

REPORT TO THE MINNESOTA STATE LEGISLATURE

DeafBlind Services Study: Effective and Efficient Use of State Appropriations and Providing Seamless Service Delivery

February 1, 2002



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

On the cover are photographs of Minnesotans who are deafblind.

The child in the field of daisies is Emily Wojcik. Emily is six years old and lives in Woodbury with her family. She was born with CHARGE syndrome which caused her vision and hearing loss as well as life threatening complications. Emily has been hospitalized eighteen times in her short life span and is now much healthier. She attends school at Valley Crossing Community School with her interpreter/intervener.

In the middle of the page is Wendy Williams who is pictured walking with her guide dog. Wendy lives in Faribault and is a psychologist at the Minnesota State Academy for the Blind. Over the years she has been an active volunteer and member of the Minnesota DeafBlind Association, the only consumer organization for deafblind people in Minnesota.

George Failes, on the right towards the top, is a St. Paul native who has had a hearing loss since he was a young boy. As a young adult, George also began losing his vision. His hearing and vision have both deteriorated over time. George was recently honored as one of the recipients of the McKnight Foundation's 2001 Virginia McKnight Binger Awards For Exceptional Service to Others.

The young woman in the lower left is Claire O'Kane. Claire is 18 years old, lives in Arden Hills and attends

school in White Bear Lake. She was brain injured as an infant from two brain tumor surgeries. She is legally blind and has total hearing loss in her left ear. Claire has other developmental delays and is starting to learn and use tactile sign language.

In the picture at the bottom right, Adrienne Haugen (on the left) sits with her guide dog, Abbey, and two friends. All three of the people pictured have Usher Syndrome Type II which is an inherited condition that causes severe hearing loss and a progressive vision loss. Adrienne currently lives in Olivia, Minnesota.

Wendy, George, Adrienne, Emily's parents, Ken and Karen, and Claire's mother, Terry, were all members of the DeafBlind Task Force that developed this Report.

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DEAFBLIND TASK FORCE REPORT

DeafBlind Services Study: Effective and Efficient Use of State Appropriations and Providing Seamless Service Delivery

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Task Force Mission

Chapter 9
Senate File No. 4
2001 First Special Session
Article 13

Section 23. **[DEAF/BLIND SERVICES STUDY.]** The department of human services shall convene and lead an interagency workgroup for the purpose of studying and developing recommendations regarding:

- (1) how the state can most effectively and efficiently use state appropriations and other resources to provide needed services to deaf/blind children, adults, and their families;
- (2) how state agencies can work together to enhance and ensure that a seamless service delivery system exists across agency lines for persons who are deaf/blind; and
- (3) how other existing barriers to the effective and efficient delivery of service for deaf/blind Minnesotans can be removed.

The workgroup shall include representatives from the departments of human services, economic security, children, families, and learning; the state academy for the deaf; the state academy for the blind; the Minnesota commission serving deaf and hard-of-hearing; a consumer who is deaf/blind; a parent of a deaf/blind child from the metro area and a parent of a deaf/blind

child from greater Minnesota; and anyone else that the workgroup finds necessary to complete its work.

The departments of human services, economic security, and children, families, and learning shall share equally in the costs of the workgroup.

The workgroup shall report its findings and recommendations to the legislature by February 1, 2002.

Executive Summary

This report is a summary of the work of a deafblind task force comprised of deafblind individuals, parents of deafblind children, state agency representatives and other knowledgeable professionals. The report addresses many critical issues regarding the service delivery system for deafblind Minnesotans.

The members of the task force thank the Legislature for bringing us together and providing the opportunity to focus on our common interests. We believe that we are now all “on the same page” and that by working together, coupled with some help from the Legislature, much can be done to improve the service delivery system for deafblind Minnesotans and their families. And although faced with upcoming budget cuts and restrictions, the three state agency members of the Task Force pledge to do whatever they can to implement the recommendations for state agencies contained within this Report.

The primary concern that previously divided us and created confusion in the eyes of legislators was whether current state appropriations for deafblind services were being used effectively and efficiently.

