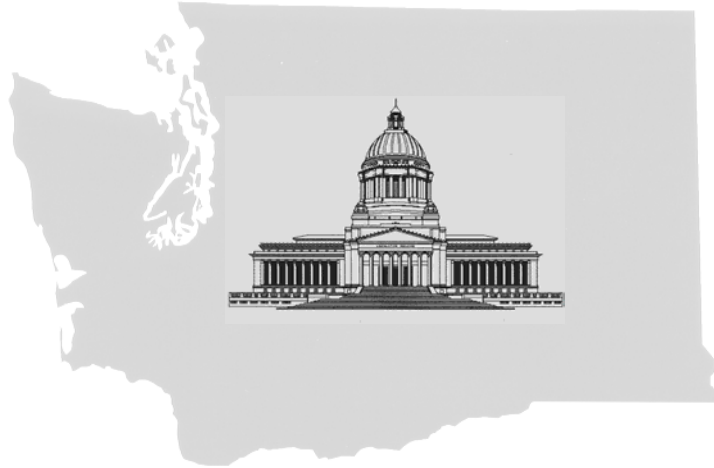


**State of Washington
Joint Legislative Audit and Review Committee (JLARC)**



**Performance Audit of
Developmental Disabilities
Division**

Interim Report

December 4, 2002

*Upon request, this document is available
in alternative formats for persons with disabilities.*

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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.

**PERFORMANCE AUDIT
OF DEVELOPMENTAL
DISABILITIES DIVISION**

INTERIM REPORT

DECEMBER 4, 2002



STATE OF WASHINGTON
JOINT LEGISLATIVE AUDIT AND
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Based on the conclusions of previous JLARC analyses of the Developmental Disabilities Division (DDD) within the Department of Social and Health Services (DSHS), the Legislature directed JLARC to complete a comprehensive audit of the Division.

This interim report focuses on the first objective of the audit: describing DDD services. Future reports will address Medicaid waivers and case management issues.

JLARC finds that there has been an 87 percent increase in total DDD clients in the past 10 years, with those considered community based increasing by 98 percent (from 16,212 to 32,043). However, many clients carried on the caseload rolls receive no paid services through the Division. Of the client records reviewed, 33 percent were receiving no Division paid services.

Of those DDD clients who are receiving paid community-based services, most are receiving more than one. Traditionally, analysis of client expenditures has focused on the cost of a single service; this is inaccurate. A focus on the cost of one service does not show the entire expenditure picture for the Division's clients.

But a focus only on the Division's budget is equally inaccurate. Eighty-one percent of DD clients receive services from other parts of DSHS. JLARC reviewed one area, Medical Assistance, where the costs of acute medical services – such as doctors, hospitals, and drugs – are found for community clients. We added the costs of DDD's services with Medical Assistance services and found that for young children, 84 percent of their total costs fall primarily under the Medical Assistance budget. This means that most of these children's costs never appear in the Developmental Disabilities Division's budget.

Finally, and of key concern, is the process by which the level of need for services is determined. Our extensive fieldwork leads us to conclude that current assessment procedures cannot ensure that clients with similar needs receive similar services. Current assessment tools fail in one of two ways: they either fail to link the assessment of service need with a service plan, or the procedures for their use are so poorly defined or followed that inconsistency is a predictable outcome.

In a time of budget cuts, policy makers need to know that clients with similar needs are getting similar services. Currently, there is no way of determining this in DDD.

INTRODUCTION

Over the past two years, JLARC has conducted four mandated studies of the Division of Developmental Disabilities (DDD). 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.

Performance Audit of Developmental Disabilities Division

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 the state’s institutions.
4. JLARC’s Current Three-Part Performance Audit: community services, managing the federal Medicaid program, and case management.

