



Washington State
Department of Social
& Health Services

Report to the Legislature

**STATE-FUNDED FAMILY SUPPORT
PROGRAMS**

Chapter 518, Laws 2005, Section 205(1)(e)(iv)

November 1, 2006

Department of Social & Health Services
Aging and Disability Services Administration
Division of Developmental Disabilities
P.O. Box 45310
Olympia, WA 98504-5310
(360) 725-3521
Fax: (360) 407-0955

TABLE OF CONTENTS

	<u>Page</u>
I. Executive Summary	2
II. Introduction	6
A. Report Background	6
B. Organization of Report	7
III. Current Environment	10
A. Background of the Family Support Program	10
B. Program Descriptions	12
C. Service Definitions	16
D. Washington Administrative Code	18
E. Financial	18
F. Information Systems	19
IV. Findings and Recommendations	22
V. New Integrated Program	34
A. Description	34
B. Proposed Major Steps and Timeline	36

Appendix A – Program Detail

**Addendum – Family Support Stakeholder
Workgroup Study**

ACKNOWLEDGEMENTS

We wish to thank the individuals listed below for actively participating in the development of this report. Without their invaluable contributions, this report would not have been possible.

Stakeholders

Ms. Cathy Murahashi	King County Parent Coalition
Ms. Dee-Dee Garmon	The Arc of Grays Harbor and Grays Harbor Family Parent Coalition
Ms. Diana Stadden	Pierce County Coalition for Developmental Disabilities and Autism Society of Washington
Ms. Donna Patrick	WSDDC
Mr. Ed Holen	WSDDC
Ms. Grier Jewell	The Arc of Washington State
Mr. Lance Morehouse	The Fathers Network, Spokane County Parent Coalition
Ms. Margaret-Lee Thompson	The Arc of King County/King County Parent Coalition
Ms. Sue Elliott	The Arc of Washington State

DSHS Staff

Ms. Debbie Couch	Region 6 DDD
Ms. Diane McCalmon	Region 3 DDD
Mr. Doug Washburn	Central Office, DDD
Ms. Janine Stallings	Region 4 DDD
Ms. Jennifer Motley	Region 6 DDD
Ms. Kathy Leitch	Assistant Secretary, ADSA
Ms. Linda Rolfe	Director, DDD
Ms. Lorna Morris	Region 1 DDD
Ms. Nichole Jensen	Region 3 DDD
Ms. Sandy Powers	Region 2 DDD
Ms. Shan-Shan Chien	Region 4 DDD
Ms. Sharon George	Region 5 DDD
Ms. Shirley Everard	Central Office, DDD

Consultants

Ms. Christina B. Maiers	MTG Management Consultants, LLC
Mr. William L. Bangs	MTG Management Consultants, LLC

ACRONYMS

Acronym	Definition
ADL	activities of daily living
ADSA	Aging and Disability Services Administration
AFH	adult family home
CAP	Community Alternatives Program
CCDB	Common Client Database
CMIS	Case Management Information System
CMS	Centers for Medicare & Medicaid Services
CNP	Categorically Needy Program
DDD	Division of Developmental Disabilities
DSHS	Department of Social and Health Services
FPL	federal poverty level
FS	Family Support
FSO	Family Support Opportunity
HCB	Home- and Community-Based
HSRI	Human Services Research Institute
ICF/MR	Intermediate Care Facility for the Mentally Retarded
JLARC	Joint Legislative Audit and Review Committee
MPC	Medicaid Personal Care
POC	Plan of Care
SEIU	Service Employees International Union
SHPM	Social and Health Program Manager
SIS	Support Intensity Scale
SNL	service need level
SSI	supplemental security income
SSP	State Supplemental Payment
TFS	Traditional Family Support
WAC	Washington Administrative Code
WSDDC	Washington State Developmental Disabilities Council

I. Executive Summary

I. Executive Summary

Approximately 67 percent of individuals in the Division of Developmental Disabilities (DDD) caseload live with their families. These families contribute their time and resources to cover the extraordinary expenses and supports necessary to keep their family member at home.

Many families need some services from DDD in order to ensure the stability of this natural support system. Seeking assistance from the state is a difficult decision for families to make. When families take steps to ask for help, it is often after they have exhausted other alternatives. The DDD Family Support (FS) Program provides a way for these families to partner with the state to support their family member with a developmental disability, and provides a low-cost program with a vital array of services to families.

The overall intent of the FS Program is to keep families intact by providing them with assistance in caring for their family member with developmental disabilities. Specific services provided include respite care; therapies; adaptive equipment and related costs; training; supports and counseling; and medical, dental, and nursing services, which are not covered by Medicaid or private insurance.

The FS Program currently administers multiple, separate programs to families receiving support, which creates confusion. Multiple programs provide different levels of support for people with similar needs. As a way to create a more equitable program structure, a proviso was issued by the legislature mandating that the Department of Social and Health Services (DSHS) develop a service delivery model that combines all existing programs. This report is in response to that proviso and provides the following recommendations:

- Combine Traditional Family Support (TFS), Family Support Opportunity (FSO), and the FS Pilot into one FS Program, and provide the services afforded by TFS and FSO.
- Include the Emergency Services Program and a onetime expense option.
- Prioritize families according to those most in need.
- Use family income for children and personal income for adults as one eligibility factor. Income is not an eligibility factor for families or adults served in FSO or TFS. Legislative action on the proposed FS Program should address whether current participants would be served in the new program without regard to income.
- Create specific regulations regarding unspent funds.
- Widely disseminate information about the new program structure.
- Commit additional resources to the Community Service Grants.

- Recognize that families are a primary long-term care system for people with developmental disabilities.
- Recognize that FS is for children and adults who do not have access to supported living services outside the home.
- Modify the needs assessment to more accurately predict need for the FS Program.
- Implement a new organizational structure for consistent FS Program implementation.
- Clearly describe service options (who is eligible for what?).
- Create a separate budget category for state-funded FS that is separate from Waiver and State Supplemental Payment (SSP).
- Allow people to receive other in-home or day services.

DSHS recommends a new program structure as discussed below. Legislative action is required to accomplish the new program structure.

Number Served	1,440 estimated. ¹
Award Amount	Amount will vary depending on level of need, from \$2,000 to \$6,000 per year.
Funding Allotted	\$4.1 million.
Eligibility Requirements	<ul style="list-style-type: none"> ● Individuals with developmental disabilities living with their families. ● Individuals currently receiving FS services or on the FS waiting list. ● Service level determined by the new assessment tool. There will be four levels determined by the need of the caregiver, supervision, activities of daily living (ADL), behavior, and medical. Further considerations will be: <ul style="list-style-type: none"> » Date family placed on waiting list. » Eligibility for SSP or other funding. » Other services received. » Date of application.
Award Determination	<ul style="list-style-type: none"> ● Determine the award level based on assessed need. <ul style="list-style-type: none"> » Level moderate \$2,000. » Level medium \$3,000.

¹ DDD has also asked for additional funding in the decision package for FY 2008 and FY 2009, which may increase this number.

	<ul style="list-style-type: none"> » Level high \$4,000. » Level severe \$6,000. • Conduct evidence-based study to determine relevance of levels.
Services Provided	Listed in the service recommendation in subsection III.C.
Additional Characteristics	<ul style="list-style-type: none"> • All ages are eligible for services. • DDD conducts a background check on respite providers and other contracted providers. • Income is a factor of eligibility. • Financial eligibility will be determined based on the federal poverty level (FPL). Families of children or adults will be eligible for the program if their taxable income is at or below 400 percent of the FPL. • If a family requires more than the award amount, consider moving the individual to a relevant waiver. • Family may receive other DDD-funded services. • Paid providers will be subject to the provisions of the Service Employees International Union (SEIU) bargaining agreement. • This program will use state-only funds.

The new FS Program will provide a more straightforward program structure for both case managers and families. Through these changes, DDD will continue to make a positive impact in the lives of families and people with developmental disabilities and strive to keep families intact.

A separate report was also developed by interested stakeholders. That report is attached to this document and offers the desired future program structure proposed by the advocates. The report solely represents the opinions and views of the stakeholder group.

II. Introduction

II. Introduction

DDD provides support and services for children and adults with developmental disabilities. Approximately 35,700 people are currently enrolled with DDD. Within DDD, the FS Program provides assistance to families who have a family member with a developmental disability living at home. Approximately 67 percent of people on the DDD caseload live within the family home. The FS Program provides families with some of the support necessary to keep eligible individuals at home with parents or other relatives.

The overall intent of the FS Program is to keep families intact by providing them with assistance in caring for their family member with developmental disabilities. Specific services provided include respite care; therapies; adaptive equipment and related costs; training; supports and counseling; and medical, dental, and nursing services, which are not covered by Medicaid or private insurance.

The FS Program provides an additional resource to families caring for a family member with a developmental disability. The program aims to empower families and communities and to serve as a partner in meeting people's needs. These values are expressed by the division's message below.

People with developmental disabilities and their families are valued citizens of the state of Washington. The Division of Developmental Disabilities strives to develop and implement public policies that will promote individual worth, self-respect, and dignity such that each individual is valued as a contributing member of the community.

While the FS Program intends to provide some services to families to achieve this message, programmatic and funding issues and constraints have emerged. As a way to address these issues, the Washington State Legislature instructed DDD to examine the FS Program's current service structure and provide recommendations for creating an integrated program. This report is the response to the legislature's request.

The following subsection further discusses the background, objectives, and scope of this report.

A. Report Background

The FS Program currently administers multiple, separate programs to families receiving support, which creates confusion. Multiple programs provide different levels of support for people with similar needs. This structure developed due to various budget steps taken in the past 30 years. A proviso was issued by the legislature mandating DSHS to develop a single service delivery model providing FS services. Specifically, the proviso states that:

The department shall provide recommendations to the appropriate policy and fiscal committees of the legislature on strategies for integrating state-funded family support programs, including, if appropriate the flexible family support pilot program, into a single program.