We now agree on steps that can be taken to address this issue. Our recommendations focus on changing current appropriation language so that current state funds can be used in a more flexible, efficient and

effective manner, including the development of a pilot consumer directed grant program. These changes have no cost implications for the state and can be found on page 16 under “Task Force Priority Recommendations for the 2002 Legislative Session.” To our knowledge, there is unanimous support for these recommendations among task force members and others who attended our meetings.

For the 2002 Legislative session, we also recommend that the Legislature add sign language interpreter services to the Medical Assistance (MA) and MA waiver benefit sets so that deafblind Minnesotans can more fully participate in their care and services. Last year when the Legislature added payment for foreign language interpreters to the MA benefit set, sign language interpreters were overlooked.

Finally, we ask that the 2002 Legislature add support service providers (SSPs) and interveners to the MA and MA waiver benefit sets so that more deafblind individuals can get the services they really need to become more independent and self-sufficient.

In addition to recommendations for legislative action in 2002 and 2003, this report includes numerous recommendations for state agency action. If implemented, these recommendations will go a long way toward providing deafblind Minnesotans and their family members with a “seamless” and more effective and efficient service delivery system.

Introduction to Deafblindness

The term “deafblind” is probably most often associated with that most famous of deafblind individuals, Helen Keller. However, as much as she accomplished in bringing awareness of this dual sensory loss to the world, the truth is that Helen Keller only marginally represented the ordinary experience of those who are deafblind.

What does it mean to be deafblind? Does it automatically imply that everyone with this label is without any vision or hearing? No. In fact, the often-used descriptors of “*deafblind*” or “*hearing and vision impaired*” are quite vague. They offer little information as to the severity of the combined condition, or the resulting challenges that may disrupt one’s participation in the many activities of daily life.

Functionally, a person is deafblind if they have *any* combination of vision and hearing loss which interferes with the ability to access the environment or to acquire information. It can imply profound deafness and total blindness, though cases of this extreme nature are quite rare. More likely, “deafblind” individuals have some degree of residual vision and/or hearing. Some cases of deafblindness may also be associated with other physical or cognitive impairments.

The needs of the deafblind are unique. Without a “distant sense” to utilize, (i.e. vision or hearing), their

needs are vastly different from the needs of those who are either only deaf or only blind. It is commonly estimated that 80-90% of the information we acquire comes to us through hearing and vision. People who are blind rely upon their sense of hearing to access information, while people who are deaf rely upon their sense of sight. However, for those with combined deafness and blindness, the strategies necessary to compensate for this lack of access to information are neither obvious nor simple.

To gain just a glimpse of the tremendous daily challenges that come along with deafblindness, consider your ordinary morning routine. Imagine, without using vision or hearing, trying to prepare breakfast, shower and shave, choose your clothes, and cross a few streets to get to the local bus stop. Each of these tasks, done with ease using sight and hearing, require for a deafblind person a level of skillful planning and organization that would astound and overwhelm even the most resourceful among us.

What are the needs of this population?

The bottom line is that the communication, learning, and independent living needs of each person are unique. Some use fully tactile sign language. Others depend upon a limited but still visual mode of sign language. Still others use Braille output or amplified, slower, nearby voicing and other forms of communication. Many deafblind children, who have not

yet developed a formal language, communicate using a combination of touch cues, object cues, gestures and pictures.

A wide range of abilities with respect to learning and independence may be seen. Some deafblind young adults are veritable computer wizards, having taken full advantage of adaptive computer technology and training. Others have never even been given an opportunity to do so. Some deafblind individuals have developed advanced skills that allow them to travel safely and independently far beyond their local communities. Others have not yet developed the confidence to leave the security of their own homes. In many cases, they have not been given the opportunity to learn the skills.

Clearly, the range of intelligence and ability, motivation and courage is no different from that of those who are sighted and hearing. The opportunities, however, to pursue life goals and live independently and self-sufficiently are far more scarce.

The term deafblind refers to a population of great diversity, and it is this very diversity that makes it impossible to have a “one size fits all” model for services. Instead, services **MUST** be individualized based upon that deafblind person’s language, communication, coping, social and cognitive skills and limitations. This single fact is at the core of many of the following critical issues, needs and problems

confronting deafblind Minnesotans and their service delivery system.

