submit the technical amendment, the Division conducted an extensive series of site reviews that documented to its satisfaction that internal efforts over past few years had improved the quality of care as well as the accuracy of documentation to the point where effective care was being provided and managed in ways that would meet current CMS expectations.

This waiver amendment has been approved by CMS with an effective date of July 1, 2002.

DDD has outlined the appropriate action steps to implement this revenue generating opportunity. Division officials already have completed the following action steps:

- ✓ Implemented the required quarterly monitoring visits by private service coordination agencies;
- ✓ Conducted a series of random visits to a significant sample of homes to confirm that improvements have been completed (visits completed during Fall 2002);
- ✓ Drafted and gained approval of necessary rule amendments by the Joint Committee on Administrative Rules (accomplished on February 4, 2003; confirmation by the Secretary of State's Office was pending at the time of this analysis);
- ✓ Submitted, in collaboration with IDPA, the technical waiver amendment to CMS.

Because this technical amendment reclassifies an existing service as eligible for Medicaid reimbursement, there should be no program development action steps required. However, the Division may need to provide additional support to ensure that all eligible consumers are enrolled in the Medicaid program and qualified to receive HCBS waiver services – and that the required documentation is submitted in a prompt, accurate and comprehensive fashion by all caregivers to ensure maximum reimbursement.

DDD estimates that the re-inclusion of family host home services under the HCBS waiver program will increase annual federal revenue by approximately \$1.0 million in FY 2003, with annualized federal reimbursements approaching \$3.0 million annually in FY 2004 and thereafter. Although the approved amendment has an effective date of July 1, 2002, it is not expected that all appropriate documentation can be generated for FY 2002 or FY 2003, consequently less the maximum amount of revenue is projected for these fiscal years.

2. Include “Home-based Personal Supports” as an Approved HCBS Waiver Service. DDD has determined that personal supports, as provided to people who have developmental disabilities in Illinois, are very similar to services that have been included as HCBS waiver services in other states. Currently these services are provided as direct care staff assistance to people receiving service through the Division’s “Home-based Services” program. DDD officials explain that their analysis indicates that more than 50 percent of the monies currently expended in the “Home-based Services” program can be classified as direct care staff assistance. Therefore, as part of the technical waiver amendment to re-establish coverage of host family homes referenced above, DDD has gained CMS’ approval to add personal supports furnished as part of the Home-based Services program to the list of approved HCBS waiver services.

In anticipation of the approval of the technical amendment, the Division initiated action steps to prepare providers and caregivers to supply the necessary documentation to back up Medicaid reimbursement claims for home-based personal supports. Other action steps that are either under development or should be considered include:

- ✓ A comprehensive analysis should be completed of the eligibility of the 1,441 people receiving Home-based Services. This analysis would enable DDD to better predict the final amount of federal revenue potentially associated with this initiative. Also, this analysis would allow DDD to ensure that the four criteria required of CMS for retroactive claims have been met. Those criteria are:
 - The person met all Medicaid eligibility criteria on the retroactive effective date;
 - The person met the HCBS waiver level of care criteria on the retroactive effective date;
 - The service was being delivered on the retroactive effective date in accordance with a plan of care; and
 - A degree of choice can be established for the consumer.

DDD through the proposed analysis should be able to identify the exact number of individuals receiving these services who would have to be retroactively enrolled in the HCBS waiver, if any. CMS has been known to agree to such retroactive enrollments in HCBS waiver programs, but such approvals are not a given.

- ✓ Clear and concise protocols should be developed for use by consumer and family representatives and the caregiver community, in collaboration with IDPA, to ensure

proper documentation of services and service claims. DDD also should promulgate proper instructions and guidance to those responsible for developing and implementing individual plans of care for individuals receiving Home-based Supports, to ensure that services are properly described in the plans.

- ✓ A review of the entire list of available Home-based Services furnished during FY 2003 suggests that the direct care staff assistance that now is represented as HBS Personal Supports was spread over a number of discrete Home-based Services program codes in previous years. The applicable service descriptors would include such items as: individual therapy, work adjustment training, crisis intervention, habilitation training, family therapy, developmental training, respite care, and perhaps a few others. None of these services were referred to as “personal supports” prior to FY 2003. The absence of common service descriptors could create a significant documentation problem for DDD. It may require extra training and monitoring to ensure that all documentation, from the plan of care through billing, have the properly articulated information that will support federal reimbursement for all claimed expenditures.
- ✓ Caregivers who intend to hire and supervise their own personal supports staff must be fully trained in the qualifications that Home-based Personal Support workers will be required to meet as well as in how to manage payroll-related documentation that will be needed by the Division. While the Division has significant experience in managing such training, introducing a new set of caregivers to the rigors of CMS documentation expectations could require additional effort.

The Division’s FY 2003 fiscal and program data indicates that it restructured its program codes related to the Home-based Services program. Within this array, fully 87.5 percent of the unduplicated count of persons receiving Home-based Services received what is now labeled “HBS Personal Supports.” Expenditures on the services received by these 1,261 individuals totaled \$9.9 million in FY 2003 – 80.5 percent of all projected program expenditures. If it is assumed, conservatively, that one-half of these individuals will be found to be eligible for both Medicaid and the HCBS waiver program, then upwards of \$4.5 million of Home-based Services costs will become eligible for Medicaid reimbursement as of the effective date of the requested technical amendment. Given the implementation issues that will have to be addressed, it is likely that \$1.0 million in new federal Medicaid reimbursement may be recouped during FY 2003. This amount could annualize into roughly \$2.25 million in FY 2004. Division officials hope that CMS will approve retroactive claims for such services, which would allow DDD to increase FY 2004 revenue to approximately \$6.0 million.

3. Include “At Home” Day Programs as a Billable Component of HCBS Waiver Services. The state’s current rate-setting methodology for non-residential services under its DD home and community-based waiver program does not permit the state to claim Medicaid reimbursement for medical, behavioral and other support services furnished in a waiver-eligible individual’s home. As a result, DDD pays for such services out of general revenue. This is a service that CMS has allowed many states to include in their HCBS waiver programs, either as a component of a billable day program or as a component of residential habilitation services, should the person not be able to participate in activities that meet CMS’ expectations of day habilitation or other day

programming. Claims data provided by DDD indicates that almost 100 percent of the individuals currently receiving this service are enrolled in the state's HCBS waiver program.

"At-Home Day Programs" are now included in the DD waiver program as a component of residential habilitation services. IDHS has also created new edit protocols in the state's management information system that will allow these services to be claimed as an HCBS residential habilitation service under the state's adult DD waiver program. Since all providers affected by this change are currently furnishing fee-for-service-related programming, DDD officials also conclude that only limited transition issues should be involved in implementing this change. Additional issues that DDD should consider include:

- ✓ An analysis of the eligibility and the documentation history of affected waiver individuals and community service providers should be initiated prior to implementation. DDD has had difficulty in the past in implementing new elements of "residential habilitation services," and effectively dealing with these issues prior to implementation could maximize the revenue impact of this initiative.
- ✓ If DDD has not already done so, the exact language of the approved HCBS waiver request should be reviewed. CMS is closely reviewing service definition expansions that have significant revenue impact. Submission of an adjusted claim for 24 months of retroactive services could pique CMS' interest and lead to a closer examination of this initiative. DDD should have supporting documentation available for IDPA, should questions arise.
- ✓ A review of FY 2002 and FY 2003 claims data indicates that the number of persons receiving "At-Home Day Programs" is declining slightly, although the percentage of individuals who are enrolled in the HCBS waiver program is increasing. DDD may want to investigate the long-term predictability of utilization of this service as it creates its revenue budget projections for future years.

DDD officials estimate that approximately \$1 million in additional revenue could be generated by adjusting the state's existing day service rate-setting methodology or by expanding the definition of approved HCBS services. Moreover, an additional \$2 million could be recovered on a one-time basis by adjusting the state's waiver claims for FY 2002 and FY 2003, if these changes can be accomplished within existing, approved rate-setting methodologies.

4. Convert All Developmental Training Services to a Fee-for-Service Methodology. Claims data made available by DDD indicates that a total of \$183.2 million was spent on Developmental Training services on behalf of 18,392 individuals during FY 2003. This amount represented an increase of 1.7 percent compared to the \$180.1 million spent during FY 2002 on behalf of 18,183 individuals. Since DDD approaches Developmental Training (DT) as basically four different service components, it is more helpful to demonstrate the changes in these four sub-categories:

- DT paid as a fee-for-service on behalf of SODC residents
- DT paid as a fee-for-service on behalf of individuals eligible for Medicaid, primarily persons enrolled in the states developmental disabilities HCBS waiver program;

- DT paid as part of a contract payment to community service providers serving individuals who are not living in a SODC but who may or may not be enrolled or eligible for the HCBS waiver program, and
- DT paid as a fee-for-service on behalf of people living in ICFs/DD.

Table 5.1: Developmental Training

Developmental Training						
	FY 02 People	FY 02 \$\$\$	\$\$ Per Capita	FY 03 People	FY 03 \$\$\$	\$\$ Per Capita
DT – SODC	1,411	\$14,064,000	\$9,967	1,382	\$13,311,113	\$9,632
DT – FFS – HCBS	6,972	\$61,832,000	\$8,869	7,257	\$66,169,798	\$9,118
DT – Grant	3,600	\$33,268,000	\$9,241	3,570	\$32,977,892	\$9,238
DT – ICF/DD	6,200	\$71,000,000	\$11,452	6,183	\$70,800,000	\$11,451
Total	18,183	\$180,164,000	\$9,908	18,392	\$183,258,803	\$9,890

The data presented in the above Table 5.1 indicates that the growth in overall DT funding occurred primarily in the component that is for persons enrolled in the HCBS waiver program. The number of individuals in all other categories actually declined. [N.B. The data on grant recipients are estimates provided by DDD. Actual data was not available.]

The changes in funding become of even greater concern when the federal Medicaid reimbursement for the expenditures in each category is examined. Claims data made available by DDD indicates that almost 100 percent of the Developmental Training services provided to individuals residing in SODCs and ICFs/DD were claimed for federal Medicaid reimbursement during both FY 2002 and FY 2003. And, approximately 84 percent of the expenditures for Developmental Training services provided to individuals enrolled in the state’s HCBS waiver program or otherwise receiving DT services from a provider that accepts fee-for-service payments were claimed for federal Medicaid reimbursement. But, in contrast, none of the \$33 million in DT services delivered through grant payments could be claimed for federal Medicaid reimbursement – primarily because it was impossible to collect documentation for services and payments using methods acceptable for Medicaid claims.

DDD officials estimate that approximately two-thirds of the 3,600+/- individuals receiving grant-funded DT services are, or could be, eligible for the HCBS waiver program. DDD/IDHS, therefore, proposed as part of the Governor’s FY 2003 budget that such developmental training services be converted to a fee-for-service payment structure, and that as many recipients as possible be enrolled in the HCBS waiver so that related expenditures could be added to the state’s claims for Medicaid reimbursement under the DD waiver program. But, the Illinois Legislature rejected this proposal, mainly due to opposition from community provider agencies that were fearful, if the funding of such services were to be converted from a grant to a fee-for-service basis, they would lose administrative flexibility and potentially face new problems in managing agency cash flows.

The study team finds it extremely unusual that such a clear-cut and effective revenue opportunity is being resisted. While the objections of some community provider agencies may have some substance, it is very unusual for a state to have almost \$33 million in annual expenditures for program services that cannot be tracked to individual consumers and service delivery episodes (i.e., the basic requirements for qualifying these services for federal reimbursement). This is as much an issue of effective management of public funds as it is the effective management of federal revenue opportunities (see a full discussion of related issues, see Chapter III). That this is happening during a period of severe fiscal constraints makes it all the more compelling that this issue be resolved.

DDD is currently reviewing its options with regard to developing the most compelling arguments to address the objections of community provider agencies. Tactical plans have been discussed that may create a scenario that deals with the providers' concerns. In anticipation of the possibility that converting DT grant funding to a fee-for-services basis development will be raised again during FY 2004, DDD should consider the following action steps:

- Fully analyze the 3,600+/- individuals presently receiving granted-funded Developmental Training services to determine, with a high level of confidence, the number who already enrolled in, or potentially are eligible to enroll in, the state's HCBS waiver program. To the extent that this analysis identifies a significant number of potentially new enrollments would be needed, a technical amendment to the state's approved HCBS waiver request should be developed.
- DDD should initiate action to require a full accounting of the \$33 million spent on grant-funded DT services. This accounting should include an unduplicated count of individuals receiving such services, the units of service delivered, and the outcomes achieved. This information should be developed in a format that not only assures public accountability for such expenditures but also provides the minimum information required to convert such funding to a fee-for-service basis, with the intent of claiming federal Medicaid reimbursement for qualifying expenditures once legislative/executive branch approval to proceed has been obtained.
- DDD/IDHS fiscal staff should fully analyze the per unit costs of grant-funded Developmental Training services to determine a reasonable fee-setting methodology that accommodates all reasonable variations in service costs among the existing DT service providers. To the extent that this methodology is consistent with the existing methodology used to pay FFS providers of DT services under the HCBS waiver program, this step should greatly facilitate any future conversion of grant-funded DT services to a fee-for-service mechanism. To the extent that it not possible to use the existing FFS methodology, DDD/IDHS fiscal staff should develop a tactical plan for maximizing provider acceptance of a more flexible fee-setting methodology – within the guidelines accepted for provider-specific fees by CMS.

If the Division's projection that one-third of the people receiving grant-funded Developmental Training services could be enrolled in the HCBS waiver program, it seems reasonable to assume

that up to one-third of the \$33 million in expenditures could be claimed for federal Medicaid reimbursement – which would generate approximately \$5.5 million in new federal revenue on an annualized basis.

5. Review All Other Grant-Funded Services to Pinpoint Potential HCBS Waiver Services.

Previous paragraphs have identified specific non-HCBS services that the state furnishes to persons with developmental disabilities, but which do not qualify for Medicaid reimbursement. In addition, DDD has an in-home respite service that is not considered to be eligible for claiming as an HCBS waiver service. As a result, DDD pays for such services out of general revenue. These and other existing DDD-funded services are allowable services under the DD waiver programs of other states, either as discrete services or, in some cases, as a component of a billable day program or as a component of residential habilitation services.

DDD should engage in a complete analysis of the services that are not currently considered eligible as HCBS waiver services (excluding those listed separately in previous sections). This analysis should be designed to identify those services that could be included within the current definition of approved HCBS waiver services and also could be added as new or redefined HCBS waiver services, given the experience of other states. The analysis also should identify the cost-effectiveness of policy and operational decisions related to covering such services under the state existing HCBS waiver services for persons with developmental disabilities.

Given the absence of solid data on the characteristics and Medicaid/waiver eligibility of persons currently participating in grant-funded DDD services, it is impossible to project the potential new federal Medicaid revenue that might be generated by an aggressive effort to gain approval to include all appropriate existing services within existing or new service definition under the state's DD home and community-based waiver program. Claims data made available by the Division and anecdotal information gleaned from DDD managers suggest that upwards of \$15 million in FY 2003 community services are being funded out of state general revenue which might be incorporated in existing or new service definitions under the existing HCBS waiver program. If one-third of those services were being delivered to individuals who are or could be enrolled in the HCBS waiver program, the state could generate approximately \$2.5 million in additional federal Medicaid revenue.

6. Transition of 18 to 22 Year Old Youth from IDCFS to IDHS-Funded Programs.

The Illinois Department of Children and Family Services (IDCFS) currently serves approximately 245 youth with developmental disabilities who are aged 18-22. Approximately 165 of these young people are living in out-of-home residential facilities funded and operated by IDCFS and 80 are residing in CILA settings that the department supports. At present, the cost of supporting these youth is being borne with state general fund only. It is very likely that all – or almost all – of these youth would qualify for enrollment in the state's HCBS waiver program for adults with developmental disabilities.

The 80 youth residing in CILA settings are receiving supports and services that would qualify for federal Medicaid reimbursement under the existing HCBS waiver program if they were enrolled. Furthermore, it is possible that the 165 youth living in residential facilities are receiving services that could qualify for reimbursement, but additional research would be required to determine

whether it makes more sense, programmatically and fiscally, to: (a) leave such young people in their current residential setting and seek to maximize reimbursement for existing services; or (b) transfer such individuals to new residential settings where they would qualify for residential habilitation and other services under the state's existing DD waiver program.

DDD/IDHS and IDCFS officials have agreed to the transfer responsibility for the care of 245 youth between the ages of 18 and 22 to DDD. This action is to be accomplished in two stages. The first stage will involve transferring programmatic and fiscal responsibility for the 80 youth living in DCFS-funded CILAs during FY 2003. The second stage will entail transferring responsibility for the remaining 165 individuals in this age group to DDD during FY 2004.

IDCFS transferred \$10.5 million to the DDD budget during FY 2004. This action has allowed DDD to deliver services that can be claimed as part of the state's DD waiver program, thereby generating approximately \$5.25 million in new federal Medicaid revenue on behalf of the 80 youth currently residing in CILAs. The amount to be transferred during the second phase will depend on the services that will be received by the 165 individuals who will move out of existing residential facilities into CILAs or other waiver-reimbursable residential settings. Should these young people all choose to live in CILAs or other waiver-reimbursable residential settings, it is likely that, when waiver costs are added to the cost of service coordination and day programs that the average annual cost of their waiver services will be at least \$50,000 a year per person. Should that be the case, the new federal Medicaid revenue that would be generated on behalf of these 165 youth could approach or exceed \$4.125 million annually. DDD and IDCFS have an extensive work plan developed to effectuate the transition of the 245 youth to the auspice of Division.

7. Improving the Efficiency of Medicaid Claiming on Behalf of All HCBS-Eligible Persons. A review of expenditure and claims data supplied by DDD officials plus anecdotal information obtained from Division managers surfaced a number of instances in which it appears that individuals enrolled in the HCBS waiver program are receiving services that are paid for by DDD out of general state revenues without being claimed for federal Medicaid reimbursement. While this practice apparently varies from service to service, the data suggests that in some cases significant federal Medicaid revenue is being lost due to a lack of internal controls within the system of payments, documentation, and claims. The effect can be spotted best when examining data related to specific service codes.

For example, data on FY 2003 CILA claims indicates that 6,250 individuals were enrolled in the HCBS waiver program and received CILA services (PPO CILA), at a total cost to DDD of \$215.6 million. Yet DDD included only \$179.1 million of those expenditures (involving 6,009 people) in its Medicaid reimbursement claim. DDD staff are aware of this issue and are diligently pulling together claims data in order to increase the proportion of FY 2003 expenditures that are reimbursed by the federal/state Medicaid program. However, the creation of systems that will prevent this problem from recurring in FY 2004 and beyond are still under development.

CILA payments are made by DDD to community provider agencies as grant awards, in advance of the delivery of services. These awards are based on projected units of service to be delivered

to enrolled service recipients. The providers are responsible for submitting utilization documentation – after the fact – that enables DDD to generate claims for federal Medicaid reimbursement for services delivered to individuals enrolled in the HCBS waiver program. Anecdotal information gleaned from discussions with DDD personnel and supported by conversations with provider agency administrators suggest that DDD has had no significant internal controls or authority that allows it to hold provider agencies accountable for failing to submit required documentation to justify Medicaid claims. At times in the past, DDD has devoted staff to monitoring and following up with community provider agencies that failed to submit timely documentation. But budget priorities and personnel shortages have necessitated the redirection of these resources. Recently, DDD has been able to create a database that should help it to monitor the submission of utilization documentation, but IDHS has no viable authority to hold community provider agencies accountable for failing to submit such documentation.

Furthermore, claims data supplied by DDD indicates that during FY 2003 6,956 individuals enrolled in the DD waiver program received Developmental Training services. The cost of these services was approximately \$66.0 million. However, that same data shows that DDD submitted Medicaid claims for only \$59.9 million of that amount (involving the cost of services to 6,880 persons). Again, this result strongly suggests that about \$6 million in claimable expenditures were not included in DDD claims for federal Medicaid reimbursement. Apparently, the shortfall was attributable to inaccurate reporting of DT utilization data by community provider agencies or issues involving individual Medicaid eligibility.

While these two service codes represent the greatest dollar value in HCBS waiver claims, when expenditure and claims data for all FY 2003 HCBS waiver service codes are aggregated, the data suggest that a total of \$97 million in DDD expenditures for HCBS services on behalf of HCBS enrollees were not claimed for federal Medicaid reimbursement last fiscal year. While some of the shortfall may have been due to individual moving in and out of Medicaid eligibility (see Section C-3 of this chapter for a discussion of Medicaid eligibility issues), un-claimable days spent in a hospital, or similar developments, the bulk of this amount can be explained only by the missing and inaccurate utilization reporting by community provider agencies. As a result, the state may be losing as much as \$30 to \$35 million annually in federal Medicaid revenue.

