State of Washington
Joint Legislative Audit and Review Committee (JLARC)

Performance Audit of the
Division of Developmental Disabilities

Report 03-6

June 19, 2003

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The Joint Legislative Audit and Review Committee (JLARC) carries out oversight, review, and evaluation of state-funded programs and activities on behalf of the Legislature and the citizens of Washington State. This joint, bipartisan committee consists of eight senators and eight representatives, equally divided between the two major political parties. Its statutory authority is established in RCW 44.28.

JLARC staff, under the direction of the Committee and the Legislative Auditor, conduct performance audits, program evaluations, sunset reviews, and other policy and fiscal studies. These studies assess the efficiency and effectiveness of agency operations, impacts and outcomes of state programs, and levels of compliance with legislative direction and intent. The Committee makes recommendations to improve state government performance and to correct problems it identifies. The Committee also follows up on these recommendations to determine how they have been implemented. JLARC has, in recent years, received national recognition for a number of its major studies.
In the 2002 Supplemental Operating Budget, the Legislature directed JLARC to conduct a performance audit of the Developmental Disabilities Division (DDD) in the Department of Social and Health Services (DSHS).

DDD has recently come under considerable scrutiny; this audit completes JLARC’s fourth analysis of the Division. In the summer of 2002, the federal government completed its review, with DSHS conducting its own, in-house reviews as well.

These reviews, including this final JLARC audit, point to the need for dramatic changes in the management practices of the Division. While there may be disagreement on what brought on the need for this change, there is agreement that change is essential. In direct response to a consultant’s recommendation, in October 2002—as this audit was being conducted—the Secretary of DSHS reorganized, moving the Division into the newly created Aging and Disabilities Services Administration.

**MAJOR FINDINGS**

For this reorganization to be successful, substantial efforts must now be made to establish basic and credible practices previously missing. This report, and JLARC’s interim report published in December 2002, point to the need for change in three areas: 1. Changes in case management practices; 2. Changes in the way “packages” of services or benefits are viewed; and 3. Changes in the management of federal Medicaid dollars.

**Case Management**

Case managers in this Division work with clients with complex needs. Caseloads are growing; procedures are poorly defined; and effective automated systems to help case managers manage their caseloads are missing. JLARC found that, because an assessment process is not consistently applied, it is impossible to determine if clients with similar needs are receiving similar services. Procedures for the use of existing assessment tools are so poorly defined or followed that inconsistency is a predictable outcome. The case managers we spoke with in our field visits all expressed frustration with the current assessment process and with its tools and its procedures.

JLARC is also concerned with another aspect of the assessment process. When asked who was assessed, case managers frequently responded that they performed a service assessment on those they knew needed a service. This runs contrary to the basic purpose of an assessment: to determine if a service is needed.

The impacts of a poor assessment process ripple through the Division. Just as there is no way to determine if clients with similar needs are getting similar services, there is no way to determine if levels of service are too high, too low, or appropriate. Basic budget questions cannot be answered. JLARC was asked to review case manager staffing levels. Without an accurate understanding of the service needs of clients—an acuity measure—we could not determine if case manager resources are appropriate. Ultimately, it is the service needs of clients that dictate appropriate case manager levels. Comparisons between Washington and other states on case management levels become meaningless without such information.
Managing the Public Benefits Package

Through analysis of information found in five different information systems—systems that are not integrated and do not normally “talk to each other”—JLARC determined that only two-thirds of the public benefits going to disabled clients are actually managed by DDD. Even after this extensive analysis, we know that we have not captured all funding sources in this calculation, such as special education.

Each type of service may be critical to a client, especially for community-based clients. Clients receive, and may require, a “package” of services. While housing services (paid for through DDD) are critical, so too are medical services (coordinated by Medical Assistance in DSHS) and economic supports, such as Supplemental Security Income (SSI), tracked by Economic Services in DSHS. While case managers are very aware of the importance of each to a client, they have no information system to inform them what a client’s “complete service package” might be. Thus they are unable to coordinate that package.

The Federal Medicaid Program

With $1.1 billion of DDD’s $1.2 billion biennial budget comprising either federal funds or the state match required to receive those funds, the federal Medicaid program now dominates. The changes that JLARC and others have identified as needed by this Division must be made while paying close attention to Medicaid guidelines. Such guidelines are not always clear and easy to understand by those faced with the task of making changes, yet meeting them will be essential to change efforts.

The federal government has determined that DDD does not currently adhere to those guidelines, and has told the state to return $26 million in “disallowed” payments. Continued participation in Medicaid’s “waiver” program requires meeting these guidelines. Without such participation, the federal match on some of the most expensive services provided to developmentally disabled clients is at stake. As advocates sue DSHS, seeking additional funding claimed to be required to meet these guidelines, legislative fiscal control over the program may also be at risk.

CONCLUSION

Success for DDD has been defined as an ability to get some level of services to clients. Expenditures for needed infrastructure—information systems, case management systems, assessment systems—were seen as secondary. Now, as the caseload increases and the complexity of the Medicaid program becomes more obvious, the Division suffers from the absence of that infrastructure. Accurate client counts do not exist, nor do consistently applied assessment procedures.

Developing this infrastructure—these supports, policies, and procedures—will not happen overnight. Some components such as computer systems will have a price tag attached. The cost of not developing these supports will be the continuation of a system that knows too little about its clients, their service needs, and whether or not those needs are being met.

RECOMMENDATION 1

DSHS should develop an assessment process for developmentally disabled clients that is consistently applied, to all clients, in all parts of the state. Clients must be assessed before a determination of service need is made.

RECOMMENDATION 2

DSHS should submit to the Legislature a plan for implementing a case management system in DDD.

RECOMMENDATION 3

A detailed report on the impacts of the recent reorganization of DSHS—bringing DDD into the new Aging and Disabilities Services Administration—should be submitted to the Legislature for its review.
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CHAPTER ONE – INTRODUCTION

PERFORMANCE AUDIT OF DDD

Over the past two years, JLARC has conducted three mandated studies of the Division of Developmental Disabilities (DDD) in the Department of Social and Health Services (DSHS). These studies are:

1. **Voluntary Placement Program (VPP):** a focused review of the program established to allow parents to place their developmentally disabled children in foster care and maintain custody.

2. **Caseload and Staffing:** a review of the client caseloads and case manager resources in DDD.

3. **Capital Study of the Residential Habilitation Centers (RHCs):** an analysis of the real estate value of the land and facilities at Washington State’s institutions.

The Legislature believed that these studies pointed to the need for a broader audit of the Division. The 2002 Supplemental Operating Budget directed JLARC to complete a comprehensive performance audit of the Division. This audit includes a detailed analysis of community-based services: what services are provided, case management, and the importance of the Federal Medicaid program.

The first step in describing the results of this performance audit was taken in December 2002, with an interim report focusing on a description of community-based services. Combined with a detailed analysis of the types and costs of services, JLARC determined that most DDD clients receive more than one service from the Division (a service “package”) and that DDD clients are likely receiving services managed and paid for through other parts of DSHS. Thus, a focus on the cost of only one service is inaccurate. Additionally, a focus on costs incurred only by the Division draws an incomplete picture of the resources utilized by clients and how client services must be managed.¹

This report concludes the current performance audit with additional analyses of case management practices and the resources utilized by DD clients, along with a review of the Division’s use of Federal Medicaid funds.

Chapter 2 focuses on case management practices in Developmental Disabilities, describing what constitutes case management in this state and other states. We also looked closely at comparisons made between Washington’s staffing level and staffing levels in other states. Here we found the information used to make these comparisons misleading and unreliable. In fact, the source of the information frequently referenced by DSHS to make such comparisons (the National Association of State Directors of Developmental Disabilities Services) declared that its study should not be used to make direct comparisons between states.

More importantly, we found inconsistent case management practices and standards among DDD field offices. This is of great concern in the area of client service needs assessment: without a consistent assessment process, it is not possible for the Legislature to know if clients with similar

service needs are receiving similar services. And this lack of consistent practices and standards makes it impossible to determine if staffing levels are appropriate, too high, or too low.

Chapter 3 contains the final phase of our analysis of the different funding sources of public benefits for DDD clients. When we add DDD budgeted services with medical services and income assistance services, we find that DDD budgeted services account for only two-thirds of the total expenditures for these clients. Discussions with case managers in the field emphasized the importance of this “package” of services to clients. Yet getting at the information necessary to understand the cost of the package was very difficult, illustrating the lack of effective coordination of these resources and the lack of information technology to effectively manage fiscal and program resources. Navigating the maze of programs and their related rules and eligibility criteria is sure to be as confusing to clients as it is to those trying to understand the program.

