

Self-Directed Services Pilot Program Evaluation Report February 2008

Prepared for:

Oklahoma Department of Human Services
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**Self-Directed Pilot Program
Evaluation Report
February 2008**

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Background

Introduction

Oklahoma's Self-Directed Care Act delineates requirements and responsibilities for self-directed care in Oklahoma. The Act requires that "self-directed care pilot programs for the citizens of the state who have disabilities shall be based on the principles of consumer choice and control" (SB 1015 Section 4.A.1). The Act also specifies "program evaluation which shall include an indication of whether consumer satisfaction for Self-Directed Care Pilot Program consumers is higher than or equal to consumer satisfaction for home- and community-based waiver clients or other comparable waiver programs, as measured by a third party."

Oklahoma's Department of Human Services (OKDHS)/Developmental Disabilities Services Division (DDSD) contracted with the Center for Learning and Leadership/University Center for Excellence in Developmental Disabilities (UCEDD) to conduct the program evaluation and to provide a summary report of progress on implementation of the Self-Directed Services Pilot Program.

Purpose of Study

Consumer self-direction and choice is a growing national trend (Congressional Research Service Report for Congress, January 2005). Self-directed service programs represent a philosophical approach to service delivery that maximizes a consumer's ability to: (1) assess their own needs, (2) determine how and by whom those needs will be met, and (3) define what constitutes quality. Depending on the program, consumers may be able to choose which services to receive; select the days and times for service delivery; hire, manage, and terminate the workers of their choice, including family members; and manage their budgets by setting wages and/or purchasing items that enhance their independence such as home modifications or assistive devices.

Legislative intent to achieve consumer self-direction was specified in Oklahoma's Self-Directed Care Act by the following statement:

"The Legislature finds that it recognizes the need to nurture the autonomy of citizens of this state who have disabilities by providing home- and community-based care services in the least restrictive and most appropriate setting possible. The Legislature hereby intends to provide such individuals with more choices in and greater control over the purchase of the home- and community-based care services they receive." With the implementation of the "In-Home Supports Waiver" in 1999, OKDHS/DDSD took steps to provide more flexible services to people with developmental disabilities within requirements specified by the federal Centers for Medicare and Medicaid Services for waived services. The In-Home Supports Waiver (IHSW)

laid a foundation for people with developmental disabilities and their families to select services necessary for each individual to remain in his or her own home or the family home, and to have more flexibility and choice to manage the supports needed to remain in their home setting. However, limitations in the IHSW provisions restricted people with disabilities (consumers) to service access and choices based on only what was available from those agencies under contract with the Oklahoma Health Care Authority.

Based on the Legislative intent and existing features of the IHSW, minimum expected results from design and implementation of the Self-Directed Services Pilot Program included:

- (1) Improvements to program infrastructure which would enable increased self-direction, flexibility, and choice at an “aggregate cost that shall be equal to or less than the cost of a home- and community-based waiver or comparable waiver program”
- (2) Increased “consumer”/family satisfaction
- (3) A “scope of services” in compliance with state statutes and rules and federal guidelines

Approach

Design of the Self-Directed Services (SDS) Pilot Program

As required under the Act, OKDHS/DDSD convened a Self-Directed Services Committee to assist with developing the pilot program. Representation was designated by the Legislature to include consumer, family, advocate, agency, professionals, and at-large appointees designated by the President Pro Tempore of the Senate and the Speaker of the House of Representatives. A membership list of the committee is provided in Appendix A.

Features of the Pilot Program

Table 1 provides a side-by-side comparison of features in the In-Home Supports Waiver and the new Self-Directed Services Pilot Program. Implementation of a “self-directed” approach required the committee to redefine the role and responsibilities of the “consumer” and “case manager,” and to add defined roles and responsibilities for a “fiscal intermediary/agent” and an “employer of record.” Definitions for these terms are provided in Appendix B.

**Table 1. Side-by-Side Comparison
In-Home Supports Waiver (IHSW) and Self-Directed Services (SDS) Pilot Program**

Feature	IHSW	SDS Pilot Program
Fiscal		
Fiscally responsible:	Agency	Fiscal Intermediary
Service Providers		
Employed by:	Agency	Employer of Record
Supervised by:	Agency	Consumer and/or Employer of Record
Rate of pay determined by:	Agency	Employer of Record negotiates rates with service providers based on approved guidelines
Scheduled by:	Agency	Employer of Record determines scheduling directly with service providers
Can service providers be a relative?	Yes; provided they are hired by Agency	Yes; Employer of Record can hire directly
Case Manager		
	Assessing the need for services and locating, managing, coordinating, and monitoring those services	Employer of Record assumes many of the functions of the case manager; the case manager takes on other functions such as education, guidance and reviewing plans of care
Supplies		
Where supplies can be purchased:	Medicaid Approved Supplier	Retail store or Medicaid Approved Supplier
Non-Traditional Services		
New non-traditional service option:	No	Yes; ability to use therapies such as swimming lessons instead of traditional physical therapy
Transportation (Adults)		
New transportation option:	No	Yes; pay mileage for transportation to services and pay for bus passes

SDS Committee as a Team

The SDS Committee was formed to assist OKDHS/DDSD in the development of the pilot program. The family and self-advocate members of the committee took responsibility for preparing themselves to participate as informed, proactive partners with OKDHS/DDSD and others on the committee. They became familiar with the philosophy of self-direction. They reviewed SDS programs from other states to determine what features, assessment tools, and training materials might be applicable to Oklahoma's program. Two of the family members served as co-chairs of the SDS Committee. One of those co-chairs was the primary liaison to the Director of DDSD.

The committee spent time debriefing after meetings and discussed not only the content of the meetings, but the process and structure. Early on, the committee members addressed the meeting logistics and recommended finding a meeting space that accommodated all community members, as well as OKDHS/DDSD staff. As a result, meetings were scheduled at locations in the community with telephone access for people who were unable to be physically present. The committee members also concentrated on the best way to present information in meetings and prepared documents that were concise and represented the consensus of the group.

Other Team Members

OKDHS/DDSD identified agency staff with key roles in development of Medicaid Waivers to attend the SDS Committee meetings. The case managers who participated in the pilot program, and their supervisors, also attended the majority of the meetings.

An OKDHS/DDSD staff member was assigned to serve as the SDS Pilot Program Coordinator. The coordinator established communication with all program principals (OKDHS/DDSD staff, pilot program participants, SDS Committee members, program evaluators, and the Director of DDSD.) The coordinator facilitated information transfer from one group to another, attended committee meetings, program participant meetings, and other informational and planning meetings related to implementation of the pilot program.