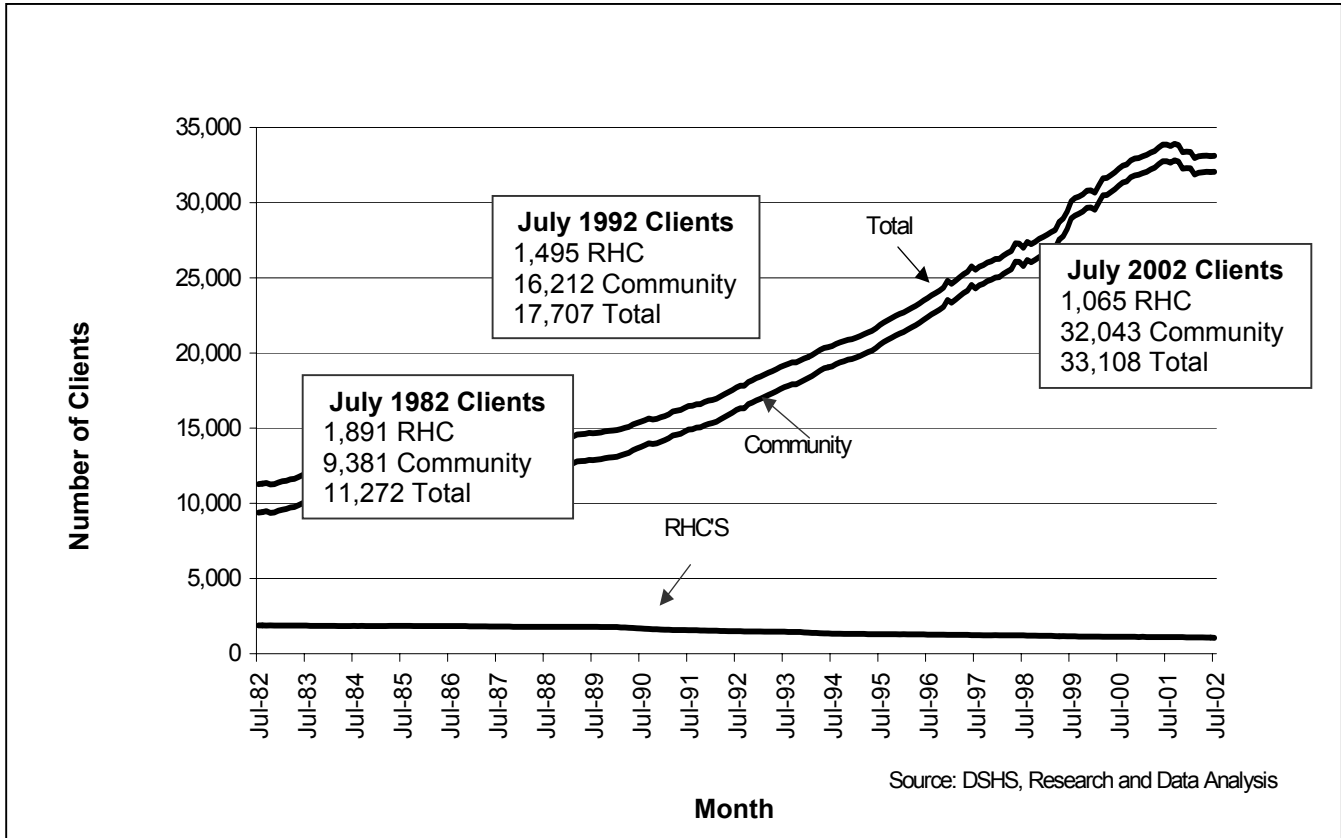
These studies have examined the operations of the Division in order to understand the services it provides. The services are diverse in nature, as are the apparent needs of the clients.

Some services are easy to understand, such as providing a few hours of what amounts to day care so that parents can get some respite from the demands of caring for children with disabilities. Some are very complex and sometimes risky, such as 24-hour supervision of clients who may pose a risk to their community. This interim report analyzes the services provided to community-based clients. Reports will follow that review, in-depth, DDD’s use of Medicaid, and case management.

DDD CASELOADS

As Exhibit 1 below illustrates, caseload growth has been among community clients, with a steady decline in the population of the Residential Habilitation Centers (RHCs), the state’s five institutions for the developmentally disabled.

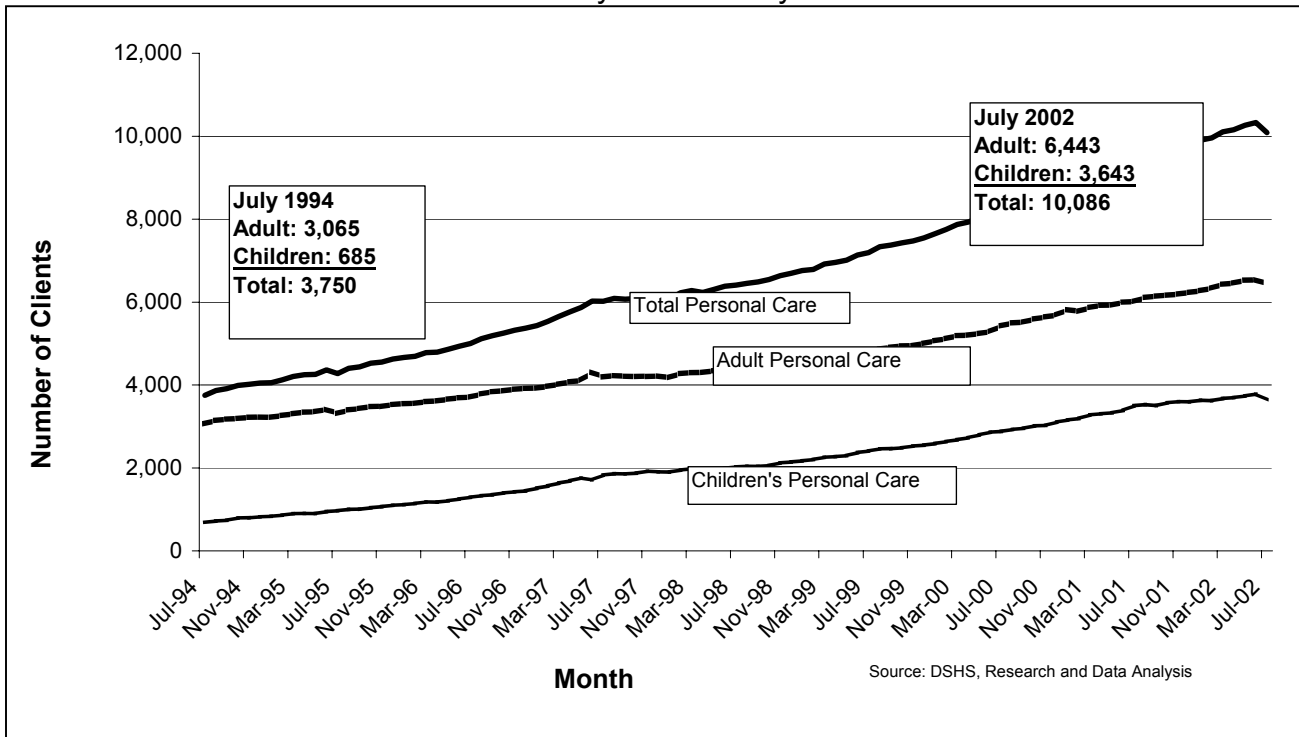
Exhibit 1: DD CLIENTS: Community and Total Populations Have Increased While Institutional Populations Have Decreased



