Pilot Program for DeafBlind Services

A Report to the Minnesota Legislature

Deaf and Hard of Hearing Services Division
444 Lafayette Road North, St. Paul, MN 55155-3814   651-296-3980

For more information, contact:
Minnesota Department of Human Services
Deaf and Hard of Hearing Services Division
444 Lafayette Road
St. Paul, Minnesota 55155-3814
(651) 296-3980 Voice
(651) 297-1506 TTY

This information is available in other forms to people with disabilities by calling 651-296-2544 (voice), toll free at 1-800-333-5433, or 1-800-627-3529 (TTY).

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This report cost $1,715 in staff time to prepare.

I. EXECUTIVE SUMMARY

Since the fall of 2002, the Department of Human Services Deaf and Hard of Hearing Services Division (DHHSD) and the Department of Employment and Economic Development State Services for the Blind (SSB) have been collaborating to conduct the DeafBlind Consumer Directed Services Pilot Program. A preliminary report of the program was presented to the legislature on January 1, 2003. This is the final report.

The two purposes of the pilot program are 1) to help adults who are deafblind live independently and become more involved in their families and/or community and 2) to help children who are deafblind improve their communication skills and knowledge of their environment and to improve family members' ability to communicate and interact with the deafblind child.

Consumer satisfaction. Despite the challenges associated with assuming responsibility for directing their own service programs, the consumers who participated in the program found that the ability to choose from a wider variety of service options was very effective in meeting their unique needs. In addition, given that the majority of program participants are from Greater Minnesota where few agencies that provide specialized services for deafblind people exist, the program provided participants with the ability to find and hire qualified individuals who could provide them with needed services. Participants did express certain concerns relative to the program design and administration, but DHHS will continue to address those concerns and improve the "consumer-friendliness" and efficiency of the program's operation.

Cost effectiveness. While the pilot program used less state *grant* money to deliver an hour of Support Service Provider (SSP) and intervenor service, a comparison of the hourly rates fails to account for certain "hidden" costs associated with the pilot program that are difficult to measure. In addition, because SSB will not continue providing fiscal agent services for the program after this fiscal year, consumers will have to use some of their program dollars to purchase these services. However if the intangible value of the aforementioned flexibility is factored into the equation, it's clear to us that the program should continue.

Also, because less state grant money is needed to purchase an hour of SSP or intervenor services, consumers are then able to use the balance of their grant allocation to purchase equipment, assistive devices, or other essential services they need to maintain their independence at no added cost to the state.

Effective use of state grant dollars. To ensure that the State's grant dollars are used as effectively and efficiently as possible, the program's case managers will be trained to assure that all program participants are appropriately screened for MA and MA waivered services eligibility. In this way, the State's grant money will only be used for services that are not covered by MA or for those consumers who are not MA-eligible.

Proposal. The DHHSD will continue to offer the consumer-directed program to the fourteen (14) current program participants. If the Legislature wants to expand the program to more deafblind individuals, an additional appropriation would be necessary since the DHHSD does not have enough staff or state grant funds to accommodate a larger program. The fiscal note in

Attachment A includes associated costs for expanding the program to serve an additional 16, 40 or 56 individuals.

II. PILOT PROGRAM LEGISLATION

Minnesota Session Laws 2002, Chapter 375, Article 2, Sec. 53. [PILOT PROGRAM FOR DEAF-BLIND SERVICES.] (a) The commissioners of human services; children, families, and learning; and state services for the blind shall meet with deaf-blind citizens, parents of deaf-blind children, and the Minnesota commission serving deaf and hard-of-hearing individuals to determine which agency can most efficiently and effectively develop and administer a pilot program for consumer-directed services to provide needed services to deaf-blind adults, children, and families. (b) The planning for this pilot program must proceed using current appropriations. The agency that develops the pilot program described in paragraph (a) shall provide a report to the senate and house of representatives policy and fiscal committees having jurisdiction over human services issues by January 1, 2003, that addresses future funding for the program. The report shall include the program proposal, recommendations, and a fiscal note.

III. BACKGROUND

The recommendation to create a consumer directed model to deliver services to deafblind Minnesotans was made by the DeafBlind Task Force in their February 2002 Report to the Legislature. The DeafBlind Task Force Report is available by calling the DHHSD at 651-296-3980 (voice) or 651-297-1506 (TTY) or on the Internet at:
http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_005245.pdf

Funding for the program came from existing DHS state grant funding for deafblind services. These non-entitlement dollars are legislatively designated for services to increase the independence and community integration of deafblind individuals and families with deafblind children. Four state-funded deafblind programs sustained budget cuts of 8-10% to make funding available for the pilot program. Because SSB agreed to be the fiscal agent for the pilot program, DHS transferred grant funds from DHHSD to SSB through an interagency agreement. Costs of program development and administration were absorbed internally by SSB and DHHSD.