OKDHS/DDSD also contracted with E. P. and P. Consulting to provide technical assistance to the SDS Committee and OKDHS/DDSD about Medicaid regulations governing SDS programs and considerations for developing such a program within Oklahoma's Medicaid Waiver.

Information Exchange and Program Refinement

The information exchange that took place during the implementation of the pilot program was reflective of principles seen in communities of practice. Communities of practice are described by Etienne Wenger as *...groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly* (<http://www.ewenger.com/theory/>). During the SDS Pilot Program implementation, information and ideas were exchanged by the families, case managers, SDS Committee members, consultants, OKDHS/DDSD staff, and the

Director of DDSD. Information reflected the concerns, challenges, and perspectives of each group. Families asked questions and made suggestions for ways to make the program easier to use. Case managers identified concerns about day-to-day operations and projected future challenges in meeting program regulations. OKDHS/DDSD staff and the Director of DDSD were challenged to identify ways to address the suggestions and concerns of the families and case managers, and how to communicate what changes were being implemented and where they were encountering barriers that seemed insurmountable. The consultants searched for answers to Medicaid-related questions and identified possible models to serve as guides for Oklahoma's program.

There were multiple points of information input and multiple methods of information sharing. The SDS Program Coordinator held regular meetings with families and others involved in the pilot program. The SDS Committee, program participants, OKDHS/DDSD staff, Director of DDSD, and consultants had ongoing communication via email, conference calls, and meetings to disseminate information, answer questions, identify problems, and develop solutions. This interchange and shared learning experience created an environment that was open to contributions from all parties. It enabled families to use their day-to-day experiences as a means to work out details of the program, and enabled OKDHS/DDSD to refine the program using the ideas and experiences of the participants, SDS Committee, and consultants.

Training

The implementation of the pilot program included opportunities for both formal and informal training. Program participants were trained by the fiscal intermediary company, Acumen, in the procedures and forms necessary for setting up records and maintaining accounts to pay staff and to receive reimbursements for goods and services. They also received training on OKDHS/DDSD program guidelines, as well as received copies of the drafted policies for the program.

The SDS Committee and most of the pilot program participants participated in field-testing and reviewed drafts of SDS training material that was being developed by the Center for Learning and Leadership in conjunction with the implementation of the pilot program.

Implementation of the SDS Pilot Program

Participant Selection

Institutional Review Board approval was obtained by the evaluator to ensure that appropriate consent and confidentiality for participants would be maintained during study data collection. Participant selection, based on requirements of the Act, provided for an OKDHS/DDSD assessment process to help determine if the consumer could direct his or her own services or "designate an eligible representative to assist the person in directing such care" and that

participation in the pilot program was voluntary. Efforts were made to select participant families representing both children and adults with developmental disabilities.

A selected sample of 15 individuals were asked to participate in the SDS Pilot Program. Family members of nine children and six adults representing Oklahoma City and Tulsa volunteered to participate. One family subsequently dropped out due to plans for moving their household during the study timeframe. Fourteen families completed the study. The selected sample was not intended to be representative of the statewide population currently eligible to receive in-home supports. Instead, the sample was selected to provide comprehensive insight into family experiences using self-directed supports.

Table 2. Self-Directed Services Pilot Program Participants

Participant	Number	Location
Consumer/Family Members	15	
<ul style="list-style-type: none"> • Family members of children • Family members of adults • Family member of an adult who dropped out of the pilot program 	9 5 -1	Tulsa County Oklahoma County
Agency Staff	4	
<ul style="list-style-type: none"> • OKDHS/DDSD Case Managers • OKDHS/DDSD Supervisors 	2 2	Tulsa County Oklahoma County
Total Participants	18	

Pilot Program Implementation

The pilot program was implemented on August 1, 2006 and will continue through July 31, 2008. Program elements for the participants included an opportunity to participate in orientation and training about features of the Self-Directed Services Pilot Program. On completion of a Plan of Care meeting with their case manager, the participants who volunteered became a part of the pilot program.

Data Collection and Analysis

Introduction

Data collection included two features: (1) cost analysis of financial data comparing the IHSW and the SDS Pilot Program and (2) questionnaire data analysis of both closed and open-ended responses from (a) participants to address customer satisfaction issues and (b) agency staff to address coordination and administration issues.

Sample Selection

All of the participants in the Self-Directed Services Pilot Program were included in the evaluation study sample. Each participant was contacted by telephone and asked if they would be willing to participate in the evaluation. Consent forms, approved by the Institutional Review Board (IRB# 13199), were mailed, e-mailed, and faxed to participants for review and signature. On completion of the consent process, signed forms were returned to the evaluator prior to data collection.

Questionnaires

Data collection instruments were developed by the evaluator in collaboration with OKDHS/DDSD to address specific features of the SDS Pilot Program. The consumer/family member instrument included 37 questions with 23 of those on 5-point Likert scales or with “yes/no” options. Remaining questions were structured as short answer and open-ended to elicit details about the program impact and participant experiences during the program period. The agency staff instrument included 12 questions on a Likert scale and eight open-ended questions (Appendices C and D).

Four Likert scales were used in the evaluation included the following response choices:

- Satisfaction (1=very dissatisfied to 5=very satisfied)
- Extent (1=not at all to 5=great extent)
- Amount (1=much less to 5=much more)
- Difficulty (1=not difficult to 5=very difficult)

Data Collection

Data collection was accomplished through individual interviews conducted either in-person or by telephone with each participant using the questionnaire as a guide. Of the 15 consumer/family members who began the pilot program, 14 (93%) completed the study and provided consumer satisfaction questionnaire responses. Of the four OKDHS/DDSD agency staff, all four (100%) completed the study questionnaire.

Data Analysis

Cost Analysis

The cost analysis compared individual expenditures and total program expenditures from both the IHSW program and the SDS program for 12 participants. In fiscal year 2006, data was not found in the IHSW for one adult and one child. The 2006 IHSW data was provided by OKDHS/DDSD and the 2007 SDS Pilot Program data was provided by the fiscal intermediary. The data included each participant's annual budget allowance and itemized expenditures. The annual budget allowance was the same in 2006 and 2007 for both adult (\$18,540) and child (\$12,360) participants.