The Division of Developmental Disabilities should create adequate internal controls to be able to aggressively monitor provider performance with regard to the effective documentation of services delivered. These internal controls should apply to all services funded by DDD – not just HCBS waiver reimbursable services. Included in these controls should be the capacity to reconcile 4th quarter payments against documentation of services delivered. Putting such a system of internal controls into place will require a significant investment in IT capacity and staff resources; but it is a dollar investment that pales in comparison to the needless waste of available federal Medicaid revenue.

B. Expanding the Use of the Medicaid HCBS Waiver Authority

The statutory provisions authorizing the Medicaid home and community-based waiver authority (Section 1915(c) of the Social Security Act) afford states considerable latitude in crafting programs to support individuals who otherwise would require institutional services. A state may

select the target group it wishes to serve under a particular waiver program as long as members of the target group are, in the words of 42 CFR 441.301(b)(1)(iii), "... [Medicaid] recipients who the agency [i.e., the Single State Medicaid Agency] determines would, in the absence of these [HCBS] services, requires the Medicaid covered level of care provided in —

- (A) A hospital (as defined in 440.10 of this chapter);
- (B) A NF [nursing facility] (as defined in Section 1919a) of the Act; or
- (C) An ICF/MR (as defined in 440.1 50 of this chapter)..."

States may choose to further limit the target group to individuals with a particular diagnosis or condition or may limit the group served by age or other characteristics such as restricting participation to individuals who are being relocated from a particular category of Medicaid of Medicaid-certified institutional settings (e.g., ICFs/MR). Beyond limiting eligibility by age or diagnosis, a state may cap the total number of individuals to be served through a particular waiver program in any given year. In contrast to a State plan services, which confers an entitlement on all eligible individuals who are Medicaid-eligible and found to be in need of the particular service, states may restrict participation in a HCBS waiver program to a specific number of individuals tailored to the programmatic goals it seeks to achieve and the amount of state/local matching available to support such services.⁴ Because the waiver authority does not confer an open-ended entitlement to services similar to a Medicaid State plan service, waiver programs affords states the option of managing the service delivery process within specified resource constraints.

The other major advantage of the waiver authority is that it permits states to claim federal financial participation for non-medical services and supports that otherwise would not be reimbursable under federal Medicaid law. Moreover, the fact that the waiver authority does not mandate that a particular constellation of services be furnished to program participants gives states additional flexibility in managing resources. Federal waiver regulations at 42 CFR 440.180 describe certain categories of services states may choose to cover under an approved Section 1915(c) waiver program, but CMS does not require states to offer certain services. Instead, the list of services and supports to be made available under a particular HCBS waiver program "... are defined by the agency [i.e., the Single State Medicaid Agency] and approved by CMS" (42 CFR 440.180 (a)(3)(b)). The only limitation is a waiver covered services must be necessary to assist program participant to avoid institutional placements. States, therefore, can tailor a "package" of services and the services definitions to fit the target population of the particular waiver program. Once an individual is enrolled in a wavier program, however, a state may not limit access to covered services that are necessary to ensure the person's health and safety.⁵ Within this limitation, a state may craft service definitions and impose utilization limits on specific services as a means of offering an appropriate mix of services while controlling costs.

⁴ SMD letter, December 23, 1996, referencing 1994 regulatory changes made to the Factor C value and SMDL# 01-006, Olmstead Letter No. 4, Sections 2 and 3, January 10, 2000, pp. 4-5.

⁵ See SMDL# 01-006, Olmstead Letter No. 4, Section 3. Access to Services Within A Waiver, January 10, 2000, pp. 5-6.

Given the flexibility of federal HCBS waiver policies, states have the option of creating separate waiver programs for specified sub-groups within a broader target population. For example, within the broad target group of individuals eligible for ICF/MR level of care, a state may decide to operate several targeted waiver programs – e.g., one for adults, another for children, another that serves only individuals with autism or yet another for individuals who are being moved out of public and/or private ICFs/MR. A number of states now operate two or more separate waiver program targeted to discrete sub-groups among the MR/DD population.

General Implications for Illinois. A variety of opportunities are open to the State of Illinois to garner additional FFP while expanding access to community developmental disabilities services. In addition to the enhancements in the state’s existing adult DD services waiver program discussed above, the state could create a waiver program targeted to children with developmental disabilities and/or to SODC and/or private ICF/DD residents who are moving back to the community. A family support waiver program might be aimed at reducing the state’s current reliance on congregate residential placements for children. A waiver targeted to persons leaving SODCs and ICFs/DD could provide the state with a vehicle for reducing its reliance on such large congregate care settings while fashioning a set of Medicaid-reimbursable community services especially tailored to the needs of this target group. In either case, the state would be in a position to craft a phase-in strategy coordinated with the fiscal constraints it expects to face.

The purpose of this section of the chapter is to sketch out some possibilities for using the HCBS waiver authority as a general-purpose tool for pursuing the state’s broader DD system change agenda within an environment of confined state resources. Obviously, the choice of which, if any, of these options should be pursued – and which future waiver options should be assigned priority – will rest with Illinois policymaker in consultation with affected DD stakeholders. The aim here is simply to lay out some of the available options, taking into account the information the project team gathers on the challenges presenting facing the state’s DD service delivery system.

It also should be noted that, while the HCBS waiver authority offers numerous options for expanding federal financial participation in the costs of delivering community-based developmental disabilities services, administering waiver programs is a labor intensive undertaking, as state DDD officials and local community provider agencies have learned through their experiences in running the existing adult DD services waiver program. Therefore, in weighing the merits of launching an additional waiver program targeted to another discrete portion of the DD population, state policymakers will need to include this factor in its calculations. And, if a decision is made to initiate a second waiver program, a portion of the additional FFP should be set aside to cover the costs of effectively managing the program.

The Case for Multiple Waivers in Illinois. Many states operate only one specialized HCBS waiver program for persons with developmental disabilities (e.g., AL, AK, CA, VT, and MN are a few examples of such states). Rather than manage access to services by tailoring supports to particular DD sub-groups by age, type of disability or the nature of the services required (out-of-home vs. in-home only), these states have chosen to manage costs and utilization through intensive person-centered planning.

On the face of it, managing one waiver program certainly is easier than managing multiple waiver programs. One waiver program means only one set of annual reports to CMS, one identifier in the data system to bill and report on waiver services and one set of program rules and policies. Waiver providers do not have to use separate identifiers in reporting encounter/billing data, depending on the particular waiver program in which the individual is enrolled. For consumers, a single waiver program may be easier to understand as well. Making policy changes may be easier as amendments to only one waiver request (and associated changes in state rules/policies) are required. Thus, states must consider the infrastructure and management investments needed to manage multiple waiver programs as they weigh the decision of submitting an additional HCBS waiver request.

Some states have discovered, however, that it is difficult to exert critical cost and utilization controls where individuals representing all age groups and level/types of service needs are enrolled in the same “full service” waiver program. The problems of managing access to variable levels/types of HCB supports within the context of a single waiver program were compounded by the issuance by CMS of Olmstead Letter No. 4 in early 2001. This letter indicates that a state may not restrict access to any service covered under a Medicaid HCBS waiver program. This interpretation of policy has led a growing numbers of states to craft multiple waiver programs covering specific target groups and offering different service packages. Typically, these states will operate a comprehensive waiver that include out-of-home residential services as part of its services menu, plus a “supports” waiver program that offers a flexible array of in-home and community-based support, but excluding 24-hour residential services.

Multiple waiver programs give state officials the tools to offer an array of services suited to the person’s/family’s present support needs without necessarily opening up access to the full complement of supports as soon as an individual qualifies for HCBS waiver services. For example, new funding to serve children living at home can be targeted specifically to such children and their families and not get “lost” within a comprehensive waiver program. Multiple waivers also afford a state the opportunity to start small and increase utilization as resources and expertise grows. The state always has the option of amending existing waiver requests, folding programs together, or reconfiguring waiver programs as they grow and the needs of the target populations evolve. In fact, as a long-term strategy operating two waivers—a comprehensive waiver for adults and children and a supports waiver for adults and children – may well be a reasonable outcome for Illinois. But, until the state’s DD service system gains additional in experience in managing waiver-funded services for children, a series of separate waiver programs probably offers wider opportunities to manage “growth” in a measured way.

1. HCBS Waiver Options for Children with Developmental Disabilities

As pointed out in Chapter II, a review of recent expenditure patterns for specialized developmental disabilities services in Illinois demonstrates that, in comparison to other states with similar demographics, relatively few children receive specialized long-term developmental disabilities services in Illinois. Furthermore, expenditures of behalf children with developmental disabilities who do receive state-funded services are heavily weighted toward out-of-home residential services furnished mainly in large congregate settings. In comparison to other states, Illinois offers limited in-home supports to families wishing to keep a child at home.

DDD's current 3-Year Strategic Plan established a goal of adding 470 families to the state's Family Assistance program over two years as a means of helping such families maintain their son or daughter with a disability at home. The creation of a separate HCBS waiver program targeted to children with developmental disabilities who are living in their families' homes could substantially increase the amount of funds available for family supports.

The creation of HCBS waiver programs for children along the lines suggested below would allow the state to manage within available resource limits. A series of children's waiver programs also would highlight Illinois' efforts to serve more children at home. During the near-term, therefore, the NASDDDS project team recommends that Illinois officials explore the feasibility of creating a family supports waiver program aimed at children whose families need modest levels of support, plus a second, intensive supports waiver program for children with multiple disabilities – including youngsters with complicated medical and behavioral support needs.

Family Support Waiver Program. According to a study published in June 2003, Illinois leads the nation in providing cash assistance to families supporting a child with developmental disabilities at home. The study notes that, "Illinois had the largest cash subsidy program in the United States in 2000, with over \$16 million in annual spending. The program also had the most generous per capita payment level, at over \$8,000 annually per family. The Illinois program, however, reached a comparatively small number of families (1,941 [in FY 2000]), given the size of the state's general population."⁶

It is clear given the state's current level of spending on family support services that Illinois has a strong commitment to supporting families who are caring for children with disabilities at home in a flexible manner. Data furnished to the project study team by DDD officials indicate that 1,504 children living with their families received cash subsidies totaling \$8.9 million during FY 2002, or an average of \$5,937 per family. If a way can be found to leverage these and other family support funds to draw down additional federal Medicaid dollars, the state should be in a better to extend supports to additional families and children. Family Assistance payments to families that currently qualify for Medicaid benefits potentially could serve as the required matching dollars to launch a family support waiver program.

However, these Family Assistance payments can qualify as the required matching dollars ONLY if the nature of the program is dramatically changed. To qualify for Medicaid reimbursement, expenditures made by families will have to be documented, made in accordance with a written plan of care, and meet all other Medicaid rules. Significant levels of accountability for this funding must be demonstrated in order to qualify for Medicaid reimbursement. Shifting what is now a very flexible form of funding into a HCBS waiver program runs the risk of introducing undesirable rigidities and bureaucratic red tape, so DDD officials will want to work closely with families to assure that funding remain as flexible as possible. Some states (Missouri and Wisconsin are good examples) use their family support funding as match for items coverable

⁶ Parish, Susan L., Pomeranz-Essley, Amy, and Braddock, David, "Family Support in the United States: Financing Trends and Emerging Initiatives," *Mental Retardation*, Volume 41: Number 3:174-187, June 2003, p.177.

under the state's DD waiver programs, but also retain a pool of flexible state dollars to make modest grants to families for items and services that are appropriate to the family needs but non-allowable costs under federal HCBS waiver rules.

The first stage in developing a children's family support waiver program would involve identifying Medicaid-eligible youngsters living with their families who are receiving DDD family support funding. Children/families currently eligible for Medicaid benefits are the easiest group to refinance, plus their waiver enrollment will have no impact on Medicaid State plan costs since presumably these children already are receiving Medicaid-reimbursed state plan services. Initially, the proposed family support waiver program should provide a limited array of services to enrolled children/families, such as in-home respite, individual and family support (very broadly defined) and/or in-home supports to children already receiving such state-only funded service. Depending on the total new dollars that can be generated, it may be possible to add a few additional services with cost caps as well, such as housing modifications and adaptive equipment. Federal policy afford states considerable latitude in crafting a "package" of benefits with reasonable utilization controls that assure participants access to the services and supports necessary to safeguard their health and well-being – a requirement of federal HCBS regulations – without creating access to high-priced, out-of-home or round-the-clock care.

Fundamentally, the proposed waiver program should offer enrolled individuals/families the same types of services currently available through existing grant funding channels, with the possible addition of a few new services that would assist families to keep a child with a disability at home. The state dollars re-captured by claiming FFP for a portion of the family assistance/family support cost currently being funded by the state would be used to extend such services to new individuals/families who are enrolled in the program. In other words, rather than an expanding benefits to individual/families already receiving family support services, the aim of the proposed waiver program initially would a refinance existing services and use the additional FFP to extend services to additional individuals/families.

The next step in the evolution of the proposed family support waiver program would be to require all individuals participating in DDD-funded family assistance/family support programs to apply for Medicaid services and seek enrollment in the FS waiver program. As DDD requires individuals/families to apply for Medicaid and enroll in the waiver program if found eligible (see discussion under Section C-3 below), total enrollment in the FS waiver program should increase. As this happens, DDD, in cooperation with IDPA, can request upward adjustments in the utilization and expenditure caps under the waiver request, as needed.

The third stage in the development of a family support waiver program might involve the addition of a waiver of parental deeming (see discussion under Section B-2 below). By utilizing the parental deeming option, Illinois could offer services to children/families who already are receiving services but cannot meet Medicaid income and asset eligibility standards under the State plan. By counting only the child's income, not the family's income, many more children could become eligible for the FS waiver services. Expanding eligibility might be important to families with children in out-of-home placement whose youngsters qualify for Medicaid only while institutionalized. These families now would have the option of returning the child to the

family home without the loss of Medicaid funding that would be available through the proposed FS waiver program.

Whether Illinois goes forward with an expanded eligibility option may depend on how Illinois chooses to target new revenue generated from other activities suggested in this report. Certainly one option would be to use some of the revenues earned through refinancing services to adults to expand community-based long-term services and supports for children. Of course, any decision to expand eligibility is tempered by the overall effects on the Medicaid budget, including the impact of adding a new eligibility group to the proposed FS waiver program. In any discussion of possible expanded eligibility, it is reassuring to recall that the HCBS waiver authority allows states to cap the number of participants, thus the impact of expanding eligibility can be predicted more accurately than expanding eligibility to under the State plan, which creates an entitlement for every beneficiary meeting the eligibility criteria. Since this is not the case with HCBS waiver programs, states can exert greater control over the number of individuals enrolled and the fiscal impact of expanding eligibility.

A fourth step in the evolution of a family supports waiver program could be the inclusion of family-directed options for managing services, including the use of fiscal intermediaries, micro-boards and other emerging models that give families and consumers greater control and choice over the services and supports they receive.

By leveraging the state general revenue dollars already being expended for family assistance, respite services to children, case coordination services and client and family support services, Illinois DDD officials should be able to identify a sufficient funding base among children who are currently eligible for Medicaid benefits to launch a family supports waiver program. As noted earlier in the report, DDD serves about 7,681 children under the age of 17, of whom about 6,961 live in non-institutional (non-SNF/ICF-MR) settings. Based on FY 2002 data, DDD spends more \$39.4 million in grant funds on community services to children aged 0-17.⁷ This figure undoubtedly underestimates actual expenditures on children since it does not include spending for Program 500 case coordination, Program 160 client and family support services and Program 150, diagnosis and evaluation services. Based on estimates developed from data provided by the DDD Data Support Unit, these programs serve several thousand children with an approximate additional expenditure of \$4.8 million.⁸ Thus, DDD spending on children's services and support in the community probably totals in excess of \$44 million. Because DDD could not accurately determine the portion of the approximately \$8.8 million spent on demonstration projects was for children's services, these funds are not included in any of the financial estimates. Since \$8.8 million is a substantial amount of funds, DDD should review how and for

⁷ Data provided by IDHS/DDD Data Support Unit, file Clients-0-thru 17-FY 2002-FY 2003.

⁸ The \$4.8 million for these program categories is based on a rough estimate of the average cost per person for selected services times the number of children served. The average cost per individual served includes both children and adults as the Illinois data system does not furnish an age-specific breakout, only aggregate data. Since the average cost per person includes adult costs, *this figure may over- or under-estimate the actual costs of services to children*. Without client specific data on grant-funded services, it is impossible to make an accurate analysis of the true costs of services provided to children.

whom these funds are being expended since potentially the base resource pool for the children's waiver services could be increased.

By piecing together information available from a number of data sources drawn from several state agencies, it is possible to create a general sense of the state's expenditures on behalf of children with developmental disabilities who have long-term service needs. Although these data do not provide a definitive description of services to these children, they are illustrative. Of the estimated \$44 million DDD spent on services to children in FY 2002, \$23 million was earmarked for services to a total of 439 youngsters, ages 0-17, who were living in residential schools and children's group homes. The remaining \$21 million in grant funds was used to serve approximately 6,500 children who were receiving non-residential home and community-based services. Certainly not all of these funds or all of the children they serve could be claimed as waiver-reimbursable services.

Given the types of services that typically are included in a state family support waiver program, it is possible to identify those DDD-funded programs that could be included, should a family-support HCBS waiver program be developed. Base funding for a family supports waiver program can be found in several existing DDD funding categories, including Program 69, the Home-based Family Assistance Program, Program 72D, Family Assistance and Support, and Programs 89D and 87D, the Residential and In-Home Respite programs. FY 2003 data indicate that total spending on these programs was about \$13.9 million. Assuming that 58 percent of the involved children are or could be Medicaid eligible, (i.e., the existing eligibility rate among infants and toddler receiving early intervention services), about \$8 million could be expected to be available in potential Medicaid matching funds. This amount of GF funding could leverage services to approximately 2,600 individuals if DDD spent the average of \$6,100 per capita on children enrolled in a supports waiver program that it now spends per child in the Home-based Family Assistance Program.

Of course these are very rough estimates that do not take into account infrastructure investments, but they do provide a very rough approximation of the number of children that could be served under a family support waiver program simply by leveraging existing state general revenue expenditure in this area. Unfortunately, because no client specific data are available on children, it is not possible to develop a typical profile of expenditures for children served by DDD except within specific program categories. Thus at this juncture it is not possible to make firm estimates of the portion of current DDD funding that might be available to form the basis of an HCBS family support waiver program.

DDD needs to analyze the types of services families purchase with current DDD grant funds in order to make sure that a HCBS waiver program will not disrupt supports and services valued by such families. Family advocates indicated to the NASDDDS study team that they are concerned about the potential for disruptions in existing DDD-funded services and supports to families as the Division folds in-home supports and home-based supports into the state existing HCBS waiver program for adults with developmental disabilities. As a part of the analysis of service utilization patterns, DDD needs to identify the services and supports currently used by families that are not Medicaid allowable costs (e.g., cash stipends or purchase of personal items such as furniture or clothing). This information should be used in making decisions regarding the

services that should be covered under the proposed family supports waiver program versus the services the state should continue to support with general revenue dollars. This action is particularly important if DDD intends to use funds now targeted for cash stipends through the Family Assistance Program as a portion of the funding for a new HCBS family support waiver program. The actions Wisconsin has taken to segregate waiver-eligible family support expenditure from non-waiver-eligible family support costs provides a useful model for the type of distinction Illinois officials, in collaboration with family advocates, should strive to achieve.

Another critical step is to identify all Medicaid eligible children currently served by DDD. A second level analysis involves estimating the number of youngsters, age 0 through 17, who potentially will meet the level of care requirements for enrollment in an HCBS waiver program. This information would form the basis for deciding whether the development of a family supports waiver program makes sense and, if so, the number of participants – and the estimated expenditures – the state is likely to be able to accommodate during the first three years the waiver program is in effect. DDD officials should create a mechanism to collect this information.

In analyzing who is Medicaid eligible, DDD may want to review children being served in out-of-home residential placements. The new waiver may provide the option for some of these children to return to family settings. But for some of this group, the initial children's family supports waiver program may not provide a comprehensive enough array of supports to create appropriate community alternatives for such children. Other children may not be eligible for Medicaid benefits once they return to their natural families under current Illinois Medicaid rules. For this reason, a later section of this chapter proposes some alternatives for serving this group utilizing the HCBS waiver option.

A third critical step is to develop a "profile" of typical supports and services to a family caring for a child with developmental disabilities at home. This profile can serve as the basis for developing cost estimates for the proposed family supports waiver program. Absent client specific data, no real estimate of the actual costs of services to families is possible.

If eventually DDD considers using the expanded eligibility option discussed later in this chapter, further analysis of the number of children potentially eligible for family support waiver services will be required to inform any decision about increasing in the waiver utilization cap. Once DDD has some experience and knowledge regarding the costs of State plan services for children that enrolled in the FS waiver program, better estimates of the fiscal impact on the State plan services of expanded eligibility are possible. Armed with actual figures, DDD would be in a better position to argue for the expansion of eligibility.