As directed by this proviso, DSHS/Aging and Disability Services Administration (ADSA) organized a stakeholder group to provide input in the restructuring of the program and draft a response to the legislature. This report is the result of that effort and provides the findings, recommendations, and a desired course of action for implementing one FS Program.

1. Report Objectives

Specifically, the objectives of this report are to:

- Provide an overview of the current FS Program.
- Discuss issues associated with integrating programs.
- Provide recommendations for overcoming those issues.

Overall, this report strives to increase the accountability and transparency of the FS Program by developing an integrated program structure.

2. Scope

This report is based on the legislative proviso and assumes agreement about integrating and streamlining multiple programs. The scope of this report is to provide findings and recommendations for the structure and organization of the new program. A model for the integrated program will be presented within this report, as well as transition strategies for implementing it.

In addition, this report solely addresses the provision of a state-only-funded FS Program. It does not address any service or program delivered through Washington's DDD Waiver Program.

B. Organization of Report

The remainder of this report provides information pertaining to the integration of the FS Program. Specifically, this report presents the following sections:

- *Current Environment* – Provides an overview of current FS Program environment.
- *Findings and Recommendations* – Presents programmatic and technical findings and their associated recommendations with regard to integrating the FS Program.

- *New Integrated Program* – Provides a description, work steps, and timeline for developing the new integrated program.

III. Current Environment

III. Current Environment

The intent of this section is to provide an overview of the current environment of the FS Program, including background of the FS Program and information concerning its programs, services, finances/resources, and information systems.

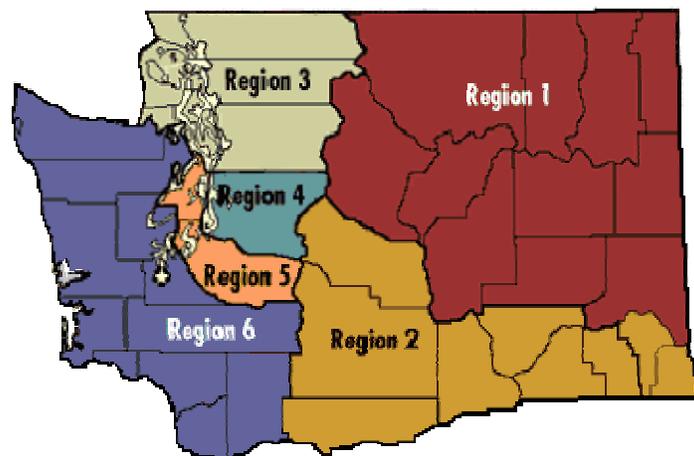
A. Background of the Family Support Program

During the 1970s, Washington State realized the value and importance of family in supporting people born with developmental disabilities. Shifting from institutional placement to a more community, family-based approach, the legislature began providing modest amounts of funding through DSHS to assist in meeting the family's needs. Since this time, the FS Program has been dedicated to helping to keep families intact and offering them some support in caring for their family member.

This subsection outlines the current structure, mission, and purpose of the FS Program.

1. Program Structure

The FS Program is administered by DDD, which is within ADSA. The FS Program is managed through DSHS regional offices. Below is a map of Washington State that outlines the counties according to DSHS regions.



2. Mission and Purpose

The FS Program supports the mission of DDD, which is presented below.

The mission of the Division of Developmental Disabilities (DDD) is to endeavor to make a positive difference in the lives of people eligible for services, through offering quality supports and services that are:

individual/family driven; stable and flexible; satisfying to the person and their family; and able to meet individual needs. Supports and services shall be offered in ways that ensure people have the necessary information to make decisions about their options and provide optimum opportunities for success.

Given this mission, the purpose of the FS Program is to provide a low-cost, high-impact way for the state to partner with and invest in the well-being of families. The program allows families to have an intermittent break from their caregiving duties and helps defray some of the costs associated with supporting a family member with a developmental disability living at home. In addition to these services, a onetime expense for emergencies is sometimes provided to help the families through difficult times when health and safety may be jeopardized.

Without the option of the FS Program, many families that do not receive services may be forced to ask for out-of-home placement because they literally cannot do it all. The FS Program mitigates this option by giving the family a break with respite services and assisting with payment of needed therapies and medical supplies that insurance and Medicaid do not cover.

DDD currently administers more than one Family Support program, including the current pilot program to provide FS services. Each is capped based on available funding. There is a long waiting list for family support services. A proviso in the 2005–2007 operating budget directed DDD to implement a flexible Family Support Pilot program and develop recommendations for a single FS Program.

The division worked with stakeholders to define the following qualities of a single FS Program:

- Need-based.
- Family-driven.
- Easy to use.
- Easy to administer.
- Responsive to changes in the family's circumstances, needs, roles, and ages.
- Respectful of cultural, economic, and social differences.
- Connected to natural community resources.

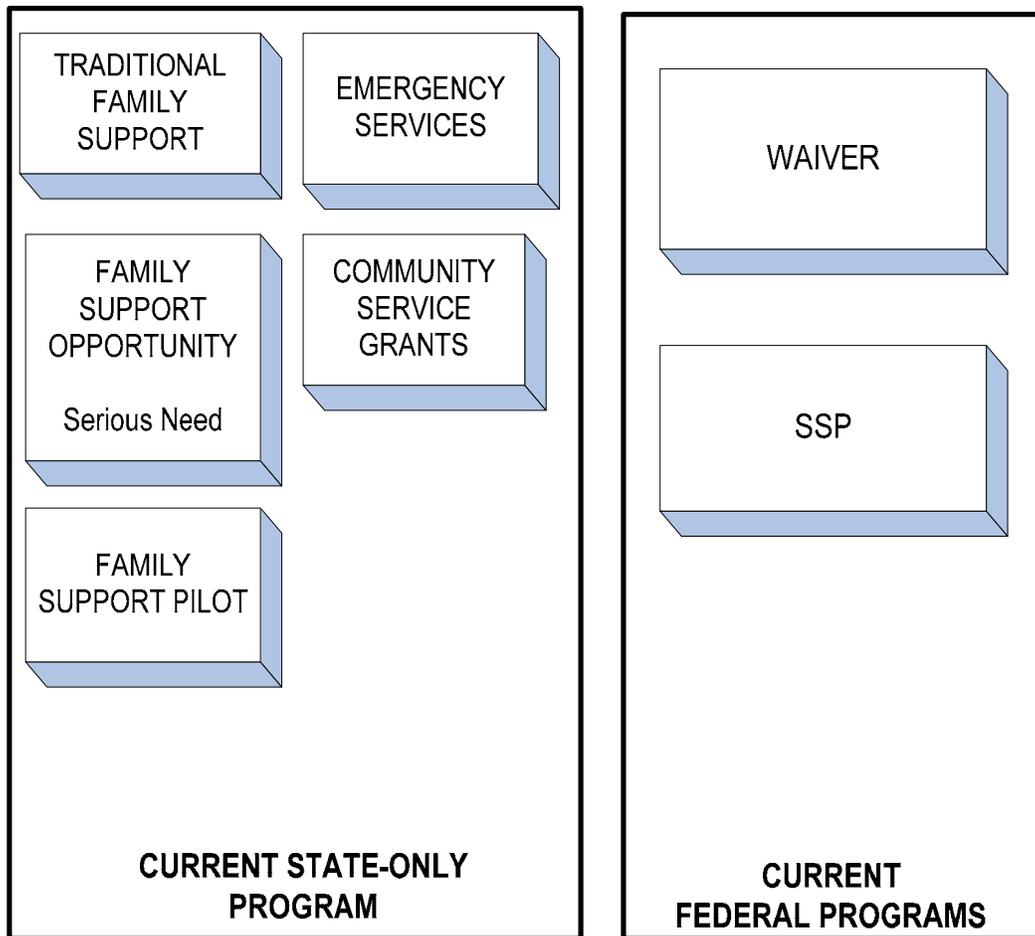
Simply put, the FS Program is a key component of the long-term care DDD system. It does not address the needs of everyone on the caseload, but it works well for those people with varying degrees of natural support from their families. In December 2005, the Washington State Core Indicators Survey asked families the following question:

Do you feel that family support has helped you to keep your child at home?

Seventy percent of families responded positively to this question, illustrating that the FS Program provides families with some resources to keep their family intact. In addition, the FS Program fosters an effective partnership with families who provide the majority of support.

B. Program Descriptions

This subsection provides brief information about each of the programs offered through the FS Program. Illustrated below, these programs provide a variety of services for DDD recipients.



Programs that use state-only dollars are TFS; FSO, including Serious Need; Community Service Grants; Emergency Services; and the FS Pilot. Waiver Respite is a federal-match program, and SSP is funded by a portion of the state's SSI supplement. All of the state-only programs are discussed below, and

additional detail, including eligibility criteria, award determination, and services provided, is presented in APPENDIX A. Waiver and SSP are also discussed in APPENDIX A.

1. Traditional Family Support

The purpose of the original program offering family support services, TFS, was to reduce or eliminate the need for out-of-home residential placement of an individual with developmental disabilities where it is in the best interest of the person to continue living with his/her family.²

Characteristics of the program include those presented in the table below.

Number Served	254 (FY 2005).
Amount Spent	\$968,348 (FY 2005).
Annual Award Amount ³	<ul style="list-style-type: none"> ● Award amount based on need level without regard to income. ● Service need level (SNL) 1: without Medicaid Personal Care (MPC) – \$15,400; with MPC – \$6,800; with nursing – \$29,544. ● SNL 2: without MPC – \$6,000; with MPC – \$3,400. ● SNL 3: without MPC – \$3,400; with MPC – \$1,700. ● SNL 4: \$1,700.

TFS was replaced by FSO in an effort to provide more resources to a greater number of families.