Chapter 4 provides an extensive review of how DDD manages its $550 million in federal Medicaid funds, and how Medicaid dominates the provision of services to the developmentally disabled. Of key concern is a very critical review by the federal government of the operations of the program and a demand to pay back $26 million in previously expended federal Medicaid funding. How the Medicaid program is managed has been, and likely will continue to be, the subject of litigation in federal courts. This is particularly important as settlement of these cases—or losing the cases—can be very expensive (the most recent case would have cost Washington State up to $107 million per year) and involves the courts in dictating services and service levels.2

The report concludes with three recommendations focused on the need to improve basic management practices. Recommendation 1 addresses the need for a consistent assessment process. Recommendation 2 addresses a plan for developing a case management system. Recommendation 3 recommends that a report be submitted to the Legislature on the progress of DSHS’s recent reorganization.

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**DSHS Reorganizes**

In October 2002, as JLARC was conducting this audit, the Secretary of DSHS announced a major reorganization. DDD was moved from the Health and Rehabilitative Services Administration into Aging and Disability Services (formerly named the Aging and Adult Services Administration).

It is too early to determine whether this reorganization will have any impact on the major concerns raised by this and previous audits of the Division. The reorganization is a direct response to a consultant’s recommendation that the Division be “realigned” with other parts of human services that enjoy greater credibility. Given that the former Aging and Adult Services Administration manages a Medicaid program—that includes waivers—with a focus on the provision of chronic care to the disabled, the reorganization may yield better management decisions and more effective coordination of services. But because of the problems identified by both JLARC and outside consultants, simple reorganization alone will not be sufficient. Major changes in management practices will be required.

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2 ARC of Washington v. Lyle Quasim, Case No.C99-5577FDB, United States District Court, Western District of Washington at Tacoma. Cost estimate from legislative fiscal committee staff.
CHAPTER TWO – CASE MANAGEMENT IN DEVELOPMENTAL DISABILITIES

Overview

In May 2002, JLARC evaluated caseload and case management staffing issues in DDD and found that until steps were taken to ensure reliable information, decision makers could not accurately determine the number of staff needed to manage the Division’s clients.3

JLARC had originally set out to develop a means for estimating case management staffing requirements. That effort was thwarted by the absence of basic information related to workload; that is, an accurate count of clients based on eligibility standards applied evenly across Washington State.

Here we address a related issue: are there generally accepted models of case management for the developmentally disabled? If so, and assuming an accurate count of workload is possible, could we then compare Washington to other states to determine whether or not we have appropriate case management resources to serve our developmentally disabled clients?

Our extensive analyses of other states, and the data used to make comparisons between states, lead us to conclude that current national comparisons are both inaccurate and misleading.

Within Washington, we have serious concerns with the lack of case management standards across regions and among offices. Previously, JLARC documented in detail the seriousness of this problem related to client assessments. Because of the lack of standards in the assessment process, whether or not clients with similar needs are receiving similar services cannot be known.4

This lack of consistent processes and procedures also makes impossible an accurate measure of workload and staffing requirements. To make a valid case for more or less staff, the Division must first develop consistent work practices and work standards, and determine if those standards are being met. Simply put, without consistent work practices, work standards related to those practices, and some benchmark to measure against—some standard—we are not able to determine if the cases-to-case manager ratio is appropriate, too high, or too low.

Analyzing Case Management

In conducting this audit, we found very little information available to compare how states manage their DD caseloads. Such an absence can be contrasted to children’s services, where a national standards-setting body identifies both standards for practice and standards for staffing levels. Because of this absence of information, JLARC contracted with two consultants: one to conduct an extensive review of DD case management models on a national level, and one to conduct an in-depth analysis of DDD’s computer-based case management processes. In each instance, the goal was to compare case management in DDD—either to other states or to other parts of DSHS. The results of the consultants’ analyses are incorporated into this report.

Case Management In Developmental Disabilities

To develop an understanding of case management practices in developmental disabilities, JLARC focused on two areas:

1. We reviewed national studies and sought models for case management in other states.
2. We looked within Washington State, visiting each region at least once, to better understand how case management works here.

While specific case management tasks may vary from state to state depending on state requirements and the case management model used, there are generally accepted case management tasks. They include:

- Intake and eligibility assessment
- Individual care plan development and monitoring
- Crisis intervention and placement
- Healthcare and clinical care coordination
- Incident reporting and review
- Quality assurance and assessment of providers

Nationally, case management in developmental disabilities can be represented by three approaches that have evolved over the past 30 years. The three approaches are useful ways to understand how states have organized case management functions outlined above in response to changing needs and service demands:

1. **Traditional Case Management** – The focus is on obtaining services for eligible clients. Either an intake worker or a case manager determines the individual’s eligibility for services. States vary in how eligibility is determined. Some states like Washington use the IQ score as the primary means for determining eligibility for services. Other states such as Connecticut and Florida rely on the client’s IQ score as well as their functional needs.

In this model, a case manager works with the individual to access services. Once the person has transitioned into the new service, the contact hours of the case manager fade.

2. **Service Coordination** – In an effort to address concerns about the lack of care coordination, the duties of developmental disabilities case managers have expanded in some parts of the country and now emphasize the provision of ongoing contact with clients, families, and service providers. Typically, a service coordinator works with individuals to develop an individual plan of services and assists clients in accessing appropriate services to meet the service plan.

3. **Support Brokerage** – In this model, the case manager develops a plan with the individual and other people important in the client’s life. The plan might include a specific budget with dollars attached to each service required. This model can be considered as the newest of the three.
JLARC Analysis of Data Used to Compare States

Over the past several years, DDD has requested significant increases in funding to hire more case managers. The Division often compares itself highly unfavorably to other states in regard to their ratio of clients to case managers, claiming that Washington has the highest ratio in the nation.

JLARC reviewed national studies and case management models across the nation to determine if we could make a valid comparison among Washington and other states. Using the structure of the generally accepted case management tasks and models outlined above, particular attention was paid to comparisons of case manager-to-cases ratios.

There is very little information available to make state-to-state comparisons. DSHS has in the past referenced information provided by the National Association of State Developmental Disabilities Directors (NASDDD). JLARC’s analysis led us to conclude that this information cannot be used to draw any meaningful comparisons among states. Indeed, NASDDD has put a disclaimer on their work, specifying that it should not be used for direct state-to-state comparisons.⁵

As an example of why it would be misleading to compare states using this study, the survey instrument used for collecting the information to develop each state’s ratio did not take into account:

- How each state defines a case
- How each state defines a case manager or a caseworker
- Who is included in the caseload count
- What is expected of a case manager or a caseworker in terms of case management responsibilities

Meaningful comparisons can only be made when definitions of who gets counted as a case manager and who is included as a client are clear. Each state—and in some situations each local authority—defines what constitutes a developmental disabilities case differently.

For example, there are four commonly accepted definitions of a developmental disabilities case:

- Anyone seeking services (pre-eligibility assessment);
- Anyone found eligible for services, regardless of whether they currently receive services or will be receiving services;
- Anyone who is eligible for services and is receiving any type of service funded by the developmental disabilities agency; and
- Anyone who receives services funded through a federal home and community-based services waiver.

Washington has thousands of clients included in case counts who receive no specifically defined DDD service. Whether or not this is true in other states was not taken into account in the

NASDDD data. In order to make valid state-to-state comparisons, having this sort of information is essential.

Finally, we were unable to find any other national study that has established a comparable “apples-to-apples” database to address the funding and staffing for Washington’s Division of Developmental Disabilities.

**Case Management Resources**

Previously, JLARC documented problems with DDD’s business processes. Finding inaccurate client counts led us to find that the Legislature could not rely on information supplied by DDD to make budget decisions.\(^6\)

During our site visits we also sought to identify common case management procedures and practices, with an emphasis on the assessment process. We found little in the way of standards and concluded that it is not possible to determine if clients with similar needs receive similar services. A consistent, verifiable assessment process does not exist in Washington.\(^7\)

Some variation in practices is to be expected—the number of professional staff in an office can sometimes dictate whether or not staff can specialize. However, we found that the lack of management and business standards meant that it is impossible to determine if clients in different parts of Washington State receive similar levels of case management services. Such inconsistencies make it impossible to ascertain whether or not case management resources in the Division are adequate.

**Managing To Emergencies**

One common theme in all the offices we visited is how emergencies dominate overall workload. Case managers consistently indicated that reacting to client crises drives their day-to-day work. They would summarize their work plan as reacting to the first phone call of the day.

Perhaps the nature of the clientele and their complex needs creates an operating environment where some component of the client population will always be “in crisis.” This is not necessarily because of the lack of adequate case management, but because of the involved nature of the client’s “needs.” Processes to better handle “crises and emergencies” are part of effective management systems.