To date, at least fifteen states operate "supports" waiver programs for defined DD target populations in tandem with "comprehensive" DD waiver programs. As explained earlier, comprehensive waiver programs cover a full range of services, including out-of-home residential placements in settings offering up to 24-hour, round-the-clock care. Supports waiver programs, in contrast, typically cover a more limited array of services to assist children and adults to live with their families or reside in supported living settings where full-time, round the clock supports are not available or required. These supports waivers cover a flexible array of in-home and community-based services, such as day and vocational programs and family support services.

Many of the latter waiver programs offer self-directed support options for families and individuals who wish to direct their own services.

Supports waivers typically do not cover 24-hour, out-of-home residential services. States with both a supports waiver program and a comprehensive waiver program find they can better manage access to costly out-of-home services, while bringing services to families that may help them continue to provide care to a family member at home. While many of these supports waivers serve both children and adults, states have the option to cover any target group or subgroup they wish. States can and do choose to operate waiver programs serving children only. According to data on Web site of the National Association of State Medicaid Directors, nine states operate 14 different waivers for children under 18 years of age. For example, Colorado, Louisiana, Missouri, Michigan, Nebraska, Oklahoma, South Dakota and Wyoming all operate HCBS waivers targeted solely to children that offer a limited service menu intended to assist families to keep a child with disabilities in the family home. Utah's supports waiver program offers family support services to individuals under age 22, while restricting certain other covered services to adults. The Ohio Level 1 waiver program offers a good example of how a state can establish utilization controls on selected services to manage costs. The variety of waiver programs supporting children to live at home with families indicates the broad latitude states have in creating HCBS waiver with specific target groups and covered services.

Children's Intensive Supports Waiver Program. DDD's 3-Year Strategic Plan establishes a goal of reducing the number of children being served in out-of-state facilities by at least 50 percent by June 30, 2003. This goal could serve as the starting point for developing new community-based alternatives for children in residential services. Illinois' current heavy reliance on congregate out-of-home settings to serve children with developmental disabilities is poorly aligned with the mission statement and beliefs articulated in DDD's Strategic plan, especially the plan's emphasize on creating person-and community-centered service/support options.

Preliminary FY 2003 expenditure and utilization data supplied by DDD officials indicate that spending on services furnished in residential schools declined by about \$1.8 compared to the previous fiscal year and that 44 fewer children were served in such facilities compared to FY 2002. These figures apparently are a welcome sign of progress in DDD's campaign to bring children back to Illinois from out-of-state residential settings. The FY 2003 data set, however, also indicates a \$550,000 year-to-year increase in spending on children's group homes.⁹

As with adult services, out-of-home residential services are the most significant expenditure category in the area of DDD-funded children's services. If the \$47.8 million in estimated FY 2003 SNF-Pediatric services is included, DDD's overall expenditures last fiscal year on behalf of the 1,116 children placed in out-of-home residential facilities of various types rise to nearly \$70 million dollars a year. It is not only that Illinois provides specialized long-term services and support to a comparatively small number of children with developmental disabilities but the bulk of its existing expenditures are committed to out-of-home residential services. The state's heavy reliance on congregate residential service options is not in keeping with national trends; nor is it in synch with the stated aspirations of DDD's Strategic Plan.

⁹ Data provided by IDHS/DDD Data Support Unit, file Clients-0-thru 17-FY 2002-FY 2003.

Clearly, there are a group of children in Illinois – as there are in every state – that require extensive supports to remain at home. In many cases, the services and support currently available through DDD – as well as those that might be available through a family support waiver program along the lines proposed above – are insufficient to permit children with extensive support needs to be care for at home. Some of these youngsters may qualify for services under the state’s Medical Technology waiver program, which is operated by the University of Illinois at Chicago. But, there also are a significant number of children who require extensive non-medical home and community-based supports (e.g., youngsters who pose significant behavioral challenges to the family and community). If properly designed, an HCBS waiver program targeted to such children would serve as a true institutional alternative that would allow the State of Illinois to reduce the number of children placed in large congregate care facilities.

The primary aim of a HCBS waiver program designed to furnish intensive in-home and community-based support to children with developmental disabilities would be to “jump-start” deinstitutionalization efforts within the state. In order to generate sufficient savings to divert children with similar service need profiles from being placed in out-of-home facilities, no doubt it would be necessary to target a small group of institutionalized children who, with proper in-home services and supports, could be returned to their family’s home, a specialized foster home or a similar type of individually tailored living setting. Once the targeted HCBS waiver program is established, the balance of diverted versus deinstitutionalized children can be increased. From the perspective of program financing, children living in out-of-state placements would represent particularly attractive targets, since the state currently pays 100 percent of the cost of their care – which runs \$100,000 or more per child, per year. Thus, when the child is returned to the state and enrolled in the proposed waiver program, the state can begin billing the Medicaid program for the services he/she receives (minus the cost of room and board plus any other non-allowable expenses).

A proposed intensive supports waiver for children might include the following target groups: (a) children living at home for whom the only other viable placement option is an out-of-home in residential facilities (located either in-state or out-of-state); (b) children currently residing in out-of-home settings (again, either in-state or out-of-state) who, with intensive home and community-based support, could return to their family home; and (c) children at imminent risk of out-of-home placement due to intensive support needs. As with other waiver programs, DDD could implement the program in stages, starting with those Medicaid-eligible children already served in out-of-state or in-state institutions and expanding to those with unmet needs as funding, service providers, and expertise accumulates. By targeting this waiver program to a discrete group of children and operating it in tandem with the family supports waiver program discussed above, DDD would be able to limit the state’s “exposure” and focus efforts on creating home and community-based capacity to serve youngster who at present are served almost exclusively in large, congregate residential facilities.

DDD could limit participation in the proposed children’s intensive supports waiver program initially to Medicaid-eligible youngsters living in out-of-home placements, with the intent of expanding eligibility to additional groups of children as savings accumulate from leveraging the funding of initial participants. One issue that will have to be addressed is the creation of the community infrastructure necessary to support such children, including planning, service

coordination, and quality monitoring supports. Provider development and recruitment also may pose problems, particularly for children with intensive behavioral services needs who are returning home. Since historically Illinois has relied primarily on out-of-home care facilities to serve such children, there may not be an adequate pool of community providers who have the expertise to support such children and their families.

2. Reducing Reliance on SODCs and SNF-Peds

Between 1980 and 2001, Illinois trimmed the number of individuals served in state-operated developmental centers (SODCs) in half, but movement out of state facilities has slowed over the past few years, with a net reduction of 130 people (excluding deaths) between FY 2001 and FY 2003.¹⁰ In its 3-Year Strategic DDD has established a goal of creating community placements for 500 SODC residents over the three-year period beginning July 1, 2001 and ending June 30, 2004.

There are two basic approaches to using the HCBS waiver authority to promote Illinois' deinstitutionalization goals: either: (a) expand the current adult DD services waiver program and set aside a specific number of program "slots" and dollars each year within the state's overall waiver caps to meet the community support needs of individuals who are expected to be moved out of SODCs; or (b) create a separate deinstitutionalization waiver program designed specifically to build the community capacity necessary to shift SODC residents to the community as part of a carefully phased, multi-year process.

Certainly DDD could elect to continue to serve SODC residents who choose to move to the community through the existing adult services waiver program, without any special earmarking of funds or program slots. Earmarking waiver funding/slots specifically for deinstitutionalization efforts might raise the level of awareness that the present waiver program already serves as a vehicle to provide alternative community-based services to individual transferring out of SODCs. Given the limited number of individuals who have moved out of the SODCs over the past year or so, however, a case can be made for creating a separate waiver program dedicated to assisting individuals who are transitioning from SODCs to the community. A targeted deinstitutionalization waiver program would give Division officials the opportunity to carefully manage the impact and downsizing costs on SODC budgets. It also would allow DDD to segregate and target resources toward this effort, thus creating a clearer rationale for why an enhanced array of services and supports and, in some instances, higher payment rate may be required to adequately serve this particular target population. Establishing higher payment rates for these individuals also may address concerns raised by community provider agencies about the adequacy of current CILA rates to serve individuals with intensive medical and behavioral support needs. Furthermore, a separate waiver program would make it easier to coordinate the placement process with SODC budgets, including the possibility of adopting an alternative SODC rate-setting methodology, as proposed in Chapter IV, that permits the state to retain the maximum amount of federal financial participation during the downsizing process.

This same logic could be applied to downsizing SNF-Pediatric facilities that serve children with developmental disabilities if state officials are interested in adding this component to a separate

¹⁰ Discharge data provided by DDD indicate no net reduction due to discharges in FY 2001, FY 2002 a net reduction of 34 individuals and FY 2003 a net reduction of 96 individuals, excluding deaths.

deinstitutionalization waiver program. In FY 2003, DDD expended an estimated \$47.8 million (including FFP) to support 720 individuals in SNF-Peds facilities – 319 of whom are 17 years old or younger. Certainly, there are children currently residing in these facilities who could be served effectively in the community if the appropriate services and supports were available to them. A deinstitutionalization waiver program could prove to be an effective vehicle to accomplish such out-placements. One drawback to including SNF/Peds placements in a deinstitutionalization waiver program is that it would be harder to establish and maintain the cost-effectiveness of waiver services (due to the lower annual average per capita cost of SNF/Peds services compared to SODC services).

Any effort to downsize large congregate care facilities must take into account the fact that a facility incurs certain fixed costs that are not tied directly to the number of individuals receiving services at any particular point in time (heating and electric bills; grounds maintenance and up-keep; etc.). These fixed costs must be accounted for in any state downsizing plan. By shifting dollars out of an institution's budget only as certain cost-related benchmarks are achieved (e.g., the mothballing of particular residential units), a state can successfully negotiate this “double-funding” dilemma as a facility is being downsized. Clearly many states have already developed effective procedures for managing state facility downsizing/closure initiatives. Chapter IV of this report contains a suggested alternative rate-setting methodology that would maximize federal Medicaid reimbursements during the downsizing/closure process should Illinois officials chose to establish an ambitious, multi-year set of out-placement goals. DDD currently has a “downsizing methodology” that supports providers who are interested in creating smaller facilities. This methodology has been available for a number of years and has allowed many ICF/DD or SNF/Ped providers to successfully create smaller facilities.

At present eleven states no longer operate state developmental centers. Using a combination of the financing options available from CMS to cover the costs of downsizing and the expansion of HCBS waivers, these states eliminated their past reliance on large, state-operated facilities. By shifting substantial resources to the community, these states were able to offer the array of intensive medical and behavioral supports needed by the individuals leaving state facilities.

Two states, Georgia and Idaho, currently operate HCBS waivers specifically targeted to individuals with developmental disabilities leaving SODCs. During the 1980s, when many states first launched HCBS waiver programs for persons with mental retardation and other developmental disabilities, it was quite common for the primary focus of a state's waiver program to be on assisting individuals who were moving from public institutions to the community. But, as HCFA (now CMS) liberalized its policies governing the approval of state HCBS waiver requests and states sharply expanded waiver participation levels, deinstitutionalization became a less important goal in the vast majority of states. Wisconsin provides a good example of how many states currently handle deinstitutionalization in the context of their existing MR/DD waiver programs. Rather than crafting a separate waiver program, Wisconsin has established higher per diem payment rates for counties that are planning and managing community services for individuals leaving state-operated developmental centers. This approach is predicated on the assumption that individuals residing in the state's three institutions have multiple disabilities and costly, complex service needs. Therefore, the

Wisconsin Department of Health and Family Services transfers a portion of state facility funding to the community as each individual leaves a SODC.

3. Converting Private ICF/MR Capacity to HCBS Waiver Capacity

During FY 2003, Illinois had a certified capacity of approximately 7,400 beds in “DD Long Term Care” program. This capacity involved roughly 6,550 certified ICF/DD beds and 950 SNF-Peds certified beds. The ICF/DD bed capacity was divided further into facilities with more than 16 residents and those that had 16 or fewer residents. The capacities of these two ICF/DD program groupings were approximately 2,950 and 3,525, respectively. The DD Long Term Care program ran at an overall occupancy rate of 91.9 percent during FY 2003. ICF/DDs with 16 or fewer residents had a 95.1 percent occupancy rate while the other ICF/DD facilities and SNF/Peds facilities had occupancy rates of 90.9 percent and 83.1 percent, respectively. DDD’s existing 3-Year Strategic Plan expresses interest in reducing the state’s present level of reliance on DD Long Term Care facilities, but, thus far, this interest has not been translated into explicit public policy initiatives.

As mentioned earlier in this report (see Chapter II), comparative data indicates that Illinois relies on institutional placements for people with developmental disabilities to a significantly greater extent than almost all other states. While the effects of long-term institutional placement on the personal growth and vitality of people with developmental disabilities has been widely recognized for years, there also are fiscal reasons for states to consider the conversion or transformation of large segments of its institutional capacity to supports and services that can be offered in home and community-based settings. The HCBS waiver program, as previously noted, provides an excellent vehicle for accomplishing such a transformation without substantially reducing the level of federal financial participation. States have found that it is possible to move many, if not most, people who currently live in ICFs/DD and/or SNFs/Peds into less structured and restrictive community living and programming environments.

Other states also have found that deinstitutionalization, if accomplished through effective person-centered planning and access to sufficient supports in the community (outside the home), can be achieved in a cost-effective manner. Cost effectiveness is possible for two basic reasons. The first reason is that, despite the level of need exhibited by persons currently living in public and private institutions, states have had great success (as measured by independent means) providing effective care in the community without some of the clinical services and physical plant features required by regulation in the institutions. The second reason is that, once person-centered planning is fully developed, states are finding that a significant number of people with developmental disabilities and their families or guardians begin to request less intense levels of specialized care over time than typically is provided in institutions. Many states have found that, although the conversion of institutional beds to community capacity cannot always be accomplished in a “cost-neutral” manner, the improvement in consumer satisfaction, quality of life, and other tangible benefits are worth the limited investment of additional dollars.

Converting Small Community-Based ICF/DD Financing to the Waiver Program. Claims data supplied by DDD suggests that opportunities exist to convert a limited number of ICFs/DD to community-based capacity using the HCBS waiver program, assuming that the consumers and

their families and/or guardians will choose to participate in the waiver program. This step is possible because DDD, over the past 15-20 years, has developed a number of small, four- to six-bed ICFs/DD. The average FY 2003 billing rates (\$181.44/day or \$66,225/year – without day program costs) are significantly higher than the rates currently claimed for CILAs (the most likely alternative residential placement options for individuals now living in ICFs/DD). The average daily CILA payment rate for CILAs with 24-hour supervision was \$124.43/day or \$45,418/year – without day program costs. Additionally, other data provided by DDD indicates that the residents of these smaller ICFs/DD have less intensive needs, as “grossly” measured by data historically used by the Division to indicate the severity of developmental disabilities among the population served. These factors strongly suggest that, even if the current residents of four or six person ICFs/DD require services that typically could not be accommodated within the typical CILA payment rate, it is likely that, with effective person-centered planning, the need of such individuals it could be met in a cost-effective manner.

A number of states have converted small, ICF/MR-certified community residences to their DD waiver programs over recent years. The experiences of these states are instructive. Some states have rolled small (4-6 beds) community ICFs/MR into their MR/DD waiver program. Other states have adopted a policy of offering ICFs/MR with 7 and 15 residents incentives to convert their financing to the state’s HCB waiver program. Often, these conversions have been accompanied by incentives for providers to allow persons who wish to move to more individualized community living arrangements (staffed apartments, etc.) where they have access to a broader range of community activities. Conversions of this type can be accomplished by downsizing the existing facility and/or developing smaller, more individualized alternative living arrangements. It is difficult to accomplish such dispersion initiatives in a cost neutral manner because any reduction in the cost of care of moving out of the highly regulated congregate care environment of an ICF/MR is balanced by the loss of some economies of scale.

Still other states have created incentives for larger ICFs/DD (7-15 residents) to convert to HCBS waiver funding while maintaining its existing capacity. Such action is possible because CMS currently allows individuals enrolled in the HCBS waiver program to live in homes with a capacity no larger than 15 individuals. While not accomplishing the same policy goal of creating smaller, more personalized living environment for persons with developmental disabilities, this approach does afford persons living in such facilities greater flexibility in their life style and also leaves open the possibility than some facility residents will choose to live in smaller, more integrated community living arrangement in the future.

It is unlikely that converting small, community-based ICFs/MR to waiver financing will result in increased federal Medicaid revenue. Accomplished effectively, however, such conversions may offer existing facility residents a higher quality of life, enhanced community integration, and improved satisfaction.

Any decision to reduce institutional capacity and shift financing toward HCBS waiver services should be part of an overall tactical plan to reallocate system capacity to better match consumer and family preferences. This tactical plan should be based on a careful assessment of current and anticipated future consumer needs. This needs assessment should be designed to allow individuals with disabilities and their families/guardians to articulate their service/support needs

in terms that are not dictated by existing program models or facility types (supply). Furthermore, the analysis also should have a geographic focus, thus ensuring that DDD is able to delineate demand by the community of choice of its consumers and families. Individuals currently residing in State Operated Developmental Centers and other institutional settings as well as their families should be included in this assessment.

Once a general analysis of current service/support demands has been completed, the results should be compared with existing state/local service capacity and a multi-year tactical plan should be developed in collaboration with all major system stakeholders. This tactical plan should articulate the desired types and quantities of living environments, offer a general sense of expressed personal outcomes of participating consumers and families, and specify the types, quantities, and levels of supports or services that will be needed to assist persons with developmental disabilities as they pursue their outcomes. The plan should include a set of effective measures to inform consumers, families, and guardians of the opportunities generated by this new policy direction. The resulting tactical plan also could include a set of incentives to encourage the provider community to provide leadership in this effort.

C. Medicaid Eligibility and HCB Waiver Services

1. Background

Basic Eligibility Policies. Illinois is one of eleven states that base eligibility for Medicaid services on a pre-1972 definition of disability. These states often are referred to as 209(b) states because this is the section of the Social Security Act that permits states to continue to use a state disability definition that pre-dates the establishment of the federal Supplemental Security Income program. Although the state uses the same disability standards as are used in federal SSI policy, Illinois, in determining Medicaid eligibility, applies more restrictive income eligibility standards than are used in determining eligibility for federal SSI benefits based on disability. As a result, an individual with a qualifying disability can be found eligible for federal SSI benefits and not be eligible for Medicaid services. SSI eligibility does not automatically ensure access to Medicaid eligibility as it does in a large majority of states. In fact, according to the *Medicaid Resource Book* published by The Kaiser Commission on Medicaid and the Uninsured, until 2001 Illinois had the most restrictive Medicaid income eligibility standard of any state in the nation.¹¹ Restrictive eligibility probably has contributed to some degree to Illinois' more limited use of the HCBS waiver authority.

The Illinois Medicaid program now bases income eligibility on 100 percent of the Federal Poverty Level (FPL). In 2003, the FPL for a single adult is \$748.00 per month income, or \$8,980 per year. With the exception of the new optional eligibility coverage for working adults with disabilities described below, Illinois applies its Medicaid income eligibility standard very strictly, counting all income above this standard in determining eligibility. Many states, for example, disregard cost-of-living increases in federal benefits. Illinois, in contrast, counts these increases in calculating income eligibility for Medicaid benefits. Illinois does permit individuals

¹¹ Schneider, A, et al., *The Medicaid Resource Book*, The Kaiser Commission on Medicaid and the Uninsured, July 2002, p. 28.

with higher incomes to “spend-down” their income in order to qualify for health and medical services available through the Medicaid program. These individuals must incur medical and remedial expenses that reduce their income to the level that makes them eligible for Medicaid benefits.

Illinois participates in the State Children’s Health Insurance Program (SCHIP). In Illinois, the program is known as KidCare. On July 1, 2003, Illinois raised the family income eligibility limit for KidCare from \$28,237 to \$30,516 per year for a family of three. Kids Care affords participating children full coverage of Medicaid State plan services, without any cost sharing requirements. The recent expansion in SCHIP income eligibility is expected to make an additional 20,000 children eligible for Medicaid benefits.

Also included in the July 1 KidCare revisions are provisions extending Medicaid coverage to uninsured parents whose children are enrolled in Medicaid or KidCare (FamilyCare). Over three years the income eligibility standard for a family of four is scheduled to increase from about \$9,000 to \$16,560 per year. Under this new eligibility provision, Illinois expects that 65,000 parents will enroll in the FamilyCare component of the program during the first year and more than 300,000 parents will enroll over a three year period. Although Illinois offers children Medicaid through income-related eligibility options, Illinois is one of only four states that do not offer coverage to children with disabilities who qualify for adoption subsidies.