The actual data shows that in 2006, adult consumer participants used a total of \$76,219 compared to \$75,389 in 2007. The average amount spent by the four adult participants remained the same. In 2006, adults spent on average \$19,055 per year compared to \$18,847 in that of 2007. The same trend was seen for the children participants. The total amount spent in 2006 for children was \$71,543 compared to \$71,270 in 2007. Average spending for the eight children was \$8,909 in 2007 and \$8,943 in 2006. (Table 3)

Table 3. Cost Comparison IHSW vs. SDS Pilot Program

	IHSW 2006 ^{1,2}		SDS Pilot 2007 ³	
	Total	Average	Total	Average
Adult (n=4)	\$76,219	\$19,055	\$75,389	\$18,847
Child (n=8)	\$71,543	\$ 8,943	\$71,270	\$ 8,909

1 IHSW Fiscal Year 2006 data were only available for 12 of the 14 pilot participants. The cost comparison for the SDS Pilot does not include one adult and one child.

2 Effective August 16, 2006 the FY06 capped budget for all IHSW participants was Adults = \$18,540, Children = \$12,360. Average amounts in this table include approved exceptions authorized within the waiver regulations for one time or emergency costs such as architectural modifications.

3 Effective Fiscal Year 2007 the capped budget amount for the IHSW was increased: Adults = \$19,225, Children = \$12,820. SDS Pilot participants were excluded from that increase until August 1, 2007 which was after the pilot evaluation period.

As the data indicate, there was not a substantial difference in the total cost of the two programs. However, upon examination of the itemized expenditures and the reports, there is a clear financial benefit to families in the SDS program.

Families reported receiving more goods and services for their money due to the features of the SDS program that are not part of the IHSW program.

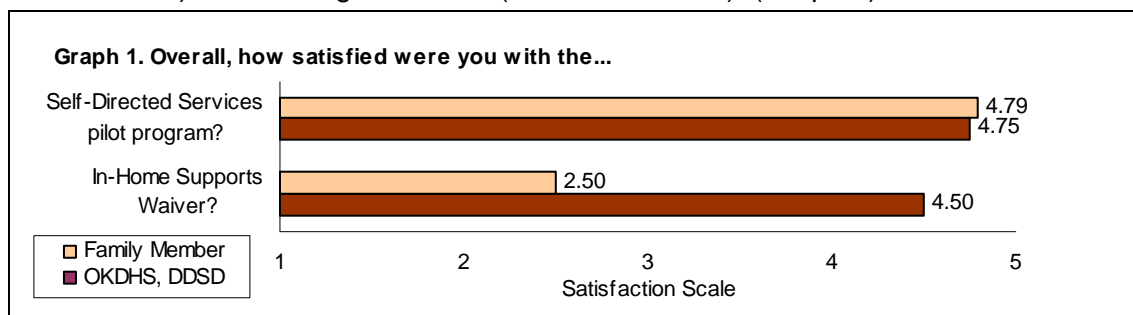
- Families were allowed to hire their own workers, which cut down on agency overhead and resulted in more funds being available for direct services.
- Families could buy supplies from local retail stores instead of a Medicaid supplier. The cost savings in the SDS program for diapers was over 48% and for wipes was over 80% when compared to that of the cost while on IHSW. Due to this savings, they were able to pay for more service hours.
- Families had the choice to use non-traditional services, such as ballet lessons, instead of occupational therapy. The ballet lessons cost less and increased the child's opportunity to make friends and be involved in their own community.
- Families could negotiate the rate of pay directly with service providers based on approved guidelines. They suggested that this resulted in an increased pool of providers who were more satisfied with their pay.
- Families also commented that the SDS program allowed flexibility to use more funds in some periods of the year and less in others, which allowed the families to budget more effectively based on their child/adult's needs.

Questionnaire Data Analysis

The analysis of questionnaire data included both closed and open-ended responses from (a) participants to address customer satisfaction issues and (b) agency staff to address coordination and administration issues. Charts detailing the responses including the means and percentages from the questionnaire items are located in Appendix E.

Specific components of the SDS program measures included: 1) Overall satisfaction with IHSW and SDS pilot, 2) Implementation of the SDS pilot, 3) Satisfaction with SDS program features, 4) Training for the SDS pilot, 5) Self-determination, and 6) Workload issues.

1) Overall Satisfaction. Family members and OKDHS/DDSD staff were very satisfied with the Self-Directed Services Pilot Program. Family members indicated much a higher satisfaction with the SDS program (mean score 4.79) than with the original In-Home Supports Waiver program (mean score 2.50) while agency staff responded that they were very satisfied with both the pilot (mean score 4.75) and the original waiver (mean score 4.50). (Graph 1)



Family participants reported that the SDS program either met or exceeded their expectations. Even those who said the program still needed some work agreed that it would be a step back, not to continue this program. All the family participants said that they wanted to continue in the program after the pilot period ends.

“It has exceeded my expectations because of the ease of use with the program.”

“Yes, it has met my expectations and probably beyond.”

“I would be sick if we had to go back to the old way.”

“Definitely, I would be very disappointed if we don’t get to continue in the program.”

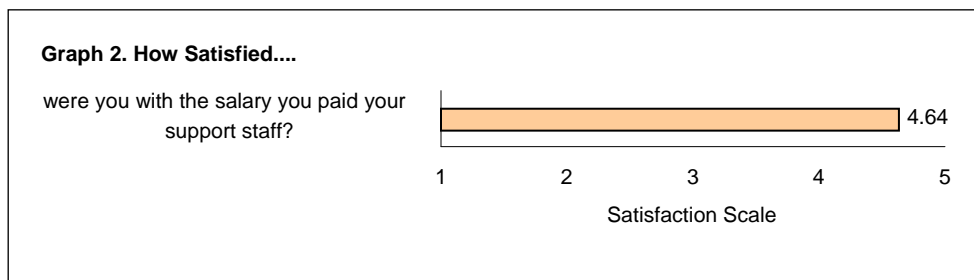
2) Implementation of the Pilot Program. The pilot program was designed to allow family participants 1) control and flexibility in managing their annual budget, 2) control and flexibility in administrating their plan of care, and 3) the opportunity to direct goods and services identified in their plan of care.

Family participants indicated that, to a great extent, they had been given the flexibility to manage their annual budget (mean score 4.64), administer their plan of care (mean score 4.57), and direct goods and services identified in their plan of care (mean score 4.57).

3) Satisfaction with the Program Features:

Employer of Record. In the SDS Pilot Program, family members assumed the responsibility of the employer of record. As employers, they had the ability to hire and fire service providers and set the rate of pay based on previously approved guidelines and the plan of care.