A thorough understanding of the severity of combined hearing-vision loss and its enormous impact on the life of a deafblind person is key to providing effective supports and skills training. However, due to the fact that the institutions designated to provide these very supports often have difficulty finding and retaining people with expertise in deafblindness, this “thorough” understanding is often lacking. As a result, parents of deafblind children, and deafblind individuals themselves, typically face a lifetime of challenges from both the dual sensory loss *and* the institutions that serve them.

Critical Issues Confronting Deafblind Minnesotans and the Deafblind Service Delivery System

A. THE NEED FOR EARLY IDENTIFICATION OF DEAFBLINDNESS

Before even attempting to determine how to develop services that address a person's unique communication, language, coping, social and cognitive skills and limitations, it is necessary to IDENTIFY that a person is deafblind. And it is critical that a person's dual sensory loss be identified as close to the onset of that loss as possible. This is true whether the dual sensory loss is present at birth, occurs during childhood, adulthood or as part of the aging process.

Without proper and timely diagnosis, deafblind individuals often end up receiving services that may be appropriate for deaf, or blind or developmentally disabled persons but that do NOT adequately provide them with the specialized services, skills and knowledge that they need to move toward independence and self-sufficiency.

Unfortunately, this happens all too often.

Why?

- First, professionals are often unfamiliar with both the implications of and available services for deafblind

individuals. So instead of “going someplace” they do not understand or know, they use a primary disability label that they do understand and services they know, without realizing that that the label chosen will steer the client away from the exact services they need.

- Second, many medical professionals who conduct hearing or vision testing do not understand the impact of the dual loss on their own testing procedures. They may also assume that poor performance during the testing is due to intellectual or processing limitations on the part of their client, rather than to a lack of appropriate input or communication.
- Third, vision screenings do not test peripheral vision or nightblindness, so retinitis pigmentosa and other retinal conditions often go undetected.
- And fourth, health professionals rarely understand the importance of periodic testing for loss in the other sense when they are working with either a deaf or a blind individual.

In our Recommendations, we offer suggestions for what can be done to better identify the dual sensory loss of hearing and vision as close to the onset of the dual loss as possible.

B. THE NEED TO EMPOWER CONSUMERS AND THEIR FAMILY MEMBERS

Once a person is identified as being deafblind, it's a HUGE challenge for the individual and/or their family members to adjust to the new diagnosis and learn about the range of specialists and services that can help them identify and make informed decisions about the person's needs and services. This is true regardless of whether the deafblind individual is in need of educational, rehabilitation, medical, vocational, or human services.

When access to the information is available, most deafblind individuals and family members still lack the self-advocacy skills needed to work within a confusing service delivery system to get the services needed to enhance independence and self-sufficiency.

As a result, many deafblind individuals who are properly identified as such still do not get the services they need. Neither they nor their family members know what to ask for or how to “work the system” to get what is needed.

Why?

- First, most deafblind consumers encounter multiple obstacles in gaining access to information. Either information is not brailled, it is not available in large print, the interpreter working for the person is not adequately trained in the person's specific

communication style or the person providing the information does not allow the time necessary for a deafblind individual to access, understand and then respond to printed information. In addition, most deafblind people who could use computers, with appropriate adaptations, either lack the financial resources to buy a computer or the necessary adaptations or do not have access to the type of training needed to help them to effectively learn to use a computer.

- Second, parents are often overwhelmed by the process of attempting to identify available and appropriate resources and by decision-making pressures while also trying to cope with the stress of having to care for and raise a deafblind child.
- Third, “specialists” often have expertise related to only one aspect of the deafblind person’s needs without much insight as to how it interrelates or interacts with the person’s needs as a deafblind individual. As a result, parents and consumers often “straddle” traditional deaf or blind services -- usually with inadequate results. All too often, the opinions and recommendations of professionals experienced in only one of these sensory disabilities are ineffective for the deafblind consumer, parent, or family.

- Finally, generic self-advocacy workshops are seldom modified to allow for the special communication and learning needs of most deafblind individuals.

Again, in our Recommendations, we offer suggestions for what can be done to enhance the opportunity of deafblind individuals and family members to access the information and self-advocacy skills they need to move toward independence and self-sufficiency.