The Children’s Administration in DSHS has organized itself such that case managers specialize in either handling initial “crises” in the form of reported child abuse (Child Protective Services) or in securing long-term placement and stability (Child Welfare Services). Staff specialize in handling different client needs, and management organizes and assigns staff appropriately.

**Computer-Assisted Case Management Tools**

JLARC has documented the large increase in the Division’s caseload, almost doubling in the past 10 years. While the exact count has been found to be inaccurate, the fact that there has been an increase is not in doubt. But the number of cases is only half the information needed to


\(^7\) For a detailed discussion on the problems with an inconsistent assessment process, please see: Joint Legislative Audit and Review Committee: Performance Audit of Developmental Disabilities Division: Interim Report 02-13, December 2002.
understand what case management resources are needed to manage this caseload. Consistent and reliable data on client acuity—measuring the intensity of their service needs through a verifiable assessment process—is also absent.

The sheer size of the Division’s caseload—some 32,000 clients—is a strong argument for developing computer-assisted means of accurately determining caseloads, measuring acuity levels, and managing services. But our field visits quickly indicated that these systems do not exist in DDD, and there was little understanding of how such systems might assist the Division in managing its caseload.

As such, JLARC conducted an in-depth analysis of other parts of DSHS to see how they use technology to assist in the case management processes. Using the generally accepted case management tasks identified earlier as a framework, Exhibit 1 on the following page illustrates the results of that analysis. Other parts of DSHS have been successful in using computer-based tools in their case management function. This review illustrates that DDD’s current system does not fully support any of these processes.8

As stated earlier in this report, DDD was recently moved to the new Aging and Disabilities Services Administration. DSHS has indicated that their new assessment tool, “CARE,” will be adapted to be used for developmentally disabled clients. This may be an important first step, yet assessment is only one of the components of case management. Efforts at automating and standardizing other case management and client tracking tasks must be pursued.

Case Management Conclusion

We were able to develop a general understanding of the primary components of case management in developmental disabilities. However, we were not able to find credible information that would allow us to compare cases-to-case manager ratios in Washington to those in other states.

Settling on valid and reliable in-state standards for case management must be accomplished in connection with an effective assessment process. Only with a valid and consistently applied assessment process in place will the Division be able to demonstrate to the Legislature that the service needs of the Division’s clients are accurately evaluated. Ultimately, these service needs should determine appropriate case manager resources, not merely a headcount of clients.

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### Exhibit 1: Automated Case Management Systems In DSHS

<table>
<thead>
<tr>
<th>Case Management Functions</th>
<th>DSHS Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Aging CA</td>
</tr>
<tr>
<td>Determine Program Eligibility</td>
<td>P</td>
</tr>
<tr>
<td>Determine Financial Eligibility</td>
<td>N</td>
</tr>
<tr>
<td>Assess Client Condition and Needs</td>
<td>Y</td>
</tr>
<tr>
<td>Develop Service Plan</td>
<td>P</td>
</tr>
<tr>
<td>Identify High-Risk Clients</td>
<td>N</td>
</tr>
<tr>
<td>Coordinate Services and Resources</td>
<td>N</td>
</tr>
<tr>
<td>Monitor Case</td>
<td>P</td>
</tr>
<tr>
<td>Incorporate Program Requirements</td>
<td>P</td>
</tr>
<tr>
<td>Manage Crises</td>
<td>P</td>
</tr>
</tbody>
</table>

Y=Yes, system supports function  
N=No, system does not support function  
P=Partial support of system function

Aging and Adult Services Administration CA (Comprehensive Assessment)  
Aging and Adult Services Administration CARE (Comprehensive Assessment Report and Evaluation)  
Children’s Administration CAMIS (Case Management and Information System)  
Developmental Disabilities Division CCBD (Common Client Data Base)  
Economic Services Administration WorkFirst E-JAS (Electronic Jobs Automated System)  
Division of Vocational Rehabilitation STARS (Service Tracking and Report System)  
Division of Alcohol and Substance Abuse TARGET (Treatment and Assessment Report General Tool)

Source: Sterling Associates.
CHAPTER THREE – PUBLIC BENEFITS IN DEVELOPMENTAL DISABILITIES

Overview

Discussions about the adequacy of services to the developmentally disabled focus almost exclusively on those services provided directly by the Developmental Disabilities Division. But as with most clients in DSHS, DD clients tend to use the services of many parts of DSHS. To understand a total package of services going to a client, it is important to look across all of DSHS, and not just at one division, such as DDD. Exhibit 2, below, illustrates that 81 percent of DDD clients use services managed and budgeted for by other parts of DSHS.

<table>
<thead>
<tr>
<th>DSHS Area</th>
<th>Percent Using Services From Other Areas of DSHS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aging and Adult Services</td>
<td>93%</td>
</tr>
<tr>
<td>Economic Services</td>
<td>86%</td>
</tr>
<tr>
<td><strong>Developmental Disabilities</strong></td>
<td><strong>81%</strong></td>
</tr>
<tr>
<td>Mental Health</td>
<td>78%</td>
</tr>
<tr>
<td>Alcohol and Substance Abuse</td>
<td>69%</td>
</tr>
<tr>
<td>Vocational Rehabilitation</td>
<td>66%</td>
</tr>
<tr>
<td>Medical Assistance</td>
<td>65%</td>
</tr>
<tr>
<td>Juvenile Rehabilitation</td>
<td>57%</td>
</tr>
<tr>
<td>Children and Family Services</td>
<td>53%</td>
</tr>
</tbody>
</table>

Source: DSHS, Research and Data Analysis. Fiscal Year 2000 Client Services Database.

Previous JLARC analyses detail the importance of primary medical services (e.g., doctors, hospitals, drugs) to DDD community clients provided and budgeted for through Medical Assistance in DSHS. As Exhibit 3, on the following page illustrates, for young clients, more money is spent through Medical Assistance than through DDD. For school-age youth, the split is about even.

Economic and Income Assistance

Our extensive site visits of DDD offices across Washington State indicate the importance to DDD clients of a third area: economic and income supports, such as Supplemental Security Income (SSI) and food stamps. So we took our earlier analysis one step further to illustrate the use of these supports by DDD clients.
Another component of a DDD client’s service package—apart from specialized DDD and medical services—are economic and income supports. These are managed by and budgeted for either through the Federal Social Security Administration (e.g., Supplemental Security Income-SSI) or DSHS’s Economic Services Administration (e.g., Temporary Assistance to Needy Families-TANF).

**Exhibit 3: Expenditures For Community-Based DDD Clients, January 2001 Through December 2001**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>DDD Budgeted Services</th>
<th>Primary Medical Assistance</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth through 5</td>
<td>$7,169,900</td>
<td>$37,049,575</td>
<td>$44,219,475</td>
</tr>
<tr>
<td>6 through 20</td>
<td>$54,962,769</td>
<td>$50,979,084</td>
<td>$105,941,853</td>
</tr>
<tr>
<td>21 through 44</td>
<td>$176,615,473</td>
<td>$37,475,918</td>
<td>$214,091,391</td>
</tr>
<tr>
<td>45 through 64</td>
<td>$83,741,040</td>
<td>$20,575,305</td>
<td>$104,316,345</td>
</tr>
<tr>
<td>65+</td>
<td>$9,771,825</td>
<td>$8,135,038</td>
<td>$17,906,863</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$332,261,007</td>
<td>$154,214,920</td>
<td>$486,475,927</td>
</tr>
</tbody>
</table>

Source: JLARC analysis of DSHS-SSPS, CHRIS, and MMIS payment records.

Case managers described SSI and food stamps as key resources, necessary to maintain clients in community settings. Indeed, DDD services—or medical services—alone will not sustain a client. A “package” of services is used. For instance, as Exhibit 4 below illustrates SSI (Supplemental Security Income) expenditures are greater than expenditures for county services for employment and day programs.