Illinois is one a handful of states thus far that have chosen to expand Medicaid eligibility options for working individuals with disabilities under the Ticket to Work and Work Incentive Improvement Act (TWWIA). Using the new Medicaid Health Benefits for Workers with Disabilities (HBWD) program, Illinois permits qualifying workers with incomes up to \$1,477 per month for a single person and \$1,990 per month for a couple to participate in the this special Medicaid eligibility category. Enrollees in HBWD also are allowed to accumulate up to \$10,000 in assets without losing Medicaid eligibility. Depending on income, enrollees pay a monthly premium that ranges from \$0 to \$100 to receive access to the full range of Medicaid services. During 2002, approximately 250 individuals were enrolled in Medicaid under the HBWD option. Expanding Medicaid coverage to working individuals with substantial disabilities is a positive step that encourages such persons to seek and retain employment without fear of losing critical Medicaid health insurance benefits.

Income Eligibility for Institutional Care. The Illinois Medicaid program pays for hospital, nursing home, or ICF/MR services on behalf of any eligible recipient whose income is less than the cost of institutional care and is found to need such care. In Medicaid parlance the need for institutional services is called meeting level of care (LOC) criteria.

Based on this approach, even though an individual has income in excess of the income eligibility standard, he or she may be eligible for Medicaid benefits while institutionalized. The individual receives a personal needs allowance from his or her own income, with the remainder of his/her income used to pay for cost of institutional care; then, Medicaid assumes responsibility for the difference between the person’s income and the Title XIX reimbursement rate applicable to the particular category of institutional provider.

Under the Illinois Medicaid program, individuals also may become eligible under institutional spend-down provisions if their income is above the private pay rate for institutional care. Consequently, even individuals whose income exceeds the maximum amount allowable to receive Medicaid benefits in the community can gain access to Medicaid-funded institutional services.

For institutionalized children, Illinois does not “deem” parental income; this means the state disregards the income of the family in determining the Medicaid eligibility of a child who is institutionalized for an indefinite period of time. Only the child’s income counts toward eligibility. By contrast, parental income is taken into account in determining the eligibility of children with disabilities who are in of need Medicaid-reimbursable services, including home or community-based long-term supports.¹² Illinois does offer a variety of expanded eligibility options for children, including coverage under the State Children’s Health Insurance Program (SCHIP). Illinois has not opted to include in its Medicaid state plan the so-called Katie Beckett eligibility option authorized under Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982. This special eligibility option allows states, under certain specified conditions, to disregard the income of families in determining the Medicaid eligibility of children with severe disabilities who are living with their families (see additional discussion below).

Income Eligibility and HCBS Waiver Services. In order to be eligible to participate in Illinois’ HCBS waiver program for adults with developmental disabilities, a noninstitutionalized individual must meet all of the general eligibility requirements for Medicaid, including the state’s income eligibility standards. Persons who are eligible for Medicaid benefits under the state’s spend-down policies may go on and off of eligibility for HCBS waiver services if their income fluctuates from month to month. Although, as will be explained below, federal HCBS waiver regulations permits states to apply the same income rules to participants in HCBS waiver services as they use in determine eligibility for institutional services, Illinois, at present, does not make use of any of special expanded eligibility provisions under federal regulations governing the Section 1915(c) waiver program.

2. Medicaid Expanded Eligibility Options

Alternatives to Spend-down: Stabilizing HCBS Waiver Eligibility. The use of spend-down as an eligibility platform means that working individuals with incomes at or close to 100 percent of the Federal Poverty Level are at risk of gaining and losing Medicaid eligibility as their income fluctuates. The instability of Medicaid eligibility may have unintended effects on revenues as well as the willingness of individuals to apply for Medicaid benefits. Although individuals are not required to pay the amount they must spend-down but instead only “incur” the cost, many individuals are frightened of incurring large medical bills that they cannot pay.

Any individual whose income exceeds \$748.00 per month loses Medicaid eligibility until his/her spend-down obligations are met. Since federal HCBS waiver rules requires an individual to be Medicaid eligible while enrolled in the waiver program, the state cannot claim federal Medicaid

¹² As noted above, Illinois does offer expanded eligibility for children through the KidCare program that enrolls children with family income up to \$30,516 for a family of three and offers a “buy-in” program for families with higher incomes.

reimbursement for any service – a State plan or a HCBS waiver service – during any period of time the recipient of the service was not Medicaid eligible. In other words, for individuals enrolled in the HCBS waiver program, the state pays the full cost of what otherwise would be federally reimbursable services during any time the person loses Medicaid eligibility. Although the person theoretically pays for their Medicaid State plan or waiver services through the spend-down provisions, in reality the recipient incurs the expenses rather than paying the actual costs. Many of the individuals who incur spend-down cannot pay the costs (or at any rate the full cost) of their incurred bills. These unpaid bills become a part of the state’s cost for uninsured individuals, or in the case of adult DD waiver enrollees, a cost potentially borne by the provider community and/or the state.

Over time, a significant proportion of adults with developmental disabilities become eligible for Disabled Adult Child (DAC) payments under Social Security due to the retirement, death, or disability of their parents. Although most of these individuals already will be receiving SSI benefits and typically also will meet Illinois income requirements for Medicaid eligibility, once they begin to receive DAC payments as well, they may become subject to spend-down rules. Also, annual cost of living increases in federal benefit programs can push individuals off regular Medicaid eligibility into the spend-down category. Potentially, individuals may go on and off Medicaid, thus affecting the state’s ability to bill through Medicaid for the cost of the HCBS waiver services they receive. Although states have the option of disregarding income from DAC benefits and cost-of-living increases from other federal benefit programs, Illinois is one of only four states that choose to count these types of income for purposes of Medicaid eligibility.

While spend-down provisions help individuals with incomes slightly in excess of the state’s eligibility standards and substantial out-of-pocket medical expenses to become eligible for Medicaid benefits, spend-down has serious drawbacks for persons needing long-term supports. Particularly for individuals needing intensive supports, the loss of eligibility could mean the loss of their community placement, day programs or job. It also drains away dollars that otherwise could be included in the state’s claims for federal Medicaid reimbursement.

Use of a Special Income Standard. Under 42 CFR 435.217 a state may elect to use a special income standard in determining the Medicaid eligibility of applicants for HCBS waiver services. This provision of federal regulations governing the HCBS waiver program specify that, “The [Single State Medicaid] agency may provide Medicaid to any group or groups of individuals who meet the following requirements: (a) The group would be eligible for Medicaid if institutionalized...”

The special income standard is analogous to the standard used in determining the income eligibility of institutionalized individuals. It permits states to request approval to establish a special income eligibility standard under any HCBS waiver program that is no higher than the parallel income eligibility standard the state has set for individuals receiving services in Medicaid-certified institutions. The aim of 42 CFR 435.217 is to create a “level playing field” between institutional and HCBS waiver services. By allowing a state to use of the same special income standard in determining HCBS waiver eligibility that it applies to institutional services, CMS has pointed out, removes the “institutional bias” otherwise inherent in general Medicaid eligibility requirements.

This special income standard is known as the 300 percent rule. Based on the current SSI benefit level, individuals with incomes up to \$1,656 per month may be qualified to enroll in a HCBS waiver program. However, states may set its income threshold at any percentage up to the 300 percent of the federal SSI payment standard. Some states, indeed, do choose to set a lower income eligibility threshold level – often because they have previously established a lower special income eligibility standard for institutional services and, under the provision of 42 CFR 435.217, may set no higher standard for HCBS waiver services. The Illinois Medicaid program pays for hospital, nursing home, or ICF/MR services on behalf of to any eligible recipient whose income is less than the cost of institutional care and is found to need such care. In effect, Illinois permits individuals with higher incomes to become eligible for Medicaid when institutionalized than is used for the HCBS waiver. Illinois should consider applying the same standard to participants in the DD adult services waiver program as a means to create more equity of access between institutional and home and community-based services.

Determining eligibility for HCBS waiver services based on a special income standard creates a more stable program management environment since recipients of HCBS waiver services are not subject to moving in and out of Medicaid eligibility status as their income fluctuates. One additional benefit of using a special income standard from a fiscal management perspective is that the state can limit the application of the option to a particular waiver program or programs. Furthermore, the 300% rule applies only to HCBS waiver services; therefore, a state is under no obligation to extend the same policies in determining eligibility for mainstream state plan services.¹³

A special income rule also should be less cumbersome for DDD officials, community provider agencies, and service coordinators to administer. Compared to administering the spend-down provisions, the special eligibility rule makes the collection of funds a bit simpler. With spend-down, keeping track of when an individual's deductible is met, making sure that non-allowable days are not included in the state's Medicaid reimbursement claims, and that required funds are collected from the individual can become very tedious. Under a special eligibility rule, tracking of incurred costs is not required.

The NASDDDS project team was told that, to date, no attempt has been made to determine the average number of individuals enrolled in Illinois adult DD services waiver program who lose Medicaid eligibility each month due to fluctuations in their income. Such an analysis should be conducted since it would establish the number of waiver participants who are pushed into the spend-down category each month and, based on a parallel review of financial records, the potential dollar amount of lost federal Medicaid reimbursement.

Data collected by the National Association of State Medicaid Directors (and supplemented by information received through a NASDDDS survey) indicate that 27 states use the 300 percent

¹³ Moreover, the 300 percent rule applies only to the participants in the waiver program or program to which a state elects to apply the rule. The state is under no obligation to apply this expanded eligibility option to other Medicaid recipients.

rule in regulating eligibility for MR/DD waiver services.¹⁴ At least three additional states use 100% of the FPL, one state uses an income standard of \$1,242 per month, one state uses 250 percent of the federal SSI payment standard, and nine states peg waiver financial eligibility to 100 percent of the federal SSI payment standard. This information certainly establishes that many other states have found operating under the special income rule permitted by 42 CFR 435.217 to be beneficial. The use of this option allows states greater latitude in enrolling individuals in their waiver programs who, in all likelihood, otherwise would be uninsured and relying on specialized community DD services and supports financed entirely with state general revenues.

Post Eligibility Treatment of Income (PETI). Under federal Medicaid regulation (42 CFR 432.230), institutionalized individuals may qualify for Medicaid benefits with higher incomes than generally are permissible under standard income eligibility rules. As noted earlier, institutionalized individuals in Illinois may have incomes up to the Medicaid payment rate for the particular class of institutional services and still qualify for Medicaid benefits as long as they remain in a Title-XIX-certified institution. Furthermore, persons with higher incomes may spend down their income to qualify for Medicaid.

In the case of institutionalized persons (i.e., nursing facility residents or individuals served in ICFs/MR), generally the state collects the individual's income in excess of a specified "personal needs allowance." For institutionalized persons, this allowance is usually an amount deemed necessary to cover personal items, such as clothing and person hygiene products. Income beyond this personal needs allowance is collected from the person to offset the cost of providing care. The collected funds are deducted from a facility's Medicaid payment claim on the individual's behalf. 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 amount of the state-specified personal needs allowance.

A similar type of eligibility is allowable for individuals enrolled in HCBS waiver programs. These eligibility policies are contained in 42 CFR 435.735. As with institutionalized individuals, a personal needs allowance is set-aside for the HCBS waiver participant, known as the maintenance allowance. The maintenance allowance typically is an amount sufficient to cover the cost of the individual's room, board, personal expenses, and non-covered medical or remedial expenses. Thus, the maintenance amount under the HCBS waiver is always larger than the institutional personal needs allowance, which only is needed to cover personal effects such as toiletries and clothing. Just like institutional facilities, provider of HCBS waiver services are required to collect the remaining income of an individual covered by the PETI provisions to offset the cost of services billed to Medicaid for waiver services. One helpful feature of the PETI provisions is that the amount recovered from the beneficiary typically is known and generally stable from month to month; and, unlike spend-down, PETI recoveries do not affect the person's eligibility for Medicaid or his/her continued enrollment in the HCBS waiver program.

¹⁴ The NASMD data can be found on the Association's Web site at <http://www.nasmd.org>. Information supplemented survey information collected by Robin Cooper, NASDDDS.

The maintenance amount is set at the state's discretion. Some states choose to ignore earned income up to 300 percent of the federal SSI payment standard in order to encourage MR/DD waiver participants to engage in gainful employment and increase their earnings over time. Other states collect back from the individual all funds in excess of the federal SSI payment standard or use the same type of standard disregards and reductions as are used in determining federal monthly SSI payments. Still other states "peg" the protected income amount to the Federal Poverty guidelines. A number of states also make allowances for individuals with high out-of-pocket expenses related to their disability (such as uncovered medications or equipment). The PETI option offers a way to assure both a stable platform for Medicaid and waiver eligibility while preserving funds for the person's use and still collecting funds from the individual to offset services costs.

In Illinois, PETI policies may prove easier to administer than tracking spend-down requirements – both for DDD and community provider agencies. Provider agencies only would be required to collect "excess income" (i.e., the amount that is above the state-established maintenance allowance). The amount of the maintenance allowance usually is established as a part of the initial individual program planning process and is reviewed by the person's service coordinator, the individual with disabilities and the community provider agency and can be changed at any time the person's income changes. The provider's claim is then offset by the amount collected. Because the provider's claim is offset by the excess income, providers have an incentive to make the required collections. Rather than just *incurring* the costs as required under spend-down, payments actually are infused into the service system. The PETI approach also removes the requirement to report to Medicaid monthly that the person has met spend-down requirements and thus retains Medicaid eligibility. Plus, there is less room for errors resulting in the loss of benefits.

In order to implement PETI, DDD, in conjunction with IDPA, would have to agree on a maintenance threshold. If the *maintenance* amount were set at 100 percent of the Federal Poverty Level, personal income in excess of this amount would be¹⁵ collected to offset waiver claims. Using the poverty level as the amount of the maintenance allowance would not cause any expansion of Medicaid eligibility, but it would stabilize the eligibility of persons affected by current spend-down requirements. Income in excess of this amount (up to \$1,656 per month, or 300% of the federal SSI payment standard) is collected would offset the HCBS provider's claim for services.

While this maintenance allowance mirrors the current Illinois Medicaid income eligibility standard, unless the individual qualifies for continued Medicaid coverage under the TWWIIA provisions, non-SSI eligible individuals with earned income may find that they lose all their income earned above the FPL. If the maintenance amount includes all earned and unearned

¹⁵ For someone who is working, the first \$65 (\$85 if the person has no other income in a month) of earnings in a month are disregarded. After that SSI benefits are reduced by \$1 for every \$2 the person earns in a month. Any monthly expenses that a person with a disability incurs that are needed by the person and are related to his/her impairment and paid by the person are deducted from the monthly earnings limit. These expenses are deducted before the Social Security Administration applies the \$1 for \$2 computation. If the person has only earnings and no unearned income and doesn't pay any work-related expenses, the person can earn up to \$1,189 in a month in 2003 (\$1175 in 2002) before the person's SSI federal cash payments stop.

income and is set at 100 percent of the FPL, the individual accrues little, if any, financial reward for working.

For individuals receiving SSI the Social Security Administration automatically reduces benefits to working individuals, allowing them to keep some income but reducing the SSI benefit as the person earns more money. Thus SSI offers some incentives to work as individuals can keep some of their earned income. In order to create this same type of incentive for non-SSI recipients, Illinois could also choose to set the maintenance amount to allow individuals to keep a portion of the earned income, much like SSI allows. Pegging the reductions to the SSI formula acts as an incentive for working individuals. Some states count only unearned income—such as federal benefits or pension benefits—toward PETI payments.¹⁶ They exempt earned income, thus creating incentives to work.

Other states set maintenance allowance at a variety of levels. Alaska allows individuals to retain income up to the full 300 percent of the SSI payment standard; Wisconsin allows individuals to retain all income up to \$732, but then also adds on a variety of “disregards” allowing individuals to keep more income. For example, Wisconsin ignores the first \$65.50 of earned income in addition to the needs allowance. Individuals may also retain income needed to purchase medical or remedial supplies not covered under Medicaid. Wisconsin includes a special housing allowance for individuals that may need to rent larger space in order to accommodate personal care workers or for those living in areas with high housing costs. States have considerable flexibility in setting the maintenance allowance, providing incentives for individuals to work, and recognizing disability-related expenses.

Expanding Medicaid Eligibility for Children with Disabilities By Waiving Parental Deeming.

Some individuals may not qualify for Medicaid benefits while in the community and may only access Medicaid when institutionalized or when in out-of-home residential placement. Ineligibility while in the community can create a “bias” toward out-of-home placement because children and adults qualify for Medicaid *only* if they choose institutional placement. The institutional bias may mean that families seek out-of-home placement for their children as this is the only option they have—their children are not eligible for Medicaid services that would otherwise help them stay within the family home.

Medicaid regulations offer two ways to obtain benefits for children with severe disabilities who do not qualify for Medicaid in other ways. Both these “doors” have the same result: keeping the family’s income from being counted as being available to the child. These “doors” are the Katie Beckett or TEFRA option and the HCBS Waiver option. These options are collectively known as “parental deeming” as the rules choose *NOT* to “deem”, that is include, parental income when making the child eligible for Medicaid.

The TEFRA 134 (Katie Beckett) Option. States have the option under federal Medicaid law to offer Title XIX coverage to certain children with severe disabilities without taking into account the income and resources of the child’s parents. These provisions were added federal law by Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 and are currently found in

¹⁶ A paper discussing the complex interactions between income eligibility and work incentives is available from NASDDDS upon request.

Section 1902(e)(3) of the Social Security Act (42 U.S.C. 1396a(e)(3)). Known as the Katie Beckett option, Section 1902(e)(2) of the Act allows states that elect to do so to disregard the resources of parents in determining the Medicaid eligibility of children under age 19 (or up to age 22 if enrolled in school) who:

- 1) meets federal SSI disability criteria applicable to children;
- 2) would be eligible for Medicaid benefits if he/she were residing in an institution; and
- 3) receiving in-home medical care that otherwise would have to be provided in a Medicaid-certified institution.

On a case-by-case basis, states that have adopted this special eligibility option determine whether it is appropriate to provide care to potentially affected children outside an institution. The state must also demonstrate that estimated Medicaid costs to support the child at home is no higher than the estimated cost of serving him/her in a Title XIX-certified institution. The TEFRA option makes it possible for middle class families to keep a child with severe disabilities and, often, complex medical challenges at home with costly medical and social supports financed by the state Medicaid program.

The Medicaid benefits complement any benefits that may be available to the child through the family's own health insurance coverage. No "extra" benefits are associated with this special eligibility option — i.e., the child is able to access the regular service coverages available under the state's Medicaid program. States that have added this special eligibility option to their Medicaid state plans include (but are not limited to) Wisconsin, Minnesota, and Arkansas.

The key drawback to the TEFRA option from a state policy perspective is that, once the coverage is part of the state's plan, a state may not deny access to Medicaid coverage to any child who meets the criteria of Section 1902(e)(3) and, therefore, may encounter problems in controlling the costs of coverage. Because eligibility is offered to children regardless of family income, some states are reluctant to extend Medicaid coverage to families that do not otherwise meet the state's financial eligibility criteria. Furthermore, given the current budget shortfalls, states are very reluctant to add new, open-ended entitlement features to their Medicaid programs.

Waiving Deeming of Parental Income Under a HCBS Waiver Program. An alternative to the TEFRA eligibility option is to waive parental deeming requirements under a HCBS waiver program that includes children with severe disabilities as part of the target population. Such a deeming waiver fulfills much the same basic purpose as the TEFRA eligibility option – i.e., it permits states to extend at-home eligibility to children with severe disabilities who otherwise would not qualify for Medicaid benefits due to the excess income and resources of their parents. A waiver of parental deeming under a HCBS waiver program reduces the bias toward institutional care for children while still permitting the state to exercise greater control over the total number of youngsters benefiting from this option as well as the array of services and supports they receive. With nearly 1,400 children currently residing in-state and out-of-state long-term care facilities, Illinois, as noted earlier, is spending a considerable amount of money on institutional care for children. A carefully crafted waiver of parental deeming would allow the state to begin creating cost-effective home and community-based alternatives to placing children in large congregate care settings. The best approach would be to consider the merits of such a

parental deeming waiver in conjunction with the proposed children’s waiver options discussed above (see Section B-1 of this chapter).

Some states have created HCBS waiver programs primarily to allow children at high risk of institutionalization to gain access to home-based Medicaid state plan services. Colorado, for example, operates a Section 1915(c) waiver program that provides case management services for children with severe disabilities who are living with their families. The principal aim of the program is to allow participating families to access the Medicaid state plan services that will allow them to care for their children at home. Other states, such as Missouri, South Dakota and Oklahoma, have taken similar steps, crafting HCBS waiver programs that allow children with severe disabilities to gain access to eligible “regular” Medicaid state plan services by waiving parental deeming requirements.