The pilot program began in the fall of 2002 and is in its third year of operation.

IV. PILOT PROGRAM DESIGN

The pilot program planning group, consisting of representatives for DHHSD, SSB, the MN Department of Education, deafblind adults and parents of deafblind children, designed the broad outline of the program, including the number and categories of participants, application process, program eligibility criteria, process for selecting participants, amount of funding available to each participant and what services would be allowed. For more information about the program and the planning group, see the January 1, 2003, report to the legislature. The report is available by calling the DHHSD or on the Internet at:
http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_005244.pdf

In the first year, SSB provided the program case managers to work with the four families and three deafblind adults who were chosen to participate in the pilot program. The case managers worked with the program participants to develop individual service plans which identified: (1) each participant's needs related to maintaining independence and integrating into the community, (2) measurable outcomes that each participant would achieve relative to enhanced independence and/or community integration, and (3) the goods and services needed to accomplish the outcomes. The plans allowed each participant to customize their own services while demonstrating how they would use and account for their program funds.

In the second year, the number of program participants was expanded to fourteen. SSB continued to provide case managers for the original seven participants but DHHSD assumed case management responsibility for the seven new participants.

In the third year, all case management was done by DHHSD. SSB remained the fiscal agent throughout all three years. Participants purchased "employer of record" services[1] from non-profit financial entities while SSB handled purchases of equipment and supplies and paid invoices for the direct services received by participants.

V. SUMMARY OF PILOT PROGRAM FINDINGS

A) Program Effectiveness and Customer Satisfaction

Consumer satisfaction was evaluated twice. The first evaluation was conducted in November of 2002 with a written survey. The second was conducted in February of 2004 via in-person or over-the-phone interviews.

Results from both surveys indicated that all participants believed that consumer-directed services are an effective means for helping them achieve increased independence and/or community integration. The adults in the program agreed or strongly agreed[2] that they feel more independent and more involved in their families and/or communities as a result of the services and goods they receive in the program. Families agreed or strongly agreed[3] that their child's communication skills and knowledge of his/her personal environment has improved and that their family's ability to communicate with the deafblind child has improved.

Consumers who had previously received services from traditional service providers reported they were able to get a lot more service hours[4] in the pilot program than from the traditional providers

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[1] Financial entities or employers of record were needed to hire and pay for service providers who were employees of the consumers in the program.

[2] On a scale of 1-5, the average was 4.5 with '5' indicating the person "strongly agrees" with the statement that they are more independent or more integrated into their family and community because of services/goods received in the program, '4' indicating the person "somewhat agrees", and '3' indicating they were "neutral."

[3] Average of 4.3 on a 1-5 scale with a question similar to the one asked of adults (see previous footnote).

[4] Average of 5 on a scale of 1-5 with '5' indicating "I receive a lot more service hours in the pilot program." and '4' indicating "I receive a little more service hours in the pilot program" and '1' indicating "I receive a lot less services in the pilot program."

and that being able to purchase adaptive equipment and other goods if needed was very important[5].

Anecdotally, one family said the benefit of the program was that they could offer their intervenor a higher hourly rate than the intervenor had previously earned from a traditional agency. Because they live in a rural area where there are no other trained intervenors available, the family reported that it was critical that they were able to pay the intervenor enough to keep the intervenor interested in working with their child.

Similarly, one of the deafblind adults in the program commented that she finds the pilot program more beneficial than traditional programs because she is able to create a job description for her service provider that meets her unique needs for a combination sighted guide, interpreter, and SSP.

Examples of services purchased via the consumer directed pilot program include:

- Support Service Provider (SSP) [6] services to assist with grocery shopping, clothes shopping, bill paying, transportation to medical and other appointments, correspondence, and reading of daily mail.

- Assistive equipment such as Braille kitchen measuring equipment, a large screen computer with adaptive software to access the internet and e-mail, and white canes.

- Training to learn how to use a tactile mode of sign language for communication.

- Equipment that enlarges print materials and adjusts print/background colors so mail and other correspondence can be read.

- Intervenor[7] services to expose deafblind child to new concepts and language and to teach the family effective ways for interacting with a deafblind child.

- Equipment needed to make “experience books” that were used to reinforce language and concept development following activities in the family and community.

- Adaptive computer controls and software programs so their young adult could learn to manipulate a computer.