**Exhibit 4: DDD Clients’ Use of Public Benefits (One Month)**

<table>
<thead>
<tr>
<th>Benefit Category</th>
<th>Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>DDD Community Services</td>
<td>$25,992,927</td>
</tr>
<tr>
<td>DDD Residential Habilitation Centers (RHCs)</td>
<td>$12,725,201</td>
</tr>
<tr>
<td>Primary Medical</td>
<td>$12,313,260</td>
</tr>
<tr>
<td>SSI (Supplemental Security Income)</td>
<td>$5,559,840</td>
</tr>
<tr>
<td>Social Security</td>
<td>$4,738,017</td>
</tr>
<tr>
<td>DDD County Services</td>
<td>$3,403,352</td>
</tr>
<tr>
<td>Food Stamps</td>
<td>$713,458</td>
</tr>
<tr>
<td>TANF-R (Temporary Assistance to Needy Families-Regular)</td>
<td>$288,117</td>
</tr>
</tbody>
</table>

*Because this information comes from a variety of payment sources, it is an estimate. Depending on the data source, different time periods are used. Except for the RHC data, expenditures are related directly to the “snapshot” of clients eligible on August 1, 2002. Sources: RHC-DSHS EMIS: data for August 2002; Community Services: SSPS records analyzed by JLARC: data for December 2001; County Services: CHRIS records analyzed by JLARC: data for December 2001; Primary Medical: MMIS records, analyzed by JLARC: data for December 2001; SSI, Social Security, Foods Stamps, TANF-R: ACES records analyzed by JLARC, data for August 2002. Please see Appendix 4 for a more detailed description of the process utilized by JLARC to analyze this information.*
But our site visits also reveal a problem: a lack of effective coordination in the management of this total service “package.” Different parts of DSHS are responsible for different parts of the package: DDD “manages” DDD services, Medical Assistance “manages” acute medical services, and Economic Services “manages” economic supports. The creation of these “silos” of funding and management makes it difficult for clients to navigate the maze of programs. Policymakers also have difficulty developing a picture of the total “packages” of service going to DDD clients.

These public program silos also make collecting information difficult on the total public benefits package used by these clients. Through extensive analysis of various payment sources, JLARC identified and added together three key areas: DDD services, primary medical care, and economic supports.

Grouping these data into the three major areas: DDD services (RHC, Community, County), Primary Medical, and Economic Supports (SSI, Social Security, Food Stamps, TANF-R), shows that more than one-third of the public benefits going to DDD clients fall outside of the Developmental Disabilities Division’s budget. Exhibit 5 below illustrates that the DDD budget accounts for less than two-thirds of the total benefits going to these clients.

**Exhibit 5: One-Third of Public Benefits Going To DDD Clients Fall Outside of DDD’s Budget**

Other sources of services and benefits, such as basic and special education ($9,090 per year in the 2002-03 school year) and other areas of DSHS are not included in these totals. They would serve to make the picture even more complex: clients are getting services and benefits from many parts of government, with very little effective coordination of those benefits taking place.

**Public Benefits Conclusion**

In an effort to understand the workload of DDD case managers, JLARC previously noted that one-third of the caseload received no paid services through the Division. Many of these clients do, however, receive some other public benefits. Exhibit 6 below illustrates that of the 10,114 clients previously noted as receiving no DDD service, almost two-thirds did receive either primary medical care and/or economic supports.\(^9\)

<table>
<thead>
<tr>
<th>Exhibit 6: 64 Percent of DDD Clients Not Receiving DDD Paid Services Did Receive Either Medical Care or Economic Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total previously reported as receiving no DDD paid service.</td>
</tr>
<tr>
<td>How many of these <strong>received</strong> primary medical and/or economic supports?</td>
</tr>
<tr>
<td>No DDD paid service, no primary medical, no economic supports?</td>
</tr>
</tbody>
</table>

Source: JLARC analysis of DSHS SSPS, MMIS, and ACES data.

We have also noted that the absence of a consistent, verifiable assessment process makes it impossible to judge clients’ needs for services. Thus it is impossible to determine the appropriateness of service levels, whether they are DDD budgeted, primary medical, or economic supports.

It is clear that this package of services is important to maintaining DDD clients in community settings. It is also clear that the coordination of these services and benefits needs to be improved. A key step to making this improvement will be in the implementation of an effective case management system, one that assesses client needs and notes all the resources going to meet those needs, regardless of who “manages” or “supplies” them.

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\(^9\) For a detailed discussion of service levels to clients, please see: Joint Legislative Audit and Review Committee: Performance Audit of Developmental Disabilities Division: Interim Report 02-13, December 4, 2002, pages 5-10.
CHAPTER FOUR – FEDERAL FUNDING IN DEVELOPMENTAL DISABILITIES

Overview

The Medicaid program dominates the provision of health and human services in the nation and in Washington State. As states “partner” with the federal government to receive Medicaid funding, they also receive Medicaid’s complex array of rules and regulations.

In Washington, DSHS is now heavily reliant on this Medicaid funding. Over the course of the last decade, DDD’s use of federal funds in the provision of services to the developmentally disabled has increased dramatically. This increase has had profound impacts on the operations of the Developmental Disabilities Division (DDD). Now, this Division and its programs are dominated by federal Medicaid funds and the rules and regulations that accompany those funds.

This audit, previous audits conducted by JLARC, and consultant reports requested by DSHS all point to the need to change the operations of DDD. Understanding the complexities of the Medicaid program will be key to making successful changes.

Medicaid at the National Level

Federal Medicaid is the major public health insurance program for low-income Americans. It finances an array of services: doctors, drugs, hospitals, employment, therapies, assistance in activities of daily living, substance abuse prevention, nursing homes, assisted living—the list is long. Across the country, it plays a major role in funding health services.

Under federal Medicaid law, states are required to cover certain mandatory groups of clients with a set of specific services. Medicaid also provides states with the option to cover other groups and to provide other services. Both mandatory and optional coverage groups and services are detailed in each state’s “Medicaid State Plan.” An approved plan represents an agreement—a contract—between a state and Medicaid. Medicaid financing of Washington’s DD program reflects a policy decision by both the state and federal governments to fund the services. While developmentally disabled clients use mandatory services, services provided by the Division are Medicaid-optional services.

The agreement to accept Medicaid funding brings with it a host of often confusing program eligibility and service requirements. Even “experts” on Medicaid will preface their comments and analysis with a statement regarding the complexity of the system and the confusion surrounding it. This complexity makes it difficult not only for clients to understand, but also for state officials to administer.

Medicaid and DD in Washington State

Medicaid funding—and the rules and regulations that accompany it—dominate DDD’s $1.2 billion biennial budget. Participation in Medicaid requires that states share with the federal government in the cost of services. The federal component of that cost in Washington is estimated to be about $550 million for the 2001-2003 Biennium. Since the federal government pays for about half of the costs of services provided under Medicaid, a total for the Medicaid program can be estimated: approximately $1.1 billion ($550 million times 2).

As Exhibits 7 and 8 on the following page illustrate, Medicaid provides federal funding to many other areas of DSHS, with this federal funding alone accounting for 38 percent of the Department’s total appropriation.
### Exhibit 7: $5.8 Billion in Federal Medicaid Funds in the 2001-2003 Biennium in DSHS

<table>
<thead>
<tr>
<th>DSHS Program</th>
<th>Uses Medicaid Funding?</th>
<th>Federal Funding Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Assistance</td>
<td>Yes</td>
<td>$3,539,934,000</td>
</tr>
<tr>
<td>Long-Term Care</td>
<td>Yes</td>
<td>$996,606,000</td>
</tr>
<tr>
<td>Developmental Disabilities</td>
<td>Yes</td>
<td>$552,850,000</td>
</tr>
<tr>
<td>Mental Health</td>
<td>Yes</td>
<td>$492,661,000</td>
</tr>
<tr>
<td>Economic Services</td>
<td>Yes</td>
<td>$83,343,000</td>
</tr>
<tr>
<td>Children and Family Services</td>
<td>Yes</td>
<td>$75,546,000</td>
</tr>
<tr>
<td>Alcohol and Substance Abuse</td>
<td>Yes</td>
<td>$21,542,000</td>
</tr>
<tr>
<td>Administration</td>
<td>Yes</td>
<td>$19,349,000</td>
</tr>
<tr>
<td>Payments to Other Agencies</td>
<td>Yes</td>
<td>$9,219,000</td>
</tr>
<tr>
<td>Juvenile Rehabilitation</td>
<td>Yes</td>
<td>$8,312,000</td>
</tr>
<tr>
<td>Vocational Rehabilitation</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>DSHS TOTAL</strong></td>
<td></td>
<td><strong>$5,799,362,000</strong></td>
</tr>
</tbody>
</table>

Source: Legislative Evaluation and Accountability Program (LEAP) Reports.

### Exhibit 8: Medicaid's Federal Funding of $5.8 Billion is 38 Percent of DSHS's Total 2001-2003 $15.4 Billion Biennial Appropriation

- **Federal Medicaid**
  - 38%
  - $5.8 billion

- **Estimated Medicaid State Match**
  - 38%
  - $5.8 billion

- **All Other Funds**
  - 24%
  - $3.8 billion

Source: Legislative Evaluation and Accountability Program (LEAP) Reports.
Exhibit 8 also illustrates that to understand the full scope of the Medicaid program the federal and state funding shares must be added together. The estimate shows that only about one-quarter of DSHS’s budget (24 percent) is not related to Medicaid.