Performance Audit of Developmental Disabilities Division

As Exhibit 2 below illustrates, one of the drivers of community-based caseload growth during the 1990s has been the Medicaid Personal Care program. Access to Medicaid Personal Care is considered an “entitlement.” Unlike most areas in DDD, if an individual meets the financial and service eligibility requirements for Personal Care, the state **must** provide the personal care service. Services cannot be denied because of a lack of funds or because all the “slots” are filled.

Exhibit 2: Medicaid Personal Care Clients Have Increased by 169 Percent From July 1994 to July 2002



Eligibility for Services

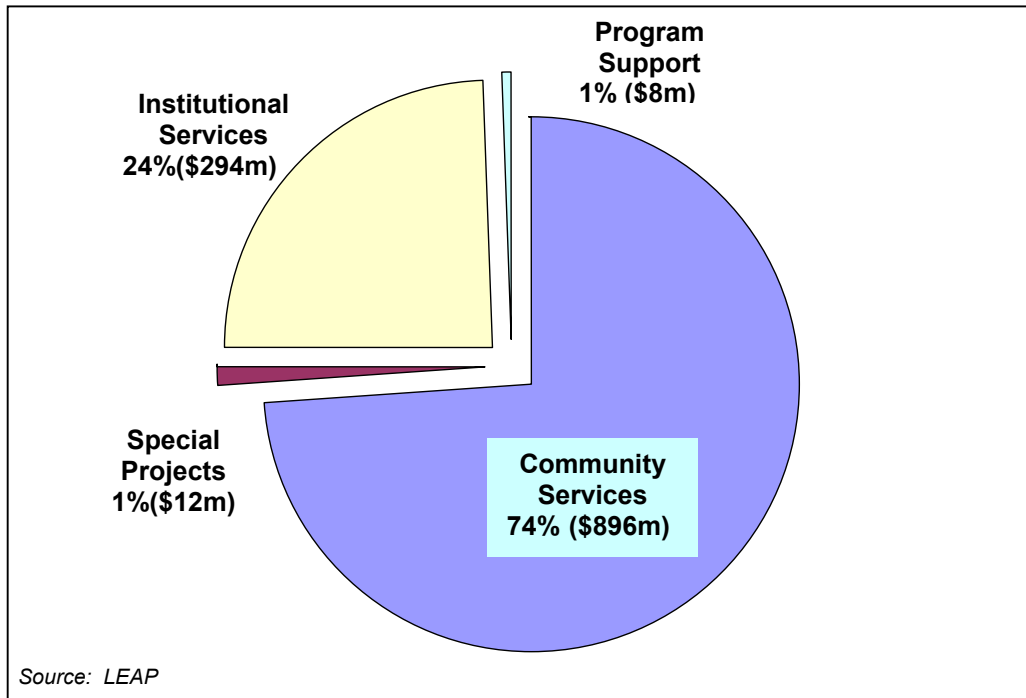
State statute (RCW 71.A) sets out the state’s role in providing services to the developmentally disabled. The Department of Social and Health Services is charged with meeting the various objectives of the statute. Although not specifically identified within DSHS, the DDD manages the provision of services.

On August 1, 2002, the Division had 32,187 clients listed in its eligibility database. The split between community-based clients (97 percent of the total) and those living in the state institutions (Residential Habilitation Centers, 3 percent of the total) as well as the Division’s budget for the current biennium are presented in Exhibit 3 on the following page.

Statute (RCW 71A.10.020) defines what qualifies these individuals as developmentally disabled and therefore eligible for services. For the developmentally disabled, eligibility is based solely on a person’s having a developmental disability. Neither financial nor service needs are the bases for eligibility for services.