C. THE NEED FOR SUPPORT SERVICES AND INDEPENDENT LIVING SKILLS TRAINING TO MAXIMIZE PERSONAL SELF-SUFFICIENCY

No one among us lives without the need for some level of support, whether it be emotional, psychological, family, physical, financial or other.

Both deafblind children and adults need varying levels of life-long special support services to maximize their opportunity for self-sufficiency. This is true regardless of the quality of the person's educational experience.

The special supports needed by deafblind people include interveners, interpreters and support service providers (SSPs). While different from one another, each serve to facilitate access to learning, to communication, to community activities, etc. For more information about the specific supports provided by each, see Appendix B.

In addition, as many young deafblind students leave the familiar supports of school and family, they experience new challenges that require additional training to establish and maintain this level of newfound independence. Many also struggle during these years with progressive vision and hearing loss. During these years, training needs include but are not limited to training in orientation and mobility skills, daily living skills, and the use of adaptive equipment and technology, including computers.

Finally, in order to living independently and gain access to the services needed to enhance self-sufficiency, deafblind Minnesotans need access to transportation. This is especially true for deafblind persons in Greater Minnesota who usually have to travel considerable distances to find and receive the services and/or supports they need.

Without these support services, deafblind adults are unable to accomplish basic but essential independent living tasks such as reading letters, shopping for groceries, voting, or attending work or school. With adequate supports, most deafblind children and adults can fully participate in all aspects of daily life.

For most deafblind Minnesotans, access to these support services are woefully lacking.

Why?

- Existing state appropriations are not adequate to provide the level of support services needed to sustain daily independence. In addition, counties are not required to provide services to deafblind individuals and few (only three to our knowledge) do so voluntarily. Finally, Medical Assistance (MA) and MA waivers do not pay for interveners or SSP services and pay for interpreters in very limited situations.
- There are not enough appropriately trained SSPs, interveners, and interpreters and in Greater Minnesota the shortage is even more serious.
- Deafblind individuals and their families are uncertain as to who can or must provide such support services.
- Compensation of deafblind service providers is inadequate, contributing to a shortage of providers.
- The adult service delivery system provides support only in relation to vocational goals but not for individuals who are successfully employed but need ongoing support to maintain independence and employment.
- Unless transportation is for needed medical care, most deafblind persons are left to their own resources to find ways to travel to jobs, educational programs, grocery and other stores, community and social events and the like.

In our Recommendations, we offer suggestions for what can be done to better ensure that deafblind Minnesotans get the support services they need to live self-sufficient and independent lives.

D. THE NEED FOR HIGH QUALITY, SPECIALIZED SERVICES IN ALL OF MINNESOTA

It cannot be emphasized enough that each deafblind person has unique communication, language, social and cognitive skills and limitations. With this in mind, it is easy to understand why the education, mental health, case management, vocational rehabilitation, and social service professionals who provide these services to deafblind children and adults must have specialized skills, and why the service itself must be “tailor-made.”

Most often, the vast majority of professionals who work with deafblind people lack the specialized communication skills required to interact effectively with their deafblind customers. It is also not uncommon for these professionals to demonstrate a lack of understanding of the implications of this dual sensory loss, and an inability to modify the existing services to meet the special needs of this population.

People who are deafblind CAN achieve their greatest potential if their needs are addressed by a service delivery system that is designed with the whole person in mind. Presently, they most often receive a patchwork of deaf services and/or blind services, neither of which understand how to address the needs of the combined dual sensory loss.

Why?

In Education:

- The dual sensory loss of deafblindness often goes unidentified and the individualized modifications needed in a deafblind students' IEP are overlooked.
- When the dual sensory loss is identified, schools often do not have personnel with expertise in deafblindness so needed modifications are not provided.
- Because most school personnel do not understand deafblindness or the value of specialized service providers, they are often reluctant to employ interveners or other needed support staff.
- Teachers and interveners trained in deafblindness are in extremely short supply.
- Due to a lack of expertise, comprehensive communication assessments are not conducted, and therefore appropriate communication supports are not provided.

In Rehabilitation:

- Current case managers in State Services for the Blind, Rehabilitation Services and the Regional Deaf and Hard of Hearing Services offices may be qualified to serve people who are blind "only" or deaf "only," but they are not qualified to serve people with the combined vision and hearing loss.