While the Medicaid program dominates both institutional (RHCs) and community-based DDD services, it is in the community where its influence has grown the most over the past 10 years. Exhibit 9 below illustrates that there has been an almost four-fold increase in the amount of federal funds used for community-based programs. This increase mirrors the caseload increase previously documented by JLARC.

**Exhibit 9: Total Federal Funding for Washington's DDD Programs Has Increased 84% Over the Past Decade, With An Almost Four-Fold Increase in Community Programs**

![Graph showing total federal funding, RHCs, and community programs over fiscal years 1992 to 2003.]

*Source: Legislative Evaluation and Accountability Program (LEAP) Reports.*

**Waivers: Meeting Medicaid Requirements**

Developmentally disabled clients first gained access to Medicaid’s benefits when it included institutional services as a state-option service; but Medicaid only paid for services in institutions. Beginning in the 1980s, this began to change, when Medicaid first allowed states to “waive” the requirement that services be provided only in institutional settings. Such waivers have developed into one of the most important vehicles for providing community-based DDD services across the country. *Appendix 3 of this report includes an overview of the Medicaid program as well as a description of how clients become eligible for Medicaid services.*

Because the federal government will participate in the cost of more services under these waivers, states have utilized them to increase the number of services they provide. The logic was at first compelling: the federal government will pay for half of the cost, so the new services come at less direct cost to the states.
But to obtain a waiver, states must enter into a contract with the federal government. The contract specifies how many clients will be permitted to receive waiver services and sets the upper limit on the total cost of those services. In addition, eligibility determination, quality control, cost control, and other procedures and obligations are defined. The federal government, thus, imposes a number of “strings” that accompany these federal dollars.

Waivers also must be renewed on a five-year cycle. Each renewal cycle brings with it a review by the federal government of the waiver’s management and the state’s adherence to the terms of the contract.

**Washington’s “CAP” Waiver**

In Washington, DDD’s waiver is called the “CAP” waiver: the Community Alternatives Program. About one-third of the community caseload (11,000 of 31,000) is on the waiver. Exhibit 10 below illustrates that expenditures for these clients dominate spending on DDD services. While only about one-third of the caseload, these clients account for 83 percent of expenditures on DDD services, due in part to their use of the expensive residential service “Supportive Living” and in part to their access to a broad array of other services.

**Exhibit 10: Waiver Clients Dominate Total Expenditures for DDD**

**Budgeted Community Services, With Non-Waiver Clients Using The Majority Of Primary Medical Services**

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Budgeted Services ($332 million total)</th>
<th>Primary Medical Assistance ($154 million total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DDD Budgeted Services</td>
<td>$274m (83%)</td>
<td>$64m (42%)</td>
</tr>
<tr>
<td>Waiver Clients</td>
<td>$58m (17%)</td>
<td>$90m (58%)</td>
</tr>
<tr>
<td>All Other Clients</td>
<td>$0</td>
<td>$350</td>
</tr>
</tbody>
</table>

Source: JLARC analysis of DSHS CCDB, SSPS, and MMIS records. All Fund Sources, January 2001 through December 2001.

**Federal Review of DDD’s Waiver Management**

In June 2002, at the same time as Washington State’s waiver was to be renewed, the Centers for Medicare and Medicaid Services (CMS, formerly known as HCFA) released a review highly critical of the operations of the DDD’s Medicaid waiver.

The review contained a number of findings and 15 recommendations for change. CMS also demanded that Washington State refund $26 million (illustrated in Exhibit 11 on the following page).
in what it calls “disallowances.” These disallowances are for expenditures related to services that CMS believes went to clients who did not meet the criteria for waiver eligibility or for services that were not included in the waiver agreement.

<table>
<thead>
<tr>
<th>Reasons:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clients not getting waiver services but were getting other Medicaid</td>
</tr>
<tr>
<td>services</td>
</tr>
<tr>
<td>$19,545,258</td>
</tr>
<tr>
<td>Clients enrolled in waiver in excess of number allowed</td>
</tr>
<tr>
<td>$3,549,015</td>
</tr>
<tr>
<td>Clients made eligible through “Exception to Policy,” deemed ineligible</td>
</tr>
<tr>
<td>by Feds</td>
</tr>
<tr>
<td>$2,575,077</td>
</tr>
<tr>
<td>Expenses for childcare, which is not a Medicaid service</td>
</tr>
<tr>
<td>$99,483</td>
</tr>
<tr>
<td>TOTAL</td>
</tr>
<tr>
<td>$25,768,833</td>
</tr>
</tbody>
</table>


The single largest area of disallowance is for clients who were not, according to CMS, receiving DDD services covered under the waiver. While the reasoning behind the disallowance is complex, it can be summarized as follows:

1. If clients are not receiving a waiver service (every month), clients must not need a waiver service, and therefore do not require an institutional level of care, so they are not eligible for the waiver.

2. Clients are therefore not eligible for other Medicaid services.

JLARC’s interviews with DDD field staff indicate that the use of the Medicaid waiver had a number of phases. One phase emphasizes the use of the waiver for clients with family support needs, one phase emphasizes the use of the waiver for clients with residential needs, while another phase emphasizes the use of the waiver in helping clients access primary medical services (frequently referred to as “accessing the medical coupon”). In the latter case, primary care services include such things as doctors, hospitals, and drugs.

While we could not ascertain exactly when these phases took place, every office in every region told the same story: the focus of the agency’s use of the waiver has changed over time. And one of the areas of focus was on gaining access to primary medical care.

The federal government believes that Washington State is using the DDD waiver to gain access to a variety of Medicaid services for those clients who would otherwise not be eligible. Their belief is that the state is using the higher income/resource limits available to waiver clients, not for waiver services, but for other Medicaid services such as primary medical care.

While DSHS is currently disputing the disallowance, CMS has raised issues that Washington must address in the management of its waiver. In particular, CMS is telling Washington that the waiver exists to keep clients out of institutions and not solely as a means to access other Medicaid services, such as primary medical care.

**DDD Medicaid Waiver and the Federal Courts**

In November 1999, advocates led by The ARC (formerly known as the Association of Retarded Citizens) sued the Department of Social and Health Services. The basis of the claim, heard before
Performance Audit of Developmental Disabilities Division

federal courts, is that Washington State is not meeting the requirements of Medicaid law as it manages its waiver program.10

While there were a number of legal arguments involved, the essence of the claim was that Washington State is not providing services to waiver clients who require them. This claim covers both clients who were excluded from any service because of funding limitations, and clients who were getting some services, but not the amount that they may “need.”

The court rejected a proposed settlement that DSHS had negotiated with ARC. Before its rejection, the suit was a major driver in the 2002 Supplemental Budget process because the settlement (subject to legislative approval and appropriation) would have committed Washington State to additional funding for DD clients. The proposed settlement also stipulated the focus of that funding.

The rejected settlement proposed yearly increases in funding that, by fiscal year 2006, would have equaled $107 million per year. In each year, how those increases would be spent was defined. Splits between current clients, new clients, and service types were stipulated, as were prohibitions on some of the uses of the settlement funds.

The lawsuit and its outcome are of particular concern, as the federal courts would have defined for the Legislature its policy priorities. While the court dismissed this particular settlement (for complex legal reasons), negotiations continue. Should negotiations be unsuccessful, trial is to commence October 2003. It is also possible that similar lawsuits may emerge in the future.

Waiver Renewal

Waivers are approved by the federal government for a period of five years. As CMS was announcing their critical review and disallowance of the current waiver in the summer of 2002, and DSHS was attempting to settle the lawsuit with ARC, Washington was pursuing the renewal process with CMS.

JLARC sought clarification from CMS on how that renewal process would work, attempting to understand timelines and the impact of a critical review of the current waiver on the application for a new waiver. Based on our discussions with CMS, we learned two key things:

1. Any new waivers must show how Washington will address the identified weaknesses of the old waiver.

2. Approval of the new waiver will be the result of a negotiation process, with no great certainty of where that negotiation will lead or how long it will take.

Currently, DSHS is in that negotiation process, having received an extension to continue with its current waiver. Extensions run in 90-day (3-month) increments, with Washington currently operating under its fourth such extension.

Medicaid Funding Conclusion

The Medicaid program imposes complex standards, rules, and regulations. The federal government’s analysis of DDD’s ability to meet these standards and regulations in waiver management found the Division with several significant problems. This audit, previous audits conducted by JLARC, consultant reports requested by DSHS, and recent organizational changes implemented by DSHS all point to the need to change the operations of DDD. All of these needed change efforts must be conducted with an understanding that DDD is a program now dominated by Medicaid funding and thus driven by the federal regulations governing the use of that funding.