Exhibit 3

DDD 2001-2003 Biennial Budget



The 32,187 DDD Clients in August 2002:
Their Service Settings

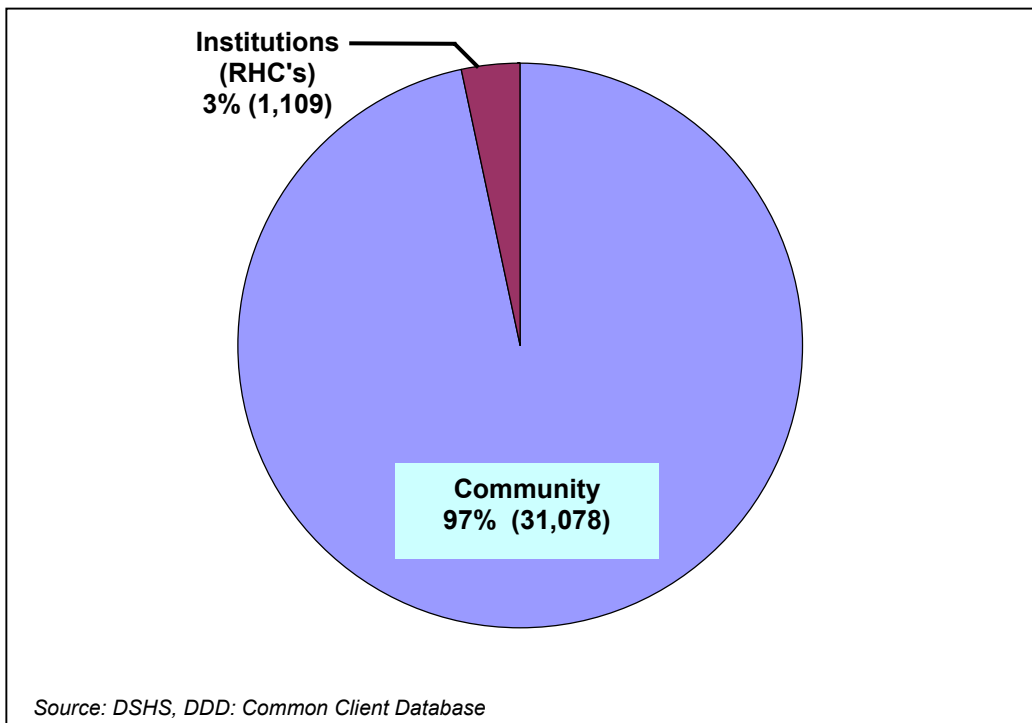
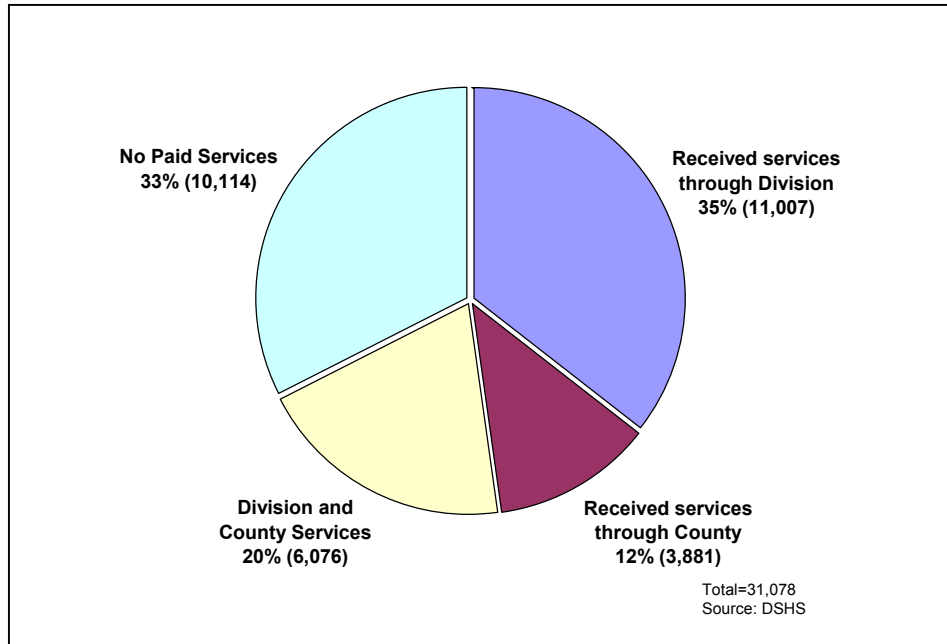


Exhibit 4 illustrates that thousands of community clients (33 percent of total) are carried on the caseload rolls who get no paid services through DDD.

Exhibit 4: One-Third of the Community Caseload Receive No DDD Paid Service



DDD SERVICES

The first service provided through the Division is eligibility determination. During initial intake, case managers determine, through reviewing an applicant’s school records, medical records, and other sources, whether or not a person has a developmental disability that began before the age of 18. (Criteria are clearly stated in statute.)

Exhibit 5 below displays the distribution of all clients on August 1, 2002, across the qualifying disabilities contained in statute. Having one or more of these disabilities makes a person eligible for services from the Division. Because some clients have more than one disability, the disability count exceeds the client count.