- Many case managers do not have the communication skills necessary to work effectively with deafblind clients, nor do they have convenient access to qualified interpreter services.
- Current rehabilitation systems that rely on the successful closing of cases do not meet the needs of deafblind people who have medical conditions that result in progressive vision or hearing losses.
- County case managers are not required to be trained in understanding and assessing the needs of deafblind people.

In Mental Health:

Many people with deafblindness have a progressive condition that worsens during adolescence and young adulthood and again in middle age. The incidence of depression is high, and the need for effective mental health and social services is great. Many, however, report limited access to such services. Why?

- There are few social workers, psychologists and other mental health workers with expertise or experience in deafblindness. They also lack an understanding of the impact of dual sensory loss.
- Funds to pay for ongoing participation in these services is limited.
- There is a virtual lack of specialized mental health services in Greater Minnesota.

- Inadequate transportation services to participate in counseling appointments or support groups.

In All Areas:

- Interpreters, interveners, and support service providers trained to work with deafblind people are in short supply in the Metro area, and unavailable in most of Greater Minnesota.

E. THE NEED TO MAXIMIZE THE USE OF EXISTING STATE APPROPRIATIONS AND RESOURCES

We believe that much can be done to improve the effectiveness and efficiency of the use of current state appropriations for deafblind services. Although the reasons why past and current appropriations have not always resulted in the most cost-effective and efficient delivery of needed services are complex, one reason that we all agree upon is that the current legislative appropriation language is overly restrictive. For example, it limits how the dollars can be used by (a) naming specific funding recipients, (b) limiting the types of services that can be provided and (c) stating that the dollars must be given to agencies, therein precluding the use of these dollars for new and innovative programs such as consumer directed service grants.

The cumulative impact of these restrictions is that deafblind Minnesotans and their families have not

always received the type, amount or quality of services they need and deserve.

In addition, services received by deafblind consumers that are currently paid for Medical Assistance and/or Medical Assistance waivers are often less effective and efficient than they need be.

Why?

- Because the current MA and MA waiver benefit sets do not include payment for interpreter, SSP or intervener services. It does little good for a deafblind person to receive medical or other MA waiver-type services if they are unable to communicate effectively with the service provider. This is often the case. MA will only pay for interpreters if the service provider has 15 or fewer employees. Otherwise MA expects the service provider to pay for the needed interpreter. In most situations the service provider will either find a reason not to accept a deafblind individual as a client if they have to pay for interpreter services or they will “cut corners” and either hire an unqualified interpreter whom they can pay less or attempt to communicate through another, most-times ineffective communication mode.
- In addition, by not including SSP and intervener services in the benefit set, deafblind people are often left without the support needed to locate and go to the office of many MA-paid service providers.

- Finally, because most deafblind Minnesotans cannot get needed support services from their county of residence, they often cannot attain the level of independence and self-sufficiency of which they are capable. Currently, unless a deafblind person is eligible for Medical Assistance, they can expect no help from their county (with the exception of three known counties). This is because deafblind persons are not included as one of the populations that counties are mandated to serve in the Community Social Services Act. This is so even though deafblind people are arguably as much or more in “need” than are most of the nine “mandated” populations in the CSSA.

In our Recommendations, we offer specific suggestions for what can be done to make more effective and efficient use of these current state appropriations and resources for deafblind Minnesotans.

Our Vision for Deafblind Services in Minnesota

To guide its discussion of how the existing service delivery system can be improved, including its discussion of how existing state resources can most effectively and efficiently be used, the task force developed an overall vision statement for the service delivery system for deafblind persons in Minnesota. The Task Force envisions a service delivery system serving deafblind Minnesotans that provides children and adults who are deafblind with access to the communication, information and mobility they need to fully participate in all aspects of society. This can be accomplished by having a service delivery system that ensures:

Early Identification

- ★ Appropriate, accurate and timely identification of combined hearing and vision loss, regardless of the person's age.
- ★ Recognition that the dual diagnosis of combined hearing and vision loss is a unique disability that requires specialized follow-up and referral after the combined sensory loss is identified.

Empowerment and Equal Access

- ★ A consumer driven process that allows individuals and their families to make informed choices based on unbiased information about the full range of legal, medical, educational, rehabilitation and community resources available.