10 Association of Retarded Citizens v. Quasim, U.S. District Court, Western District of Washington, C99-5577 FDB.
CHAPTER FIVE – CONCLUSIONS AND RECOMMENDATIONS

JLARC examined in detail case management and the nature and cost of services provided to community-based DDD clients. The lack of consistent case management processes means that it is not possible to accurately determine the number of Division clients, their service needs, or the case manager resources required to effectively manage the caseload. An increased caseload size, coupled with the complexities of the Medicaid program, demand that more careful attention be paid to fundamental management practices, such as consistently applied policies and procedures.

By adding together the major public resources accessible to DDD clients, JLARC determined that the Division manages only two-thirds of those resources. This is further evidence of both the complexity of services (multiple funding sources, multiple client “points of contact” with DSHS) and of the need for effective service coordination, both within the Division and within DSHS.

There is no easy way of managing a Medicaid program. Just as the maze of various programs is confusing to clients, it can also be confusing to program managers. Yet the responsibility still exists to pay careful attention to certain management fundamentals, such as consistent eligibility determination and assessment processes.

Success for DDD has been defined as an ability to get some level of services to clients. Expenditures for needed infrastructure—information systems, case management systems, assessment systems—were seen as secondary. Now, as the caseload increases and the complexity of the Medicaid program becomes more obvious, the Division suffers from the lack of that infrastructure. Accurate client counts do not exist, nor do consistently applied assessment procedures. Making the case to federal auditors that services meet standards becomes more and more challenging.

The Division repeatedly requests substantial increases in funding for additional case managers. JLARC’s site visits lead us to conclude that these case managers work hard, deal with often-complex client needs, with jobs made more difficult because of the lack of basic infrastructure. While the attempts of each office to try and develop clever processes and systems of their own illustrate examples of innovation, this is a statewide program that requires statewide supports, statewide policies, and statewide procedures. The Legislature cannot make accurate resource allocation decisions until basic information is available: information on clients, information on services, and information on processes.

Developing this infrastructure—these supports, policies, and procedures—will not happen overnight, and some components (computer systems) will have a price tag attached. The cost of not developing these supports will be the continuation of a system that knows too little about its clients: their service needs and how those needs are being met. The cost, as we have also learned, is the risk of sanctions and penalties from the federal government.

To move this process of change and improvement along, JLARC proposes three recommendations to the Department of Social and Health Services. All three recommendations will require the Department to keep the Legislature involved in their implementation.

RECOMMENDATION 1—ASSESSMENT PROCESS

DSHS should develop an assessment process for developmentally disabled clients that is consistently applied to all clients, in all parts of Washington State. Clients must be assessed
Performance Audit of Developmental Disabilities Division

before a determination of service need is made. This process should utilize, to the extent possible, existing computer-based assessment tools either in use or under development in DSHS. A plan for implementing this process, that identifies costs and includes an implementation schedule, should be submitted to the Legislature by September 2003.

**Legislation Required:** None  
**Fiscal Impact:** None  
**Completion Date:** September 2003

**RECOMMENDATION 2—CASE MANAGEMENT SYSTEM**

DSHS should submit to the Legislature a plan for implementing a case management system in DDD. The plan must explicitly address the case management functions identified in this report, outlining which functions will be met, how this will be accomplished, at what cost, and a timeline for implementation. Outside technical assistance should be utilized in the development of this plan.

**Legislation Required:** None  
**Fiscal Impact:** $90,000-$125,000  
**Completion Date:** December 2003

**RECOMMENDATION 3—ACCOUNTABILITY**

Detailed reports on the impacts of the recent reorganization of DSHS—bringing DDD into the new Aging and Disabilities Services Administration—should be submitted to the Legislature. The reports should address how this reorganization will impact the provision of services to the developmentally disabled, renewal of federal “waivers,” as well as detail new organizational reporting structures, including field operations. The reports should also outline the major performance and outcome measures that DDD will be held accountable for by DSHS management and the Office of the Governor.

**Legislation Required:** None  
**Fiscal Impact:** None  
**Completion Date:** Initial report, August 2003  
First follow-up: December 2003  
Second follow-up: June 2004

**AGENCY RESPONSE**

We have shared the report with the Department of Social and Health Services (DSHS) and the Office of Financial Management (OFM), and provided them an opportunity to submit written comments. Their written responses, and JLARC’s comments on agency responses, are included as Appendix 2 and Appendix 2A.

**ACKNOWLEDGEMENTS**

We appreciate the assistance of DSHS staff who provided information and data for this study. DDD field-based staff were particularly helpful as we learned about their operations. Staff in the Medical Assistance Administration and the Economic Services Administration were of great assistance in helping us match service records for DDD clients.
We would also like to acknowledge the efforts of our consultants: Sterling Associates, Alicia Smith and Associates, and the Public Consulting Group. Their analysis and expertise were essential in helping us understand case management practices and the world of Medicaid.

Thomas M. Sykes  
Legislative Auditor

On June 19, 2003, this report was approved for distribution by the Joint Legislative Audit and Review Committee.

Senator Jim Horn  
Chair
Performance Audit of Developmental Disabilities Division
APPENDIX 1 – SCOPE AND OBJECTIVES

PERFORMANCE AUDIT OF THE DIVISION OF DEVELOPMENTAL DISABILITIES IN THE DEPARTMENT OF SOCIAL AND HEALTH SERVICES

SCOPE AND OBJECTIVES

MAY 22, 2002

STATE OF WASHINGTON
JOINT LEGISLATIVE AUDIT AND REVIEW COMMITTEE

AUDIT TEAM
John Woolley

LEGISLATIVE AUDITOR
Tom Sykes

Joint Legislative Audit & Review Committee
506 16th Avenue SE
Olympia, WA 98501–2323

(360) 786–5171
(360) 786–5180 Fax

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e-mail: neff_ba@leg.wa.gov

SUMMARY
The 2002 Supplemental Operating Budget mandates a performance audit of the Division of Developmental Disabilities (DDD) within the Department of Social and Health Services (DSHS). Governor Locke’s veto action on JLARC’s budget reduced the resources available to conduct the audit, requiring an immediate focus on key policy issues. Accordingly, initial audit review will focus on a fundamental issue facing DDD: how the Division manages its Home and Community-Based Services waiver (CAP waiver), the source of federal match for state expenditures. Comparisons with other parts of DSHS that manage waivers will be included, as will comparisons with other states. In addition, a complete “picture” of services provided to Division clients will be drawn—regardless of the source of funds or organization providing the services. Finally, a methodology will be developed to assist in comparing caseworker workloads in Washington State to other states.

BACKGROUND
The 2001-2003 Operating and Capital Budgets contained three separate mandates for JLARC analyses related to the Division of Developmental Disabilities: analysis of caseload-staffing issues, analysis of the current value and uses—and alternative uses—of the real property of the Residential Habilitation Centers (RHCs), and JLARC’s analysis of the high school transition program.

JLARC’s analysis of caseloads and case staffing found substantial problems with the information the Division provides to the Legislature for budgeting purposes: client counts are inaccurate and clients who are not eligible for services are receiving them. These findings pointed to the need for a broader performance audit of the Division.

The 2002 Supplemental Operating Budget provides funding and direction for this broader audit, while refocusing the resources originally devoted to the study of the high school transition program. No changes were made to the separate analysis of the value and uses of the RHCs.

STUDY SCOPE
The proviso in the 2002 Supplement Budget contains a broad mandate for this performance audit. However, because of the Governor’s veto of JLARC’s budget, the study scope must necessarily be narrowed.
This JLARC study will focus on the Division’s performance in managing its federal “waiver.” This waiver allows the Division to provide community-based services (as opposed to services based in institutions—the RHCs) and receive federal financial participation in the provision of these services.

Because of the amount of federal funding ($406 million for the biennium in Community Services), and the lawsuits Washington State faces in the provision of these services, this is a particularly critical fiscal and policy area. Since most services provided by the Division are included as waiver services, the performance audit will still be able to address many of the issues of legislative concern and importance.

**STUDY OBJECTIVES**

1. Explain the nature of DDD services and the funding sources for these services. Describe all services and how clients become eligible for these services, and how this eligibility might change over the course of a client’s life. Included will be an explanation of the assessment process, how clients become “state only,” “waiver,” or “personal care,” and the distinguishing characteristics of “waiver” clients. Comparisons with other parts of DSHS, in particular how decisions are made on the management of waiver services, will be included. Costs associated with services provided by other parts of DSHS or other parts of government will be analyzed to develop a “total cost” description.