Exhibit 5: Disability Counts In DDD		
Mental Retardation	18,527	50%
Developmentally Delayed: (Under Age 6)	7,073	19%
Cerebral Palsy	3,084	8%
Other Condition (ICAP Only)	3,001	8%
Epilepsy	2,410	7%
Autism	1,553	4%
Child Under Age 6: Down's Syndrome	470	1%
Another Neurological Condition	455	1%
Policy Exception*	97	0.3%
*“Other Condition (ICAP Only)” refers to individuals who have a substantial handicap as determined by their score on the “Inventory for Client and Agency Planning (ICAP).” Policy Exception are those clients who do not meet any of the other eligibility criteria but through an “Exception to Policy” process are determined eligible for services.		

Source: DSHS-DDD: Common Client Database. August 1, 2002.

Performance Audit of Developmental Disabilities Division

Statute (RCW 71A.12.040) also defines what services DSHS is authorized to provide to these eligible individuals. They are:

- | | |
|---------------------------------|--------------------------------------|
| 1. Architectural services | 8. Health services and equipment |
| 2. Case management services | 9. Legal services |
| 3. Early childhood intervention | 10. Residential services and support |
| 4. Employment services | 11. Respite care |
| 5. Family counseling | 12. Therapy services and equipment |
| 6. Family support | 13. Transportation services |
| 7. Information and referral | 14. Vocational Services |

These services are arranged for, or provided by, the Division and by county human services departments. Established through contract with the Division, the role of the counties is limited to two primary service areas: early childhood intervention and employment/day programs. Other services are provided directly or indirectly through the Division.

JLARC carefully analyzed the services provided to clients. Because the caseload changes over time, we focused on a “snapshot” of clients: those eligible on August 1, 2002, and looked at what they received during the previous fiscal year.

From July 2001 through June 2002 (Fiscal Year 2002), these 31,078 community clients received \$38 million in paid services arranged through the counties and \$309 million in paid services arranged through the Division, for a total of \$347 million in direct, paid services. Exhibit 6 below provides detail on the major program areas of these services.

Exhibit 6: Major Expenditure Areas For DDD Community Clients, July 2001 Through June 2002 (Dollars in Millions)			
Division	Expenditures	County	Expenditures
Supportive Living (Intensive Tenant Support)	\$154.3	Individual Employment	\$13.3
Adult Personal Care	\$65.4	Community Access	\$8.1
Voluntary Placement Program	\$27.3	Specialized Industry (Sheltered Workshop)	\$7.2
Children’s Personal Care	\$26.1	Group Supported Employment	\$6.8
Group Homes	\$16.3	Person-to-Person	\$2.0
Family Support	\$10.1	Individual and Family Assistance	\$3
Community Support	\$8.9		
Other	\$9		
TOTAL DIVISION	\$309.2	TOTAL COUNTY	\$37.7

Source: DSHS-DDD: SSPS and CHRIS Payment Records.

While many clients receive no services, for those that do, several areas dominate DDD's community-based services expenditures:

1. Supportive Living (previously known as Intensive Tenant Support): supporting clients in living in independent residential settings, such as their own apartment or house.
2. Personal Care for Adults: assistance in activities of daily living, such as eating, bathing, and toileting. The service is provided in their own home, or in adult family homes or adult residential care facilities.
3. Voluntary Placement Program: children placed out of their home with the parents voluntarily entering into a joint custody agreement with foster care providers.
4. Personal Care for Children: assistance in activities of daily living in their own home.
5. Group Homes: a group residential service, providing services to two or more clients in the same location.
6. Individual Employment: supports are provided to clients to help them maintain employment as an individual employee of a firm or organization.
7. Family Support: provides a broad range of services, geared to reduce the need for out-of-home placement. Services might include: respite care, physical therapy, nursing services, behavior management therapy, and/or a cash grant for the family to purchase approved services or items.