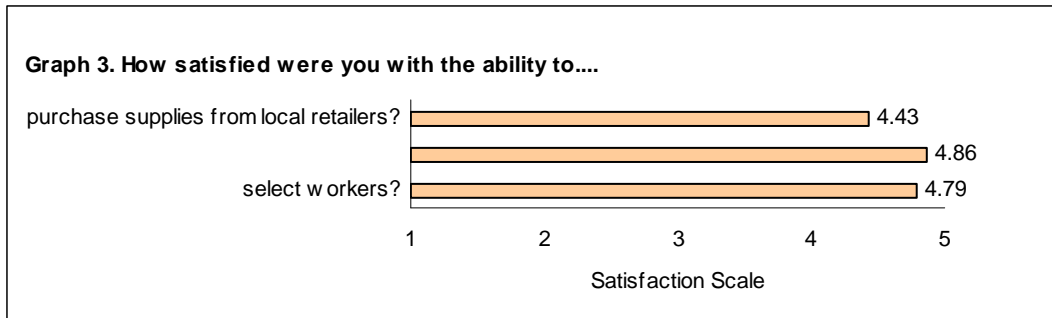
Family participants indicated very strong satisfaction with having the ability to select workers (mean score 4.79), the ability to hire and fire workers (mean score 4.86), and the salary they paid their support staff (mean score 4.64). (Graph 2)



Family participants indicated that to a great extent (mean score 4.79) they were able to manage worker hours more efficiently.

“I can manage their time without having to get approval from case management on a continuous basis because I know when I need staff.”

Supplies. The participants were given the opportunity to purchase supplies from local retailers instead of being limited to Medicaid approved suppliers. Eleven of the fifteen respondents were satisfied with the ability to purchase supplies from local retailers. Three were neither satisfied nor dissatisfied. (Graph 3)



Non-Traditional Services. The SDS Pilot Program expanded the allowable services to include non-traditional services that were not included in the original IHSW. A DDSD committee determined if the request could be approved based on Medicaid and Medicare guidelines, state and federal laws, and the consumer’s plan of care. Six children and one adult were approved for a non-traditional service including:

- ballet, swimming lessons
- camps – church, day, summer
- educational computer software and materials
- additional therapeutic materials
- YMCA & health club memberships
- workshops
- pedicures

Of those who purchased non-traditional services all (100%) responded that they were “very satisfied” (mean score 5.00) with their purchases.

"I think just being able to buy your own...non-traditional services or other items. Everything we were able to do this past summer was socially beneficial for our child. There were so many social things. With the original program there was nothing we could provide for our child that was social or any social activities. It was just the traditional things like physical therapy. He loves going to the YMCA. He loves it. He has gotten to know people. He talks to all kinds of people. It is an overall benefit."

Transportation. Adults with developmental disabilities were eligible for new transportation options including: (1) paying for a bus pass and (2) paying gas mileage on necessary errands. Four out of five of the adult participants used the new transportation options.

"The whole transportation issue changed about what we could and could not use. Much more flexibility. There is much more flexibility with the transportation in the pilot that was not allowed before. Parents actually had control instead of having an agency in the middle of all that."

4) Self-Directed Services Training. All participants in the pilot program, including family members, consumers, the fiscal intermediary, and employers of record, were included in various meetings and trainings in order to understand and administer the SDS program. The intention of OKDHS/DDSD was for all parties to be involved and work together in order to make the program successful.

Over 90% of the participants said they were very satisfied (mean score 4.69) with the SDS training they received. Ten percent of the respondents said they did not receive training. However, they did say that they participated in meetings but did not know if that was considered "training."

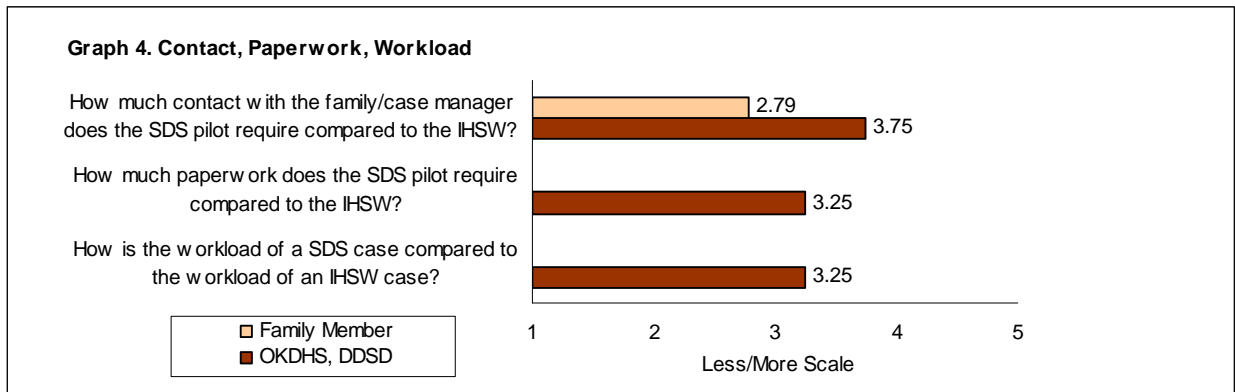
5) Self-Determination. Self-directed services programs are intended to increase the level of control participants will gain by having increased flexibility and the choice to plan and direct their lives. Caregivers in the pilot program said, to a large extent, that the program allowed for increased self-determination (mean score 4.00) and it assisted the consumer in achieving personal goals (mean score 4.21).

In the study, the term "self-determination" was undefined for the families. Families commented during the interview that they were unsure if the question was asking if they or the consumer had more self-determination. There was clarification within the comments regarding their responses to this question.

"My child is a minor and working with a CSW [Community Support Worker] gives him more community inclusion where he can learn more about self-determination."

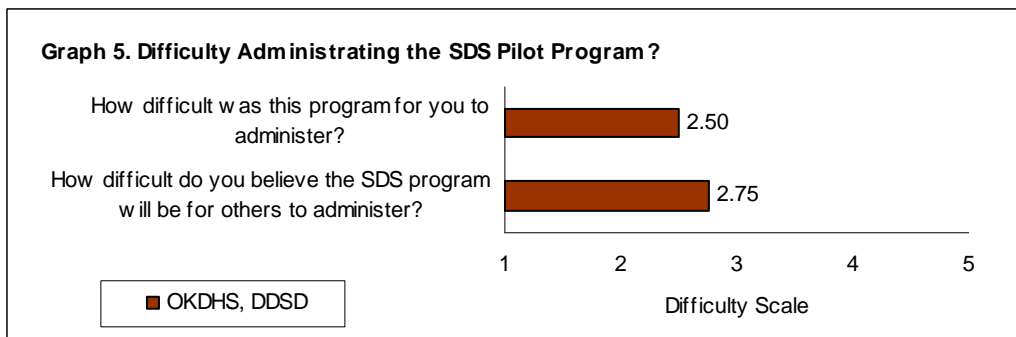
"She has grown verbally and physically. She is more motivated to do things she was not able to do prior to the SDS program. She actually wants to do more and initiates more. She can let you know when she wants more."