- ★ Promotes self-determination and bases all planning, decision making and evaluation on the unique needs of the individual.
- ★ Supports and encourages self-advocacy and advocacy.
- ★ Comparable services in rural and urban areas.
- ★ Protections for those persons who are the most vulnerable.

High Quality Services that Meet Consumer Needs

- ★ Individualized and specialized services are available for all children and adults, including those with developmental and physical disabilities.
- ★ The availability of well-trained and adequately compensated service providers.
- ★ Access to the supports for deafblind Minnesotans to:
 - communicate,
 - participate in their communities,
 - obtain and retain employment,
 - participate in family living,
 - participate in recreation and leisure,
 - have appropriate specialized services in early childhood, elementary, secondary, transition, post-secondary education and training.

Efficient, Affordable and Adequate Resources

- ★ Maximizes the use of existing resources.
- ★ Provides incentives for collaborations that result in new or improved training, service delivery and financing models.
- ★ Adequate and flexible financial resources are

available to provide necessary services.

Task Force Recommendations: Policy Directions

To respond to the immediate needs of deafblind individuals and their families, the Task Force concluded that initiatives are needed in five major policy directions, each of which addresses a theme from the vision statement. Considering how it might move forward on these policy directions during tough economic times, the Task Force has identified priority recommendations for the 2002 and 2003 legislative sessions, coupled with priority recommendations for state agency action. These priority recommendations follow while the complete list of our recommendations can be found in Appendix A.

POLICY DIRECTION #1

DEVELOP STRATEGIES TO ENSURE THAT DEAFBLIND PEOPLE ARE IDENTIFIED AS HAVING A DUAL SENSORY LOSS.

Repeatedly, consumers and professionals tell us that when deafblind individuals are “labeled” as being “deaf” or “blind” or “developmentally delayed” or anything else, they do not get the educational, vocational, or human services needed to help them move toward self-sufficiency and independence. Incentives must be put in place to increase the likelihood that the dual sensory loss is identified as the primary disability whenever a deafblind person applies for educational, employment, human service or mental health services.

POLICY DIRECTION #2

MAXIMIZE THE ABILITY OF DEAFBLIND MINNESOTANS TO BECOME MORE SELF-SUFFICIENT.

Most deafblind adults and children want and are able to become self-sufficient. As with any of us, self-sufficiency does not mean “without support.” It does mean employed and able to participate in family, social, vocational and community life the same as anyone else.

This is a distant reality for many deafblind Minnesotans. Unemployment is common, as is forced dependency on others who make decisions and “do” for them.

More must be done to increase employment opportunities for deafblind Minnesotans and to provide the support services (e.g. SSPs, interveners, interpreters, supported employment, and independent living skills training) needed to allow deafblind people to live self-sufficient lives.

Equally important, we need to recognize that self-sufficiency skills begin to develop in early childhood. Therefore it is crucial to ensure that deafblind children and their families have access to professionals trained to facilitate the development of age-appropriate independent living skills.

POLICY DIRECTION #3

ENHANCE THE ABILITY OF DEAFBLIND INDIVIDUALS AND FAMILY MEMBERS TO MAKE MORE INFORMED DECISIONS.

Any redesign of the deafblind service delivery system must put primary emphasis on empowering deafblind individuals and their family members to make informed decisions that best meet their own needs. Consumer control over decision-making must be a key feature of new service delivery approaches. Programs to teach self-advocacy skills to deafblind individuals and family members are needed as is access to objective information about services and service options.

POLICY DIRECTION #4

DEVELOP AND ALIGN SYSTEMS TO SUPPORT HIGH QUALITY SERVICES WITH GOOD OUTCOMES THAT ARE AVAILABLE IN MORE PARTS OF THE STATE.

This is a HUGE task. Better training is needed for direct service providers, such as (e.g. SSPs, interveners and interpreters) and for professionals who work with deafblind individuals (e.g. teachers, school therapists, social workers and other human service providers, doctors and other health care workers). More must be done to recruit and retain a stable work force of direct care providers. In part, this means finding ways to better compensate SSPs, interveners and interpreters to reflect the skill and knowledge level needed to work effectively with deafblind individuals. The service delivery system must develop incentives to encourage more competition among service providers. And state agencies must develop more measurable outcomes to

evaluate the effectiveness of services delivered with state dollars.