2. Family Support Opportunity

FSO was started in June 1996, and it provides a standard funding amount to families that can be spent on a variety of services. The intent of FSO is to provide various services for as many families as possible to help support the family unit.⁴ The Washington Administrative Code (WAC) authorizing FSO describes the intent of the program as being to:⁵

- Strengthen family functioning through use of the program elements.
- Provide a wide range of supports that will assist and stabilize families.

² WAC 388-825-252, (1).

³ Award determination is dependent on funds availability for all programs.

⁴ As part of FSO implementation until 2001, most participants were added to the Waiver to provide access to MPC.

⁵ WAC 388-825-200.

- Encourage individuals and local communities to provide support for the persons with developmental disabilities that live with families.
- Complement other public and private resources in providing supports.
- Recognize the ability of communities to participate in a variety of ways.
- Allow families to make use of the program elements according to the individual and family needs.
- Provide assistance to as many families as possible.

Characteristics of FSO include the following:

Number Served	621 (FY 2005).
Amount Spent	\$1,015,414 (FY 2005).
Annual Award Amount	<ul style="list-style-type: none"> ● Award amount based on need level without regard to income. ● \$1,500.

Families may apply for Serious Need funding if they require extraordinary support that exceeds the annual FSO allotment for the child or adult with developmental disabilities living in the home. The purpose of Serious Need funds is to help families get the support they require. Serious Need funds can be either short- or long-term in nature.

The Serious Need Program has the following characteristics:

Number Served	51 (FY 2005).
Amount Spent	\$63,215 (FY 2005).
Award Amount	\$452 per month. ⁶

3. Emergency Services

Emergency Services funding is designed to respond to a single incident, situation, or short-term crisis, such as caregiver hospitalization, absence, or incapacity. Funds are provided for a limited period not to exceed 2 months, and all requests are to be reviewed and approved or denied by DDD. Families do not need to be enrolled in the FS Program to qualify.

⁶ WAC 388-825-238. See APPENDIX A for additional detail.

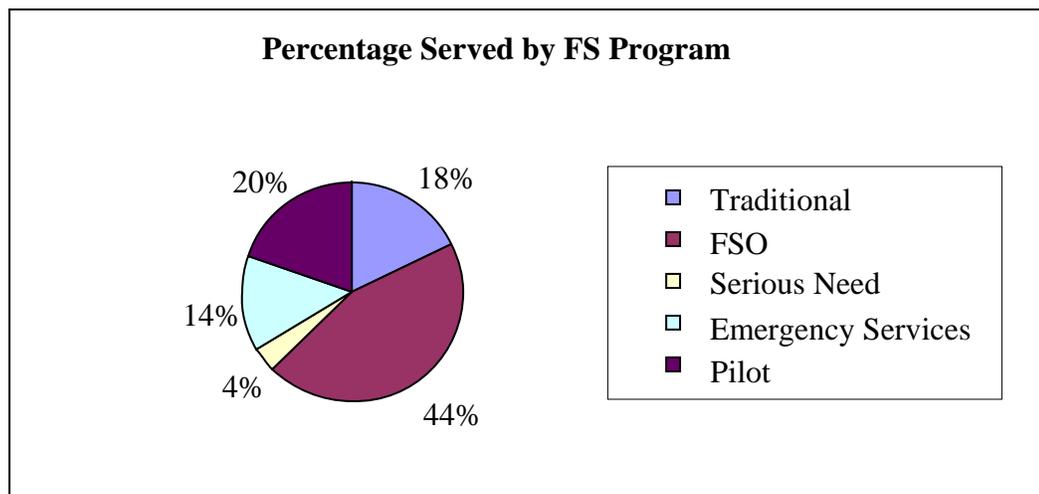
Number Served	197 (FY 2005).
Amount Spent	\$305,804 (FY 2005).

4. Family Support Pilot

The pilot is the proviso program funded by the legislature for FY 2006 (\$900,000) and FY 2007 (\$1,600,000). The intent of the pilot is to provide resources to families not being served by other DDD-funded sources. Characteristics of the pilot include the following:

Number Served	341.
Amount Spent	\$138,450 authorized through September 2006.
Annual Award Amount	Ranges from \$1,000 to \$4,000 based on income.

The chart below illustrates the relative percentage of families served by the FS Program.



5. Community Service Grants

Within various communities, organizations provide support and services for families. The FS Program offers resources through its community grant program to enhance community involvement. The intent of the Community Service Grants is to improve community capacity to provide resources that benefit families of people with disabilities. Resources for this program are earmarked to sustain information and education activities. Grants may fund short- or long-term projects with a particular focus on improving people's opportunities to be included and supported in regular community activities. Examples would include sending informational material out to families, fostering community programs to

reach out to people with disabilities, providing resource libraries, lending equipment, connecting families to other families who have children with similar disabilities, and developing list serve and chat rooms where parents who have children with disabilities can learn from one another. DSHS awarded \$486,532 in FY 2006 to various organizations around the state.

C. Service Definitions

Services provided under TFS, FSO, and the pilot, are presented in the table below.

Services That Can Be Authorized	TFS	FSO	Pilot
Respite Care	✓	✓	✓
Training and Support	✓	✓	✓
Specialized Equipment	✓	✓	✓
Environmental Modifications	✓	✓	
Therapies	✓	✓	
Behavior Management	✓	✓	✓
Medical and Dental Services	✓	✓	
Nursing Services Not Covered by Another Resource	✓	✓	✓
Special Formulas or Specially Prepared Foods	✓	✓	
Parent/Family Counseling	✓	✓	✓
Specialized Clothing	✓	✓	
Specialized Utility Costs	✓	✓	✓
Transportation Costs	✓	✓	
Community Guide Services	✓	✓	
Employment Services			✓

FS Program funds are to be spent on the services defined below. These definitions appear in WAC 388-825-230 unless otherwise noted.

- *Plan* – Development, by the family and case manager, of an FS plan that includes needs assessment, referral, service coordination, service authorization, case monitoring, and coordination for community guide services.⁷
- *Respite Care* – Intermittent relief to the family caregiver; may include community activities providing respite.

⁷ WAC 388-825-210.

- *Caregiver Education and Training* – Examples are disability-related support groups or parenting classes. This does not include registration or costs related to conferences.
- *Specialized Equipment* – The purchase, rental, loan, or refurbishment of specialized equipment, adaptive equipment, or supplies not covered by other resources, including Medicaid. Specific examples are mobility devices, such as walkers and wheelchairs, communication devices, and medical supplies. Diapers may be approved only for those 3 years of age and older.
- *Environmental Modifications* – Physical adaptations to the home required by the Plan of Care (POC) for the person to continue to live [with his/her family].⁸ Includes home damage repairs caused by the individual and home modifications specific to the individual's disability.
- *Therapies* – Occupational therapy, physical therapy, communication therapy, behavior management, visual and auditory services, or counseling needed by developmentally disabled individuals and not covered by another resource such as Medicaid, public schools, or child development services funding.
- *Medical and Dental Services* – Not covered by any other resource. These services may include the payment of insurance premiums and deductibles but are limited to the portion of the premium or deductible that applies to the individual.
- *Nursing Services* – Not covered by another resource; encompasses services that can only be rendered by a registered or licensed practical nurse. Examples of such services are ventilation, catheterization, and insulin shots. Parents can provide this service without licensure and will not be paid providers of this service for their natural, step-, or adopted child.
- *Special Formulas or Specially Prepared Foods* – Necessary because of the individual's disability and prescribed by a licensed physician.
- *Parent/Family Counseling* – For grief and loss issues, genetic counseling, or behavior management. Payments cannot be approved for services occurring after the death of the DDD individual.
- *Specialized Clothing* – Adapted for a physical disability, excessive-wear clothing, or specialized footwear.
- *Specialized Utility Costs* – Inclusive of extraordinary utility costs resulting from the individual's disability or medical condition.

⁸ Ibid.

- *Transportation Costs* – “Reimbursement to a provider for non-medical transportation required to access waiver services specified in the plan of care.”⁹ If another resource is not available, transportation costs including gas, ferry, or transit, so an individual can receive essential services and appointments; per diem costs may be reimbursed for medical appointments. Funds cannot be used for the purchases or rental of a car or for airfare.
- *Community Guide Services* – Available to support the family by becoming well connected to resources or supports in the community. After an assessment, a case manager will give the individual information about a community guide, whose services can be used, if desired, by the family.¹⁰
- *Employment Services* – Assistance in securing employment (only available in the pilot).

D. Washington Administrative Code

Currently, there are separate rules governing programs that provide FS services and additional rules for Waiver and SSP. These rules are listed below.

- TFS (including Emergency Services) – WAC 388-825-250 through WAC 388-825-256.
- FSO (including Serious Need and Community Service Grants) – WAC 388-825-200 through WAC 388-825-248.
- FS Pilot – WAC 388-825-500 through WAC 388-825-595.
- SSP – WAC 388-827.
- Home- and Community-Based (HCB) waivers – WAC 388-515-1510.