2. Evaluate the Division’s use of the Home and Community-Based waiver. Review the recent (2002) federal audit of the waiver, analyze its implications, and compare its findings to findings in other states. Review and analyze the Department’s responses to the federal audit, comparing proposed strategies to address federal findings to those employed in other states and other parts of DSHS. Analyze the potential legal and fiscal impacts of waiver audits and the Division’s responses.

3. Analyze the Division’s caseload ratios in comparison with other states. Determine how to ensure comparisons are valid, and develop alternative comparisons if appropriate.

**TIMEFRAME FOR THE STUDY**

Interim findings are to be submitted to the fiscal committees of the Legislature by December 1, 2002, with a final report due by June 30, 2003.

**JLARC STAFF FOR THE STUDY**

John Woolley   (360) 786-5184   woolley jo@leg.wa.gov
APPENDIX 2 – AGENCY RESPONSES

- Department of Social and Health Services
- Office of Financial Management

JLARC’s comments on agency responses follow as Appendix 2A
May 20, 2003

Tom Sykes  
Joint Legislative Audit and Review Committee  
506 16th Avenue SE  
Olympia, WA 98501-2323

Dear Tom:

Thank you for the opportunity to review and respond to the Joint Legislative Audit and Review Committee’s preliminary report entitled Division of Developmental Disabilities Performance Audit.

The Office of Financial Management (OFM) agrees with the conclusions of the report that case, data, and federal funding management issues are significant challenges facing the Department of Social and Health Services’ Division of Developmental Disabilities. In general, we believe the recommendations outline appropriate next steps the Department can take to begin to address current infrastructure weaknesses within the Division of Developmental Disabilities. OFM’s comments on the recommendations are attached.

Again, thank you for this opportunity to provide comment on this report.

Sincerely,

Marty Brown  
Director
<table>
<thead>
<tr>
<th>RECOMMENDATION</th>
<th>OFM POSITION</th>
<th>COMMENTS</th>
</tr>
</thead>
</table>
| **Recommendation 1:**  
DSHS should develop an assessment process for developmentally disabled clients that is consistently applied to all clients, in all parts of Washington State. Clients must be assessed before a determination of service need is made. This process should utilize, to the extent possible, existing computer-based assessment tools either in use or under development in DSHS. A plan for implementing this process, that identifies costs and includes an implementation schedule, should be submitted to the Legislature by September 2003. | Concur |  |
| **Concur** | | |
| **Recommendation 2:**  
DSHS should submit to the Legislature by December 2003 a plan for implementing a case management system in DDD. The plan must explicitly address the case management functions identified in this report, outlining which functions will be met, how this will be accomplished, at what cost, and a timeline for implementation. Outside technical assistance should be utilized in the development of this plan. | Concur | OFM agrees that development of a plan for design and implementation of an automated case management system within DSHS’ DDD is a top program priority. DSHS will need to determine how best to complete such a plan within the suggested timeframe and within existing resources. |
| **Concur** | | |
| **Recommendation 3:**  
A detailed report on the impacts of the recent reorganization of DSHS – bringing DDD into the new Aging and Disabilities Services Administration – should be submitted to the Legislature. The report should address how this reorganization will impact the provision of services to the developmentally disabled, renewal of federal “waivers,” as well as detail new organizational reporting structures, including field operations. This report should also outline the major performance and outcome measures that DDD will be held accountable for by DSHS management and the Office of the Governor. Initial report to be due August 2003, a first follow-up report to be due December 2003, and a second follow-up report to be due June 2004. | Partially concur | OFM agrees that the Legislature might find a report from DSHS regarding the goals and impacts of its recent reorganization helpful.  
OFM believes, however, that asking DSHS to submit three different versions of this report is both unnecessary and counter to recent legislative efforts to reduce paperwork requirements of DSHS. OFM suggests that this reporting requirement be scaled back to a single report on this topic to be due December 2003. |
Thomas M. Sykes, Legislative Auditor
Joint Legislative Audit and Review Committee
506 16th Avenue SE
Olympia, Washington 98501-2323

Dear Mr. Sykes:

Thank you for the opportunity to respond to the recommendations made in the Division of Developmental Disabilities Performance Audit—Preliminary Report

Recommendation # 1  DSHS concurs
Recommendation # 2  DSHS concurs
Recommendation # 3  DSHS partially concurs

DSHS concurs with all of the recommendations in the audit. We would like to offer the following comments.

We concur that a reliable and consistent assessment instrument and process is needed. It must be able to address the needs of people of all ages (birth through death); all living situations (in home and out of home); all needs intensities (mobile to non-mobile, community protection to medically complex). Such an instrument must be electronic in order for the department to ensure that the information is available and useful. DSHS does plan to build on the CARES assessment instrument that is already in production for adults with developmental disabilities who use Medicaid Personal Care. We appreciate the recognition that DSHS will need to report to the legislature the costs and implementation schedule that will be required to implement a valid and reliable complex assessment system.

We concur that a case management information system is necessary for case managers to perform their jobs reliably and for the department to account for the resources needed and used by clients with developmental disabilities. This is an important investment for the legislature and the department to make. Currently there is no specific legislative appropriation being considered to address this recommendation. This will require the department to find the
financial resources for the outside technical assistance within the DD 2003-05 budget appropriation.

On Recommendation #3 – The Department agrees that a report should be submitted to the legislature. It would be preferable to do only one report due at the end of 2003.

Sincerely,

DENNIS BRADDOCK
Secretary

cc: Marty Brown, Director, Office of Financial Management  
Kathy Leitch, Assistant Secretary, Aging and Disability Services Administration  
Linda Rolfe, Director, Division of Developmental Disabilities  
Kari Burrell, Executive Policy Advisor, OFM  
Wayne Kawakami, Senior Budget Assistant, OFM
We are pleased that OFM and DSHS concur or partially concur with the audit’s three recommendations. However, two issues warrant additional JLARC comment:

In regard to **Recommendation 2–Case Management System**, we would remind DSHS that we do not suggest that they fund a new case management system from existing resources. Here, we are stating that there is likely to be a small cost associated with hiring outside expertise to assist in developing a plan for such a system. That plan must identify costs associated with the new case management system, along with implementation timelines, and be submitted to the Legislature for consideration during the 2004 Supplemental Budget setting process. Because DDD has had little experience with successfully implementing automated systems, we believe outside assistance and expertise is required.

With **Recommendation 3–Accountability**, we believe that three reports are required because the Legislature must gain a higher level of confidence in the changes that will be linked to this reorganization. The first report should be designed to inform the Legislature on the specifics of the reorganization, expected substantive changes, how those changes are to be accomplished, and timelines associated with those changes. The second and third reports will then provide detail on the success in meeting those targets identified in the first report. One report will be of little assistance or utility to the Legislature as it maintains oversight of this high-profile program area.
Across the country, Medicaid plays a major role in funding health services. As Exhibit 3-1 below illustrates, it accounts for 17 percent of all personal health care expenditures in the U.S.

**Exhibit 3-1: Medicaid Accounts for 17 Percent of America’s Total Personal Health Care Expenditures, Almost Half of All Nursing Home Expenditures**

<table>
<thead>
<tr>
<th>Services</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Personal Health Care Services</td>
<td>17%</td>
</tr>
<tr>
<td>Hospital Services</td>
<td>17%</td>
</tr>
<tr>
<td>Physician and Other Professional</td>
<td>12%</td>
</tr>
<tr>
<td>Prescription Drugs</td>
<td>17%</td>
</tr>
<tr>
<td>Nursing Home Care</td>
<td>48%</td>
</tr>
</tbody>
</table>

Source: Kaiser Family Foundation, Medicaid Fact Sheet. Total services include dental care, other professional services, medical equipment, and other personal health care services.

**Primary Care and Long-Term Care**

Medicaid can be illustrated as having two principal components: the provision of primary (or acute) care services, and the provision of long-term (chronic) care services. Primary care includes services such as doctors, hospitals, and drugs, with long-term care services expected to last for some greater length of time, such as in-home assistance, assisted living, or nursing homes. DDD services fall into the area of long-term or chronic care.

As Exhibit 3-2 on the following page illustrates, nationally, primary care accounts for about 55 percent of total Medicaid expenditures, with long-term care accounting for 38 percent (payments to hospitals for “disproportionate share,” or DSH, make up the remainder).
At its beginning in the 1960s, Medicaid’s focus was on paying for primary medical care for low-income individuals. Medicaid would also pay for some long-term care services, such as DDD institutions (known in this state as Residential Habilitation Centers) and nursing homes. These institutionally based services are where Medicaid’s role in providing services (chronic) to the developmentally disabled began.

When clients are eligible for these Medicaid chronic care services, they are also automatically eligible for Medicaid acute care services. These two areas, which dominated Medicaid at its inception, are illustrated in Exhibit 3-3, on the following page.