Many states do not set up special HCBS waiver programs for children but instead build a parental deeming option into their principal HCBS waiver programs. Tying expanded Medicaid eligibility to HCBS waiver programs means that the number of children gaining access to Medicaid eligibility is limited by the utilization and expenditure caps the state establishes for the program. In addition to capping the number of individuals to receive services, the state also may craft the array of HCB services and supports to meet the particular needs of sub-sets of children who are at high-risk of institutionalization. If, for example, a state is experiencing increased demand for institutional services among children with autism spectrum disorder, it may decide to include behavioral supports and family therapies as service coverages under its HCBS waiver program in an effort to dampen demand for expensive institutional placement involving such youngsters.

3. Determining Level of Care for HCBS Waiver Eligibility

In order to qualify for Medicaid-reimbursable home and community-based services an individual must otherwise be in need of institutional care. In federal HCBS waiver policy this requirement is interpreted to mean that the individual must meet the state’s level of care (LOC) criteria for admission to the appropriate category of Medicaid-certified long-term care facility – almost always an ICF/MR-certified facility in the case of persons with mental retardation or other developmental disabilities. 42 CFR 441.301 (b) (iii)(A),(B) and (C) requires that home and community-based services be offered, “only to recipients who would, in the absence of these [home and community-based] services require the Medicaid covered level of care provided in a—(A) A hospital, (B) A NF [nursing facility]; or (C) An ICF/MR..”

The LOC determination criteria and process are established by the state and then approved by CMS. The state describes in its HCBS waiver request the criteria and process it will use in conducting LOC determinations, including the forms that will be used and the procedures that will be followed. CMS does not prescribe this process. The state describes its own process and CMS approves it. Section 4442.5 of the *State Medicaid Manual* (Evaluation-Assurances and Documentation) indicates that states can opt to use a process that is identical to the way they establish LOC eligibility for individuals choosing institutional care, or may use an alternative process as long as the process is comparable to its institutional process.

Under state regulations, Illinois uses a LOC determination process based on the requirements of

the Omnibus Budget Reconciliation Act of 1987 (OBRA-87). The process is the same whether the person seeks ICF/MR (or SNF/Peds) level of care or enrollment in the state's adult DD services waiver program. The state's LOC determination process includes a pre-admission screening and then a full assessment of the person's needs if he or she appears to have a developmental disability. The Developmental Disabilities Pre-Admission Screening/Independent Service Coordination (DD-PAS/ISC) Agencies perform these screening and assessments. The LOC screening entails the following assessments:

1. an ICAP (a functional screen)
2. a psychological assessment
3. a medical review, including a medical history, medication review and physical examination, completed by a licensed medical practitioner (MD, RN, physician's assistant or advanced practice nurse). This review must be current (i.e., performed within 90 days of the evaluation).
4. Any additional assessments based on individual needs, such as communication, physical therapy, behavioral therapy, audiology or occupational therapy assessments.

Based on these assessments, the PAS/ISC agency determines whether the individual requires the level of care required for admission to a Medicaid-certified long-term care facility (including for PASARR purposes need for care in a nursing facility) and active treatment.

Adopting a Simplified LOC Determination Process. For purposes of waiver eligibility, the use of full-blown PAS/ISC assessments is more labor intensive than required by federal policy. Many states assess waiver LOC eligibility using a simple, straightforward functional screening process. Comprehensive evaluations are conducted once the person is determined to be eligible for the HCBS waiver program and service dollars (a waiver "slot") are available.

For example, Kansas and Indiana use the Developmental Disabilities Profile (DDP) to assess LOC eligibility for their HCBS waiver programs targeted to persons with developmental disabilities. The DDP is a well-validated, functional screening tool originally developed by the State of New York. Kansas and Indiana officials performed a DDP on each applicant for HCBS waiver services. They made the reasonable assumption that individuals currently enrolled in the DD waiver program met LOC criteria as they have been assessed for eligibility through other processes already in place. After screening a random but statistically significant sample of current waiver participants, these states determined the DDP score required to meet LOC eligibility. Indiana also has a QMRP review all screens to be sure the scores provide a valid basis for waiver eligibility. The Single State Medicaid Agency also reviews a sample of all screens annually. Because the DDP may not completely accurately screen certain segments of the DD population, Indiana uses the following process:

"Routine" LOC (initial) evaluations will be completed in the field by the AAA or Bureau of Developmental Disabilities QMRP, using the functional screen. (page 52d). "Non routine" LOC evaluations will be reviewed and completed by OMPP staff for individuals under the following circumstances:

- 1) an IQ of 65 or above;

- 2) dual diagnoses with an of IQ 55 or above;
- 3) significant medical conditions requiring specialized medical supports or that significantly interfere with participation in services;
- 4) requires two or more staff on-site for any part of the day for more than 30 days;
- 5) under age 18; or
- 6) police involvement due to maladaptive behaviors.

Non-routine LOC evaluations will require psychological, social, and medical information to be submitted in addition to the functional screen¹⁷

A number of other states (Utah, Colorado, Wyoming, and South Dakota) use the ICAP, another functional screen validated for populations with developmental disabilities. Some states have developed their own functional screening tools, such as Wisconsin, Virginia, and North Carolina.

As noted above, CMS permits states to use a different process to establish level of care for purposes of participating in a HCBS waiver program as long as the process is comparable to its institutional LOC process. Section 4442.5(B)(5) of the *State Medicaid Manual* reads as follows,

Indicate whether the evaluation and reevaluation instrument and process is identical to that used for hospital, NF, or ICF/MR admissions. If it differs, explain how and why it differs and provide an assurance that the outcome of the new evaluation/reevaluation form is reliable, valid, and fully comparable to the form used for hospital, NF, or ICF/MR placement.

A functional screen would be a simpler to use and less labor-intensive than the state's existing process, savings could be investing in screening all individuals for DDD-funded services, rather than just those requesting Medicaid-funded services. A universal screening and intake process would be a practical, near-term step toward creating the type of single point of entry system discussed in Chapter III of the report. It also would offer state policymakers and administrators a clearer picture of current unmet demand for specialized, state-financed developmental disabilities services and supports.

DDD should review a sample of individuals determined ineligible for adult DD waiver services to ascertain the basis for such denials and whether the present LOC eligibility process is affecting entrance into the HCBS waiver program. [N.B., The NASDDDS project team was told that PAS/ISC agencies frequently do not formally deny eligibility for waiver services but instead informally tells individuals that they are not eligible.] DDD also should consider validating the ICAP as a screening instrument for waiver eligibility LOC determinations and, perhaps, for receiving any state-financed services furnished through the DDD service delivery system.

Review the Requirement for Active Treatment as a condition of Waiver Participation. As pointed out in Chapter II, in order to participate in the Illinois HCBS waiver program for adults with developmental disabilities an applicant must not only meet the state's ICF/MR level of care criteria but also be found to be in need of active treatment services. While active treatment needs are a prerequisite for admission to an ICF/MR-certified facility, CMS has acknowledged on

¹⁷ Indiana Supports Waiver, Appendix D-1, Attachment 14, November 2001.

repeated occasions that the need for active treatment is *not* a requirement of participation in an HCBS waiver program (see, for example, Medicaid Letter Number 97-10, “Guidelines for What Constitutes an ICF-MR Level of Care Under a Home and Community-Based Services Waiver”). More recently, a summary report on President Bush’s New Freedom Initiative, entitled *Delivering on the Promise* (Chapter III, Actions to Address Barriers) noted that CMS must: “Clarify that the need for “active treatment” is distinct from level of care and not required in order for an individual with MR/DD to qualify for services under an HCBS waiver.” This statement gives additional support to the interpretation that the need for active treatment is not an eligibility requirement for HCBS waiver programs. Furthermore, federal HCBS waiver regulations state that the individuals enrolled in the waiver *would* be eligible for entrance into an ICF-MR “but for the provision of such [HCBS] services,” based on language contained in the authorizing statutes under Section 1902(c)(1) of the Social Security Act. Based on these interpretations, most states have removed references to active treatment from their waiver eligibility criteria recognizing that the waiver program functions as an alternative to the need for active treatment in an institutional setting.

DDD assured the review team that at present the inclusion of the active treatment requirement has not had a primarily dampening effect on waiver eligibility. This may be because the present waiver program focuses on individuals with the most substantial needs (particularly out-of-home placement). As DDD looks toward including other populations – for example individuals living at home or those needing modest levels of support to remain in the community – the active treatment requirement may have an impact on eligibility for these populations. It is worthwhile, therefore, for DDD to monitor CMS interpretations for any new guidance regarding active treatment and the waivers with an eye toward eventually removing active treatment as a state waiver eligibility criteria.

D. Improving Medicaid Community Service Participation Levels

Medicaid has evolved from a program of health insurance for low-income individuals and families to a program offering an extensive array of institutional and home and community-based long term supports for individuals with disabilities of all ages and a wide variety of disabling conditions. In order to participate in the Medicaid program, states must offer a set of mandatory services, described in 42 CFR 440.210 and 42 CFR 440.220. These mandatory services include basic health and medical services, such as physician’s services and hospital and nursing home care. States also may elect to include a set of optional services under their Medicaid State plans, including physical, occupational and speech therapy, home health services, and ICF/MR services. Optional service coverages are detailed in 42 CFR 440.225. Medicaid also allows states to apply for a variety of waivers, including HCBS waivers, as a means of expanding eligibility and the types of services offered under a state’s Medicaid program.

As noted earlier in this report (see Chapter II), Braddock, et al. report that three out of every four dollars states expended on specialized long-term services and supports for persons with developmental disabilities in FY 2000 were channeled through the federal-state Medicaid program. Clearly Medicaid financing of community services is now an essential part of serving individuals with developmental disabilities. Therefore, this section of the chapter is devoted to an analysis of the various ways the Illinois Medicaid program impacts on children and adults with

developmental disabilities. We also explore possible steps state policymakers might take to make more effective use of Medicaid financing on behalf of this population.

1. General State Plan Coverages

Illinois has a comprehensive state Medicaid plan that covers many optional services important to individuals with developmental disabilities. Services such as speech and language, occupational and physical therapies are covered. Personal care and private duty nursing is available along with targeted case management to children ages 0-3 with disabilities. Home-based ventilator care is offered along with prosthetic devices and hospice care. The Illinois state Medicaid plan covers chiropractic care along with optometry and podiatry services. Although consumers indicate concerns about accessing dental care (a concern common to many other state Medicaid programs across the country), the State plan provides some dental services as well.

Early Periodic Screening, Diagnosis, and Treatment Services (EPSDT). Federal EPSDT rules require states to conduct periodic medical, vision, hearing, and dental screenings for Title XIX-eligible children as a part of their preventive care programs. The second purpose of EPSDT is to ensure that children receive the services they need to treat identified health problems. EPSDT mandates that Medicaid-eligible children receive coverage of all services necessary to, “diagnose, treat, or ameliorate defects identified by an EPSDT screen.”¹⁸ CMS regulations also indicate that EPSDT services must include, “services within the Medicaid statute whether or not the services are generally included under the state’s Medicaid plan.”¹⁹

Data on the number of EPSDT screenings expected to be performed in Illinois and the actual number performed indicate that the state generally is carrying out obligations under federal laws and regulations. Extensive use of EPSDT also is evidenced by the claiming for school-based health services and early intervention services under the state’s Medicaid program. According to CMS statistics for 1999 (the most recent year in which compiled statistics are available), Illinois screened 92 percent of the children expected to be eligible based on CMS predictions.²⁰ The high rate of screening indicates that Illinois makes good use of the EPSDT benefit.

School-based Medicaid Claims. States have the option of claiming Medicaid for school-based health and health-related services on behalf of Title XIX-eligible children, such as therapies, case management and nursing services. The Illinois Department of Public Aid (IDPA), the single state Medicaid agency, is responsible for the administration of the State plan. IDPA, in close cooperation with the Illinois Board of Education, has done exemplary job in maximizing Medicaid financial participation in the cost of furnishing school-based health services to children from low-income families. IDPA reports that 934 school districts—all but a very few—claim Medicaid reimbursement for school-based services. Medicaid claims cover the cost of services provided by both school employees and contracted providers. The services reimbursed are linked

¹⁸ SMD Letter 001-006: Olmstead Update No. 4, Attachment 4-B, Subject: EPSDT and HCBS Waivers, dated January 10, 2001, p. 1.

¹⁹ Medicaid and School Health Guide, CMS August, 1997, p.73.

²⁰ Annual EPSDT Participation Report, FY: 1999, issued by CMS 10/15/02.

to the health and health-related services specified in each child's Individual Education Program. Illinois DPA has been effective in seeking Medicaid reimbursement for school-based services, thus there is little likelihood that a significant amount of additional federal revenue can be obtained in this area of Medicaid policy.

Early Intervention Services. The Early Intervention Bureau (EIB) within the Illinois Department of Human Services manages the state's program of infants and toddlers, ages 0-3, with disabilities and significant developmental delays. As pointed out in Chapter II, EIB contracts with a statewide network of 25 Child and Family Connections (CFC) to provide intake and case management (IFSP development) services to eligible newborns and toddlers and to track client information. According to an October 2002 report on the status of early intervention services which IDHS filed with the state General Assembly, in FY 2002 Illinois' EI program served 20,993 infants and toddlers. The report indicates that the national participation rate in EI programs is about 2 percent of children under age three. Illinois exceeds this rate, despite the fact that the state uses stricter entrance requirements than the average state. Data from this same report indicates that 58.1 percent of children with Individualized Family Support Plans (IFSPs) were Medicaid eligible. Given Illinois' somewhat restrictive Medicaid eligibility requirements, the state's EI participation and Medicaid eligibility rates appear to be at quite acceptable levels. Under the circumstances, there did not appear to be a clear rationale for conducting an in-depth analysis of ways in which the state might improve its EI Medicaid claiming practices.

2. Managing Participation in Medicaid

Under-Enrollment. Until this past year, DDD did not maintain a comprehensive database on individuals enrolled in the adult DD services waiver program. As a result, there was a considerable (but undocumented) degree of under-enrollment in Medicaid among participants in waiver-reimbursable service (see further discussion of this point under Section A-7 above). At present, there are no requirements that individuals apply for Medicaid benefits when they enter the DDD services system, thus potentially eligible individuals may not be enrolled.

As Chapter III points out, Illinois lacks a fully functioning single point of entry system. Although PAS/ISC agencies perform a single point of entry function for persons seeking to enroll in specialized Medicaid-funded services (e.g., admission to ICFs/MR and SNF/Peds; enrollment in the adult DD services waiver program; etc.), they do not track the potential Medicaid eligibility of persons enrolled in DDD grant-funded community services or applicants for such services. Because a considerable portion of the state's community service system is funded with grant dollars, individuals with disabilities and their families may go directly to community provider agencies when seeking services. As noted earlier providers may choose to serve individuals if they can be accommodated them within current funding level. Until recently there was no required centralized client registration or database of all individuals served with DDD funding. DDD has worked hard over the past year to obtain basic information on all individuals served through DDD funding, regardless of whether the person is enrolled in a Medicaid-financed service. This information should make it somewhat easier to pinpoint recipients of services who are potentially eligible to enroll in the Medicaid program but have not yet applied. But, additional steps will need to be taken if the state is to maximize federal Medicaid revenue.

In the 39 states where Medicaid eligibility is linked directly to SSI eligibility, it is relatively easy to identify service participants who are potentially eligible to participate in Medicaid-financed services. In 209(b) states such as Illinois, however, Medicaid eligibility is determined separately from eligibility for SSI benefits. Also, because 209(b) states are permitted to use standards for establishing a qualifying disability that are more restrictive than those used by the federal SSI program, situations may arise where an individual qualifies for federal SSI benefits but is not eligible for Medicaid benefits. Tracking eligibility as individuals' income changes also is more challenging in 209(b) states. In states that base Medicaid eligibility on federal SSI disability standards, the Social Security Administration tracks changes to income and shares this information with participating states. Once a person's income reaches the allowable SSI maximums, the person usually is automatically dis-enrolled from SSI and Medicaid simultaneously. For the above reasons, it is even more critical that Illinois regularly track the Medicaid eligibility status of individuals receiving DDD-funded services.

Based on FY 2002 expenditure data provided by DDD, The State of Illinois expended approximately \$39.3 million on community services targeted to children aged 0-17.²¹ If even half of these funds could be matched with federal Medicaid dollars (seemingly a conservative estimate based on the experiences of other states and Illinois' experience with early intervention services, the state could collect \$19.5 million in additional federal revenues just for children's services. This leaves nearly \$500 million in the adult system, approximately 60 percent of which already is tied to Medicaid financing through the state's HCBS waiver program for adults with developmental disabilities. If even 70 percent of the unmatched balance could be matched with federal Medicaid payments the state would receive an additional \$84 million in FFP. Of these funds, a percentage, no doubt, would have to be invested in improving service programs to meet Medicaid qualifying standards and to strengthen the state DD service delivery infrastructure to assure compliance with Medicaid accountability and oversight requirements. Even so, there would be a net gain for the state.

Given the other cost drivers, it will be important to obtain an accurate estimate of the number of children and adults currently receiving DDD-funded community services and supports who are qualified to enroll in the Medicaid program. This estimate will form the basis for a more detailed analysis of aggressively enrolling new individuals in the Medicaid program, both in terms of the existing DD adult services waiver program as well as the other alternative waiver program suggested in Section B-2 of this chapter.

3. Instituting a Medicaid Application and Utilization Mandate

Beyond the expanded eligibility options discussed earlier, another approach to increasing Medicaid enrollment is to institute a requirement that all individuals and families who are potentially eligible apply for Medicaid benefits as a condition of enrolling in DDD-funded services. Such a mandate would obligate all potentially eligible individuals/families to apply for Medicaid and, if found eligible, enroll in the program. Medicaid would become the funding of first resort for all needed and allowable services to Title XIX-eligible, thus allowing the state to maximize federal financial participation in DDD-funded community and institutional services. If a person is ineligible for Medicaid or does not meet HCBS waiver eligibility requirements, DDD

²¹ Children's Services Expenditures Y-T-D FY 2002 and FY 2003.

certainly has the option to fund services with state-only dollars if the individual meets DDD eligibility criteria and is included in one of the Division's priority populations. This mandate extends to HCBS waiver enrollment.

DDD will have to develop more robust information tracking systems in order to effectively manage a service delivery system in which Medicaid revenues are maximized (see Chapter III for suggestions on claiming enhanced FFP in the design and implementation of an upgraded management information system). Meanwhile, the following sequential steps should be taken to institute a mandatory Medicaid application/enrollment policy:

- First, DDD should analyze existing information on all recipients of DDD-funded services in order to ascertain the number of individuals who are potentially Medicaid eligible. DDD is in the process of completing such an analysis. Determining the names and locations of individuals who are potentially eligible for Medicaid benefits but not currently enrolled in the program forms the foundation of any analysis of potential increases in Medicaid enrollment and FFP for DDD-funded services.
- Second, DDD should restructure the PAS/ISC intake process to improve data collection on the Medicaid eligibility status of recipients of and applicants for DDD-funded services. PAS/ISC agencies should be given explicit directions regarding the type and quality of information they are required to gather and report on DDD-funded service recipients/applicants.
- Third, DDD should require that all recipients of and applicants for DDD-financed services be screened to ascertain if they are Medicaid eligible and meet the level of care (LOC) requirements to participate in the state's adult DD services waiver program. Simplifying the LOC screening process (as proposed above) and assuring the process appropriately screens all eligible individuals are important aspects of implementing maximizing FFP in DDD-funded community services.

In most states, the HCBS waiver program increasingly is the funding stream of "first resort." State-only funds are used to fill gaps left by individuals who are ineligible for Medicaid benefits or who fail to meet the eligibility requirements of the state's HCBS waiver program(s) for persons with developmental disabilities. State dollars also are used to cover non-allowable Medicaid costs, such as room and board expenses. All individuals are screened for Medicaid and waiver eligibility as they enter the services system.

Some states have already instituted Medicaid application/enrollment mandates, while other states have a "de facto" mandate. Minnesota, for example, has had long-standing rule that requires state officials to seek federal funds for any and all services and individuals that can be covered under federal programs. Pennsylvania's COMPASS/ISCS system allows individuals to simultaneously apply for all relevant federal/state programs and benefits on entry into the state's human services system. Wisconsin has a mandate that requires individuals who are Medicaid and HCBS waiver eligible to receive their services through those funding streams.

E. Claiming Medicaid Reimbursement for Case Management (Service Coordination) Services

1. Current Medicaid Claiming Practices in Illinois

PAS/ISC agencies provide service coordination (case management) to individuals with developmental disabilities who are enrolled in DDD-funded community services programs. Funding for service coordination to DDD clients comes from several program sources. Individuals enrolled in the adult DD services waiver program (as well as other recipients of Medicaid-funded services) receive Individual Service and Support Advocacy (ISSA) services through PAS/ISC agencies. The ISSA service coordinators are required to make four face-to-face contacts with the individual each year to:

1. Prepare and review the Individual Service Plan;
2. Complete an annual Consumer Satisfaction Survey;
3. Plus one visit to the person's home; and
4. One visit to the person's day or vocational program.