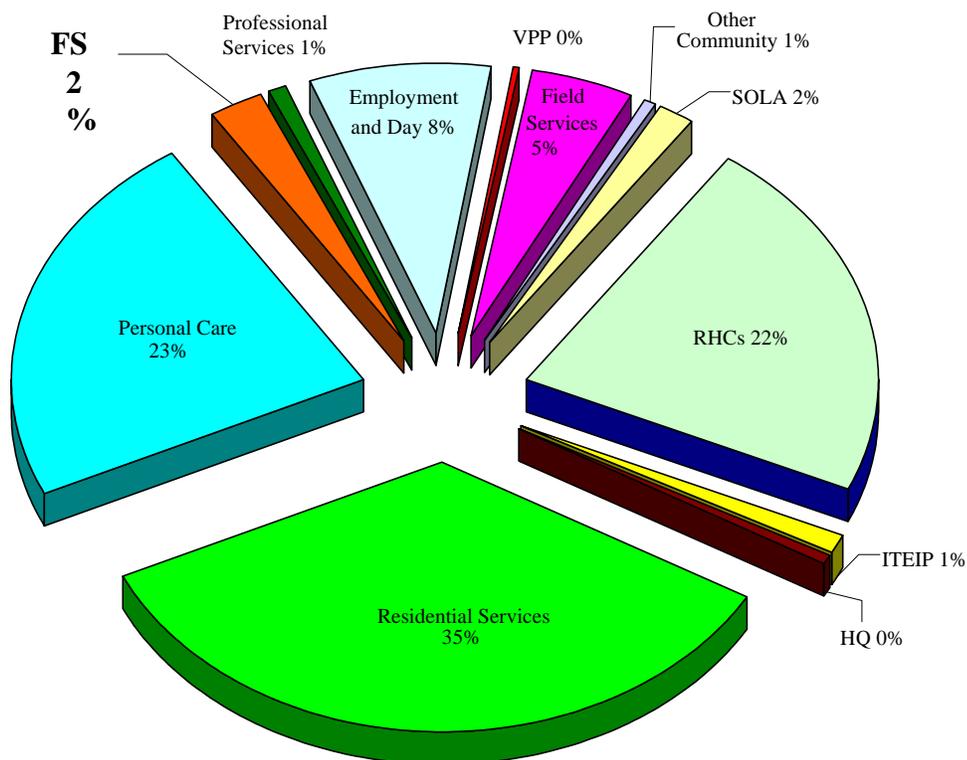
E. Financial

The FS Program is funded through DDD and composes 2 percent of the budget. On the next page is a chart depicting DDD’s budget allocation. Within the 2 percent, funds are allocated among the Family Support programs based on rules that determine access and historical expenditure patterns for each program.

⁹ Ibid.

¹⁰ WAC 388-825-220.

DDD 2005–2007 Budget



F. Information Systems

DDD uses various information systems to administer its programs. For the purpose of this report, however, only the assessment tool and program databases are discussed.

1. Needs Assessment

The Joint Legislative Audit and Review Committee (JLARC) recently conducted an audit of DDD that delivered the following recommendations:¹¹

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 ... The assessment process should utilize, to the extent possible, existing computer-based assessment tools either in use or under development in DSHS.

¹¹ JLARC Performance Audit of the Division of Developmental Disabilities, Report 03-6, June 19, 2003.

In response, DSHS is developing a needs assessment tool. The program is currently in Phase 3 of a five-phased project with the automated DDD assessment to be completed June 2007.

In the future, everyone (current recipients and those currently on the waiting list) requesting services from DDD will receive the assessment in order to determine eligibility and need. Outcomes of the assessment tool are to more accurately target those with the greatest need, as well as provide decision makers with more reliable data with which to determine program performance and budgetary requirements.

2. Various Databases

Currently, case managers must use three separate databases depending on an individual's eligibility for the FS Program. Case managers must access the Common Client Database (CCDB) for TFS, the FSO database for those on FSO, and the pilot database for those receiving FS Pilot services. Each database contains programmatic and demographic information that could be shared.

IV. Findings and Recommendations

IV. Findings and Recommendations

During stakeholder meetings, a number of issues were presented, and recommendations were developed and discussed. This section highlights the main issues, findings, and recommendations associated with developing a single, coordinated FS Program. Findings and recommendations presented in this section are not exclusive but are considered the most pertinent for this discussion and have been prioritized.

Finding 1 – Pilot eligibility and services are too limited.

Many families do not meet the eligibility requirements to qualify for FS Pilot services. In October 2005, 4,805 questionnaires were sent out to potentially eligible families. Out of the 1,080 returned, 341 families received funding awards as of October 2006. Most of the remaining families were deemed ineligible for the pilot because they were either financially eligible for MPC or were no longer eligible for DDD services.

The pilot was created to provide services to families that do not receive any other DDD services. The pilot does not allow for therapies (except behavior management), home modifications, or transportation. The exclusion of therapies creates problems for individuals who require services such as speech, physical, or occupational therapy. Assisting a family with transportation costs or a home modification, such as a wheelchair ramp, enables the person to stay at home with his/her family, thus not requiring more costly out-of-home living arrangements.

Recommendation 1a – Combine Traditional Family Support, Family Support Opportunity, and the pilot into one Family Support Program, and provide the services offered in Traditional Family Support and Family Support Opportunity.

The services listed below were provided under the TFS and FSO Programs. It is recommended that the new consolidated program provide all services listed based on the need of the person.

- Respite Care
- Caregiver Education and Training
- Specialized Equipment
- Environmental Modifications
- Therapies
- Behavior Management
- Medical and Dental Services
- Nursing Services Not Covered by Another Resource
- Community Service Grants
- Community Integration Services
- Special Formulas or Specially Prepared Foods
- Parent/Family Counseling
- Specialized Clothing
- Emergency Services
- Specialized Utility Costs
- Transportation Costs

Recommendation 1b – Include the Emergency Services Program and a onetime exceptional needs program for people not in the Family Support Program.

If the primary caregiver becomes sick or hospitalized, the person with a developmental disability may be left with no one who is trained or competent to take care of him/her. In these cases, the state provides emergency funding to help during this heightened time of need.

Funding for onetime exceptional needs that cannot be paid for by another resource and are instrumental in keeping a family member in the home should also be included.

Finding 2 – A large waiting list exists due to limited funding.

There is a large list of families waiting for services. As of October 1, 2006, 9,875 families have expressed an interest in, but do not receive, FS services. Approximately one-third (4,100 receive a paid service, and 5,775 do not) of those on the waiting list are receiving MPC or day program services.

Currently, the waiting list is kept in chronological order by date of request. Since a needs assessment is not completed at the time the family is put on the list, there is no way to determine the family or individual level of need. Typically, needs change over time, and without an assessment to determine specific need, it can be difficult to match needs with appropriate services.

A pamphlet recently published by the Washington State Developmental Disabilities Council (WSDDC) titled, “The Waiting Game,” contains numerous personal accounts of parents expressing frustration over the lack of communication with DDD. Parents feel as if they were put on a waiting list and forgotten, without updates or an end to waiting in sight.

Recommendation 2a – Prioritize families according to those most in need.

There are varying levels of need of families on the waiting list. Initially, data from the mini assessment may be used in conjunction with the date the family was added to the waiting list to determine priority. The mini assessment data will have need-level information, which will initially help determine who will receive services. As of September 5, 2006, 2,772 mini assessments have been completed.

Eventually, the new assessment tool will be used to determine which families require urgent attention. The new assessment tool will more accurately assess need and determine the most relevant services to authorize. This will move the system from “first come, first served” to a need-based program.

One of the challenges to this recommendation is the lack of resources available to deliver the assessment. It will take a considerable amount of time to conduct a needs assessment for everyone currently on the waiting list. Additional resources would help to conduct the initial assessment and allow for those most in need to receive much-needed support.

Recommendation 2b – Continue to use income as an eligibility criterion.

The department recommends continuing to use income as an eligibility criterion, and to base award determination on need. This will allow those in the most need to receive necessary assistance in order to keep their families intact.

Finding 3 – Some individual authorizations are not spent each year.

There are common misconceptions among families regarding how financial resources are allocated in the FS Program. Some families believe that if they do not use their allocation, the money will be given to other families in need. In reality, funds are earmarked for a specific family and remain in the account until the family uses those funds. If the funds go unused, remaining funds are allocated back into the state general fund.

One reason why families may not spend their entire award amount is because the money is treated as a reserve/risk account in case of emergencies. This creates inefficiencies because families with the greatest need are not given the support they require. The assessment tool will address this issue, since the intent of the assessment is to match need with resources.

Recommendation 3 – Create specific regulations regarding unspent funds.

While the assessment tool will more accurately determine the amount of support funding needed by a family, DDD regulations should be written specifying that funds not used for the year may be returned to the program or as cause for reassessment. These situations are expected to be rare since the entire process will more accurately allocate funds, thereby ensuring the effectiveness and impact of the FS Program in the long run.

Finding 4 – Families do not receive enough information and are often not aware of the benefits available to them.

Using National Core Indicators data gathered by DDD, a recent study conducted by the WSDDC compared Washington State’s developmental disabilities program to other state programs and analyzed performance data from previous years. The intent of this study was to determine whether DDD is doing better or worse than previous years at meeting the needs of individuals with developmental disabilities. Issues, findings, and recommendations were ranked 0 to 5, with 5 being the highest level of concern.

“...First connected with DDD to secure services for her son... her case manager said that wait for family support and home help would be about a year. Now six years later, the family is still waiting.”

The Waiting Game, 9

One finding that received a ranking of 5 is that families do not believe they have sufficient access to information about DDD services and other public benefits. Supporting evidence of this finding includes the following:

- 33.8 percent of families report getting little or no information about services and support available to them.
- Of those that do receive information, 54 percent claim they do not understand at least some of the information.
- 52.4 percent claim they are not getting information about public benefits available to them.

Recommendation 4a – Widely disseminate information about the new program structure.

Training on the new FS Program model should be readily available to all stakeholders, including, but not limited to, case managers, families, self-advocates, and providers. In addition, information about the changes will be widely disseminated through the DSHS Web site, and community education flyers and mailers will be sent out to those currently receiving services, people on the waiting list, and advocacy and support groups throughout the state. To ensure that information is disseminated thoroughly, a communication plan will be developed and implemented.

Recommendation 4b – Commit additional resources to the Community Service Grants Program.

The current Community Service Grants Program provides structure and support within the community to parents and self-advocates. By building on existing community partnerships and networks, the Community Service Grants are an important component of strengthening community organizations and involvement

as well as improving families' and communities' access to information and capacity to help each other. This recommendation supports adding further resources to the Community Service Grants in order to ensure their continued success in connecting parents with much-needed information/education and access to community-based generic resources.

Finding 5a – The Family Support Program serves both adults and children.