This emphasis on institutionally based services for the provision of long-term care, frequently referred to as Medicaid’s institutional bias, began to change with the movement towards de-institutionalization in the 1970s.

**Waivers and Personal Care**

Medicaid first incorporated alternatives to institutional care when it permitted states to “waive” the requirement that Medicaid pay only for institutional care. These “Home and Community Based Waivers,” began in 1981, and are for clients who would otherwise require an institutional level of care. Through the waivers, Medicaid began to participate in the cost of care.
States now had the option of including in their Medicaid program such services as: housing, employment, therapy, respite care, and others.

### Exhibit 3-3: Medicaid of the Past—Two Options

<table>
<thead>
<tr>
<th><strong>Primary Care Services Examples</strong></th>
<th><strong>Long-Term Care Services Examples</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Sometimes called “acute care”</em></td>
<td><em>Sometimes called “chronic care”</em></td>
</tr>
<tr>
<td>Doctors</td>
<td>Nursing Homes</td>
</tr>
<tr>
<td>Hospitals</td>
<td>Intermediate Care Facilities for the Mentally Retarded (ICF/MR or in Washington, Residential Habilitation Centers)</td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
</tr>
</tbody>
</table>

*Clients not automatically* eligible for chronic care

*Clients also automatically* eligible for acute care services

States need to request and receive approval for a “waiver” with approval and renewal not automatic.11

Another significant change occurred in the Medicaid program in the late 1980s. Medicaid began to help pay for “personal care” services (assistance with activities of daily living). Clients could receive these services without meeting institutional level of care requirements, and states were not required to get special approval from the federal government to provide the services.

Distinctions remain in the types of services included in a waiver versus personal care. Generally, waivers include a much broader range of services that are often more expensive in nature than those offered via personal care. These can include residential services with high staff-to-client ratios, employment services, and other services approved in Washington State’s waiver. On the other hand, personal care services include the less costly services of providing assistance with activities of daily living, such as dressing, eating, bathing, and toileting. Exhibit 3-4, on the following page, illustrates how Medicaid long-term care evolved to encompass a very broad range of health care services since the 1960s.

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### Exhibit 3-4: Current Medicaid Services—Many Options

<table>
<thead>
<tr>
<th>First Available</th>
<th>Primary Care</th>
<th>Institutionally Based Long-Term Care</th>
<th>Long-Term Care Through Waivers</th>
<th>Long-Term Care Through Medicaid Personal Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1960s</td>
<td>1960s</td>
<td>Early 1980s</td>
<td>Restricted services in many locations</td>
<td>Restricted services in many locations</td>
</tr>
<tr>
<td><strong>Scope of Services</strong></td>
<td>Many Services</td>
<td>Restricted service location</td>
<td>Broad services in many locations</td>
<td>Restricted services in many locations</td>
</tr>
</tbody>
</table>

**Service Examples**

- **Primary Care**
  - Doctors, Hospitals, Drugs
  - Nursing Homes, ICF/MR

- **Institutionally Based Long-Term Care**
  - Community-based residential: expensive, intense staffing model
  - Employment programs
  - Family Support

- **Long-Term Care Through Waivers**
  - Assistance in activities of daily living in client’s home
  - Community residential: less expensive models, such as adult family homes
  - No employment or family support

- **Long-Term Care Through Medicaid Personal Care**
  - Not automatically eligible for chronic care.
  - Automatically eligible for acute care.
  - Automatically eligible for acute care.

### Eligibility Based on Need

One key to understanding Medicaid is the distinction between the provision of primary and long-term care. For primary care services, Medicaid resembles an insurance plan with an emphasis on “it will be there when and if you need it.” Many thousands of Washington’s citizens have Medicaid primary care coverage and use it when they require, for instance, a visit to a doctor. This is not the case for long-term care. Provision of long-term care services covered through Medicaid requires an assessment that clients specifically require such services.

Meeting Medicaid’s definition of need for long-term care is one of two eligibility requirements. The second eligibility criterion is based on income and resources.

### Eligibility Based on Income

To be eligible for Medicaid, clients must meet financial eligibility guidelines. As with the rest of Medicaid, the details of eligibility are difficult to grasp. While the contract with the federal government allows for some state flexibility, in simple terms, there are three primary “pathways” of financial eligibility. Exhibit 3-5, on the following page, illustrates these pathways and how they compare in terms of allowable income.
### Exhibit 3-5: Medicaid Eligibility Financial “Pathways”

<table>
<thead>
<tr>
<th><strong>Categorically Needy</strong></th>
<th><strong>Medically Needy</strong></th>
<th><strong>Institutional/Waiver</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Very low income, with net income about $550 per month for an individual. This also includes individuals receiving TANF (Temporary Assistance to Needy Families), SSI (Supplemental Security Income), and other mandatory groups.</td>
<td>Gross income can be higher, but because of incurred medical expenses, individual’s or families’ net income meets “categorically needy” income levels of $550 per individual.</td>
<td>Because of the cost of institutional services, those in institutions—or at risk of institutionalization (waiver)—have an individual allowed income level 3 times higher than those in the “categorically needy” level.</td>
</tr>
</tbody>
</table>

### Income and Resource Limits

| Lowest of Three Pathways | Middle of Three Pathways | Highest of Three Pathways |

Each pathway has complex rules on who may enter, based in large part on client or family income and resources. Basically, the lowest income level is attached to the “categorically eligible” pathway, the next highest “medically needy” pathway, with the highest income and resources permitted for those who enter through the “institutional” pathway.
APPENDIX 4 – CALCULATING PUBLIC BENEFITS

JLARC, as part of this performance audit, brought together client, program, and cost data information in a manner never before accomplished. Bringing together this information—necessary to draw a picture of the benefits going to DDD clients—proved to be time consuming, with a number of technical hurdles. This appendix outlines some of the steps we took in this process.

Client Data

The process began with a “snapshot” of DDD clients eligible on August 1, 2002. Client demographic information (name, age, address, and other characteristics) was obtained through a data extract provided by the Developmental Disabilities Division. This information resides in the Common Client Data Base (CCDB). Also included in this snapshot of information from the CCDB was information on the type of residence for each client (Are they in their own home? An intensive tenant support service?), and client disabilities (Are they autistic? Are they developmentally delayed?).

Payment For DDD Services

The Division also provided JLARC with payment records, related to this snapshot of clients, from the Social Services Payment System (SSPS) and the County Human Resource Information System (CHRIS). With these payment records, JLARC was able to develop information on the level of purchased services managed through the Division’s budget. These are the services we came to call “DDD Budgeted Services.”

Payment For Primary Care Medical Services

JLARC’s next step was developing a method to link the demographic and DDD payment information to data on the use of primary care medical services by the DDD clients identified in the August 1 snapshot. Such information is kept in the Medicaid Management Information System (MMIS). DDD provided us with a match between their system, which is based on a DD client ID, and the MMIS system, which is based on a “PIC Code” by developing a table that had both numbers matched.

The Medical Assistance Administration contracts for the operations of the MMIS. Medical Assistance took the data supplied by DDD, matched the data with their vendor, and provided JLARC with a data extract for calendar year 2001, of all medical expenditures associated with the snapshot of clients. Routines have been established over the years to allow for such extracts, to help ensure their accuracy, and to reduce the potential for errors.

Economic Services

In the next step, the Economic Services Administration provided JLARC with a data extract, for the August 1 snapshot of clients, from the Automated Client Eligibility System (ACES). Here, information on eligibility for Medicaid or income assistance services, such as Supplemental Security Income (SSI) or food stamps, is maintained. Because of the inaccuracy of the social security number information in DDD’s CCDB, matching this data had to be done on both social security numbers and names. Again, because this type of match has been done in the past, routines have been developed to help ensure the accuracy of the data and reduce errors.
Completing The Picture

Subsequent to getting the information (with the MMIS data alone accounting for over 1 million records), JLARC established links between each data set. It is this linking—made difficult by the lack of a consistent coding structure—that allows us to look at the full package of services utilized by clients. And it is the linking that posed the greatest technical difficulty throughout the analysis.

Thus, we can view the collection of this information as a progression, with each step making more accurate our understanding of a total public benefits package. The first step focused on DDD budgeted services, of great importance to some DDD clients, but as our analysis discovered, of less importance to some as the next step. And that next step was analysis of primary medical care expenditures. Finally, we obtained information on income supports. Only with all three, are we able to develop some measure of the relative importance to individual clients of each service area as well as the amount of resources provided to DDD clients.

But even with these three elements, we recognize that this is not a complete picture. DDD clients receive other services—ranging from mental health to basic and special education—not included in our datasets. A more complete picture remains to be drawn.