Eighty percent of families and 60% of adults considered the most important aspect of the program to be the flexibility they had to purchase both services *and* goods.[8] While all participants

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[5] Average of 5 on a scale of 1-5 with ‘5’ indicating it was “very important” to be able to purchase goods and services in the program,‘4’ indicating it was “somewhat important” and ‘1’ indicating it was “not at all important.”
[6] An SSP provides a deafblind person with access to the visual and auditory environment.
[7] Intervenors work with deafblind children in their homes or in the community to expose them to new experiences and concepts and provide them with corresponding vocabulary and language.
[8] Participants were asked to rate four features of the program by assigning #1 to the most important, #2 to the second most important, etc. The four features were 1) flexibility to purchase a variety of goods and services, 2) control over how to spend

reported that the consumer-directed model requires more work in terms of planning and managing their own services as compared to traditional services, eighty-three percent agreed the flexibility and control they had within the program made the extra effort worthwhile.

Based on feedback from the participants, the program's operational procedures were changed each year to try and make the program easier to use. Overall, all participants were satisfied with the program but recommended there be less paperwork and a more active role on the part of the case managers in helping participants comply with the procedures and rules designed to assure program accountability.

Two program participants left the program after one year. One deafblind adult left after he received the specialized equipment he needed to enhance his ability to use his remaining vision. The second was a family who determined that the outcomes they wanted for their child all required intervenor services. They struggled finding qualified individuals in their rural community to provide intervenor services and ultimately decided it was easier to leave the challenge of getting qualified service providers to a community-based agency.

B) Cost Effectiveness

Some proponents of consumer directed services expected the pilot program to be a more cost-effective use of state grant dollars than the traditional means of providing SSP and intervenor services through community based agencies[9]. Tables 1 and 2 on the following page highlight some of the costs of the two models for providing services.

An overall dollar-for-dollar comparison of the two service delivery models is difficult to make because the hourly rate of the pilot program fails to account for certain "hidden" costs. The pilot program did use less state *grant* money to deliver an hour of direct SSP/intervenor service. However, while the pilot program was more cost effective strictly in terms of grant dollars used to purchase comparable services, it is not possible to conclude that the total program is more cost effective than traditional programs.

Costs that are not factored into the pilot program direct service rate but which traditional programs would typically factor into their direct service hourly rate include:

1) case management services from DHHSD and financial services from SSB which are estimated to be 24% of the total pilot program cost[10],

2) administrative overhead for DHHSD and SSB estimated to be 10% of total pilot program cost[11],

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their budget allocation, 3) control over who they hired as their service providers, 4) control over what type of services they needed.

[9] Historically, DHS has purchased traditional SSP and intervenor services through the Request For Proposal process, contracting with community-based non-profit agencies to deliver specific services.

[10] SSB and DHHS absorbed approximately $26,000 in staff time for case management, program coordination and financial services in FY04. Percentage calculated on estimated program cost of $108,800 ($71,400 grants, $26,000 personnel, $11,400 administrative).

3) case management and administrative costs would need to be split between the direct SSP/intervenor service hourly rate and into the purchase of goods by consumers in the program but a breakdown of staff time spent assisting with direct services versus the purchasing of goods is not available,

4) responsibilities for recruiting and supervising service providers, coordinating services, monitoring timesheets, etc, all of which were done by the consumers in the program,

5) mileage reimbursement for SSPs or intervenors and training of service providers which consumers pay for separately out of their grant dollars,

Despite the difficulty comparing the costs of the two program models, if the intangible value of the flexibility that the pilot program offers to participants is factored into the equation, it's clear that the program should continue. For example, a consumer who lives in a small town in Greater Minnesota might need amplification devices for communication, adaptive equipment to read print materials, assistance with activities of daily living such as grocery shopping, and transportation because he cannot drive. In the pilot program, this individual can plan his/her budget to purchase a personal "pocket talker" (portable amplification system), a Zoomtext program for computers that allows him to adjust the font and colors of his screen, SSP services to assist with grocery shopping and other errands, and transportation services from a neighbor because no bus service is available in his/her small town. Most of these services would not be available from a traditional service provider/agency.