There is a general perception that FS assists only children with developmental disabilities. In reality, 48 percent of the people are adults living at home with their families. It is important to recognize that families with adult members with developmental disabilities who live at home are eligible for support.

Finding 5b – It is less expensive to keep families intact.

Families provide most of the long-term care for people with developmental disabilities. An investment in families is desirable. The cost for out-of-home placement depends on the severity of the person's disability and ranges from \$48 per day in an adult family home (AFH), to \$232 per day in a community residence, and to \$440 in a 24-hour institution. Helping families cope with caring for an individual with developmental disabilities is better for the person and more cost-effective.

Recommendation 5 – Recognize that families provide most of the in-home care for people with developmental disabilities and that Family Support is for children and adults who live in the family home.

Families are the primary source of support for people with a developmental disability. From the time a child is born and throughout his/her adult life, families typically provide the long-term support their family member requires. As stated earlier, an estimated 67 percent of people with a developmental disability live within the family home. The intent of this recommendation is to recognize that families are the primary support of people with developmental disabilities and that the FS Program provides services to all individuals, regardless of age, living in the family home.

Finding 6 – The assessment tool has been developed and is being tested.

The department has developed an assessment tool in response to JLARC's recommendation that DSHS develop "an assessment process for developmentally disabled clients that is consistently applied, to all clients, in all parts of the state." An independent assessment performed in June 2006 by the Human Services Research Institute (HSRI) stated that the development of the assessment tool is on the "right track related to the JLARC recommendation to develop a standardized

assessment.” The report praised the department for selecting a high-quality assessment tool, the Support Intensity Scale (SIS), for determining need for community developmental disabilities services and stressed the importance of testing the tool.

Currently, the department is developing a testing process to determine whether it accurately assesses FS need. Once testing is completed, modifications, if necessary, will be made, and the system will be implemented on time next year.

Recommendation 6 – Modify the needs assessment to better fit the Family Support Program.

An objective of DDD is to ensure that the new assessment tool appropriately measures family need. This recommendation centers on modifying the needs assessment tool to better capture the specific requirements of families. The assessment tool is in the development stage and will be tested in fall 2006. Once the tool is tested, appropriate modifications can be made based on the test results.

Finding 7a – Consolidating programs will require changing the Family Support Program’s organizational structure.

The current program’s administration developed over time through a series of program and organizational changes. Since the department is required to create a consolidated program structure, the department also must develop the organizational structure to support this new program.

Finding 7b – Each support program has its own defined set of rules.

TFS, FSO, and the pilot are currently being implemented by case managers under three separate WACs, which creates inconsistency in interpretation and confusion about allowable expenses.

Finding 7c – The Family Support Program operates with separate databases.

Currently, a case manager must use separate databases for each of the programs he/she administers. Use of separate databases creates inefficiencies since case managers must use a different system depending on the program serving each different program participant. At present, DDD is developing a new Case Management Information System (CMIS) to reduce the number of systems or databases case managers use. The FS database will not be incorporated into CMIS until Phase 5; therefore, DDD will have to develop an interim solution for the new FS Program.

Recommendation 7 – Implement a new organizational structure for consistent Family Support Program implementation.

With the consolidation of TFS, FSO, and the pilot into one program, the FS Program must develop a single set of rules and an organizational structure to govern and administer this new program. The first step is to create a headquarters program structure that can:

- Develop a single set of rules based on approved program goals.
- Disseminate information and train and monitor performance on the rules.
- Create a successful transition process for families from three programs.
- Create and implement a communication plan for the new program.
- Develop and report on program measures that track expenditures against program goals.

Finding 8 – Determining allowable expenses is challenging.

Due to individuals' distinct needs related to their developmental disability, it is difficult and time-consuming to determine appropriate allowable expenses. Current allowable expenses are not clearly defined. Lack of clarity creates inconsistency throughout the state as to what is an allowable expense and what is not.

Recommendation 8 – Clarify and clearly describe service options, including who is eligible for what.

A framework describing permissible service expenses should be developed to help case managers and families determine what an allowable expense is. As highlighted in the JLARC report, there are regional inconsistencies on what is considered an allowable expense. By having examples and descriptions of items covered by the program, as well as those that are not, a considerable amount of confusion and inconsistency could be avoided.

Finding 9 – The Family Support Program composes only 2 percent of the total Division of Developmental Disabilities budget but has a considerable positive impact upon families.

The FS Program makes up approximately 2 percent of the overall DDD budget. This small portion of the \$1.2 billion biennial budget has a tremendous impact on families and communities served. Recipients frequently state that FS Program funding often makes the difference between staying together as a family or having to place their family member in an out-of-home residential setting. Empirical evidence has shown that families receiving FS “reported an improved capacity to keep up with the household routines, pursue hobbies, seek enjoyment outside of the home, and cope with habilitative needs.”¹² Overall, FS allows the family to determine the unique needs of its family member, which positively affects the entire family.

“For over 22 years I have partnered with the State and Federal Government in meeting the needs of my daughter with significant disabilities. [Through this partnership] thousands upon thousands of taxpayer dollars were saved each year. We need to invest tax dollars in people, in the family, in the community and in partnerships for the best outcomes for the individual with disabilities and their families, and the best return of taxpayer dollars.

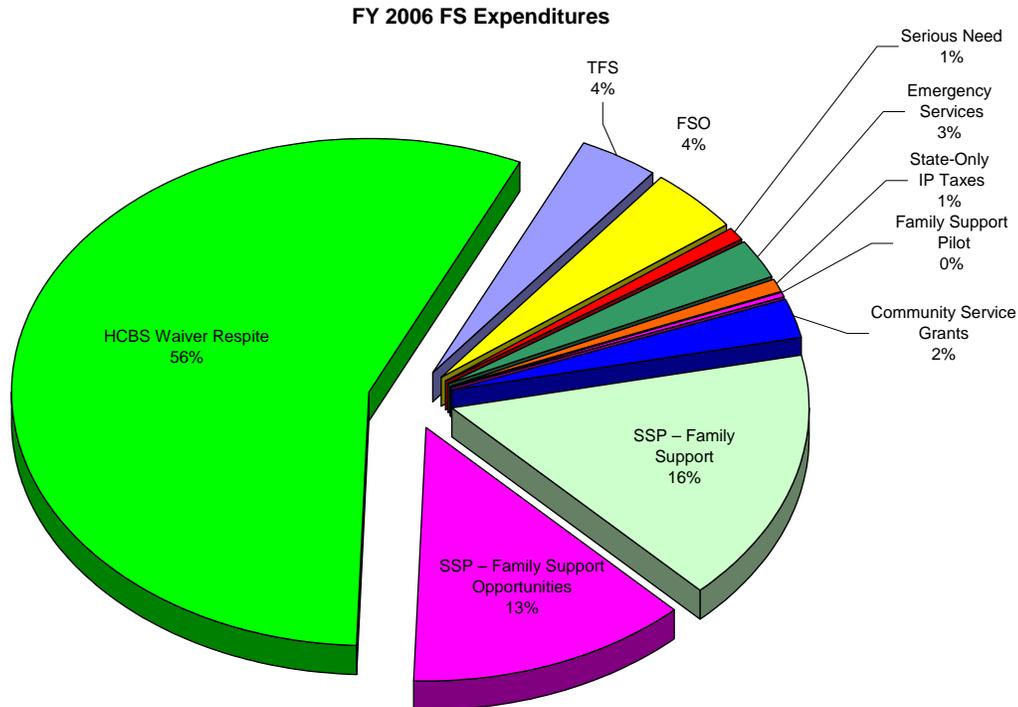
Stakeholder

Recommendation 9 – There is no recommendation for this finding.

Finding 10 – Waiver services, State Supplemental Payment, and state-only programs are combined in the same budget.

Currently, services in Waiver and SSP are funded out of the FS Program budget. As the pie chart below illustrates, Waiver and SSP account for approximately 85 percent of the FS budget. Including the federally mandated programs with the state-only budget creates a misconception about the actual funds available for a FS Program. Separating the FS Program from Waiver and SSP would ensure that all stakeholders could track state-funded FS expenditures.

¹² University of Washington, “The Family Support Opportunities Program,” 1997, p. 8.



Recommendation 10 – Create separate budget category for state-funded Family Support.

The current financial management of the FS Program creates confusion and misconceptions about how much money is actually available for FS. By creating separate budget categories for SSP and Waiver, the amount of money available in the FS Program will be clear to all stakeholders.

Finding 11 – Families with a member who has a developmental disability incur higher living expenses.

A well-documented finding is the additional cost incurred by the family of a person with developmental disabilities versus a family without. While expenses vary depending on the individual’s disability and medical needs, the average cost for a family member with developmental disabilities is 2.2 times higher than one without. With the prices of child rearing increasing in general, raising a child with

“The ... family has already declared bankruptcy once in order to help care for their daughter. When she was just 6 years old she needed an expensive surgery to survive.” Her mother switched careers in order to be at home for [her daughter] after school, but being self-employed means no health insurance. Despite being a two-income family, the [family] just don’t make enough to cover their daughter’s medical needs.”

The Waiting Game, 26

a disability has become extremely costly for families.

According to the latest figures from the Children's Defense Fund, parents will spend, on average, between \$121,230 and \$241,770 to raise a child to the age of 18, not adjusting for college or inflation.¹³ For a child with a disability, that range increases to between \$266,706 and \$531,894. Most families cannot absorb this enormous financial responsibility and find themselves with considerable financial burden and debt. This financial hardship puts an incredible strain upon the family, making additional financial support particularly valuable and important.

"There are therapies that can help [their daughter] but they are hard to find or afford. They pay out of pocket for respite care to have someone help care for their daughter. Additional needs, like special chairs, a 'stander' and a stroller also break the bank. "Each item costs over \$3,000."

The Waiting Game, 29

Recommendation 11a – Complete a study of family/individual costs relative to severity of disability.