Additional visits may be scheduled as needed by the person, but the service coordinator must document in the individual's record the justification for additional face-to-face contacts. PAS/ISC agencies bill ISSA at a rate of \$37.14 per hour (FY 2003), calculated on a quarter hour, fee-for-service basis. DDD claims ISSA service costs as a Medicaid administrative expense under the state's administrative recovery plan. Individuals enrolled in the HCBS waiver program also receive some case management services – called service facilitation – through community provider agencies that furnish home-based supports (in-home supports). There also is a component of the day training rate that supports case management services.

PAS/ISC agencies also provide service coordination services to individuals who are part of the class covered by the *Bogard* settlement agreement. These are individuals with developmental disabilities receiving “specialized services” while living in nursing facilities.

Based on interviews with the PAS/ISC agencies, all other service coordination services are furnished on an “as needed” basis. The PAS/ISC agencies provide information and referral services to individuals/families seeking services who contact them. PAS/ISC agencies receive grant funding to cover the costs of service coordination services furnished to children and non-waiver eligible adults through the Program 500 appropriation.

2. Alternative Case Management Claiming Options Available Under Federal Medicaid Policy

Four options are available to states interested in claiming federal Medicaid reimbursement for case management activities: (1) administrative case management, (2) optional targeted case management under the state's Medicaid state plan, (3) case management claimed as a waiver service, and (4) case management as a component of another Medicaid-reimbursable service. Each of these options has specific requirements that proscribe the conditions under which FFP may be claimed. Decisions as to the best option rest on the scope of case management activities

performed and the best reimbursement option for those activities. Chart V-1 offers a side-by-side comparison of the three reimbursement options for stand-alone case management under Medicaid.

Under the **administrative option**, states may claim FFP for “necessary and proper administration” of the State plan (42 CFR 433.15(b) 7). Given this limitation, administrative case management applies only to those activities directly tied to a service billed to Medicaid, either through the State plan or as a HCBS waiver service. Thus, if a case manager attends a meeting with the state vocational rehabilitation agency, say, to arrange financing of supported employment services, this time is not claimable as a Medicaid administrative expense. The same rule applies to attending a school program or setting up a class at a community college on behalf of the individual. Although one could argue that these services have an impact on the individual and may actually interact with Medicaid services, these types of activities do not relate, strictly speaking, to Medicaid financed services. Presently, Illinois claims reimbursement for case management services to individuals with developmental disabilities enrolled in the adult DD services HCBS waiver program via the state’s administrative cost recovery plan as well as a component of the service rate for CILA services.

Targeted case management (TCM) is an optional Medicaid state plan coverage. Although CMS has never published final regulations implementing this coverage option, coverage of targeted case management is authorized under Sections 1905(a)(19) and 1915(g)(2) of the Social Security Act. CMS has issued guidance on targeted case management through State Medicaid Director letters and the *State Medicaid Manual*. In a State Medicaid Director letter dated January 19, 2001, CMS described targeted case management as follows:

“....services which will assist an individual eligible under the State plan in gaining access to needed medical, social, educational, and other services. Case management services are referred to as targeted case management (TCM) services when the services are not furnished in accordance with Medicaid statewideness or comparability requirements. This flexibility enables States to target case management services to specific classes of individuals and/or to individuals who reside in specified areas.”

Targeted case management differs substantially from other Medicaid state plan services in that states can limit the types of Medicaid recipients who are eligible for the benefit as well as the individuals and entities that can provide such services. Other state plan services, in contrast, must be furnished on an entitlement basis to any eligible individual with “medical necessity” for the particular service. Under targeted case management, states can choose a specific target group and limit the benefit to those individuals. For example, a state could elect to restrict targeted case management services only to individuals enrolled in a particular HCBS waiver program(s), or to individuals with a certain condition, such as a brain injury or autism. Presently, Illinois uses the targeted case management coverage option to provide service coordination to infants and toddlers, ages 0-3, who are participating in early intervention services and non-institutionalized individuals with chronic mental illnesses.

Another unique feature of the targeted case management benefit is that states can limit beneficiaries’ right to freely choose among qualified providers of TCM services *but only in the*

case of individuals with developmental disabilities or chronic mental illnesses. Under all other Medicaid State plan services, the individual has the right to choose any qualified provider of the particular service. Under the targeted case management benefit, the state may limit the choice of providers to certain agencies or organizations expressly assigned to deliver case management services to individuals with developmental disabilities or chronic mental illnesses. This limitation on freedom of choice permits states to craft single point of entry case management systems that allow only designated agencies to perform case management functions.

The targeted case management option permits states to claim FFP for a wide range of case management activities, including time spent assisting individuals in accessing non-Medicaid funded services. Coordinating a comprehensive plan of care, attending school meetings or working on behalf of the individual with non-Medicaid organizations and providers are all allowable costs under the targeted case management benefit.

The third Medicaid financing option is **coverage of case management as a HCBS waiver service**. Case management may be provided as part of a covered service under a waiver granted in accordance with Section 1915(c) of the Social Security Act. Section 1915(c)(4)(B) specifically indicates that case management is a service which may be provided as part of a home and community-based waiver program. To include case management under a HCBS waiver program, a state must define the service and specify provider qualifications as part of its HCBS waiver application. When offering case management services under a waiver program, the service must be available to all individuals enrolled in the program. Individuals also must be afforded freedom of choice among qualified providers—i.e., a state cannot limit providers of this service to a specific agency or type of agency, such as a county or community developmental disabilities board. Any entity or individual that meets the qualifications must be treated as an eligible provider of case management services and, thus, it is more difficult to establish a single point of entry system under a HCBS waiver program in which one organization or agency is responsible for furnishing case management services within a designated geographic catchment area. Table 5.2 on the following page summarizes the principal features of the three freestanding options for claiming Medicaid reimbursement for case management services.

The fourth Medicaid financing option is to claim federal reimbursement for **case management activities as a component of another Title XIX covered service**. For example, since preparation of a service plan by a home health provider is a required activity, a separate payment cannot be made for this activity under Medicaid regulations. But, the state's home health payment rate may include the cost of service plan preparation. Under the HCBS waiver program authority, case coordination activities performed by residential service providers may be reimbursed as a part of the rate paid to the provider agency for residential habilitation services. This type of coverage is analogous to the service facilitation functions performed by community provider agencies under Illinois' HCBS waiver program for adults with developmental disabilities. This option makes the most sense when case management is an integral component of another direct service, rather than a stand-alone service.

Table 5.2 Medicaid Funding for Case Management

	HCB Waiver	Targeted Case Management	Administrative Claiming
Statutory Authority	Section 1915(c) of the Social Security Act	Section 1915(g) of the Social Security Act	1903(a) of the Social Security Act
Regulations	42 CFR 441.300 - 308	Proposed: 42 CFR 431, 440,441,447	42 CFR 433.15
Persons Who May Be Served	-Medicaid eligible individuals who qualify for HCB waiver program (i.e., individuals who meet ICF/MR level of care)	-Medicaid eligible persons who fall within the target group definition -A state may operate multiple TCM programs for various groups -No "institutional" need test	-Medicaid eligible individuals for whom activities are performed by an administrative entity
FFP rate	FMAP service match rate	FMAP service match rate	50% FFP match rate
Covered Activities	"Services which will assist individuals in gaining access to needed waiver and other state plan services as well as medical, social, educational and other services, regardless of the funding source for the services to which access is gained" ("standard" CMS definition) -Other activities defined by the state and approved by CMS	-Services to assist individuals in gaining access to needed medical, social, educational or other services, including: -Follow-up or monitoring an individual's progress or status -Service plan development -Monitoring to assure services are received -Other activities as defined by the state and approved by CMS	Activities that promote the "proper and efficient" administration of the Medicaid state plan, including: -Medicaid eligibility determination and redetermination -Medicaid intake processing -Preadmission screening -Prior authorization -Medicaid outreach -Other activities as defined by the state and approved by CMS
Limitations	-Individual must be enrolled in HCB waiver -May not simultaneously claim for HCB and TCM for the same person -"Direct services" may not be furnished	-TCM cannot be provided to institutionalized individuals - Prior authorization activities cannot be conducted -"Direct services" may not be furnished	-FFP only available for assisting individuals to gain access to Medicaid services -"Direct services" may not be furnished -No individual right to services or selection of provider
Providers	-Provider type and qualifications defined by state and approved by CMS -Must offer freedom of choice of any qualified provider	-Provider type and qualifications defined by state and approved by CMS -May limit provider types to specific entities or organizations	-Typically the single State Medicaid Agency -May be performed by an entity other than the Single State Medicaid Agency through an Interagency agreement

3. Alternatives Available within Illinois' DD Community Services System

Illinois' existing Federal Medical Assistance Percentage (FMAP) or matching ratio, for both service and administrative costs is 50 percent²². States with higher service matching ratios (ranging up to 78% in the case of Mississippi) are able to obtain enhanced FFP by claiming case management activities as a service rather than as an administrative cost. But, in Illinois, where the state's service and administrative reimbursement rates are identical, there is no advantage to one approach over the other. However, when recovered as an administrative expense, a somewhat narrower range of activities can be claimed for federal reimbursement than is the case when such activities are claimed as service costs, either as a HCBS waiver covered service or as targeted case management services under the state Medicaid plan.

There may be opportunities to increase the amount of FFP Illinois receives for service coordination (case management) activities performed on behalf of Medicaid-eligible persons with developmental disabilities. DDD officials should review the present ISSA administrative claiming methodology to determine whether it would be advantageous to switch the state's basic method of claiming reimbursement for service coordination to the targeted case management coverage option. There are two potential advantages of switching to the TCM coverage option. First, as noted above, the state would be able to receive reimbursement for a wider range of service coordination activities performed on behalf of present recipients of ISSA services. Time spent dealing with schools, vocational rehabilitation agencies and other providers of generic community services would be billable as Medicaid expenses. And, second, the state would be able to define a TCM target population that includes Medicaid-eligible recipients of grant-funded services as well as current recipients of ISSA services. Because the state's adult DD services waiver program at present does not cover key community DD services such as grant-funded developmental training and host family services, any time that a service coordinator from a PAS/ISC agency spends working with Medicaid-eligible individuals who are not enrolled in the waiver program are not being claimed as Medicaid expenses, but could be under a properly crafted TCM state plan amendment.

DDD fiscal records indicate that \$4,526,905 was expended on Program 500 grant funds for case coordination services during FY 2002. A total of 3,436 individuals received these services, of whom approximately 3,000 were 18 years age or older.²³ If we assume that 80-90 percent of adults with developmental disabilities who are receiving such services would qualify for Medicaid benefits (an estimate that squares with most states' experience), it is clear that the state should be able to generate at least \$1.5 to \$2 million in additional FFP by broadening the target population for Medicaid-reimbursable case management/service coordination services. These figures do not take into account the revenue potential associated with including selected groups of children with developmental disabilities as a target population – either as an adjunct to or separate from the adult DD services target population.

²² Illinois will receive a 52.95% FMAP for the five quarters beginning on April 1, 2003 as part of the federal initiative to temporarily enhance federal support of the Medicaid program.

²³ This figure deserves some review, however, since the FY 2002 *projected* caseload for this service category indicated that 7,164 individuals would be served.

Despite repeated attempts, the NASDDDS project team was unable to ascertain the exact methods used in establishing the amount of administrative claims for service coordination. Lacking access to the detailed methodology, it was not possible to determine if non-allowable expenses were being billed to Medicaid or to assess the potential advantages of shifting the state's claiming method to a TCM state plan coverage. Absent a review of the current methods, no trustworthy analysis of present activities and payments is possible.

Switching to the targeted case management option not only would offer the state potentially a better mechanism to finance service coordination activities but it would provide a means of moving toward the type of single point of entry system discussed in Chapter III. As noted earlier, federal law and regulations governing the targeted case management coverage option permits states to restrict the types of providers of TCM services in the case of services to individuals with developmental disabilities. Under a properly constructed TCM state plan amendment, PAS/ISC agencies could be designated the exclusive providers of case management/service coordination services within their respective catchment areas, thus strengthening the role of these agencies as the single door through which individuals with developmental disabilities and their families can access specialized state-funded services and supports.

Very few states use administrative claiming as their basis for recovering federal Medicaid payments for case management services furnished to individuals with developmental disabilities. With the exception of four states, case management services for persons with developmental disabilities are claimed either through the TCM state plan option or as a service under an approved HCBS waiver program.²⁴ States clearly prefer the flexibility of claiming reimbursement for non-Medicaid related activities performed by the case manager/service coordinator on behalf of Title XIX-eligible individuals.

Over the past few years several states have changed from waiver-reimbursed case management services to the targeted case management coverage option for individuals enrolled in HCBS waiver programs. Pennsylvania, for example, switched to the TCM coverage option after a CMS review team voiced concern about the Commonwealth's practice of limiting the vendors of case management services to county-designated base services units. If Pennsylvania continued to cover case management services under its HCBS waiver programs for persons with mental retardation, it would not be able to restrict the providers of such services to county-designated contract agencies, thus undermining basic concepts underlying the state's single point of entry philosophy.

North Carolina also was recently cited by CMS for failing to offer HCBS waiver participants with developmental disabilities freedom of choice among providers of case management services. As a result, North Carolina has decided to open case management to all qualified providers. Consequently, the state Division of Mental Health, Developmental Disabilities and Substance Abuse Services has had to redesign case management, restructure the responsibilities of its local management entities, and institute extensive training on case management roles and responsibilities.

²⁴Cooper, Robin and Smith, Gary, *Medicaid and Case Management for People with Developmental Disabilities*, NASDDDS, April 1998, p. 45

F. Conclusion

Current federal Medicaid policies afford states a wide range of options for claiming Medicaid reimbursement on behalf of children and adults with developmental disabilities who are in need of home and community-based services and supports. These options often are surrounded by a complex web of federal statutory, regulatory and administrative policies which state officials and disability advocates must take into account in fashioning a revenue management plan best suited to the policy objectives the state hopes to achieve.

In this chapter, we have examined Illinois current methods of claiming Medicaid reimbursement for persons with developmental disabilities and compared them to the current options available under federal Medicaid law and regulations as well as to the policies and practices followed by other states in financing specialized services for the MR/DD population. Special attention has been devoted to analyzing the state's existing approach to using the Medicaid home and community-based waiver authority to capture federal financial participation in the cost of community-based developmental disabilities services. We elected to emphasize the HCBS waiver authority because clearly it is the primary vehicle available to states interested in improving the rate of Medicaid recovery of state expenditures for specialized MR/DD services.

Due to the lack of critical elements of utilization and cost data – especially information on the Medicaid eligibility status of persons currently receiving granted funded services as well as individuals and families waiting for specialized DD services – the project team was unable to develop firm revenue estimates in connection with many of the financing options raised in this chapter. Hopefully, however, we have been able to marshal a sufficient body of facts and figures to illustrate the merits of completing a more in-depth analysis once a robust database is available. Certainly, the results of our analysis underscore the importance of pursuing some of the system management improvements discussed in Chapter III of the report.

Chapter VI

CLAIMING ADMINISTRATIVE COSTS

The federal government matches state spending on allowable Medicaid costs. Generally, federal matching payments for administrative expenses are open ended (i.e., not subject to expenditures caps).¹ The matching rates for administrative costs, unlike state service matching rates, are uniform across all participating states. Administrative match rates, however, do vary by function.

Most types of allowable administrative costs incurred by state Medicaid programs are matched on a dollar-for-dollar basis by the federal government (i.e., a 50/50 matching ratio). States, however, receive a 75 percent federal match for expenditures in connection with certain administrative functions, including:

- training or compensation of physicians, nurses and other skilled professional medical personnel used by the state Medicaid agency (or other state and local agencies) to administer the state's program;²
- operation of a Medicaid management information system (MMIS);
- survey and certification of nursing facilities and ICFs/MR;
- performance of medical and utilization reviews or quality assurance by a Quality Improvement Organization (formerly referred to as a Peer Review Organization) or an External Quality Review Organization.
- operation of state Medicaid fraud control units (MFCUs).

In the case of MMIS systems and MFCUs, states are reimbursed by the federal government for 90 percent of allowable start up costs (e.g., design and installation). In addition, the federal government pays 100 percent of the costs incurred by states in verifying the immigration status of Medicaid applicants and beneficiaries.

In 1997, the states collectively spent \$6.6 billion (federal and state dollars combined) on administering their Medicaid programs. This amount represented 3.9 percent of total Medicaid

¹ The federal government's matching payments to Disproportionate Share Hospitals (DSH), in contrast, are subject to annual, state-specific caps.

² CMS notified state Medicaid agencies on November 21, 2002 that, effective January 1, 2003, enhanced federal matching at the 75 percent level no longer would be available for activities performed by elementary and secondary school staff members functioning as skilled professional medical personnel (see SMDL #02-018).

spending that year, or an average of \$163 dollars per Medicaid recipient.³ There were wide state-to-state variations in the percentage of total Medicaid outlays obligated for administrative costs, ranging from a high of 9.3 percent of total Medicaid outlays in Oklahoma to a low of 1.7 percent in New Jersey. Illinois' administrative costs were above the national median for all states as measured both on a per recipient basis (\$186) and as a percent of total Medicaid outlays (5.1%).⁴ These state-to-state variations are due in part to the fact that some states historically have been more aggressive in claiming federal administrative matching funds (for example, in connection with the provision of school-based health services). But, another factor is the differences in how states classify various types of expenditures. For example, some states treat case management services as an administrative cost, while others treat it as a service cost (either under the targeted case management state plan option or as a coverage under HCB waiver programs, or a combination of both approaches).

A. Administrative Claiming Strategies: State-Operated Services

Medicaid rules allow states to claim reimbursement for administrative activities using two basic methods. Allowable administrative expenses can be claimed as an administrative component of the unit cost for a Medicaid service and hence become part of the rate or fee set for that particular Medicaid service. Allowable administrative expenses also can be claimed for administrative activities undertaken as part of the state's responsibility for the management of a Medicaid program or a related Medicaid function.

The State Operated Developmental Centers are facilities that deliver Medicaid reimbursable services, the only type of Medicaid-reimbursable service provided directly by state staff of the Division of Developmental Disabilities. Thus, the IDHS has the opportunity to allocate a broad range of administrative expenses to the Medicaid reimbursable costs of the services delivered in each state developmental center.

The Department of Human Services' Office of Fiscal Services coordinates the calculation and billing for services provided in the developmental centers. The Department has a long-established methodology for calculating the administrative expenses associated with State Operated Developmental Centers that are over and above the direct expenses budgeted for the operation of each center. It was very clear from all of the interviews conducted by the NASDDDS project team that Departmental managers involved in calculating SODC-related administrative expenses had a clear understanding of the methodology and the expertise to ensure that the methodology was applied as designed.

This methodology has been developed in conjunction with a nationally recognized consulting firm (Maximus, Inc.). It has three major components, the first two of which are used as components of each developmental center's billing rate. The third component is billed separately from the developmental center billing rate as part of an administrative claim for the Department.

³ Schneider, Andy, *The Medicaid Resource Book*, The Kaiser Commission on Medicaid and the Uninsured: Washington, DC, July 2002, p. 145.

⁴ Ibid, p. 146.

This is a choice that has been made, but not one that had to be made. The first two components of the developmental center's billing rate:

Administrative Expenses From Other State Agencies. Federal Medicaid rules allow states to create reimbursement methodologies that include expenses from state-operated or state-delivered services (those provided by state staff or by a state agency through a contract with a provider agency). The Department has a component in its administrative cost recovery methodology that is euphemistically called the "Statewide Cost Allocation Process." This component represents the aggregate dollar amount of expenditures from state agencies other than the Department that have been determined to be "allowable" under Medicaid as administrative expenditures in support of developmental center operations. This aggregate amount gets added to the total cost of delivering services in the developmental centers as the billing rates for the nine developmental centers are calculated.

Review of this methodology suggests that it includes the appropriate step down calculations from state agencies outside of the Department of Human Services. Included are expenses incurred by the Department of Public Aid and Bureau of the Budget, among other agencies that have responsibility for Medicaid-related administrative functions. Review of this Statewide Cost Allocation Process (SWCAP) methodology and its associated increases to the billing rates for the nine developmental centers strongly suggests that there is no opportunity to increase revenue from this component of the methodology for claiming administrative expenditures.