Table (1) COST OF SSP/INTERVENOR SERVICES PROGRAMS PROVIDED BY "TRADITIONAL" SERVICE PROVIDERS

Vendor	Direct service cost	"Direct service hour" includes:	Additional cost	Total cost
Traditional services – Twin Cities	$38.25 per hour	SSP service, payroll taxes, supervision /training of SSPs, service needs assessment, coord. of services, travel costs	· 18% agency overhead/ administrative costs above per-hour service cost	$46.23 per hour
Traditional services – Greater MN	$53 per hour	SSP service, payroll taxes, supervision /training of SSPs, service needs assessment, coord. of services, travel costs, community outreach	· None; includes all program and agency administrative costs	$53 per hour

[11] Estimated cost of $11,400 for state personnel share of office rent, furnishings, telephones, computer, office supplies. Estimated administrative expenses were calculated for the equivalent of a .5 FTE.

Table (2) COST OF SSP/INTERVENOR SERVICES PROVIDED IN PILOT PROGRAM

Vendor	Direct service cost	"Direct service hour" includes:	Additional cost	Total cost
Pilot Program	$15 - $25 per hour	SSP or intervenor service	· Payroll costs = 16-25% of hourly rate	$17.40 - $31.25 per hour*

*Note the aforementioned costs that traditional programs include in their direct service hourly rate but which are not included in the pilot program direct service rate.

It may appear that a cost savings for SSP and intervenor services results in an overall costs savings to state grant dollars. However, this is not the case. While consumers may have been able to get *SSP and intervenor services* at a lesser hourly rate, they were then able to apply any "savings" (compared to if they had received SSP/intervenor services from a traditional provider) to the purchase of goods or the purchase of other needed services that are not available in traditional programs. This is precisely the reason consumer direction is appealing because consumers with "non-traditional" needs receive the support they need at no additional cost to the state.

C) Program Structure

<u>Case Management</u>

Initially, we expected that participants in the program would need limited assistance from case managers to develop their service plans and monitor budget spending. However in the first year of the program, staff and program participants both reported that the participants needed more assistance than expected. Some of the reasons cited were:

- Developing individual goals and outcomes was new for consumers. They needed considerable help determining whether what they wanted related to increased independence and/or community integration, and if so, how to state it in terms of measurable outcomes.
- It was difficult to determine the number of hours of service needed to achieve various outcomes so budgeting was imprecise and periodic adjustments were desirable.
- In some areas of the state, it was difficult to find service providers. As a result, spending was often delayed and budgets had to be re-negotiated. In addition, consumers needed help finding qualified service providers.
- SSB's purchasing procedures were foreign to consumers and difficult for them to understand and follow.
- Some of the concepts and procedures of the program were difficult to comprehend by consumers whose first language is not English. As a result, more face-to-face meetings were needed.
- Parents of deafblind children are typically overwhelmed with the responsibilities of raising a disabled child and need ongoing support and reminders to complete program reporting requirements.

- Adults who are deafblind require extra time to navigate and read print materials and to correspond whether by e-mail or telephone/TTY.

In the second year, the number of program participants doubled from seven to 14. Case management duties for the original seven participants continued to be provided by SSB. DHHSD assumed responsibility for case management services for the seven new participants.

Also in the second year, case managers were asked to offer increased assistance to consumers. This proved challenging to the staff from SSB for several reasons. First, the SSB program case managers had been selected based on the notion that consumers would independently manage their program responsibilities and case managers would mostly handle the processing of invoices from the consumer's budget. The SSB case managers had extensive experience in SSB's purchasing system but did not have the skills needed to provide the other types of assistance consumers needed. Second, the SSB staff were housed in the Twin Cities area and the additional travel needed to offer more intensive, in-person help was not feasible considering the pilot program duties were added to their already full-time jobs. Third, some of the program participants use American Sign Language (ASL) as their first language and the SSB staff was not fluent in ASL so the additional cost to hire interpreters was more than originally expected.

In the current third year, all case management is being provided by DHHSD because it has staff who are fluent in ASL, located throughout the state, and experienced providing services similar to those needed for the program.

<u>Fiscal Agency</u>
State Services for the Blind has been the fiscal agent for all three years of the program. While SSB has gone 'above and beyond' in order to accommodate the pilot program, the program's needs and the purchasing procedures within SSB are not a good match on a long-term basis.

The program participants' needs often change unexpectedly during the year due to health problems, changes in their hearing/vision, difficulties retaining and replacing service providers, unforeseen opportunities for community and/or family involvement, etc. SSB's accounting system is not designed for frequent changes to a consumer's budget. In SSB's regular programs, a typical consumer develops a plan with his or her counselor and the plan remains relatively stable but is subject to review and revision as needed and must be reviewed fully by the consumer and the counselor at least annually. However, for the pilot program to be successful, consumers need to be able to adjust their budgets and service plans at any time during the year to accommodate unexpected life circumstances.

