Report to the Senate and House Policy and Fiscal Committees having jurisdiction over human service issues

January 1, 2003

Pilot Program for DeafBlind Services

Prepared by the Minnesota Department of Human Services Deaf and Hard of Hearing Services Division

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Cost of preparing this Report (as mandated by the Laws of 1994): This report cost \$1,300 in staff time to prepare.

I. EXECUTIVE SUMMARY

This report summarizes the preliminary results of a pilot program designed to provide services to individuals who are deafblind using a consumer-directed services model.

Using existing grant dollars, the Department of Human Services Deaf and Hard of Hearing Services Division and the Department of Economic Security State Services for the Blind collaborated to develop and implement the pilot program. The adults who are deafblind and the families with children who are deafblind that participated in the pilot program report that they find the initial program to be effective at meeting their needs. They would like the program to continue.

The Department of Human Services recommends the pilot program be continued and expanded so that a thorough assessment can be made of the effectiveness of a consumer-directed services model for delivering services to people who are deafblind. No additional state dollars are required to do this.

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 consumerdirected 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 Task Force was established by legislation passed in the 2001 First Special Session and the recommendation was made in response to one of the Task Force's primary charges -- to study whether state appropriations for services to people who are deafblind were being used in the most effective and efficient manner. The DeafBlind Task Force Report is available at http://www.dhs.state.mn.us/ECS/dhhs/PDF/DBtfReport.pdf.

The pilot program was established using existing state grant dollars that are administered by the Department of Human Services (DHS). These non-entitlement grant dollars are designated for services to increase the independence and community integration of deafblind individuals and families with deafblind children. The funding is not sufficient to address all of an individual's or family's needs. However with a consumer-directed approach, people are able to identify their

greatest needs, establish desired outcomes and use grant dollars to purchase the goods and services that will assist them in achieving those desired outcomes.

In May, 2002, the Department of Human Services Deaf and Hard of Hearing Services Division assembled a planning group to begin development of the pilot program. The group completed its work in July. See section VIII of this report for a list of planning group members.

IV. DETERMINATION OF AGENCY TO DEVELOP AND ADMINISTER PILOT PROGRAM

The pilot program planning group determined that the pilot program would be most effectively and efficiently conducted through a joint partnership between the Department of Human Services Deaf and Hard of Hearing Services Division (DHHSD) and State Services for the Blind (SSB). The Department of Human Services had experience designing and developing consumer directed services and administering the existing state grant funding for deafblind services. State Services for the Blind had experience developing individual plans with consumers and had the mechanism in place through which goods and services could be purchased for clients. Existing staff in both agencies would be given additional duties to develop and implement the program.

The planning group agreed that the DHHSD would design and develop the pilot program and SSB would conduct the day-to-day operation.

V. PILOT PROGRAM DESIGN

The pilot program planning group 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.

Funding for the services and goods for participants came from existing DHS state grant funding for deafblind services. Four state-funded deafblind programs sustained budget cuts of 8-10% to make funding available for the pilot program. Grant funding was transferred from DHHSD to SSB through an interagency agreement. Costs of program development and administration were absorbed internally by SSB and DHHSD.

DHHSD developed all application and program materials, conducted the application process, trained SSB staff and program participants on how the program would work, provided technical assistance and granted final approval of participants' plans for services. SSB staff met with individual participants to oversee the development of a service and budget agreement outlining how the participant would use the funding allocated to them. They also processed the purchasing of all goods and services and provided on-going support and assistance to participants.

Four families with deafblind children and three adults who are deafblind were chosen to participate in the pilot program. The program was designed to be small for two reasons:

(1) A smaller number of participants would allow the program to be implemented more quickly, allowing for preliminary findings to be included in this report, and

(2) The pilot program was required to use existing funding and if the program were too large, the financial impact on current grantees whose funding needed to be reduced to pay for the pilot program could have been devastating.