To consider income in implementing the new FS Program, the department recommends a study of family/individual costs of rearing a child with developmental disabilities relative to the severity of the disability. The results of this research-based study would enable the department to apply an evidence-based deduction relative to the person's severity of need. This would enable the department to avoid a labor-intensive income/expense verification process.

Recommendation 11b – Include people already receiving other Division of Developmental Disabilities-funded services.

The Family Support pilot does not allow people currently receiving DDD services to participate in the FS pilot. Respite for families is very important. Sometimes the stress of constantly providing care for a family member with a developmental disability can be too much for a family to take and can lead to high rates of divorce and stress-related illnesses. Giving the unpaid caregiver time to be relieved from his/her daily responsibilities helps dilute stress and can help keep the family home intact.

¹³ <http://www.democratandchronicle.com/biznews/finance/020127-pf-children.shtml>.

Finding 12 – The system creates disincentives to increase family income.

Attaching the provision of support to income rather than need requires families to consider the impact of a better job or other improvements to the family's financial situation on meeting the needs of the family's disabled member(s). Families at 250 percent of the poverty level are eligible for healthcare and MPC for the child with a disability. Some families with severely disabled children must bypass income-generating activities or promotions so that they will not lose access to healthcare or MPC benefits. The FS Pilot raises the income consideration to 400 percent of the poverty level, or \$80,000 a year, for a family of four.

"We are the working poor... I've been told that my husband should quit his job, or that I should have another child to help me get services."

The Waiting Game, 24

"[We] used to receive services for her daughter but lost them when she became a teacher. 'It is a catch 22,' she sighs. 'If I quit my job I can get services for my daughter, but then I will be unemployed and unable to provide food.'"

The Waiting Game, 40

Recommendation 12 – Because income is a factor of eligibility, create an income deduction for expenses.

Determining family need depends on a variety of factors. While income is a component of need, it does not fully encapsulate the immediate and long-term financial situation of a family. Families living with a member with a developmental disability have higher living costs. From costly therapies to respite, the family income must stretch to cover all of these additional expenses, thereby leaving far less for other members of the family.

This recommendation is to create a preliminary deduction of expenditures from income to adjust for the difference in supporting a family member with developmental disabilities. By using the FPL as a basis, DDD will determine adequate levels that will be part of the equation in determining need. In the future the division will be proposing that a study be conducted that examines how a deduction from income could be based upon family need.

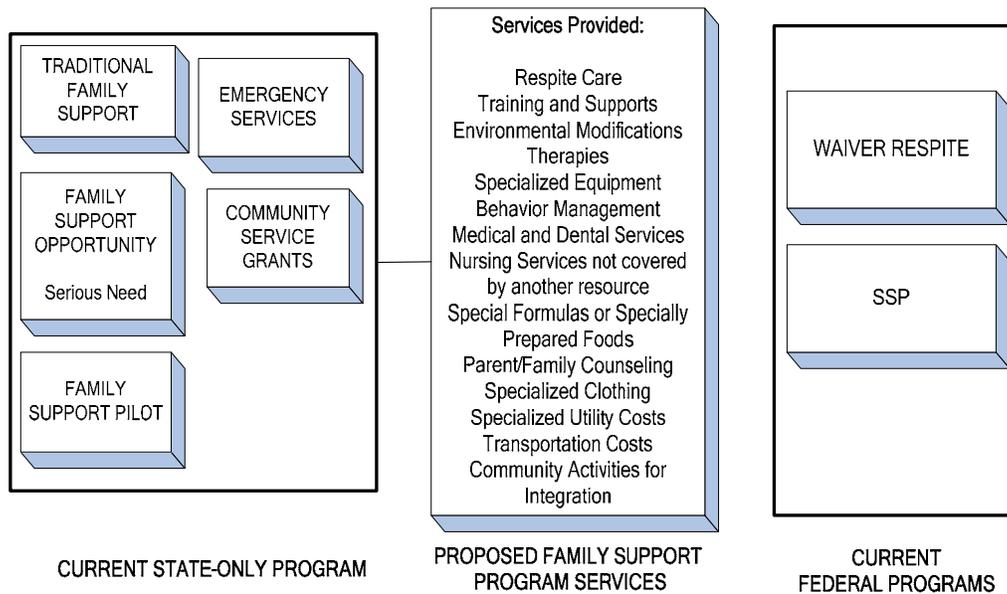
V. New Integrated Program

V. New Integrated Program

Based on the recommendations, a new integrated, state-only FS Program structure will be developed. This section focuses on providing a detailed description of the new program, as well as outlining major steps and action items required to implement the proposed program structure.

A. Description

The diagram below depicts the programs to be consolidated into the new FS Program.



Based on the recommendations presented in the previous section, the new integrated program should have the following characteristics:

Number Served	1,440 estimated. ¹⁴
Award Amount	Amount will vary depending on level of need, from \$2,000 to \$6,000 per year.
Funding Allotted	\$4.1 million.
Eligibility Requirements	<ul style="list-style-type: none"> • Individuals with developmental disabilities living with their families. • Individuals, depending on legislative action regarding income eligibility, currently receiving FS services or on

¹⁴ DDD has also asked for additional funding in the decision package for FY 2008 and FY 2009, which may increase this number.

	<p>the FS waiting list.</p> <ul style="list-style-type: none"> ● Service level determined by the new assessment tool. There will be four levels determined by the need of the caregiver, supervision, ADL, behavior, and medical. Further considerations will be: <ul style="list-style-type: none"> » Date family placed on waiting list. » Eligibility for SSP or other funding. » Other services received. » Date of application.
Award Determination	<ul style="list-style-type: none"> ● Determine the award level based on assessed need. <ul style="list-style-type: none"> ● Level moderate \$2,000. ● Level medium \$3,000. ● Level high \$4,000. ● Level severe \$6,000. ● Conduct evidence-based study to determine relevance of levels.
Services Provided	Listed in the service recommendation in subsection III.C.
Additional Characteristics	<ul style="list-style-type: none"> ● All ages are eligible for services. ● DDD conducts a background check on respite providers and other contracted providers. ● Income is a factor of eligibility. ● Financial eligibility will be determined based on the FPL. Families of children or adults will be eligible for the program if their taxable income is at or below 400 percent of the FPL. ● If a family requires more than the award amount, consider moving the individual to the appropriate waiver. ● Family may receive other DDD-funded services. ● Paid providers will be subject to the provisions of the SEIU bargaining agreement. ● This program will use state-only funds.

The new program structure will more appropriately support the purpose of the FS Program, which is reiterated below.

The purpose of the FS Program is to provide a low-cost, high-impact way for the state to partner with and invest in the well-being of families. The program allows families to have an intermittent break from their caregiving duties, as well as helps defray some of the costs associated with supporting a family member with a developmental disability living at home.

This new program creates an effective partnership model by giving the state an opportunity to invest in families. The new program's start date will be July 2008, and the program will provide a more transparent and accountable structure.

B. Proposed Major Steps and Timeline

It is of particular importance to minimize any negative effects caused by transitioning to the new programmatic structure. This subsection outlines the major steps to be taken to create a new integrated program and provides a timeline for completion. Each major step consists of defining the objectives, tasks, resources, time, and budget required to implement the recommendation. In addition, major steps are presented as part of a phased approach to program implementation.

Write New WAC

Objective	To develop corresponding policy.
Tasks	Task 1.1 – File 101. Task 1.2 – Develop draft. Task 1.3 – Review process. Task 1.4 – Complete WAC process. Task 1.5 – Conduct ongoing management of program.
Deliverable	Finalized WAC.
Resources	Program manager.
Time Required	Start date: July 30, 2007. Completion date: WAC to be completed by February 1, 2008. Time required: ongoing.
Budget	\$218,000 per biennium.

During this phase, new WACs will be developed that outline the following:

- Services to be authorized.
- Emergency Services Program.
- Inclusion of people already receiving other in-home or day services.
- Income as an eligibility criterion.
- Commitment of additional resources for Community Service Grants.
- Establishment of a review committee for requests that do not fit into the matrix.
- Specific regulations regarding unspent funds.

The final deliverable for this phase will be the finalized WAC.

Conduct Training

This phase consists of developing and conducting training modules for case managers. In addition, presentations will be developed for stakeholders, management teams, and advisory groups to ensure proper communication of the new program structure.

Objectives	To effectively communicate the new program structure to case managers, stakeholders, and program participants.
Tasks	<p>Task 2.1 – Develop curriculum.</p> <ul style="list-style-type: none"> ● Online training manual for case managers. ● Presentation for stakeholders, management team, and advisory groups. ● Stakeholder presentations. <p>Task 2.2 – Train appropriate case managers. Task 2.3 – Train case managers in CMIS. Task 2.4 – Conduct ongoing training and oversight.</p>
Deliverables	<ul style="list-style-type: none"> ● Finalized Curriculum. ● Finalized Stakeholder Presentation. ● Completed Trainings. ● Oversight to Ensure Statewide Consistency.
Resources	Social and Health Program Manager (SHPM) 2.
Time Required	Start date: July 1, 2007.
Budget	\$176,000 per biennium.

Develop Payment Codes

Objective	To develop comprehensive payment codes that align with policy objectives.
Tasks	<p>Task 3.1 – Develop payment codes to correspond to WAC. Task 3.2 – Develop matrix for payment codes.</p>
Deliverable	Finalized Updated Payment Codes.
Resources	Will be completed by program manager and SHPM.
Time Required	<p>Start date: July 1, 2007. Completion date: March 15, 2008.</p>

***Develop Reporting System and Phase Into Division of
Developmental Disabilities Assessment/CMIS***

Objectives	Develop temporary reporting system, phase into DDD assessment and CMIS.
Tasks	<p>Task 4.1 – Collect and analyze data on all FS Programs.</p> <p>Task 4.2 – Gather requirements for new integrated program.</p> <p>Task 4.3 – Work with developers to prototype changes in assessment tool and CMIS.</p> <p>Task 4.4 – Assist in development of WAC and policy (both system and program).</p> <p>Task 4.5 – Develop online help and user manual.</p> <p>Task 4.6 – Manage data collection and reporting process.</p>
Deliverables	<ul style="list-style-type: none"> ● Finalized Reporting System/Migration Into DDD Assessment and CMIS. ● Ongoing Maintenance, Enhancement, and Data Analysis.
Resources	Two business analysts.
Time Required	<p>Start date: July 1, 2007.</p> <p>Completion date: one ongoing business analyst and one business analyst through December 31, 2008.</p>
Budget	\$217,000 for first year and \$154,000 for second year.