POLICY DIRECTION #5

MAXIMIZE THE USE OF EXISTING STATE APPROPRIATIONS AND RESOURCES BY AMENDING EXISTING REIMBURSEMENT SYSTEMS.

Much can be done to make more effective and efficient use of existing state appropriations. Existing appropriation language can be amended to promote more competition among service providers and greater flexibility in how the appropriations can be used. State agencies can be asked to collaborate on training and other projects. The Medical Assistance and MA waiver programs can be amended to allow for the payment of services needed by deafblind individuals. And the Community Social Services Act can be amended to acknowledge that deafblind people are as vulnerable as the other populations that counties are required to serve.

Task Force Priority Recommendations for the 2002 Legislative Session

1) Current Legislative Appropriation Language for Deafblind Services

Concerning the current legislative appropriation language granting money for deafblind services, we recommend that the Legislature:

- (a) remove all references to specific service providers in current state grant appropriation language for services to people who are deafblind,
- (b) remove all reference to specific services for deafblind individuals so that the appropriations can be used for any service that addresses needs related to the consumer's deafblindness,
- (c) include language so that the appropriations can be used either for grants to organizations or for consumer directed services.

We also recommend that the Legislature direct the Departments of Human Services, Children, Families & Learning and State Services for the Blind to meet with deafblind citizens, parents of deafblind children and the Minnesota Commission Serving Deaf and Hard of Hearing People and determine which agency can most efficiently and effectively develop and administer a pilot consumer directed service program to deliver needed services to deafblind adults, children and their families. The Department of Human Services should also be

required to transfer appropriations for such a pilot program to the state agency determined best able to implement the pilot program.

Finally, we recommend that the Legislature direct these state agencies to implement such a pilot consumer directed service program using existing state appropriations as soon as possible after July 1, 2002 but no later than September 1, 2002.

Note: Current legislative appropriation language for deafblind services can be found at:

- Laws of Minnesota for 1985, Chapter 9, Article 1, First Special Session
- Laws of Minnesota for 1991, Chapter 292, Article 1
- Laws of Minnesota for 1997, Chapter 203
- Laws of 1998, Chapter 407, Article 1
- Laws of Minnesota for 1999, Chapter 245, Article 1, Section 2
- Laws of Minnesota for 2000, Chapter 245, Article 9, Section 29

2) Medical Assistance (MA) and MA waivers

We recommend that in 2002 the Legislature amend the Medical Assistance (MA) and all MA waiver benefit sets to allow payment for:

- a) sign language interpreters
- b) interveners and

c) support service persons (SSPs).

Task Force Priority Recommendations for the 2003 Legislative Session

- 1) We recommend that in 2003 the Legislature amend the Community Social Services Act (CSSA) to include deafblind persons as a population that counties must serve within their budget limitations.
- 2) We recommend that in 2003 the Legislature amend the Medical Assistance (MA) and all MA waiver benefit sets to allow payment for:
 - a) orientation and mobility (O & M) services and
 - b) rehabilitation teaching services.
- 3) We recommend that in 2003, the Legislature appropriate additional grant funding for support services for deafblind children and adults if the MA/MA Waiver and CSSA recommendations contained herein are not implemented.
- 4) We recommend that in 2003, the Legislature appropriate additional staff and training funds for the Deafblind Technical Assistance Project of the Department of Children, Families & Learning so that they can address more of the educational issues identified in this Report, including the need for more training for interveners.

- 5) We recommend that in 2003, the Legislature appropriate funds to allow for the further development and availability of specialized job placement and supportive employment services for deafblind people throughout Minnesota.
- 6) We recommend that in 2003 the Legislature direct the Minnesota Department of Children Families & Learning to revise the state special education rules to:
- (a) increase the likelihood that deafblind children are labeled deafblind rather than deaf, blind, developmental delayed, early childhood education, or anything else,
 - (b) instruct school personnel to use the criteria for deafblindness whenever a child has either a “primary” vision or hearing loss and a “secondary” loss in the other sense,
 - (c) ensure that when an infant is identified as having a hearing loss (through Universal Newborn Hearing Screening or otherwise), recommendations are also made for a complete eye examination.