DHHSD sent program application information to all current recipients of state-funded deafblind services and to over 50 other individuals, agencies and organizations. Applications were first reviewed to determine eligibility and then program participants were randomly selected in each of these categories:

Families with a deafblind child	Adults who are deafblind
Northern Minnesota (1 family)	Northern Minnesota (1 adult)
Southern Minnesota (1 family)	Southern Minnesota (1 adult)
Twin Cities area (2 families)	Twin Cities area (1 adult)

Participants began planning their service and budget agreements in August and September of 2002. Before receiving any services, each program participant worked with a case manager from SSB to establish a service and budget plan. The plan identified: (1) the participant's needs related to maintaining independence and integrating into the community, (2) specific measurable outcomes the participant wanted to achieve to meet his or her needs, and (3) the goods and services needed to accomplish the outcomes. With this design, each participant was able to customize their own services while demonstrating accountability for how they would use their funding.

VI. SUMMARY OF PILOT PROGRAM FINDINGS

A) Program Effectiveness and Customer Satisfaction

Six of the seven pilot program participants provided feedback on the pilot program. (Due to unexpected health problems, the seventh participant has postponed the start of services.)

In the first four months of the program, the participants reported that consumer-directed services were an effective means for achieving the outcomes they wanted. Participants also reported that they are making progress toward achieving their desired outcomes.

While all participants reported that consumer-directed services require more work on their part in terms of planning and managing their own services, they all agreed it was worth the extra effort for the flexibility they had in designing services and purchasing equipment to meet their individual needs. All are interested in continuing with the program.

B) Cost Effectiveness and Efficiency

An accurate assessment of the cost-effectiveness of the program is not feasible at this time due to the short duration of the program to date. At a minimum, cost data through June 30, 2003, is

needed in order to compare the consumer-directed services pilot program with the traditional delivery of services provided by community non-profit agencies.

VII. PROGRAM PROPOSAL, RECOMMENDATIONS AND FUTURE FUNDING

A) Proposal and Recommendations

We recommend the continuation and expansion of the pilot program. Specifically:

- (1) Continue the pilot program with the current participants for SFY 04 and 05.
 - Provide increased assistance to participants in developing, monitoring and revising their service plans and budgets by developing additional materials and utilizing DHHSD regional staff located throughout Minnesota to work with program participants and their SSB case managers.
- (2) Expand the pilot program to 15 total participants (8 adults and 7 families), using current grant dollars.
 - Simplify program materials and develop a step-by-step guide for participants.
- (3) Study possible program modifications to ensure state grant funding reaches the most needy.
 - Develop eligibility criteria related to severity of disability, income and participants' other available means of support.
 - Develop a more specific definition of allowable goods and services.
 - Develop cost effective alternatives of providing fiscal/employer agents.

B) Future Funding

SFY 2004 - 2005 Biennium

Continuing the pilot program

Assuming the continuation of current agency funding levels, no new funding is required to continue the pilot program with 7 participants. Both SSB and DHHSD are willing to dedicate the resources needed to maintain the program. The grant funding used for the pilot program this year is available to be renewed in each of the next two years.

Expanding the program

Expansion of the program to 15 participants assumes both that current staffing levels at DHHSD and SSB would be maintained throughout the biennium and that the current level of state grant funding for deafblind services is not decreased.

Long term

If program participants continue to tell us that the program is successful and if the program is determined to be cost-effective, the portion of state grant funding allocated to consumer directed

services should be increased over time. However, not all adults who are deafblind and not all families of children who are deafblind are expected to be interested in consumer directed services. Therefore funding for services delivered through community agencies will also need to continue.

During the extended pilot program, DHS will determine how much of the deafblind state grant money is needed to support those consumers interested in self-directed services and how much is needed to adequately support specialized community agency programs. DHS will also identify any future funding needs when the pilot program is completed in SFY 05.

C) Follow-Up Report

The Department of Human Services will present a follow-up report to the Legislature with complete findings on the pilot program by January 15, 2004.

VIII. ADDITIONAL INFORMATION

A) Pilot Program Planning Group Members

Lynette Boyer, Minnesota DeafBlind Association, deafblind adult Mary Hartnett, Minnesota Commission Serving Deaf and Hard of Hearing People Eric Kloos, Department of Children, Families and Learning Linda Lingen, State Services for the Blind Liz McDevitt, parent of deafblind child Curt Micka, Department of Human Services Deaf and Hard of Hearing Services Division Steve Oglesbee, Minnesota DeafBlind Association, deafblind adult Jan Radatz, Department of Human Services Deaf and Hard of Hearing Services Division Susan Shogren Smith, parent of deafblind children

B) Program Materials

A sample of four program materials is attached: (1) Program Announcement and Opportunity to Apply, (2) Eligibility Criteria, (3) Selection Process, and (4) Allowable Services.