Administrative Expenses from the Division of Developmental Disabilities (DDD). As is typical of most Medicaid reimbursement methodologies that involve state-operated or state-delivered services, the Department identifies those DDD cost centers outside of the developmental centers themselves that have direct responsibility for managing developmental center operations. The allowable expenses of these seven (7) cost centers are added to the total cost of developmental center operations as the billing rates are calculated for each center. Each of these cost centers is included in the Department's "Program Administration – Disabilities and Behavioral Health" portion of its budget, which also includes cost centers for all of the Division as well as the Division of Mental Health. During FY 2002 a total of \$62,404,000 was expended in this budget category. Spending plan data that would indicate the amount of those expenditures targeted for DDD administrative expenditures in support of DD Operations was not available for this analysis.

The percentage of total expenditures related to each cost center is based upon the percentage of activity that is determined to be dedicated to managing developmental center operations. These percentage ranges from 100 percent (for those DDD cost centers that are dedicated to developmental center operations) to less than 35 percent for cost centers that have management responsibilities for developmental centers and other DDD program areas as well. The percentage considered as allowable for inclusion in the developmental center billing rates is based on a survey of DDD staff in the involved cost centers. This survey, conducted quarterly, documents the percentage of time spent on developmental center operations and related activities. This aggregate amount comprises the second administrative component to be added into the price per day of developmental center care.

A review of the cost centers that are wholly included in this calculation suggests that all appropriate, dedicated (to developmental center operations) administrative activities have been included. These cost centers have staff that spend all or parts of their work week on administrative activities directly related to developmental center operations - as distinct from those DDD and/or DHS cost centers that have “back office” or “overall” administrative activities that support developmental center operations. No other cost centers appear likely to qualify for this administrative component.

Data were not available to determine whether this administrative component of the developmental center billing rate was being calculated efficiently. The amount of each cost center’s expenditures that are allocated to the developmental center billing rate calculations are based solely on the findings of the survey of the staff in the affected cost centers. There is no baseline that is used to evaluate that data and determine how it compares to either the baseline or to a projected level of activity that would be expected to be dedicated to developmental center operations, from management’s perspective. While there is no data that suggests that this is not the most efficient allocation of expenditures from these seven DDD cost centers, there also is no data that confirms that it is.

Administrative Expenses from the Department of Human Services – In addition to the Division of Developmental Disabilities, the Department has many other administrative offices, bureaus and units that provide administrative support to the Division’s capacity to manage developmental center operations. Funding for these offices, bureaus, and units appears primarily in the “Administration and Program Support” and “Management Information System” sections of the Department’s budget. These sections represented over \$188 million in expenditures during FY 2002 and the FY 2004 recommended budget included over \$171 million for these activities.

The amount of time that staff in each IDHS office, bureau or unit spend in administrative activities that support the Division of Developmental Disabilities, and especially the developmental center operations, is determined quarterly through a survey of all designated units and staff. This survey identifies the percentage of time that all such support units (MIS, human resources, fiscal services, etc.) spend on each program area within DHS. The percentage calculated through this survey process is then applied to the allowable expenditures for each unit or cost center. When administrative activities are involved that support the Department’s ability to administer Medicaid programs, then this percentage is used to calculate the administrative claim that can be made for each involved Medicaid program.

The Department uses this method to establish a Medicaid claim for reimbursement of allowable administrative expenditures for managing the Medicaid portion of the developmental center programs. This claim is submitted independently of the Medicaid billing claim for developmental center services and is not part of the reimbursement for the actual cost of care. Other states (New York, Louisiana and California, for example) have incorporated similar expenditures in the cost of care that is reimbursed through its Medicaid per diem rate. In Illinois, since the federal financial participation rate is 50 percent, there is

no advantage to either method. Likewise, since the developmental center reimbursement rate is cost-based and reconciled (see Chapter IV) this method creates no disadvantage.

As was the case with the cost allocation methodology discussion presented in the final paragraph of the previous section (“Administrative Expenses from the Division of Developmental Disabilities”), no data were available to evaluate the efficiency of this methodology.

Data was not made available that would allow the project team to determine the amount of administrative expenditures claimed by IDHS through these three vehicles. Therefore, the efficiency of these methods could not be evaluated.

No one interviewed in the Department or the Division as part of this analysis had any knowledge of the amount of revenue that was “budgeted” for revenue related to these three administrative claiming components. No one interviewed could identify who in other agencies (Department of Public Aid or Bureau of the Budget) would have such projections. The FY 2002, FY 2003, and FY 2004 budget and spending plan data made available for this analysis contained no sections identifying revenue as it relates to these administrative expenditure claims. These two issues suggest that Medicaid (and likely other revenue as well) related to administrative expenditures for the management and support of developmental center operations should be researched in some depth.

Action Steps. There are several actions which IDHS officials might consider taking, including:

- It is possible that a detailed analysis of all expenditures and the way that the staff surveys are completed could identify areas where a more focused definition of involved activities could either generate more consistent and, perhaps, increased allowable expenditure levels that could be claimed for Medicaid reimbursement, either as components of the developmental center billing per diem or as a separate administrative claim. It should also be noted that, if such an analysis identified that a recalculation could increase the claim for administrative expenditures (either as part of the developmental center per diem or as a separate administrative claim) that an adjusted claim could be submitted that corrects those calculations on previous claims.
- The Department also should consider creating a revenue budget that identifies the level of revenue that is expected to be associated with (or claimed) for administrative expenditures in each fiscal year. It could isolate those “Program Administration – Disabilities and Behavioral Health” and “Administration and Program Support” and other general administrative expenditures that it has budgeted for management of the developmental disabilities services funded in the budget. This budget could be constructed at the cost center level to provide the greatest ability to effectively manage the revenue opportunities that can or should exist. This revenue budget could be a component of the Department’s annual spending plan and provide guidance for its management of related revenues.

B. Administrative Claiming Strategies: Community Provider Agencies

Medicaid rules allow states to claim administrative activities for community services in much the same way that it does in the area of state-operated developmental center operations, as described above. Administrative expenditures can be calculated as part of the cost of care for a Medicaid service and included as part of the reimbursement rate or fee for that service, if, in fact, the approved rate or fee setting methodology identifies it as an allowable expenditure. In this case, the administrative expenditures can be for the community provider agency itself and, if it is operating under contract with the state agency or other governmental entities that have a provider agreement with the state, for those governmental agencies as well. In this case, the involved rate or fee-setting methodology would have to identify such expenditures as necessary to provide the service itself.

States also may claim reimbursement for administrative expenditures necessary to manage Medicaid programs or services furnished by community provider agencies. In this case, the Department can incur the administrative expenses itself, or they can be incurred by another governmental agency. In these cases, such administrative expenses must be necessary for the administration of the Medicaid Program and not cost incurred in delivering the service itself. Therefore, such expenses typically are submitted as separate administrative claims for Medicaid reimbursement.

In the Division's community service system, Medicaid-financed services are paid for in two different ways. In the ICF/DD program, facility-specific rates are set for each provider. The provider then bills the IDHS or the Department of Public Aid directly for payment for all days of care that are eligible for Medicaid reimbursement (indicated to be 99% of all days of care in ICFs/DD). The Department of Public Aid then pays the provider and claims the 50 percent of the Medicaid reimbursement from the federal government.

The ICF/DD rate methodology includes an administrative component for provider agency expenditures. A review of this methodology did not find any opportunity to expand the definition of allowable administrative expenditures. All allowable administrative costs included in the rate set through this methodology are fully paid. In defining allowable administrative expenditures DDD acknowledges that this administrative component of the payment rate does not fund all provider administrative costs associated with its ICF/DD programs. Many of the excluded items, such as fund raising and lobbying expenses, financing charges, etc., typically are not allowed under the rate setting methodologies of most states. In such cases, the provider agency must find other, non-Medicaid sources of funding to cover those costs.

The other Medicaid-financed services are paid for by the Division through contractual agreements between the Division and over 340 community provider agencies throughout the state. These services typically are home and community-based waiver services (HCBS). The rates paid for each service are established through a variety of methodologies. The existing rate methodologies used for Medicaid-financed services provided by community agencies include components that are associated with the provider's administrative expenditures.

However, unlike the ICF/DD system, the Division authorizes the payment of these rates (or fees for service) directly to the provider agency as a general fund payment and does not require them to be billed through the Department of Public Aid's MMIS. At the point where the Division has appropriate documentation that a payment it authorized that involves an eligible HCBS service delivered to an HCBS waiver-enrolled person by a provider agency with a "provider agreement" to deliver a Medicaid HCBS waiver service, the Department (with the assistance of the Department of Public Aid) submits a claim for that service. The claim then triggers a federal Medicaid reimbursement to the state (through the Department of Public Aid) in payment for that documented service. Thus, the provider agency does not directly bill to Medicaid for any portion of HCBS waiver services that are delivered.

This distinction (the process for payment for services and claiming Medicaid reimbursement) is important to a discussion of claiming for provider agency administrative expenses for two reasons. A review of the rate or fee-setting methodologies for these services identified only one instance where the methodology itself unnecessarily limited the amount of administrative expenditures that were included as allowable costs. That was for the CILA and CLF programs, which share a fee-setting methodology. These programs share a methodology that allows the Department to claim Medicaid reimbursement for only 95 percent of what it pays provider agencies as the administrative component of their payment rate. In FY 2002 it was projected that this policy reduced available federal revenue by approximately \$750,000. While not a huge dollar amount in the Department's overall budget, it is revenue that is easily available.

The second reason why this distinction is important is that paying providers through a contract and then claiming Medicaid reimbursement from the federal government creates an opportunity for the Department to revise its HCBS rate-setting methodology (for claims to Medicaid, not for payments to provider agencies) that would allow IDHS to add its own administrative component to the rates claimed for federal Medicaid reimbursement. This add-on administrative component would allow the Department to shift some of its administrative expenditures from the "administrative claim" to a "service-related claim." The primary advantage here is that the amount shifted to this claiming method would be prospectively set and would not have to be reconciled. If the revised methodology were properly articulated, once the new rates including this administrative component for the Department were set, related federal revenue could increase by a significant amount.

The Department also generates "administrative claims" for activities conducted in support of its management of the Medicaid-financed services provided through contracts with community provider agencies and for its ICFs/DD. These claims are developed in much the same way as described for the state operated developmental centers. Namely, all related Department and Division cost centers are surveyed quarterly to determine the percentage of time that is spent on each Medicaid-financed program or administrative area. This data is then used to identify those expenditures that can be claimed for Medicaid reimbursement. The Department has been working with a nationally recognized consulting firm (Maximus, Inc.) to create a new, random-moment survey to determine the percentage of staff time spent on each Medicaid-related program or administrative task. However, no decision has been made on whether or when this new survey methodology will be completed and implemented.

While this survey mechanism and related calculations appear to be standard methodologies similar to those used by other states, the Department has added one twist to the process that IDHS officials acknowledge may result in claiming less federal reimbursement than is possible. The Department conducts surveys that include the administrative support activities of both its Divisions of Developmental Disabilities and Mental Health. However, it combines the data reported for both Divisions, creating a single percentage that is then applied to both Divisions. Key Department managers acknowledge that the Division of Mental Health operates with a much smaller community services budget than the Division of Developmental Disabilities. In FY 2002 the Mental Health community budget was \$361 million, as compared a DDD community budget of \$931 million. It is also acknowledged that the Division of Mental Health provides fewer Medicaid-financed services and engages in a smaller percentage of Medicaid-related administrative activities than does the Division of Developmental Disabilities. This fact strongly suggests that if separate percentages were created for each Division there would be an overall increase in the amount of the administrative claim for these two Divisions. Unfortunately, neither the claims data nor the budget data segregates related expenditures in a way that allowed the increased revenue to be predicted as part of this analysis.

Furthermore, data were not available to allow the project team to determine whether the existing process of generating administrative claims was being calculated efficiently. The amount of each cost center's expenditures that are allocated to the Division's community-based, Medicaid-financed services are based solely on the findings of the staff survey for the cost centers participating in the survey. No baseline is used to evaluate and determine how the data compare to either the baseline or to a projected level of activity that would be expected to be dedicated to community services operations, from management's perspective. While there is no data that suggests that the current approach is not the most efficient allocation of expenditures from these seven DDD cost centers, there is also no data that confirms that is the case.

Action Steps. There are several actions which IDHS officials may wish to consider, including:

- Analysis of ICF/DD Cost Report Data - The Department of Public Aid collects cost report data on ICFs/DD. Cost report data often is used to identify those facilities where the rate methodology does not create a payment level that fully funds the administrative portion of provider costs. Other states have found, upon close analysis, that provider agencies have administrative expenditures which could be allowed but are in excess of the levels permitted under existing rate methodologies. At times, these situations result in the systemic use by provider agencies of other general fund revenue sources to subsidize these un-funded administrative costs. When such an "under-funding" situation exists, cost reports frequently can identify whether the ICF/DD-related administrative expenditures are supported by other funding sources. Therefore, cost report data should be analyzed to determine if there are significant provider agency expenditures that are not fully funded as part of the rate methodology and that are being subsidized by other general fund appropriations. If that is the case, then DDD should determine if, as a matter of policy, it wishes to include all or part of those expenditures as allowable for reimbursement purposes. If the answer is yes, then the Department should revise either the level of payment allowed in the administrative component of the rate-setting methodology or

modify the methodology itself to enable these expenditures to be included in the rate that is reimbursed by Medicaid.

- Revise HCBS Claiming Methodology for CILA & CLF Services – The Division should revise its methodology for these two services to include 100 percent of all payments made for the administrative component of fees paid to CILAs and CLFs. In FY 2002, over \$222 million was paid to private providers of CILA and CLF services. Of this amount, roughly \$33.35 million was paid for the administrative component of the involved rates. Since 90 percent of affected services were delivered to persons enrolled in the state’s HCBS waiver for adults with developmental disabilities, this data suggests that roughly \$0.75 million in new federal revenue could be gained each year by instituting this simple change in the state’s rate-setting methodology.
- Create a HCBS Rate-setting Methodology that Includes Departmental Administrative Costs. In service systems similar to the Illinois DD system, Medicaid rules allow states to add an administrative component to the rate that it pays provider agencies prior to submitting a claim for federal Medicaid reimbursement. The added costs must be allowable administrative expenses associated each specific service. This approach usually requires the paying entity (in this case DDD) to operate as an Organized Health Care Delivery System (OHCDS) and pay provider agencies (or other organizations or governmental agencies) under contractual agreements for the Medicaid services they provide to individuals enrolled in the HCBS waiver program. No one interviewed by the project team during the course of conducting its analysis knew if the Division currently operated under an OHCDS designation. However, the organizational structure that the Division currently uses to pay provider agencies and then submit claims for Medicaid reimbursement is based on contractual agreements that would appear to satisfy the OHCDS requirements, thereby suggesting that this designation already exists.

The Department should conduct an analysis to determine the Program Administration (Division of Developmental Disabilities), Administration and Program Support and MMIS expenditures that can be directly associated with the delivery and billing of each HCBS service that is furnished by community provider agencies. These expenditures would include all personnel expenditures, non-personnel expenditures and capital expenditures that are allowable under Medicaid rules. Once isolated, IDHS, in collaboration with the Department of Public Aid, could create a revised rate methodology that allows a base year to be established for these expenditures, identifies the assumptions by which these base year expenditures are expected to grow (cost of living adjustment factors, utilization, etc.) and specifies that the base year will be recalibrated regularly (every three or five years).

Using this methodological approach, it will be possible to create a far more predictable platform for seeking federal Medicaid reimbursement of administrative expenditures associated with several components of the Department’s budget. This new platform could shift a significant portion of such Departmental administrative expenditures associated with the Division’s community programs from the “administrative claim” to a “service-related claim.” By including a well-designed base year and pre-approved cost adjustment

factors, it is likely that IDHS will be able to generate increased federal revenues. In addition, the number of staff that will have to be included in the quarterly survey and administrative claim process will be significantly reduced. The fiscal impact of this recommended action cannot be predicted accurately without the analysis that determines the total administrative expenditures that are shifted to the new rate-setting calculations for the waiver services furnished by community provider agencies. However, it seems likely that, if designed appropriately, the state could realize at least a million dollars a year in additional federal Medicaid revenue.

- Revising the Administrative Claims Formula. The Department should create separate claiming percentages for the Division of Developmental Disabilities and the Division of Mental Health. This task can be accomplished fairly simply by segregating the data for each division according to related cost centers. An analysis then could be completed that demonstrates the revenue impact of applying separately percentages to the administrative costs of the two divisions. This analysis should be completed for the past two fiscal years as well as the present fiscal year. There is a possibility that, if the revenue impact of applying separate claiming percentages is significant enough, that an adjusted claim could be submitted that would recoup any Medicaid revenue that would have been generated if this approach had been used in the past. Such retroactive recoveries are possible as long as the existing methodology does not require that a combined percentage be applied to the administrative activities of the two divisions. The Department should collaborate with the Department of Public Aid on the feasibility of creating and submitting such an adjusted claim.

C. Claiming MMIS-Related Costs

As pointed out repeatedly in Chapters III, IV, and V of this report, the current management information capabilities of the Department of Human Services provide an inadequate foundation for pro-actively administering a decentralized system of Medicaid-financed services to individuals with developmental disabilities. The limitations of the state's existing management information capabilities can be traced to the complexities of the Medicaid program, with its complicated layers of eligibility, coverage and administrative rules, combined with the inherent problems of managing a diverse, highly decentralized service system.

In order to evaluate the merits of new third party financing methods and manage system-wide revenues more effectively, Illinois will need to improve its DD-related management information systems. The technical aspects of how such information system upgrades should be designed and instituted is beyond the scope of this report (as well as the expertise of the NASDDDS project team). Instead, the purpose of this section of the chapter is to: (a) demonstrate the feasibility of claiming enhanced federal financial participation (FFP) in the cost of designing, implementing and maintaining such advanced information management capabilities as part of the state's overall Medicaid Management Information System; and (b) outline the steps the state will need to take in order to secure such enhanced FFP.

It is difficult to contemplate expending scarce public dollars on improving administrative support systems during a period of deep budget cuts and continuing fiscal uncertainties. But, the

expenditures involved in this initiative should be viewed as an essential, upfront investment that will pay for itself many times over by equipping system administrators with the tools they need to manage system-wide revenues more effectively. Moreover, if properly organized and presented, the federal government will reimburse the state for the lion's share of the costs of completing such information system upgrades.

1. Legal and Regulatory Basis. Congress amended Title XIX of the Social Security Act in 1972 to add provisions authorizing 90 percent federal financial participation in the cost of designing, developing and installing mechanized claims processing and information retrieval systems, plus 75 FFP in the cost of operating such systems.⁵ For Medicaid purposes, the mechanized claims processing and information retrieval systems which states are required by law to develop and operate (unless this requirement is waived by the Secretary) is called the Medicaid Management Information System (MMIS). Regulations implementing the subject requirements of the 1972 law were promulgated initially by the U.S. Department of Health, Education, and Welfare in 1974 and subsequently have been revised and reorganized on a number of occasions. At the current time, the MMIS requirements can be found in Sub-Part C, Section 433, Chapter 42 of the *Code of Federal Regulations* (42 CFR 433, Sub-part C). Detailed administrative policies governing MMIS operations are contained in Part 11 of CMS' *State Medicaid Manual*. The discussion that follows is based on the above CMS regulatory and administrative requirements.

2. Actions Steps. Historically, state MMIS systems have been designed to meet the needs of programs administered by or through single state Medicaid agencies (SSMA). But, as the scope of Medicaid operations has expanded over the past two decades and a wider range of other state agencies have been assigned key operational roles in administering Medicaid-funded services, states have sought to qualify for FFP "support" modules of the MMIS that are maintained by state agencies other than the SSMA. CMS' present policies accommodate the approval of such support modules as part of the MMIS provided the proposed module:

- will support administration of the Medicaid program; and
- meets all MMIS requirements plus, as applicable, the requirements to qualify for enhanced FFP contained in Section 11225 of the *State Medicaid Manual*.

Section 11225 (Considerations and Options) of the *Manual* indicates, in part, that a state "... need not have a single comprehensive claims processing and information retrieval system" if the multiple systems that are in place meet the following criteria:

- "... All systems feed into a single comprehensive utilization and management reporting system that meets the requirements of Chapter 11 [of the *SMM*]; Under this approach, all of these components (subsystems) comprise the [state's] MMIS."
- Maintaining "[m]ultiple systems do[es] not appreciably increase cost[s] or detract from the primary benefits expressed" in Chapter 11.

⁵ Section 235, P.L. 92-603.

- CMS “determines that such systems are likely to provide more efficient, economical and effective administration of the state plan.”

The key to obtaining enhanced FFP for the design, development, installation, operation, and/or enhancement of an MMIS is to obtain CMS approval of the state’s Advanced Planning Document (APD). An APD is defined in Chapter 11 as “a written plan of action to acquire the proposed automated data processing (ADP) services and equipment.” Additional requirements governing the contents of an APD and related equipment/service acquisitions are contained in 42 CFR 433, Subpart C and Part 11 of the *State Medicaid Manual*.