Initially, levels will be used to implement the new program structure. However, there is a request for the legislature to fund a study that looks at the relevance of income related to need.

Appendix A Program Detail

Appendix A – Program Detail

This section provides additional detail about both the state-only and federally matched programs offering FS.

A. Traditional Family Support Information

Eligibility Requirements	<ul style="list-style-type: none"> ● Individual must live in the family home. ● Available only after the individual has used full benefits through Medicaid, private insurance, school, and child development services. ● Not eligible if family is eligible for SSP.
Award Determination	<ul style="list-style-type: none"> ● Based on need within four funding levels.¹ <ul style="list-style-type: none"> » SNL 1: Individual is at <i>immediate</i> risk of out-of-home placement without the provision of FS services. » SNL 2: Individual is at <i>high</i> risk of out-of-home placement without the provision of FS services. » SNL 3: The family is at risk of significant deterioration which could result in an out-of-home placement of the individual without provision of FS services. » SNL 4: Family needs temporary or ongoing services. ● Amount of SSP available will be included in calculating the monthly allocation. ● Varies depending on whether nursing services are required or the family is receiving MPC.²
Services Provided	<ul style="list-style-type: none"> ● Respite care. ● Nursing services. ● Therapies. ● Training, supports, and counseling. ● Procurement of specialized equipment. ● Environmental modifications. ● Medical/dental services, including nursing. ● Specialized foods and clothing. ● Transportation costs. ● Extraordinary household costs.

¹ WAC 388-825-256, emphasis added.

² Many families requiring nursing and MPC have been moved to the waivers since 2004.

B. Family Support Opportunity Information

Eligibility Requirements	<ul style="list-style-type: none"> ● Individuals with developmental disabilities living with their families. ● Individuals currently receiving FS services. ● Families will receive funding based on one of the following criteria: <ul style="list-style-type: none"> » Date of application. » Date family placed on waiting list. » Eligibility for SSP or other funding.³
Award Determination	<ul style="list-style-type: none"> ● Flat amount for all eligible families.
Services Provided	<ul style="list-style-type: none"> ● Respite care. ● Nursing services. ● Therapies. ● Training, supports, and counseling. ● Procurement of specialized equipment. ● Environmental modifications. ● Medical/dental services, including nursing. ● Specialized foods and clothing. ● Transportation costs. ● Extraordinary household costs.

1. Serious Need

The following is a direct quote from WAC 388-825-238:

What amount of serious need funding is available to my family?

1. *The maximum amount of funding available is four hundred fifty-two dollars per month or two thousand seven hundred twelve dollars in a six-month period, unless the department determines your family member requires licensed nursing care and the funding is used to pay for nursing care. If licensed care is required, the maximum funding level is two thousand four hundred fifty dollars per month.*
2. *Funding must be available in order to receive serious need services.*
3. *Services paid for by serious needs funds will be reviewed by DDD every six months.*

³ Availability of SSP makes the family ineligible for other state-only funding for the same service (WAC 388-825-205).

Eligibility Requirements	<ul style="list-style-type: none"> • Must be reviewed and reapproved every 6 months. • Need extraordinary support that exceeds the annual FS allotment (under FSO).
Award Determination	<ul style="list-style-type: none"> • N/A (if someone is eligible, he/she is awarded the amount).
Services Provided	<ul style="list-style-type: none"> • Respite care. • Training, supports, and counseling. • Procurement of specialized equipment. • Environmental modifications. • Therapies. • Medical/dental services, including nursing. • Specialized foods and clothing. • Transportation costs. • Extraordinary household costs.

C. Family Support Pilot Information

Eligibility Requirements	<ul style="list-style-type: none"> • Gross annual income. • Individual must be a client. • Individual must live with family, not independently or with a spouse. • Individual must not receive any other DDD-paid services, including MPC and Waiver.
Award Determination	<ul style="list-style-type: none"> • Documented need for services with priority to: <ul style="list-style-type: none"> » Individual in crisis or at immediate risk of needing institutional services. » Individuals who transition from high school without employment/day program. » Individuals cared for by a single parent. » Individuals with multiple disabilities. • Number and ages of family members and their relationship to the individual. • Eligibility determined on having a family income 400 percent or less of the FPL (Categorically Needy Program [CNP]) eligibility is 250 percent). For a family of four, the following poverty levels apply: <ul style="list-style-type: none"> » 100 percent – \$20,000 (receive \$1,000). » 200 percent – \$40,000 (receive \$2,000). » 300 percent – \$60,000 (receive \$3,000).

	» 400 percent – \$80,000 (receive \$4,000).
Services Provided	<ul style="list-style-type: none"> ● Respite care. ● Training and counseling. ● Assistive technologies. ● Transition services. ● Assistance with extraordinary household expenses.

D. Home- and Community-Based Waivers

In 2002, the Centers for Medicare & Medicaid Services (CMS) conducted a review of DDD's Community Alternatives Program (CAP) Waiver Program. As an outcome of this review, waivers were reorganized into four groups:

- Basic.
- Basic plus.
- Core.
- Community protection.

A total of \$7,612,571 was spent on waiver respite in FY 2005. Below is a description of waiver eligibility as well as details on each of the waivers.

2. Waiver Eligibility

In order to be eligible for HCB waivers, an individual must meet the following criteria in addition to any specialized criteria established by the specific waiver:

- A client of DDD.
- Has a disability according to criteria established in the Social Security Act.
- Gross income does not exceed 300 percent of the supplemental security income (SSI) benefit amount, and the individual's resources do not exceed \$2,000. Parental income is not considered for children.
- Needs the level of care provided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR); meets ICF/MR level-of-care guidelines.
- A POC has been prepared, which shows how the individual's health, safety, and habilitation needs will be met in the community.
- Has agreed to accept home- and community-based services as an alternative to institutional services.

3. Basic Waiver Information

The basic waiver is for individuals that have a strong natural support system (family). These individuals do not need out-of-home residential services but require services such as employment/day services, respite, therapies, and personal care.

Number Served	2,981 (FY 2005).
Annual Award Amount	<ul style="list-style-type: none"> ● General: \$1,425 per year. ● Community: May not exceed \$6,500 per year. ● Emergency Assistance: \$6,000 per year.
Eligibility Requirements	<ul style="list-style-type: none"> ● Lives with family or in his/her own home. ● Meets ICF/MR level-of-care guidelines but has a strong natural support system. ● Family/caregiver's ability to continue caring for the individual is at risk but can be continued with the addition of waiver services. ● Does not need out-of-home residential services.
Award Determination	<ul style="list-style-type: none"> ● Mental Health: Limits determined by mental health or DDD. ● Personal Care: Limits determined by CARE assessment. ● Respite: Limits determined by respite assessment. ● Emergency Assistance: Pre-authorization required.
Services Provided: General	<ul style="list-style-type: none"> ● Behavior management and consultation. ● Community guide. ● Environmental accessibility adaptations. ● Specialized medical equipment/supplies. ● Occupational therapy. ● Specialized psychiatric services. ● Physical therapy. ● Speech, hearing, and language services. ● Staff/family consultation and training. ● Transportation.
Services Provided: Community	<ul style="list-style-type: none"> ● Person to person. ● Supported employment. ● Community access. ● Pre-vocational services.
Services Provided: Mental Health	<ul style="list-style-type: none"> ● Behavior management and consultation. ● Mental health crisis diversion bed services.

	<ul style="list-style-type: none"> • Specialized psychiatric services. • Skilled nursing.
Services Provided: Respite	<ul style="list-style-type: none"> • Respite.
Service Provided: Personal Care	<ul style="list-style-type: none"> • Personal care.
Service Provided: Emergency Assistance	<ul style="list-style-type: none"> • Emergency assistance.

4. Basic Plus Waiver Information

The basic plus waiver is for individuals that are at a *high* risk of out-of-home residential placement or loss of current living situation. Services include those offered on the basic waiver, plus skilled nursing, and additional employment/day funding.

Number Served	2,038 (FY 2005).
Annual Award Amount	<ul style="list-style-type: none"> • General: \$6,070 per year on any combination. • Community: May not exceed \$9,500 per year; in some situations, this limit may be increased to a maximum of \$19,000, based on assessed client need and only with prior authorization.
Eligibility Requirements	<ul style="list-style-type: none"> • Individuals live with family or in another setting with assistance. • Individuals may live in an adult family home or adult residential care facility. • Individuals meet ICF/MR guidelines and are at high risk of out-of-home placement or loss of current living situation. • Individuals require a higher level of services than those in the basic waiver and/or nursing services.
Award Determination	<ul style="list-style-type: none"> • Mental Health: Limits determined by mental health or DDD. • Personal Care: Limits determined by the CARE assessment. • Respite: Limits determined by respite assessment. • Residence: Determined based on department rate structure in CARE.
Services Provided: General	<ul style="list-style-type: none"> • Skilled nursing and all of the general services in the basic waiver.