DeafBlind Consumer-Directed Pilot Grant Program Program Announcement & Opportunity to Apply

The MN Department of Human Services Deaf & Hard of Hearing Services Division is pleased to announce a new one-year consumer-directed pilot grant program for DeafBlind children and adults in Minnesota.

Deafblind adults and families with deafblind children are invited and encouraged to apply. The application deadline is July 24, 2002. We expect the pilot program will begin by the end of August.

What is a "consumer directed" program?

It's a program that gives you more flexibility and control over the services you receive. Within limits, you pick the services that you want and you decide the person(s) who will provide you with those services.

What is a pilot program?

A "pilot program" is a way to try out a new idea for a program before the program is set up permanently.

Who can be in this pilot program?

- Families with deafblind children or youth
- Deafblind adults
- You can live in either Greater Minnesota or in the Twin Cities area
- Only 4 children and 3 adults will be picked for the pilot program.

What services can I get?

- Transportation services
- Family communication instruction
- Interpreter/SSP services
- Intervenor services
- SSP services
- Training for SSPs and/or intervenors
- Assistance to develop your service plan for the pilot program
- Other services intended to result in increased independence, communication development or community integration/inclusion

Are there any deafblind children or adults who can't be in the pilot program?

• People who presently receive the same kind of services offered in the pilot program from a Medical Assistance waiver program (e.g. CADI, MR/RC, etc.) are NOT eligible

for this pilot program. (MA waiver programs are different from MA health insurance.)

• People who presently receive these types of services from State Services for the Blind (SSB), DeafBlind Services Minnesota (DBSM), a County or the Duluth Lighthouse for the Blind are NOT eligible for this pilot program unless they agree to suspend those services while they participate in the pilot program.

How do I apply?

• Complete the attached Application Form and mail it or fax it to Jan Radatz, along with proof of your vision and hearing loss (see Application Form for more information).

What is the deadline for applying?

- Applications must be received by July 24, 2002.
- We will let you know whether you are selected for the pilot program before August 15.

If I'm accepted, how will I get the services?

- Deafblind adults selected for the program will be given \$5,100 per year to spend on services they believe will best help them attain greater independence.
- Deafblind children and their families selected for the program will be given \$5,100 per year to spend on services they believe will best help them improve communication development and/or community integration/inclusion for the deafblind child in their family.
- Each participant selected will be required to work with an SSB staff person as their case manager. Together with their case manager, participants will develop a plan for services, a budget for spending the \$5,100, a process for selecting qualified service providers, a process for paying the service providers, and a process for measuring satisfaction with the pilot program and the services received.
- Program participants will be able to select their own service providers and decide who is qualified to provide them the services they need.

Questions about the pilot program, the application form and/or the process for selecting program participants can be directed to Jan Radatz at <u>jan.radatz@state.mn.us</u>, 651-297-7154 voice/tty or Curt Micka at <u>curt.micka@state.mn.us</u>, 651-297-4526 voice/tty.

This information is available in other forms to people with disabilities by contacting Terry Schwankl at 651-296-3980 voice or 651-297-1506 tty.



DeafBlind Consumer Directed Grant Pilot Project Eligibility Criteria for Participants July 2002

Adults

- 1) Must be deafblind and provide documentation of a medically verifiable vision and hearing impairment that together interferes with acquiring information or interacting in the environment.
- 2) Must submit completed application form.
- 3) Must be 18 years of age or older. But if the person currently receives special education services from a public school via an Individualized Educational Plan (IEP), he/she is not eligible for the adult program. Instead, see the program for children/families.
- 4) Must be willing to work with SSB counselor as case manager.
- 5) The person does not receive services paid for by a medical assistance (MA) consumer directed waiver that are similar to those allowed in the pilot program.
- 6) Priority will be given to persons who are able to direct their own services, with limited assistance, including the ability to identify individuals or resources from whom services may be purchased.
- 7) Priority will also be given to persons who do not receive other state or county funded services that are similar to those offered in the pilot program while participating in the pilot program. However people may apply for the pilot program and suspend the other similar state or county funded services if they are selected for the pilot program.