Service Packages

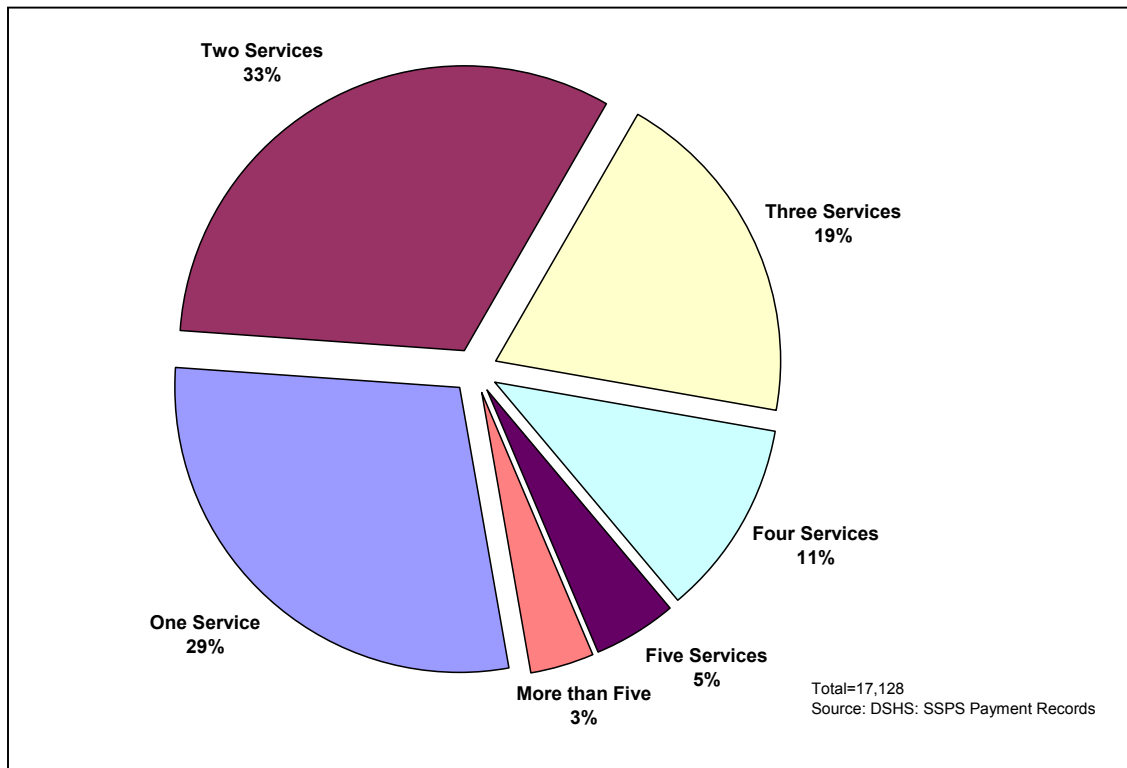
Analysis of expenditure data confirms what interviews with case managers and the review of client files lead us to believe: most clients receive more than one service from the Division. For instance, they may be receiving Children's Personal Care and Family Support. The issue of multiple services, of understanding "service packages" is very important for budgeting purposes. A focus solely on the cost of one service will not give policy makers a true picture of what clients are receiving and what the overall cost for client services are.

For instance, the Caseload Forecast Council was created by the Legislature to provide objective forecasts of caseloads in areas that are considered key budget drivers. These include caseloads in K-12 education, Medicaid, corrections, welfare, and nursing homes. The Council forecasts two areas of DDD services: Children's Personal Care and Adult Personal Care in the Medicaid program. These two services are structured around providing clients with assistance in "activities of daily living," such as eating and toileting.

Both are considered entitlements, meaning that if you meet financial and programmatic eligibility rules, you are entitled to the service. Forecasts are based on analysis of expenditure and use trends as recorded in the data that JLARC analyzed. The Department multiplies expected numbers of cases as forecast by the Council by an average cost to develop a budget for the coming biennium.

But our analysis indicates that most clients receive multiple services, so a focus on only one service – or even the two Medicaid Personal Care (Adult and Children) services – may not tell the entire budget story. For example, most of the clients included in the forecast for Children’s Personal Care receive a service called “Personal Care-Individual Provider-Child.” For our August 1, 2002 caseload, 3,802 different clients used this service from July 2001 through June 2002. Seventy-four percent of these clients (2,827) used other services as well.¹ Exhibit 7 illustrates that for those receiving a paid service through the Division, most are receiving more than just one service.

Exhibit 7: Most Clients Receiving a Division-Paid Service Get More Than One



A focus on the cost of one service will not show the entire expenditure picture for the Division’s clients. Access to a service considered an entitlement might drive demand for other services that are not entitlements. In our example, Children’s Personal Care is an entitlement, while Family Support Services is not. So, while a client may first get a paid service because of an entitlement to Children’s Personal Care, it appears that they end with more than just that one service. But, the budget picture is often driven primarily by a focus on the entitlement service – Medicaid Personal Care.

¹ Most of these clients were receiving, in addition to Personal Care, Respite Care or Family Support vouchers.

Services and Costs Outside the Division

While understanding service packages is essential to understanding what drives the Division’s expenditures, we wanted to go beyond looking only at services provided through the Division’s budget. Our extensive fieldwork indicated early on that clients get services from many other parts of DSHS.

Exhibit 8 below indicates the extent to which DDD clients use services across DSHS. It graphically illustrates the mistake made in assuming that the Division’s budget shows all the costs related to a client. As can be seen, most DDD clients (81 percent) use services provided through other parts of DSHS.

Exhibit 8: DSHS Estimates on DDD Clients	
Clients Receiving Services for DDD (FY00)	33,200
Number served by other parts of DSHS	26,976 (81%)
Other Parts Of DSHS	
Medical Assistance Administration (MAA)	25,976 (78%)
Economic Services Administration (ESA)	17,821 (54%)
Mental Health Division (MHD)	4,116 (12%)
Children and Family Services (DCFS)	3,986 (12%)
DDD clients also receive services in Vocational Rehabilitation, Aging and Adult Services, Division of Alcohol and Substance Abuse, and Juvenile Rehabilitation.	

Source: DSHS, Research and Data Analysis.