6) Workload Issues. Family members, case managers, and supervisors were asked a variety of questions regarding the workload of the SDS program. The questions focused on contact between families and agency staff, paperwork, and ease/difficulty of administration. The case managers and supervisors were asked about their contact with the family members, and they said it was somewhat more (mean score 3.75) in the SDS pilot program compared to the original IHSW. They said the contact increased initially and reduced once everyone was more comfortable with the program. (Graph 4)



Family members said that the amount of contact with the case manager was a little less but overall about the same (mean score 2.79) as in the IHSW program. Interestingly, family members said that in the original program there was very little communication with OKDHS/DDSD staff and they actually wanted and needed more contact. In the SDS program, families reported that they felt like they were more of a partner in the process of making the plan of care work. Increased contact with the case manager was viewed as a positive aspect of the program from the family members' perspective.

The case managers and supervisors said their paperwork and their workload were about the same (mean score 3.25). They reported that the SDS program was mildly difficult (mean score 2.50) to administer but that was mostly at the beginning and tapered off once they became familiar with the program. They also reported that they believed once everyone learned how to administer the program it would be much easier to administer than the IHSW program. They further reported that it is a needed program and should be offered to the community. (Graph 5)



Open-Ended Responses. Open-ended questions were added to the questionnaire to capture information about the impact and importance of the Self-Directed Services Pilot Program. Responses of the family participants were categorized into three major theme areas.

1. Quality of Life
2. Social Networking
3. Fiscal Intermediary

Quality of Life

Families in the SDS Pilot Program noticed some differences in their lives. They reported being treated with more respect from others, having less intrusion, and less stress. They reported a general feeling of a higher quality of life. Some specific comments from families included the following:

"My son is treated with a lot more respect by everyone."

"I also like the relationship we've established with the case manager; that's been so much better than on the original program."

"My son does better, dramatically better. I don't know exactly why. We haven't changed the program much, but we have a little because we have more flexibility."

"Oh, it's a huge difference. Less frustration...so that means less stress."

Social Networking

A second theme that emerged from the open-ended responses was about connecting with other families. The families who participated in the SDS Pilot Program met through meetings, training sessions, and communicated through telephone and email. During the interviews, they expressed the importance and benefits of working with and communicating with other families. They suggested having a common place to share information about services, program features, and hiring staff. They also suggested starting a quarterly newsletter for those participating in the SDS program. Typical comments from family participants included the following:

"I wish there was some way we could come up with a pool of all the workers that everyone has found that have worked well for them. And maybe I only needed them Tuesdays and Thursdays but they were able to work Monday through Friday. If there was a database that was available where we could put in this type of information and access it."

"A list of workers that had expressed a desire to work with disabled children, from an agency or other parents, perhaps."

"I think when the pilot program is all said and done it would be helpful to know what other parents have used their money for. I know that all children are unique;

maybe something that someone else has used, and that I haven't thought of, might help my child."

"Everyone needs to be able to get all the information at the same time."

"Maybe there could be some type of website or a bulletin board and parents say what they have used that has worked or not worked We need a place to share what has worked and been done successfully."

"...a place to share what has worked and been done successfully...a place where we could put this all where everyone has access so we don't have to reinvent the wheel all the time...so we don't have to guess all the time."

"Also, a lot of the time we have equipment that our children outgrow. So this would also be a great place to post this type of information. Someone else may need this information."

Fiscal Intermediary

Another theme that emerged from the open-ended responses was the role of the fiscal intermediary. This new feature had not been used in the IHSW program. Families expressed concerns and ideas about the following:

- The need to monitor the contract
- The importance of the response time of the fiscal intermediary
- The need for quality budget reports

Conclusions

The evaluation of the Self-Directed Services Pilot Program demonstrated a high level of satisfaction among the families when compared to their experiences on the In-Home Supports Waiver, yet the amount of funding allocated per person was the same in both programs. Higher satisfaction was related to the increased choice and control that the consumer/family member experienced as a result of the features in the SDS Pilot Program. Those features included:

- Ability to buy supplies from local retailers
- Ability to hire and fire staff
- Ability to set wages at a rate that had a positive impact on the quality of staff and increased possibility for retaining staff
- Ease with which the budget could be adjusted as the needs of the person changed
- Revised role of the case manager which resulted in improved contact /communications with the consumer/family member
- Use of a fiscal intermediary to manage payments and payroll
- Ability to use non-traditional services

The evaluation indicated a high level of satisfaction on the part of OKDHS/DDSD staff with both the SDS Pilot Program and the In-Home Supports Waiver.

SDS Pilot Program costs were not greater than the costs of the IHSW. There were cost-benefits in the pilot program because the family acted as the employer of record and, therefore, saved on administrative costs that were paid to agencies in the IHSW. An additional cost-benefit was the savings realized by purchasing supplies at a local retailer instead of an authorized Medicaid supplier.

Based on the data analysis, it is apparent that collaboration and partnerships increased among families, case managers, and agency staff. There was willingness on the part of OKDHS/DDSD to include families in the discussions and the decisions about the development of the SDS Pilot Program. There was a concerted effort on the part of the families to participate as informed and equal partners. The result of this collaboration and partnership appears to be a subtle, yet significant change in the way each partner perceived the other and in the way the parties interacted, particularly as compared to the lack of these relationships in the IHSW. There also appeared to be an increased understanding of each others' situation and an increased mutual respect between families and agency staff that was demonstrated.

Recommendations

Adopt All SDS Pilot Program Features

Based on the satisfaction experienced in the SDS Pilot Program, the features of the program enhanced cost effectiveness and flexibility without increasing the administrative burden.

Continue Communication and Information Exchange Opportunities

As the new program is implemented and participants experience their new roles, they will benefit from continued opportunities to share information and ideas.

Families in the pilot program recommended that they have access to a bulletin board or email list server to post questions and exchange information about the SDS program. A *Frequently Asked Questions* document also should be posted on the OKDHS/DDSD website and disseminated at program training sessions.

Provide Training for All Participants

Training procedures and content should include the policies, program guidelines, and philosophy of self-directed services.

Self-directed services require that the consumer/family member and case managers will have new roles. Taking on and transitioning into those roles will be enhanced by training both groups in the same setting at the same time. This approach will start the process of partnering and sharing responsibility for implementation of the program.

Conduct Evaluation for Continuous Quality Improvement

An evaluation plan should be developed to include baseline data collection, on-going evaluation components, a mechanism for identifying and reporting on needed improvements, and a schedule for a written summary of report findings and feedback.