Services Provided: Community	<ul style="list-style-type: none"> ● Person to person. ● Supported employment. ● Community access. ● Pre-vocational services.
Services Provided: Respite	<ul style="list-style-type: none"> ● Respite.
Services Provided: Personal Care	<ul style="list-style-type: none"> ● Personal care.
Services Provided: Residential	<ul style="list-style-type: none"> ● Adult foster care (adult family home). ● Adult residential care (boarding home).
Services Provided: Emergency Assistance	<ul style="list-style-type: none"> ● Emergency assistance.

5. Core Waiver Information

The core waiver is for individuals that are at *immediate* risk of out-of-home placement. Services include all basic plus services, except emergency assistance and adult family home and residential care services. Instead, the core waiver provides supportive living services (up to 24-hour supervision and support).

Number Served	4,010 (FY 2005).
Annual Award Amount	Based on award determination.
Eligibility Requirements	<ul style="list-style-type: none"> ● The individuals on this waiver are at <i>immediate</i> risk of out-of-home placement or are receiving residential habilitation services from a DDD contracted residential provider.
Award Determination	<ul style="list-style-type: none"> ● Limited to the average cost of an ICF/MR for any combination of services necessary to meet assessed individual need.
Services Provided	<ul style="list-style-type: none"> ● Residential habilitation and all of the basic plus services except: <ul style="list-style-type: none"> » Emergency assistance. » Adult family home. » Adult residential care services.

6. Community Protection Waiver Information

The community protection waiver is for individuals that require 24-hour, on-site staff supervision to ensure safety of others. In addition, these individuals require therapies and/or other habilitation services and meet the criteria for community protection. Services not provided under this waiver include:

- Personal care.
- Respite care.
- Community guide.
- Community access.

Number Served	392 (FY 2005).
Annual Award Amount	Based on award determination.
Eligibility Requirements	<p>Individuals on this waiver meet the criteria for ICF/MR level of care and:</p> <ul style="list-style-type: none"> • Meet DDD criteria for “community protection.” • Require 24-hour, on-site staff supervision to ensure the safety of others. • Require therapies and/or other habilitation services. • Agree to receive services from a certified Community Protection Supported Living provider.
Award Determination	<ul style="list-style-type: none"> • Limited to the average cost of an ICF/MR for any combination of services necessary to meet assessed client need.
Services Provided	<ul style="list-style-type: none"> • All core services except personal care, respite, community guide, and community access.

H. State Supplemental Payment

SSP is a state-paid cash assistance program for certain DDD participants and has the following characteristics:⁴

Number Served	291 (FY 2005).
Amount Spent	\$4,086,398 (FY 2005).
Annual Award Amount	<ul style="list-style-type: none"> • On HCB waiver: <ul style="list-style-type: none"> » \$1,350 per year. » The remainder up to the maximum allowed may be authorized to purchase HCB waiver services and will be paid directly to the provider. • Not on HCB waiver: <ul style="list-style-type: none"> » Amount will be based on the yearly maximum allowed at the time the funding source was converted to SSP.

⁴ WAC 388-827-0100.

Eligibility Requirements	<ul style="list-style-type: none"> ● Must be eligible for or receive SSI cash assistance in the month in which the DDD SSP is issued. ● Receive Social Security Title II benefits as a disabled adult/child and an individual would be eligible for SSI if he/she did not receive these benefits. ● Receive one or more of the following services from DDD with state-only funding between March 1, 2001, and June 30, 2003. ● Continue to demonstrate a need for and meet DDD program eligibility requirements for these services. ● Must have been eligible for or received SSI prior to July 1, 2003, or received Social Security Title II benefits as a disabled adult/child prior to July 1, 2003, and would have been eligible for SSI if he/she did not receive these benefits. ● For individuals with community protection issues as defined in WAC 388-820-020, the department will determine eligibility for SSP on a case-by-case basis.
Award Determination	<ul style="list-style-type: none"> ● Amount will be based on the amount of state-only dollars spent on certain services at the time the funding source was converted to SSP. ● If the type of residential living arrangement changes, needs will be reassessed and payment adjusted based on the new living arrangement and assessed need.
Services Provided	<ul style="list-style-type: none"> ● A cash grant that can be used on any services the family considers necessary.

I. Community Service Grants

Goals of the Community Service Grants are as follows:⁵

- Enable families to use generic resources.
- Reflect geographic, cultural, and other local differences.
- Support families in a variety of non-crisis-oriented ways.
- Prioritize support for unserved families.
- Address the diverse needs of Native Americans, communities of color, and limited- or non-English-speaking groups.

⁵ WAC 388-825-246.

- Be family-focused.
- Increase inclusion of persons with developmental disabilities.
- Benefit families who have children or adults eligible for services from DDD.
- Promote community collaboration, joint funding, planning, and decision making.

Eligibility Requirements	<ul style="list-style-type: none"> ● Agencies or individuals may apply for funding. ● A proposed project must address one or more of the following topics: <ul style="list-style-type: none"> » Provider support and development. » Parent helping parent. » Community resource development for inclusion of all.
Award Determination	<ul style="list-style-type: none"> ● Decisions to approve or reject Community Service Grant requests are made by DDD regional administrators considering the recommendations of their regional FS advisory councils. ● DDD director has the discretion to award Community Service Grants that have statewide significance.



Stakeholder Work Group
ADDENDUM

Developmental Disabilities’
Family Support Study

November 2006

**Creating one Individual and Family Services program for
Families of Individuals with Developmental Disabilities**

Stakeholder Workgroup Addendum
November 2006

The Department of Social and Health Services-Division of Developmental Disabilities and the Stakeholders of the Family Support Workgroup met several times this year to develop recommendations to the Legislature regarding the consolidation of several family support programs into one. We thank the Department for including us in this process and agreeing to include this addendum in their final report.

Stakeholders agree with most of the Department's findings and recommendations, including combining the separate programs into one program; developing a consistent assessment to determine the level of a family's need; and creating a separate state-only family support budget category. However, there are a few areas of disagreement which we want to share.

Over the past thirty years, there have been a number of changes which have impacted families with children with a developmental disability. This includes a significant increase in the number of single parent families; families living greater distances from relatives who would typically provide help; and medical advances which assist babies and adults with significant disabilities to live longer. In addition, the cost of medical care has increased dramatically, resulting in higher co-pays and premiums, along with decreased insurance coverage. Due to such dramatic changes in lifestyle, medical advances and health care costs, as well as the fact that families are the major care provider, the need for families and the state to partner has become more essential.

We think that the purpose of family support should be to provide a small amount of state dollars to help families stay together. These funds, along with resources from the family, can help avoid more costly state services and help keep families intact.

The following issues are areas of Stakeholder difference from the Department's Family Support study.

Issue 1: Parental income as an eligibility criteria for families of minor children who continue to live at home.

The policy issue regarding parental income for minor children who have a developmental disability and receive services by the Division of Developmental Disabilities has been debated for more than thirty years. After several studies, DSHS has in the past determined that the additional administrative process of verifying family income was more costly than what families were receiving in service.

Nowhere in the current state statutes regarding individuals with developmental disabilities (RCW 71A), does it state that income of parents of minor children should be considered for the family to receive services. The Department appears to be taking its direction from the budget proviso for the current Family Support pilot program. Since this is a fundamental change in current statute, we hope that adopting a long term policy from a budget proviso is not the intent of the Legislature.

The Department's study refers to the Children's Defense Fund figures regarding the additional

cost incurred by the family of a person with a developmental disability versus a family without. While some expenses may vary, the average cost for a family member with a developmental disability is 2.2 times higher than one without. Examples of the additional expenses include excess medical costs, therapies, environmental adaptations, medical equipment, and higher childcare costs. The increased financial burden puts additional strain on the family, making the limited amount of family support all that more important.

The argument to include parental income has often been based on the hypothesis that if a wealthy family had a child with a developmental disability, they could be eligible to receive services. The truth is, if a wealthy family has a child who lives at any state DD institution or is served by a Home and Community waiver, then the family's income cannot be considered because of federal Medicaid regulations. Applying parental income only to families in this program creates a significant inequity and disincentive to families who are caring for their sons and daughters at home. Out of home placement can cost the state up to \$440 per day and we believe not the best public policy.

We recommend that eligibility for family support services be based on a family's documented need, as determined by the new DD assessment tool. The assessment will provide a comprehensive picture of family resources, both formal and informal. Income is only one factor in a family's capacity to support their child with a developmental disability.

In order for the Legislature to discuss this important policy, we recommend the creation of Individual and Family Services legislation that allows a fair and complete public discussion on the parental income issue. We believe it is a much better forum for creating policy than through the use of budget provisos.

Issue 2: The Department's recent agreement to disallow Medicaid Parent Providers to receive respite services.

Recently we learned that DSHS and SEIU signed an agreement that parents who are their sons/daughters Medicaid Personal Care (MPC) provider will no longer be eligible to receive respite services under the Family Support program. DSHS and SEIU are evidently considering "respite" services an employee benefit. This might be true if the parent were getting paid for 24 hour care, 7 days a week. However, according to recent DSHS data, the average number of MPC hours a parent receives payment for is 108 hours a month or about 4.5 days out of approximately 30. For the other 27 days that they are not receiving a payment and not employed as an MPC provider, why would they not be eligible for "respite"? Respite is a service to families who are providing the majority of non-paid services.

This appears to us that it is yet another penalty levied against parents who continue to support their adult sons/daughters at home.

We recommend that respite be considered a service and not an employee benefit and this policy be addressed in Individual and Family Services legislation in the 2007 legislative session.

Issue 3: Change the name of the Family Support program to Individual and Family Services program.

There have been so many different versions and variations of the Family Support program throughout the past 30 years, we recommend that its name be changed to indicate a new consolidated program and to recognize the individual with the developmental disability as the reason these services are provided. We recommend that this change be addressed through Individual and Family Services legislation in 2007.

Stakeholder Workgroup Members:

Sue Elliott, Dee Dee Garman, Ed Holen,
Grier Jewell, Lance Morehouse, Cathy
Murahashi, Donna Patrick, Diana Stadden,
Margaret Lee Thompson