Typically, through the APD a state seeks CMS’ approval to solicit bids to develop a preliminary set of MIS design specifications, including the hardware and software required to implement such a system. Once federal approval of the APD is received, the state is expected to submit a detailed implementation schedule and contract services documents to CMS for approval. The subsequent reporting requirements, preliminary system evaluation, on-site observation, post-site evaluation, and final CMS approval processes are explained in Chapter 2, Part 11 of the *State Medicaid Manual*.

CMS requirements vary according to the rate of FFP being requested by a state. All requests for FFP at the 90 percent rate are subject to prior CMS approval. For the 75 or 50 percent federal funding rates, a request that does not involve sole source procurement is subject to prior approval only when the estimated costs exceeds a threshold level established by CMS (currently \$5 million). For sole source procurements at the 75 or 50 FFP rates, the current CMS prior approval threshold is \$1 million (combined federal and state costs). APDs are approved on a project-by-project basis and, thus, enhanced FFP that is approved by CMS in connection with a particular MMIS upgrade or improvement (e.g., to create a new DD management information module) must be used to complete that specific project.

The head of the single state Medicaid agency must submit to the CMS Regional Office a request for approval of an APD. Appropriate SSMA staff members also must head the project management team that is responsible for developing and implementing the APD. Moreover, the SSMA is ultimately responsible to CMS for completing the project module.

Non-Title XIX costs must be allocated out of the request for federal matching submitted as part a state’s APD. In particular, the cost allocation must take into account: (a) costs of system development and operational activities that relate to non-Medicaid-eligible beneficiaries; and (b) costs related to system functionality that is not MMIS-related, such as certain provider or institutional administrative functions (e.g., admissions).

A formal interagency service agreement must exist between the SSMA and the partner state agency that: (a) establishes the functional relationship between the agencies in performing Medicaid related activities; and (b) establishes a mechanism for passing through allowable costs incurred by the partner state agency to the SSMA in a form valid for submission as HCFA-64 claims. Only SSMA may claim federal reimbursement for APD-related costs.

- 3. Implications for Illinois.** If, as indicated in ODD’s 3-Year Strategic Plan, the goal of DD stakeholders is to improve service quality and accountability system-wide and “restructure the service system so that funding follows the individual,” it will be important to design a management information system that supports the achievement of these goals. Incremental modifications in existing program data, financial management, and reporting systems are likely to fall short of the mark. The state needs to redesign its management information system and, equally important the business processes upon which they are based, from the bottom up.

The best way to begin such an MIS planning process is to identify the desired performance characteristics of the future system. This “visioning” activity should build on the work undertaken by the Strategic Planning Standing Committee of ODD’s Statewide Advisory Council in developing the agency’s 3-Year Strategic Plan; but, it also should address the overarching service planning and delivery issues identified in Chapter III of this report. Next, the system characteristics emerging from this visioning process should be translated into a set of preliminary MIS performance expectations that can be used to lay out the rationale for a developmental disabilities MMIS module.

Close cooperation between IDHS and IDPA officials during every stage of the process is the key to obtaining CMS’ approval to develop, at the enhanced FFP rate, a revised, upgraded DD component of the state’s MMIS. As pointed above, CMS expects the single state Medicaid agency to take the lead in developing special purpose modules in collaboration with partner state agencies. Under CMS’ current policies, states may maintain multiple claims processing and data retrieval systems provided: (a) they do not appreciably increase the cost or detract from the benefits CMS is seeking from the MMIS; (b) each module or sub-system meets CMS-established criteria; and (c) all sub-systems feed into a single comprehensive utilization and management reporting system that meets CMS’ criteria. CMS policies refer to this notion as “demonstrable conceptual equivalence” – i.e., “a concept which permits States to illustrate that the system is technically different from the MMIS but still satisfies the objectives and functions of the MMIS, and is, therefore, its conceptual equivalent.”⁶

- 4. Experiences of Other States.** In recent years, other state developmental disabilities service delivery systems have revamped, or are in the process of revamping, their management information capabilities. Generally, these initiatives have been undertaken in response to the following combination of factors: (a) the shift toward highly individualized, person-centered supports; (b) the resulting proliferation in service categories, program sites and payment rates; and (c) the state’s growing reliance of Medicaid to finance specialized long-term supports for persons with developmental disabilities. All of these developments are an outgrowth of the shift in the role of state government from the primary service provider to the manager of an increasingly complex network of private providers of services and support. To perform state government’s new role effectively, officials in these states have concluded that they must employ the tools of modern information technology more effectively and create fully integrated management information system that cut across all

⁶ Section 11105E, Chapter 1, Part 11, *State Medicaid Manual*.

components of the DD service network. Here are a few examples of the activities underway in other states:

- The **Pennsylvania** Office of Mental Retardation, a unit of the state Department of Public Welfare (DPW)⁷, launched its “Transformation Project” in 2000. The Transformation Project is an ambitious, multi-year initiative aimed at completely revamping the way in which community-based services are managed within the Commonwealth. To support the intended changes in business activities system-wide, a state-of-the-art, computer-assisted management information system, called Home and Community Services Information Systems (HCSIS), is being installed in stages. Initially, HCSIS was intended to support community mental retardation services only, but DPW officials were so impressed with the system’s potential capabilities that they later expanded the scope of operations to include all nine Medicaid home and community-based waiver programs operated by the department. Ultimately, HCSIS will support the:
 - ✓ Collection and maintenance of demographic and registration data;
 - ✓ Development of individual profiles and budget spending targets for all waiver participants;
 - ✓ Aggregation of individual budget data to support fund allocation and financial reporting processes;
 - ✓ Collection and storage of provider information;
 - ✓ Provider billing processes;
 - ✓ Storage of operational and provider performance information that is readily accessible to all interested stakeholders; and
 - ✓ Integration of monitoring and evaluation data as part of a comprehensive quality management framework.

HCSIS will provide a common information platform for and be accessible to all system stakeholders – DPW officials, county agency staff, service coordinators, provider agency staff, and persons with disabilities as well as their family members – thereby providing a uniform basis for managing the delivery of state-financed community services in all parts of the Commonwealth.

As of the time the project team completed its analysis, DPW officials were in the final stages of preparing an Advanced Planning Document for submission to the Philadelphia Regional Office of CMS.

- In the summer of 2000, the Boston Regional Office of CMS approved a Planning Advanced Planning Document (P-APD) jointly submitted by the **Massachusetts** Division of Medical Assistance (DMA) and the state Department of Mental Retardation (DMR). The purpose of this P-APD was to gain CMS’ approval to conduct a preliminary study leading toward improvements in the DMR management information system. The study report recommended the creation of a Mental Retardation Module that would support DMR’s overall strategic management plan

⁷ The Department of Public Welfare functions as the Commonwealth’s single state Medicaid agency.

and build upon the current and evolving functionality of the state's MMIS. Last fall, DMA and DMR submitted an amended Implementation Advanced Planning Document (I-APD) to CMS, requesting approval of enhanced FFP to design and install the proposed MR Module, which would function as a component of the state's overall MMIS. As of the time the project team completed its analysis, Massachusetts officials were awaiting a response from CMS' Boston Regional Office.

- In the fall of 2002, the **Oregon** Department of Human Services⁸ received approval from CMS' Seattle Regional Office of an Advanced Planning Document calling for the development of a DD module to replace and modify related elements of the state's existing MMIS. The state's APD laid out a multi-stage process, estimated to cost \$2.5 million to complete. The estimated costs of the first stage of the process, involving the completion of a system analysis and detailed project plan, was \$601,531, of which the state's share would be \$61,913. In the department's APD, DHS officials explained that the state's MMIS payment system for HCB waiver services to persons with developmental disabilities (referred to as the ICF/MR waiver in Oregon) "is outdated and unable to adequately handle the large volume and complexity of data that it will be required to process." Due to a 2001 settlement agreement in a waiting list lawsuit (*Staley v. State of Oregon*), the APD noted, the state anticipates a sizeable increase in enrollment in the state's DD waiver program during the upcoming biennium, which is expected to increase the number of financial transactions by as much as fourfold. Ultimately, DHS officials hope to build a fully integrated DD management information component into the state's MMIS; but, it is likely to take four to seven years to complete the present Oregon MMIS Replacement Project. In the meantime, the APD argues that the state will need a compatible, freestanding MIS system to support Medicaid-funded community services for persons with developmental disabilities.
- In November 2000, CMS' Boston Regional Office approved an APD jointly submitted by the **Rhode Island** Department of Human Services (DHS) and the state Department of Mental Health, Retardation, and Hospitals (DMHRH). This ADP called for hiring an outside consulting firm to develop bid specifications for a new management information system to support Medicaid-funded services administered by DMHRH's Division of Developmental Disabilities (DDD). The overall aim was to create an MIS capable of supporting a coordinated approach to delivering health and community supports to adults with developmental disabilities, grounded in a new set of system management concepts and values. These values and concepts are summarized in the project's title, CHOICES – Citizenship, Health, Opportunities, Interdependence, Choices, Environments, Supports.

The bid specifications were completed by an outside consulting firm in June 2002. But, due to cuts in the agency's FY 2003 budget, DDD thus far has been unable to find the contract funds to support the design phase of the project.

⁸ DHS acts as the single state Medicaid agency in Oregon.

As other states have learned, a well designed, technically sophisticated management information system is an essential tool to running an effective, decentralized 21st Century system of publicly financed developmental disabilities services. Illinois needs to strengthen its management information capabilities and, as this section of the chapter clearly demonstrates, most of the costs of designing, installing and operating such a management information system will qualify for enhanced federal Medicaid reimbursement if the state properly structures its request to CMS.⁹

D. Conclusion

Federal matching payments are available to assist states in covering the costs of administering their Medicaid programs. Generally, the federal government matches allowable state administrative expenses on a dollar-for-dollar basis (i.e., at a 50% matching ratio), although higher matching ratios are authorized for certain, specified types of administrative expenses.

The purpose of this chapter has been to summarize the findings of the NASDDDS project team's analysis of current Medicaid administrative claiming practices in Illinois. The analysis involved an examination of existing methods used by the Illinois Department of Human Services (IDHS) in recovering federal Medicaid payments for the costs of administering state-operated developmental centers as well as Title XIX-reimbursable community services for individuals with developmental disabilities. Throughout the team's assessment, existing IDHS policies and practices have been compared to relevant federal policies as well as administrative claiming practices in other states.

It should be clear from the team's analysis that IDHS has in place a well-designed, competently managed system to recover federal Medicaid payments for allowable administrative expenditures incurred in connection with the provision of Title XIX-reimbursable services to citizens with developmental disabilities. At the same time, the team was able to identify a number of specific steps that might be taken to improve the department's existing administrative claiming methods and thereby potentially increase total federal Medicaid payments to the state. One of these proposed steps is to take advantage of the opportunity to claim enhanced federal financial participation in the costs of designing and installing an improved management information system that will allow the department to administer system-wide revenues more effectively and efficiently.

⁹ The NASDDDS Project team would be happy to refer DPA and DHS officials to individuals in other states that have developed approved Advanced Planning Documents related to the addition of a DD module to their respective states' Medicaid Management Information System.

Chapter VII

MAPPING A PATHWAY TOWARD ENHANCED FEDERAL FINANCIAL PARTICIPATION

The primary aim of the current project has been to offer Illinois policymakers and disability stakeholders a comprehensive set of options for generating additional federal revenue to finance services and supports to Illinois citizens with developmental disabilities. By this point, it should be clear to readers that instituting an effective, statewide revenue management program involves a good deal more than engaging in an isolated series of episodic attempts to uncover new and expanded sources of revenue to compensate for actual or anticipated budget shortfalls. It entails assembling necessary utilization and expenditure data, conducting carefully designed studies to model the potential effects of proposed revenue raising strategies, weighing options and alternatives as well as establishing priorities. But, effective revenue management also involves harnessing the state's strategic planning goals to its revenue enhancement initiatives, so that new dollar investments are focused on accomplishing high priority system change agenda items.

The closing chapter of the report, therefore, will concentrate on two critical topics. First, given the wide range of potential revenue enhancement strategies identified in the preceding chapters, how should Illinois officials, with the assistance of DD system stakeholders, go about setting priorities? And, second, what steps need to be taken to shore up the state/local service delivery infrastructure so that Illinois officials have the capacity to manage available revenues in a manner that both advances the state's strategic goals and also avoids costly, disruptive compliance issues and audit exceptions down stream?

The state's revenue management objectives and priorities ought to be an integral part of the state's strategic planning goals and implementation strategies. The Division of Developmental Disabilities' existing 3-Year Strategic Plan inherently recognizes the importance of creating a nexus between the agency's programmatic goals and the generation of additional revenue. The plan establishes an objective of increasing federal funding by \$19.2 million dollars before June 30, 2004.¹ As the Division prepares to update the agency's three-year strategic plan (to cover the period July 1, 2004 through June 30, 2007), in cooperation with the Statewide Advisory Council on Developmental Disabilities, consideration should be given to including a more detailed set of revenue enhancement objectives that are tied to accomplishing specific system change goals. With this general thought in mind, the project team offers the following observations regarding the establishment of revenue enhancement priorities as part of DDD's 3-Year Strategic Plan for FY 2004 through FY 2007:

¹ Goal No. 1.5, *3-Year Strategic Plan*, July 1, 2001 through June 30, 2004, Office of Developmental Disabilities, Illinois Department of Human Services, as approved by the Statewide Advisory Council on Developmental Disabilities, Planning Standing Committee, January 23, 2002, p. 9.

2. Near-Term Revenue Enhancement Strategies. The team’s report includes a number of comparatively straightforward, non-controversial steps that should result in increased federal Medicaid payments. Efforts to access a number of these new and expanded revenue options – particularly within the context of the state’s existing HCBS waiver program for adults with developmental disabilities -- already have been initiated by DDD. Most notably, DDD officials over the past year have made administrative decisions or gained federal approval for a technical amendment that allows the state to claim reimbursement for “at home day programs”, “host family home services” and “home-based personal supports” (see additional discussion in Chapter V, Section A). In the team’s judgment, the other proposals listed below could be completed relatively expeditiously. Among these steps are:

- ✓ Take prompt steps to ensure that the state fully recovers the federal share of Medicaid costs associated with opening new facilities on the campus of Lincoln Developmental Center (see Section C-1, Chapter IV);
- ✓ Institute actions to prevent the loss of certification status or eligibility on behalf of court-committed SODC residents with a history of violent, anti-social behaviors in combination with their developmental disabilities (see Section C-2, Chapter IV);
- ✓ Convert all developmental training services to a fee-for-service methodology and begin claiming for such services under the state’s adult DD services waiver program (see Section A-4, Chapter V);
- ✓ Review all other DDD grant-funded activities to pinpoint services (and recipients of such services) who could be converted to HCBS waiver funding (see Section A-5, Chapter V);
- ✓ Enroll in the state’s DD adult services waiver program Medicaid-eligible young adults with developmental disabilities, ages 18 to 22, who are currently receiving services funded by the Department of Children and Family Services, beginning with the 80 young people currently residing in CILAs (see Section A-6, Chapter V);
- ✓ Take steps to improve the efficiency of Medicaid claiming under the state’s adult DD services waiver program (see A-7, Chapter V);
- ✓ Explore the effects of adopting a special income standard for determining the financial eligibility of individuals to participate in the state’s adult DD services waiver program (i.e., as a substitute for the state’s existing spend-down policies; see B-2, Chapter V);
- ✓ Explore the effects of using federal Post Eligibility Treatment of Income policies (rather than spend-down policies) to determine the financial eligibility of persons

with developmental disabilities to participate in the state's DD adult services waiver program (see B-2, Chapter V);

- ✓ Streamline the existing process of determining ICF/MR level-of-care needs among applicants for adult DD home and community-based waiver services (see B-3, Chapter V);
 - ✓ Remove “active treatment” as a condition of enrollment in the HCBS waiver program for adults with developmental disabilities and substitute an ICAP-derived acuity of need measure (see B-3, Chapter V).
 - ✓ Institute a requirement that all potentially eligible individuals who currently receive or request DDD-funded community services apply for Medicaid benefits and, if found eligible, enroll in the state adult DD services waiver program assuming they meet all program enrollment requirements (see E-3, Chapter V);
 - ✓ Review the state's present administrative claiming methodology for service coordination (ISSA) services to determine whether it would be advantageous to switch to a targeted case management coverage option under the state's Medicaid plan (see F-3, Chapter V);
 - ✓ Revise the state's existing methodology for claiming administrative costs in connection with CILA and CLF services so that 100 percent, rather than 95 percent, of allowable costs are claimed (see Section B, Chapter VI);
 - ✓ Compare the impact on billable Medicaid administrative costs if separate percentage rates are applied to the allowable cost centers of the Division of Developmental Disabilities and the Division of Mental Health (i.e., versus continuing to use a combined percentage; see Section B, Chapter VI); and
 - ✓ Complete an initial assessment of the state's existing DD-related management information capabilities and future needs, and use the results of this assessment to prepare, in collaboration with IDPA officials, a Planning – Advanced Planning Document, seeking CMS approval (and funding) to conduct an in-depth analysis of the principal components of an improved DD MIS module as part of the state's overall Medicaid Management Information System (see C-3, Chapter VI)
3. Intermediate and Longer Range Revenue Enhancement Strategies. In addition to the near-term revenue enhancement strategies outlined above, the report suggests other possibilities that will require a considerable amount of additional analysis and/or take much longer to bring on line. Among these options are the following:
- ✓ Explore the effects of switching from a cost-based methodology to a cost-related methodology of billing Medicaid for ICF/MR expenses incurred by the nine state-operated developmental centers, especially if DDD/IDHS elects to pursue an

aggressive, multi-year plan to downsize the census of SODCs (see Section B, Chapter IV);

- ✓ Analyze the merits of creating one or more HCBS waiver programs targeted to children with developmental disabilities, including the possibility of initiating a family supports waiver program and an children's intensive supports waiver program (see B-1, Chapter V);
- ✓ Analyze the merits of establishing an intensive supports HCBS waiver program for adults with developmental disabilities as a mechanism to promote alternative community living opportunities for persons with severe, complex disabilities who currently reside in SODCs and other Title XIX congregate settings (e.g., ICFs/DD and SNF/Peds; see Section B-2, Chapter V);
- ✓ Explore the feasibility of converting the funding of persons living in private ICFs/DD to the adult DD services waiver program, beginning with residents of small, community-based ICFs/DD (see Section B-3, Chapter V);
- ✓ Consider creating a IDHS revenue budget that identifies the level of revenue that is expected to be associated with (or claimed as) administrative expenditure in each fiscal year (Section A, Chapter VI); and
- ✓ Study the effects of adding an IDHS administrative component to each rate or fee that is paid to community providers of adult DD waiver services before the seeking federal Medicaid reimbursement (see Section B, Chapter VI).

As emphasized in Chapter III of this report, a state's ability to generate and effectively manage third party revenues is tied directly to the strength and agility of the underlying state/local infrastructure it puts in place to support such activities. Some components of this infrastructure are directly correlated with the performance of revenue management activities (e.g., ready access to complete, accurate and timely utilization and cost data), while the effects of other components may not be as readily apparent to the casual observer (e.g., the existence of clear lines of responsibility/accountability and well defined roles throughout the service delivery system). As Illinois policymakers and disability stakeholders strive to generate additional third party dollars to finance services to children and adults with developmental disabilities, simultaneous improvements will need to be made in the following aspects of the state's DD service delivery infrastructure:

- Unifying responsibility for eligibility determination, intake, individual service planning, service coordination and the purchase of services within a single organizational entity in each designated catchment area of the state (see discussion under Section A, Chapter III);
- Improving the alignment between DDD's person-centered service delivery philosophy and the way in which services are planned and money is disbursed within the state's existing service system (see Section B, Chapter III);

- Improving IDHS' management information capabilities to produce the data necessary to: (a) improve the efficiency of existing third party billing procedures; (b) analyze the potential impacts of proposed, new revenue enhancement strategies; and, most importantly (c) support individualized payment and accountability structures that allow services to be tailored to the unique needs and preferences of each person and family (see Section C, Chapter III);
- Reviewing the state's existing quality assurance and improvement program to ensure that it comports with CMS new, heightened expectations (see Section D, Chapter III); and
- Developing statewide waiting list management policies that: (a) afford individuals and families across the state equitable access to state-financed DD services and supports within the constraints of available public dollars; and (b) generate extensive data on unmet needs within the state's DD population that can be used to support requests for additional funding and map out plans for improving access to needed services.

Obviously, there is a great deal of work yet to be accomplished. The members of the project team, however, were impressed by the knowledge, commitment, and dedication of the Illinois DD stakeholders to whom we spoke with during the course of the study, and feel confident that they are up to the task. Hopefully, this report will help to initiate a dialogue that leads to positive improvements in the financing of developmental disabilities services in Illinois over the next several years. If so, the time, energy, and funds invested in its preparation will have paid important dividends.