References

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Wenger, Etienne. 1998. *Communities of Practice: a brief introduction*. Last accessed February 22, 2008 at <http://www.ewenger.com/theory>.

Appendices

Appendix A: Self-Directed Services Committee

Charlotte Bowen

Statewide Independent Living Council

Lisa DeBolt

Parent

Helen Epstein

Aging Services Self-advocate

Wanda Felty

Parent

Jeff Hughes

Progressive Independence, Inc.

Juanita Killingsworth

Parent

Vyonda Martin

*Center for Learning and Leadership,
OU Health Sciences Center*

Lari Moazami

Effective Teaching and Learning, Inc.

Carol Parker

Parent

Linda Rutherford

Parent

Sally Selvidge

Parent

Mike UptheGrove

Adult Services Self-advocate

Appendix B: Self-Directed Services Pilot Program Roles and Responsibilities

Following are key roles and responsibilities of those involved with the service recipient's plan of care. For a complete list, refer to the Oklahoma Department of Human Services (OKDHS)/ Developmental Disabilities Services Division (DDSD) policy.

Roles and Responsibilities of the Service Recipient and/or Employer of Record

The major roles and responsibilities of the service recipient and/or employer of record include:

- Complete and sign the Self-Directed Services Agreement. Give the original to the case manager, fax or mail a copy to the fiscal agent, and retain a copy for your records.
- Participate in self-directed services support planning and budget development.
- Hire, supervise, train, and fire staff and ensure that all employees are 18 or older.
- Ensure that employee background checks are completed within 30 days of employment. The fiscal agent conducts the background checks after receiving the required new employee documentation.
- Report to the case manager:
 - Monthly - Send a Monthly Progress Report to the case manager on or before the tenth of each month for the preceding month.
 - As needed - If circumstances change or an emergency occurs that results in a change to the plan of care; complete incident reports
- Comply with the applicable OKDHS/DDSD policies and regulations and agency staff requests for home visits.
- Pay for:
 - Services when the amount is more than the approved budget amount
 - Services not identified and approved in the plan of care
- Record keeping – Keep originals or copies of agreements, forms, timesheets, etc.

Additionally, they will comply with the fiscal agent requirements, including:

- Sign the Fiscal Agent Authorization – Send the original copy to the fiscal agent and retain a copy for your records.
- Sign the Employee Appointment of Agent Form 2678 – Send the original copy to the fiscal agent and retain a copy for your records.
- Review, sign, and submit employee timesheets based on the fiscal agent's payroll schedule.
- Provide documentation for vendor reimbursement of goods and services.

Roles and Responsibilities of OKDHS/DDSD Case Management

The major roles of OKDHS/DDSD Case Management include:

- Meet with the service recipient and/or the employer of record and provide information about the self-directed services waiver and the traditional waiver.
- Share information about the scope of choices, options, rights, risks, and responsibilities of self-directed services.
- Assist with the development of the support plan, including the budget and an emergency back-up plan.

- Send a “notice of action” letter identifying the approved services and budget amounts to the service recipient and fiscal agent.
- Assist with needed revisions to the plan and budget due to the service recipient’s changing needs.
- Monthly – Review and document in Client Contact Manager (CCM) by the 15th of each month:
 - Monthly progress report from the service recipient and/or employer of record
 - Fiscal agent report
- As Needed
 - Review incident reports and follow-up as needed
- Conduct an annual review with a face-to-face meeting
- Assist the service recipient in maintaining Medicaid eligibility
- Explain and participate in fair hearing process
- Assist in problem resolution process and guardianship assessments and reviews

Roles and Responsibilities of the Fiscal Agent

The major responsibilities of the fiscal agent include:

- Retain the funds and monitor the service recipient’s expenditures and budget allowance
- Process employee timesheets
- Process payroll and tax information (FICA, state and federal tax, etc.)
- Process payments to vendors for goods and services authorized in the plan of care
- Provide reports to the employer of record to ensure budget management

Appendix C: Self-Directed Services (SDS) Family and Caregiver Questionnaire

Thank you for your participation in the In-Home Supports Waiver, Self-Directed Services Pilot Program. We would like to have your input on your experience with the program.

Based on your experience with the SDS program over the last year, please select the best response for the following questions.

To what extent ...	Not at all	To a limited extent	To a moderate extent	To a large extent	To a great extent
1. Were you involved in the development of the plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Was the client involved in the development of the plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Did the plan of care reflect your client's individual needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were you given the opportunity to direct goods and services identified in the plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Did the SDS program increase your flexibility in administrating the plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Did the new options for transportation increase your flexibility?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were you given the flexibility to manage the annual budget?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Did the SDS program allow you to manage the number of worker hours more efficiently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Did you have enough qualified workers to choose from?
10. Were your workers able to receive the training they needed?
11. Did the SDS program assist the client in achieving personal goals?
12. Did the SDS program allow for increased self-determination?

How satisfied were you with the...

- | | Very Dissatisfied | Somewhat Dissatisfied | Neither Satisfied or Dissatisfied | Somewhat Satisfied | Very Satisfied |
|--|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|
| 13. Ability to select workers? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Ability to hire and fire workers? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Ability to purchase supplies from local retailers? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Salary you paid your support staff? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. In your opinion, how satisfied was your support staff with their salary? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

18. Did you purchase non-traditional services? For example, health care membership or ballet lessons instead of a traditional therapy?
- YES NO

a. If YES, what kind of non-traditional services did you purchase?

b. If YES, how satisfied were you with the ability to purchase non-traditional services?

Very Dissatisfied	Somewhat Dissatisfied	Neither Satisfied or Dissatisfied	Somewhat Satisfied	Very Satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. How much contact with the case manager does the SDS program require compared to the In-Home Supports Waiver?

Much Less	Somewhat Less	Stayed the Same	Somewhat More	Much More
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Did you receive training to administer the SDS program for your household? YES NO

a. If YES, how satisfied were you with the training provided?

Very Dissatisfied	Somewhat Dissatisfied	Neither Satisfied or Dissatisfied	Somewhat Satisfied	Very Satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. Overall, how satisfied are you with the SDS program [August 2006 – July 2007]?

Very Dissatisfied	Somewhat Dissatisfied	Neither Satisfied or Dissatisfied	Somewhat Satisfied	Very Satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. Overall, how satisfied were you with the original In-Home Supports Waiver program [August 2005 – July 2006]?

Very Dissatisfied

Somewhat
Dissatisfied

Neither Satisfied
or Dissatisfied

Somewhat
Satisfied

Very Satisfied

Now we would like to ask you some open-ended questions that will help us understand the impact and importance the SDS Pilot Program had for you.