VI. PROPOSAL FOR PROGRAM CONTINUATION

Based on both consumer feedback and grant dollar cost efficiencies, DHHSD intends to continue offering the consumer-directed option to the fourteen (14) current program participants. Since the DHHSD does not have enough staff or state grant funds to accommodate a larger program, if the Legislature wants to expand the program to additional deafblind individuals, an additional

appropriation will be necessary. The fiscal note in Attachment A includes associated costs for expanding the program to serve an additional 16, 40 or 56 individuals.

Program changes in state fiscal year 2006 will include:

- Consumers will have to purchase fiscal management services from a community based agency with costs coming out of each participant's grant allocation.

- Updated program materials for consumers and case managers will be developed, including more information about allowable goods and services.

- Guidelines for case managers for investigating other financial support options for consumers that could replace program funding, including Medical Assistance (MA), will be developed and implemented. Case managers will work with consumers to assure that consumers are appropriately screened for MA eligibility and waivered services. The state's grant money will only be used for services that are necessary to promote independence and community integration but are not covered by MA or for those consumers who are not MA-eligible.

A) Program Expansion Options

Attachment A is a fiscal note for the continuation of the program and possible expansion. It has four options. The first option is the only option that does not require new funding. The DHHSD will proceed with option #1 unless additional funding is appropriated by the Legislature for one of the other options.

The four options are:

1) Continue the program as is with **14 participants**.

2) Add 16 more consumers to the program for a total of **30 participants**. The additional 16 people would be current recipients of traditional services who, from the response to the solicitation for program participants, expressed an interest in the consumer directed option.

3) Over three years, add 40 new individuals to the program who have not received grant-funded services in the past for a total of **56 participants**.

4) Offer both options #2 and #3. This would expand the program by 56 individuals for a total of **70 participants**.

Attachment A – Fiscal Note

DeafBlind Consumer Directed Services Program

Option 1 -	Continue program as is				SFY 2006	SFY 2007	SFY 2008
		14 participants		Existing grant $	71,400	71,400	71,400
	Annual cost per person	$5,100					
				Net Cost[1]	**$ -**	**$ -**	**$ -**

Option 2 -	Expand program – transfer 16 existing recipients plus 14 current participants				SFY 2006	SFY 2007	SFY 2008
		30 total participants		Existing grant $	153,000	153,000	153,000
	Annual Cost per Person	$5,100					
	Current Provider Viability and Sustainability[2]	50%	81,600		40,800	40,800	40,800
Coordinator[3]	FTE	1.0	70,000 -40% FFP		42,000	42,000	42,000
				Net Cost	**$82,800**	**$82,800**	**$82,800**

Option 3 -	Expand Program to **56 participants** over 3 years				SFY 2006	SFY 2007	SFY 2008
		# of Additional Persons[4]			20	30	40
				New grant $	102,000	153,000	204,000
	Annual Cost per Person	$5,100					
Coordinator	FTE	1.0	70,000 -40% FFP		42,000	42,000	42,000
Casemgt[5]	FTE	1.0 in year 2 2.0 in year 3	70,000/FTE -40% FFP		-	42,000	84,000
				Net Cost	**$144,000**	**$237,000**	**$330,000**

Options 2&3	Expand Program - transfer 16 existing and add 40 new recipients over 3 yrs = **70 total participants**				SFY 2006	SFY 2007	SFY 2008
Program Costs		Transfer 16 existing recipients		Existing grant $	153,000	153,000	153,000
		40 additional persons over 3 yrs		New grant $	102,000	153,000	204,000
Provider Sustainability					40,800	40,800	40,800
Coordinator	FTE	1.0	70,000 -40% FFP		42,000	42,000	42,000
Casemgt	FTE	1.0 in year 1 2.0 in year 2 3.0 in year 3	70,000/FTE -40% FFP		42,000	84,000	126,000
				Net Cost	**$226,800**	**$319,800**	**$412,800**

[1] Net Cost = Additional appropriations accounting what agency can absorb.

[2] Provider Sustainability = Funding needed to sustain existing service providers when current recipients transfer to consumer directed program.

[3]Coordinator oversees program, revises program materials, solicits new program participants, advises case managers, processes payments to financial entities. Coordination services were able to be absorbed by the DHS when the number of participants was small and the pilot program model was being developed and tested.

[4] According to the February 2002 DeafBlind Task Force Report, current state appropriations only serve approximately 10% of the estimated deafblind population in Minnesota. Additional funding allows more people to be served.

[5] Case managers conduct day-to-day operation of the program and work directly with consumers.

Minnesota Department of **Human Services**
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