To provide an example of services to DD clients delivered from outside the Division, and because of the importance of services paid through the Medical Assistance Administration’s payment system, we have concentrated our service picture to portray services provided through DDD and Medical Assistance. Medical Assistance services are generally called “acute medical” services, such as doctors, drugs, nursing, hospitals, etc. As Exhibit 9 on the next page illustrates, for the group of children ages birth to 6, these expenditures can greatly exceed the expenditures for services from the Developmental Disabilities Division’s budget.²

² The Medicaid Management Information System (MMIS) is used by MAA for payments for a number of medical services, including acute care services. However, other divisions, including DDD, also use this system to make payments for services that are eventually reflected in their budgets. We have attempted to account for this, backing out expenditures in MMIS for certain service types that are charged to DDD’s budget. However, approximately \$1.5 million for additional services may remain in our MMIS totals that are charged to DDD’s budget. In addition, services for skilled nursing facilities are likely charged to the budget of Aging and Adult Services and contained in these exhibits. These skilled nursing facility charges are also not reflected in DDD’s budget.

Exhibit 9: Expenditures For DDD Clients, January 2001 Through December 2001

Age Group	DDD Budgeted Services	Acute Medical Services	Total
Birth through 5	\$7,169,900	\$37,049,575	\$44,219,475
6 through 20	\$54,962,769	\$50,979,084	\$105,941,853
21 through 44	\$176,615,473	\$37,475,918	\$214,091,391
45 through 64	\$83,741,040	\$20,575,305	\$104,316,345
65+	\$9,771,825	\$8,135,038	\$17,906,863
TOTAL	\$332,261,007	\$154,214,921	\$486,475,928

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

A total of **\$44,219,475** was spent for community services for DDD clients who were between the ages of birth through 5 during the period of January 2001 through December 2001. Of this, **\$37,049,575**, or **84 percent** of the total was for these “acute” services. This 84 percent is not reflected in the Division’s budget.³

Further, these expenditures for services for the developmentally disabled are not restricted to DSHS. The K-12 school system plays an extremely important role in the provision of services to developmentally disabled children and young adults to the age of 21. In the 2002-2003 school year, each special education student generates state basic education, state special education and federal special education funding of \$9,090, driven out to each school district. While not included in our charts, our field research indicates the importance of the role of the K-12 system and the services it provides to developmentally disabled children. During the school day, these children are primarily the “clients” of the school system.

Because DDD clients are likely to be receiving a “package” of services – some from the Developmental Disabilities Division, some from Medical Assistance, some from other parts of DSHS, and some from the K-12 system – policy makers need to understand how well these services are coordinated. Currently, there is very little regard given to a client’s total “package.” The approach to funding, and funding decisions, tends to place services into silos – an acute care silo, a DDD services silo, a K-12 silo – making it difficult to understand the total “package.” A better understanding of the total service “package” – doing away with the silos – would give policy makers a clearer view of the impact of services on the well-being of clients. From a budget perspective, policy makers might begin to understand whether or not dollars are going to where they will produce the best results.

³ A federal grant of approximately \$7.3 million is used for the Infant and Toddler Early Intervention Program, included in the Division’s budget. Some amount of this may be expended on the clients included in the 0-6 group. Since there is no client specific information, we cannot determine how much this might be. In addition, this grant is not spent exclusively on DDD clients.

HOW ARE SERVICE LEVELS DETERMINED?

Having developed an understanding of what services DDD clients receive, we wanted to understand **why** clients receive the services they receive.

Through our field research and analysis of data sets, we attempted to identify how levels of services and service packages were developed for clients. We wanted to determine how the need for services is assessed, and in particular, if the determination of need was based on an objective assessment process. Clients with similar needs should be getting similar services. A common, consistent assessment process can ensure that this occurs. We also looked for links between an objective assessment of client needs and the services provided to meet those needs.

We found the assessment tools used by DDD to be weak at best, and a consistent assessment process lacking. Ultimately, we could not “map” the entire assessment process, as it is poorly defined and varies among DDD offices.

Assessment Tools

DDD case managers use three primary assessment tools: the waiver assessment (used to determine if community-based clients require the level of care provided in institutions), the Children’s Personal Care assessment, and the Adult Personal Care assessment.

What determines why an assessment is performed varies from office to office throughout the state. When asked why an assessment is completed, a typical response from field staff was: “because they need the service!” This runs contrary to the basic role of an assessment: to determine **if** a service **is** needed.

Through our analysis of client case records and through our extensive interviews with case managers, we failed to find any predetermined process that would define how specific service levels (sometimes referred to as a “plan of care”) are determined based on the waiver and the children’s personal care assessment tools.⁴ For instance, the waiver assessment tool first determines whether or not a client is eligible for waiver services. Case files for waiver clients seemed to include this assessment. The linkage between this assessment and the services the clients then received, answering *why* the assessment drove a particular service package, was absent.

Through interviews with case managers we could usually develop some general grasp of why they developed the package they developed, but a common, prescribed process capable of being reviewed and validated is missing. Case managers indicated to us that service packages were frequently determined by what funding was available at the time the assessment was performed rather than the result of a careful determination of what services were needed for individual clients.