23. Why did you decide to be a part of the SDS program?

24. Since the SDS program started on August 1, 2006, is there anything that is working better for you now than in the original In-Home Supports Waiver program? If so, what?

25. Since the SDS program started on August 1, 2006, is there anything that is still not working for you that was not working for you in the original In-Home Supports Waiver program? If so, what?

26. What difference has the SDS program made in your family?

27. After being part of the SDS program, what goods and services would you like to use your money for that you still can't buy or pay for through this program?

28. Has the SDS program met your expectations? Why or Why not?

29. What suggestions do you have for improving the SDS program?

30. Would you be interested in continuing in a SDS program after the pilot program has ended? Why or Why not?

31. Are there any issues that we haven't addressed that you would like to address?

32. Are **you** the person being paid through the In-Home Supports Waiver, as the support provider for your son/daughter?

YES

NO

a. If YES, what are the major reasons why **you** are the primary support provider for your son/daughter? (Check all that apply)

- Could not find a provider
- Do not like a stranger caring for my son/daughter
- Could not find a reliable provider
- Providers would not/could not work for the rate of pay
- Too much staff turnover
- No qualified providers trained to deal with the uniqueness of my son/daughter's needs
- Other, explain _____

b. If NO, what are the major reasons why **you** are not the primary support provider for your son/daughter? (Check all that apply)

- My son/daughter is under 18 years old
- I found a reliable provider
- I found a qualified provider
- I found a provider that accepts the rate of pay
- A close family friend cares for my child
- A relative or family member cares for my child
- Other, explain

Appendix D: Self-Directed Services (SDS) Case Manager and Supervisor Questionnaire

Thank you for administrating the In-Home Supports Waiver, Self-Directed Services Pilot Program. We would like to have your input on your experience with the program.

Based on your experience with the SDS program over the last year, please select the best response for the following questions.

To what extent ...	Not at all	To a limited extent	To a moderate extent	To a large extent	To a great extent
1. Was caretaker/family member involved in the development of the plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Was the client involved in the development of the plan of care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Did the plan of care reflect your client's individual needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were clients/caretakers able to manage the tasks involved in the SDS program?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Did the SDS program allow the clients/caretakers to increase self-determination?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Based on your experience...

Much Less Somewhat Less Stayed the same Somewhat More Much More

6. How much paperwork does the SDS program require compared to the In-Home Supports Waiver?

7. How much contact with the family does the SDS program require compared to the In-Home Supports Waiver?

8. How is the workload of a SDS program case compared to the workload of an In-Home Supports Waiver case?

9. How difficult was this program for you to administer?

Not Difficult Mildly Difficult Somewhat Difficult Moderately Difficult Very Difficult

10. How difficult do you believe the SDS program will be for others to administer?

Not Difficult Mildly Difficult Somewhat Difficult Moderately Difficult Very Difficult

11. Overall, how satisfied are you with the SDS program [August 2006 – July 2007]?

Very Dissatisfied Somewhat Dissatisfied Neither Satisfied or Dissatisfied Somewhat Satisfied Very Satisfied

12. Overall, how satisfied were you with the original In-Home Supports Waiver program [August 2005 – July 2006]?

Very Dissatisfied

Somewhat
Dissatisfied

Neither Satisfied
or Dissatisfied

Somewhat
Satisfied

Very Satisfied

13. Since the SDS program started on August 1, 2006, is there anything you see working better now than in the original In-Home Supports Waiver program? If so, what?

14. Since the SDS program started on August 1, 2006, is there anything that is still not working for your clients that was not working for your clients in the original In-Home Supports Waiver program? If so, what?

15. Has the SDS program met your expectations? Why or Why not?

16. Based on your experience, do you anticipate any client obstacles to self-directed services?

17. Based on your experience, do you anticipate any administrative obstacles to self-directed services?

18. In your opinion, how does self-directed services impact the clients?

19. Are there any issues that we haven't addressed about the program that you think should be?

20. What would you change, if anything, about self-directed services?

Appendix E: Self-Directed Services (SDS) Pilot Program Evaluation Questionnaire Results

	All Family n=14	Child n=9	Adult n=5	DDSD Staff n=4
Overall, how satisfied are you with the SDS program [August 2006 – July 2007]?				
Mean	4.8	4.9	4.6	4.8
% Very Dissatisfied	0.0	0.0	0.0	0.0
% Somewhat Dissatisfied	0.0	0.0	0.0	0.0
% Neither Satisfied or Dissatisfied	7.1	0.0	20.0	0.0
% Somewhat Satisfied	7.1	11.1	0.0	25.0
% Very Satisfied	85.7	88.9	80.0	75.0
Overall, how satisfied were you with the original In-Home Supports Waiver program [August 2005 – July 2006]?				
Mean	2.5	2.4	2.6	4.5
% Very Dissatisfied	14.3	11.1	20.0	0.0
% Somewhat Dissatisfied	50.0	55.6	40.0	0.0
% Neither Satisfied or Dissatisfied	7.1	11.1	0.0	25.0
% Somewhat Satisfied	28.6	22.2	40.0	0.0
% Very Satisfied	0.0	0.0	0.0	75.0
To what extent were you given the flexibility to manage the annual budget?				
Mean	4.6	4.6	4.8	
% Not at all	0.0	0.0	0.0	
% To a limited extent	0.0	0.0	0.0	
% To a moderate extent	7.1	11.1	0.0	
% To a large extent	21.4	22.2	20.0	
% To a great extent	71.4	66.7	80.0	
To what extent did the SDS program increase your flexibility in administrating the plan of care?				
Mean	4.6	4.7	4.4	
% Not at all	0.0	0.0	0.0	
% To a limited extent	7.1	0.0	20.0	
% To a moderate extent	7.1	11.1	0.0	
% To a large extent	7.1	11.1	0.0	
% To a great extent	78.6	77.8	80.0	