Children

- 1) Must be deafblind and provide documentation of a medically verifiable vision and hearing impairment that together interferes with acquiring information or interacting in the environment.
- 2) Must live with parents or foster parents.
- 3) Family must submit completed application form.
- 4) The child must be 17 years of age or younger. However if the child is older than 17, he/she is still eligible if he/she currently receives special education services from a public school via an Individualized Educational Plan (IEP).
- 5) Must be willing to work with SSB counselor as case manager.
- 6) The child/family does not receive services paid for by a medical assistance (MA) consumer directed waiver that are similar to those allowed in the pilot program.
- 7) Priority will be given to families who are able to direct their own services, including the ability to identify individuals or resources from whom services may be purchased.
- 8) Priority will also be given to children and their families who do not receive other state or county funded services that are similar to those offered in the pilot while participating in pilot program. However families may apply for the pilot program and suspend the other similar state or county funded services if they are selected for the pilot program.



DeafBlind Consumer Directed Pilot Grant Program Selection Process July 2002

- DHHSD will publicize the pilot program and application process through email lists, postings on the DB listserve, and through contacts with professionals in the field (e.g. Dr. Davenport, Joe Cioffi, Dr. Laurie Johnson) and agency personnel, including staff with the MN DeafBlind Technical Assistance Project, DeafBlind Services Minnesota, Minnesota DeafBlind Association, State Services for the Blind, DHHSD Regional offices, the Lighthouse for the Blind, etc.
- 2) An application deadline will be established and included in all publicity about the program. Applications will be sent to Jan Radatz at DHHSD.
- 3) Applications will be screened by DHHSD staff and individuals not fitting the Eligibility Criteria for Participants will be removed from further consideration. A staff person from the MN DeafBlind Technical Assistance Project will help screen applications from families.
- 4) All eligible adult applicants will be divided into 3 categories those from the Metro area, those from Northern Minnesota and those from Southern Minnesota. One applicant from each geographic area will then be chosen at random for participation in the pilot program. In addition, every attempt will be made to select one person who has previously never received the types of services offered in the pilot and one person who has received such services through traditional DHS-funded programs.
- 5) All eligible children/family applicants will be divided into 3 categories those from the Metro area, those from Northern Minnesota and those from Southern Minnesota. Two applicants from the Metro area and one applicant from each of the other two geographic areas will then be chosen at random for participation in the pilot program. In addition, every attempt will be made to select one child/family who has previously never received pilot-type services and one child/family who has received such services through traditional DHS-funded programs.
- 6) If there are no qualified adult or children/family applicants from a particular geographic area, all remaining applicants will be combined and an additional person will be chosen at random.



DeafBlind Consumer Directed Services Pilot Project July 2002

(1) Allowable services

<u>Drivers/Transportation</u> – drivers and/or transportation/mileage costs to conduct personal business or for community involvement.

<u>Family communication instruction</u> – instruction in sign language or other forms of communication that is individualized to a family's needs and is based on the most effective communication method of the deafblind child or youth in the family.

Interpreter/SSP – one-to-one service that combines interpreting and SSP services.

<u>Intervener</u> – one-to-one service that assists a deafblind person with access to the world around them, increases the person's ability to interact in his or her environment, enhances language and communication development and/or promotes independence.

<u>Plan development services</u> – consultation services during the development of a program participant's annual service plan.

<u>Support Service Provider (SSP)</u> – one-to-one service that allows deafblind people access to the world around them by conveying environmental information, providing sighted guide assistance, providing visual information to complete household tasks, reading written materials, etc.

<u>Support Service Provider/intervener training</u> – basic training to potential SSPs or interveners about deafblindness and providing support services.

<u>Other goods and services if pre-approved</u> – For adults, must be intended to result in enhanced independence. For children, must be intended to result in enhanced communication development and/or community integration/inclusion. Requires pre-approval from SSB counselor and DHS contact person.

(2) Service provider restrictions

- Spouses, parents of minors, siblings under age 18 and professional guardians/custodians cannot be paid as service providers.
- Service providers must be at least 18 years of age.
- Service providers must have a job description and work schedule.
- The consumer determines the necessary qualifications of service providers.
- Service providers must satisfy any qualifications established by the participant's Employer of Record.