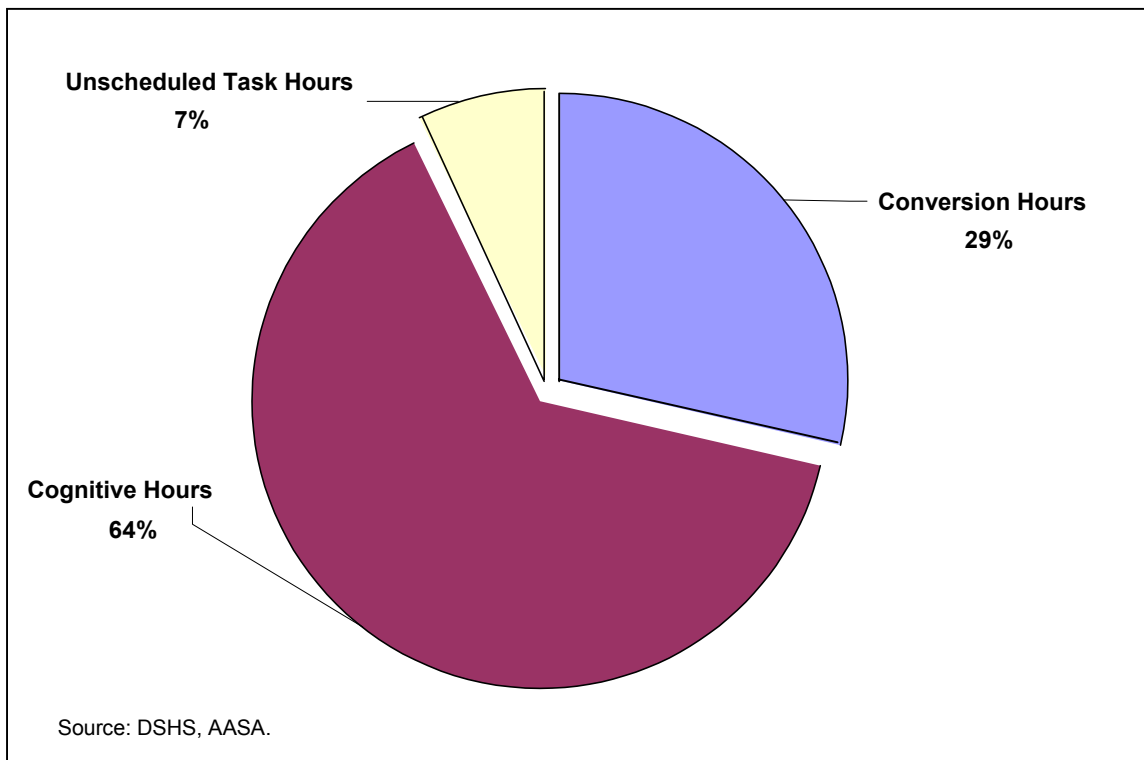
⁴ A review by federal evaluators found similar problems with assessments, reassessments, and “plan of care” development for waiver clients. See U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, “Washington Medicaid Assessment Report Community Alternative Program Waiver,” June 2002.

The “Comprehensive Assessment”

To some extent, the assessment tool used for Adult Personal Care clients makes the connection between the assessment of need and levels of services eventually provided. The “comprehensive assessment” is a computer-based tool that attempts to consider a client’s needs for assistance in activities of daily living through a series of questions and then generates the number of hours of support required for a client.

Yet even this tool allows for a tremendous amount of variation among different users. Based on information supplied by DSHS, we were able to determine that only 29 percent of the total hours determined needed for clients was developed by the assessment tool through its prescribed methodology. These hours are illustrated in Exhibit 10 below as “Conversion Hours.” Most (64 percent) of the total hours were added for “cognitive impairment” and “unscheduled tasks” (7 percent). We found no consistent methods or procedures in use in the field offices to determine client needs related to “cognitive impairment” and “unscheduled tasks.” Thus, over 70 percent of the total hours that clients are assessed as needing **cannot** be linked to a rigorous assessment process.⁵

Exhibit 10: Comprehensive Assessment's Total Hours



⁵ The average total hours for DDD adult clients with current comprehensive assessments available in the analyzed dataset was 224.7 hours. Of this, 66.2 are attributed to “conversion hours,” which are clearly prescribed in statute. Cognitive hours, or hours determine by the case manager needed for supervision, add an average of 149.2 additional hours. Unscheduled task hours, for assistance in tasks such as toileting that cannot be “scheduled” added another 16.5 hours on average. Clients generally receive fewer hours than the total developed through the Comprehensive Assessment and defined as a client’s “need.” This is because of the limits to the total hours of personal care that will be provided.

Conclusion

We examined two major cost drivers for services to developmentally disabled individuals: those provided through the Division of Developmental Disabilities (\$332 million) and those provided through the Medical Assistance Administration (\$154 million). Moreover, this total of almost \$500 million in service expenses for a single year does not include costs for those developmentally disabled clients who simultaneously receive public-funded economic services (primarily Supplemental Security Income – SSI), mental health services, children and family services, and educational support through K-12 special education. A more complete and comprehensive picture of the service packages, and the various assessment processes, however imperfect, that influence the provision of these services, remains to be drawn. Only then will policy makers have a full picture of the publicly funded resources made available for developmentally disabled individuals and their families in Washington.

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



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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.

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