	All Family n=14	Child n=9	Adult n=5	DDSD Staff n=4
To what extent were you given the opportunity to direct goods and services identified in the plan of care?				
Mean	4.6	4.7	4.4	
% Not at all	0.0	0.0	0.0	
% To a limited extent	7.1	0.0	20.0	
% To a moderate extent	0.0	0.0	0.0	
% To a large extent	21.4	33.3	0.0	
% To a great extent	71.4	66.7	80.0	
How satisfied were you with the ability to select workers?				
Mean	4.8	4.8	4.8	
% Very Dissatisfied	0.0	0.0	0.0	
% Somewhat Dissatisfied	0.0	0.0	0.0	
% Neither Satisfied or Dissatisfied	0.0	0.0	0.0	
% Somewhat Satisfied	21.4	22.2	20.0	
% Very Satisfied	78.6	77.8	80.0	
How satisfied were you with the ability to hire and fire workers?				
Mean	4.9	4.8	5.0	
% Very Dissatisfied	0.0	0.0	0.0	
% Somewhat Dissatisfied	0.0	0.0	0.0	
% Neither Satisfied or Dissatisfied	0.0	0.0	0.0	
% Somewhat Satisfied	14.3	22.2	0.0	
% Very Satisfied	85.7	77.8	100.0	
How satisfied were you with the salary you paid your support staff?				
Mean	4.6	4.6	4.8	
% Very Dissatisfied	0.0	0.0	0.0	
% Somewhat Dissatisfied	7.1	11.1	0.0	
% Neither Satisfied or Dissatisfied	0.0	0.0	0.0	
% Somewhat Satisfied	14.3	11.1	20.0	
% Very Satisfied	78.6	77.8	80.0	
To what extent did the SDS program allow you to manage the number of worker hours more efficiently?				
Mean	4.8	4.8	4.8	
% Not at all	0.0	0.0	0.0	
% To a limited extent	0.0	0.0	0.0	
% To a moderate extent	0.0	0.0	0.0	
% To a large extent	21.4	22.2	20.0	
% To a great extent	78.6	77.8	80.0	

	All Family n=14	Child n=9	Adult n=5	DDSD Staff n=4
To what extent were clients/caretakers able to manage the tasks involved in the SDS program?				
Mean				4.5
% Not at all				0.0
% To a limited extent				0.0
% To a moderate extent				0.0
% To a large extent				50.0
% To a great extent				50.0
To what extent were your workers able to receive the training they needed?				
Mean	4.0	3.8	4.4	
% Not at all	0.0	0.0	0.0	
% To a limited extent	7.1	11.1	0.0	
% To a moderate extent	21.4	22.2	20.0	
% To a large extent	35.7	44.4	20.0	
% To a great extent	35.7	22.2	60.0	
How satisfied were you with the ability to purchase supplies from local retailers?				
Mean	4.4	4.8	3.8	
% Very Dissatisfied	0.0	0.0	0.0	
% Somewhat Dissatisfied	0.0	0.0	0.0	
% Neither Satisfied or Dissatisfied	21.4	0.0	60.0	
% Somewhat Satisfied	14.3	22.2	0.0	
% Very Satisfied	64.3	77.8	40.0	
Did you purchase non-traditional services? For example, health care membership or ballet lessons instead of a traditional therapy?				
% Yes	50.0	66.7	20.0	
% No	50.0	33.3	80.0	
If YES, how satisfied were you with the ability to purchase non-traditional services?				
n	7	6	1	
Mean	5.0	5.0	5.0	
% Very Dissatisfied	0.0	0.0	0.0	
% Somewhat Dissatisfied	0.0	0.0	0.0	
% Neither Satisfied or Dissatisfied	0.0	0.0	0.0	
% Somewhat Satisfied	0.0	0.0	0.0	
% Very Satisfied	100.0	100.0	100.0	

	All Family n=14	Child n=9	Adult n=5	DDSD Staff n=4
To what extent did the new options for transportation increase your flexibility?				
n	5		5	
Mean	4.2		4.2	
% Not at all	20.0		20.0	
% To a limited extent	0.0		0.0	
% To a moderate extent	0.0		0.0	
% To a large extent	0.0		0.0	
% To a great extent	80.0		80.0	
Did you receive training to administer the SDS program for your household?				
% Yes	92.9	100.0	80.0	
% No	7.1	0.0	20.0	
If YES, how satisfied were you with the training provided?				
n	13	9	4	
Mean	4.7	4.7	4.8	
% Very Dissatisfied	0.0	0.0	0.0	
% Somewhat Dissatisfied	0.0	0.0	0.0	
% Neither Satisfied or Dissatisfied	7.7	11.1	0.0	
% Somewhat Satisfied	15.4	11.1	25.0	
% Very Satisfied	76.9	77.8	75.0	
To what extent did the SDS program assist the client in achieving personal goals?				
Mean	4.2	4.1	4.4	
% Not at all	0.0	0.0	0.0	
% To a limited extent	14.3	11.1	20.0	
% To a moderate extent	0.0	0.0	0.0	
% To a large extent	35.7	55.6	0.0	
% To a great extent	50.0	33.3	80.0	
Family: To what extent did the SDS program allow for increased self-determination?				
DDSD Staff: To what extent did the SDS program allow the clients/caretakers to increase self-determination?				
n	13	9	4	4
Mean	4.0	3.9	4.3	3.3
% Not at all	0.0	0.0	0.0	25.0
% To a limited extent	15.4	11.1	25.0	0.0
% To a moderate extent	23.1	33.3	0.0	25.0
% To a large extent	7.7	11.1	0.0	25.0
% To a great extent	53.8	44.4	75.0	25.0

	All Family n=14	Child n=9	Adult n=5	DDSD Staff n=4
Family: How much contact with the case manager does the SDS program require compared to the In-Home Supports Waiver?				
DDSD Staff: Based on your experience how much contact with the family does the SDS program require compared to the In-Home Supports Waiver?				
Mean	2.8	2.3	3.6	3.8
% Much Less	14.3	22.2	0.0	0.0
% Somewhat Less	28.6	33.3	20.0	0.0
% Stayed the same	28.6	33.3	20.0	50.0
% Somewhat More	21.4	11.1	40.0	25.0
% Much More	7.1	0.0	20.0	25.0
Based on your experience how much paperwork does the SDS program require compared to the In-Home Supports Waiver?				
Mean				3.3
% Much Less				0.0
% Somewhat Less				0.0
% Stayed the same				75.0
% Somewhat More				25.0
% Much More				0.0
Based on your experience how is the workload of a self-directed services case compared to the workload of an In-Home Supports Waiver case?				
Mean				3.3
% Much Less				0.0
% Somewhat Less				25.0
% Stayed the same				50.0
% Somewhat More				0.0
% Much More				25.0
Based on your experience how difficult was the SDS program for you to administer?				
Mean				2.5
% Much Less				25.0
% Somewhat Less				50.0
% Stayed the same				0.0
% Somewhat More				0.0
% Much More				25.0

	All Family n=14	Child n=9	Adult n=5	DDSD Staff n=4
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How difficult do you believe the SDS program will be for others to administer?

Mean				2.8
% Much Less				25.0
% Somewhat Less				25.0
% Stayed the same				25.0
% Somewhat More				0.0
% Much More				25.0

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