Task Force Priority Recommendations for State Agency Action

For the Department of Human Services

- 1) We recommend that the Department of Human Services set aside a portion of state allocations for services to deafblind adults for a two-year pilot program to pay for transportation needed to enhance the self-sufficiency and independence of deafblind adults. We also recommend that DHS determine the amount of money to set aside for this purpose and the priorities for its use by consulting with the Minnesota Commission Serving Deaf and Hard of People (MCDHH) and the Minnesota Deafblind Association (MDBA). Finally, we recommend that this money only be used as a “payor of last resort.”

In addition, we recommend that the Quad Agency team study other possible long-term solutions to the unmet transportation needs of deafblind adults, especially those in Greater Minnesota and that the self-advocacy training that they sponsor for deafblind individuals (see Recommendation #3 for the Quad Agency team) include information about other existing resources to pay for needed transportation.

- 2) We recommend that the Department of Human Services (DHS) amend the assessment tools for Medical Assistance (MA) Home Care services and for all MA waivers that determine eligibility based on how

a person's disability affects their activities of daily living (ADL) so that they take into account the unique needs of persons who are deafblind.

- 3) We recommend that DHS (a) develop and distribute to all counties a policy directive regarding the "Checklist for Related Conditions Eligibility" that provides guidelines for the appropriate assessment of whether a person who is deafblind has "adaptive behavior similar to that of persons with mental retardation" and (b) provide guidelines for the appropriate assessment of whether a person who is deafblind has "substantial functional limitations in three or more of the named life activities" (i.e. self care, understanding and use of language, learning, mobility, self direction and capacity for independent living).
- 4) We recommend that DHS provide training and written materials to all counties regarding the unique needs of persons who are deafblind, including information about how to assess their eligibility for MA and MA waiver services. Also, that DHS designate and train a "point person" within the MA Division who can serve as a resource person for county personnel who have questions about working with persons who are deafblind.
- 5) We recommend that DHS work in coordination with representatives of persons who are deafblind to monitor the effectiveness of the legislative

recommendations concerning amendments to the MA and MA waiver benefit sets and by July, 2004, determine whether a specific Deafblind MA waiver is needed in order to effectively address the unique needs of persons who are deafblind.

- 6) We recommend that the DHS Deaf and Hard of Hearing Services Division consider moving its regional offices further west in Southern Minnesota so that deafblind persons in Southwestern Minnesota have closer access to these offices.

For State Services for the Blind

- 1) We recommend that the Rehabilitation Council for the Blind establish a deafblind committee, including representatives from MCDHH, to examine and make recommendations regarding how State Services for the Blind (SSB) can improve their services for deafblind individuals. This should include an examination of the possible use of protocol for SSB counselors to use when they work with deafblind consumers.
- 2) We recommend that SSB provide all of its counselors with training regarding the service needs of deafblind individuals and “best practices” for working with deafblind consumers.
- 3) We recommend that specialized staff positions be created or preserved for SSB counselors who work

with deafblind adults. These specialized staff would be persons who can communicate directly with deafblind consumers and who understand the specific rehabilitation needs of consumers who have congenital or acquired deafblindness. We also recommend that SSB seek whatever funds necessary to create these staff positions.

- 4) We recommend that the Division of Rehabilitation Services and State Services for the Blind explore ways that they can further collaborate to help more deafblind Minnesotans obtain and retain competitive employment and that they share the results of their efforts with the Minnesota Commission Serving Deaf and Hard of Hearing People and with the Minnesota DeafBlind Association.

For the Quad Agency Team

- 1) We recommend that the Quad Agency team collaborate with the DHS Aging and Adult Services Division and the Minnesota Board on Aging to develop a plan to (1) earmark specific resources to address the needs of senior citizens who have a combined hearing and vision loss and (2) provide information to all senior citizens about the need for regular testing of both hearing and sight and the resources available to people with a hearing and/or vision loss.

- 2) We recommend that the Quad Agency team coordinate and support the development and maintenance of a comprehensive web site for deafblind consumers, family members and professionals with information about deafblindness, resources, issues, etc. We also recommend that the Quad Agency team seek corporate sponsorship for the development and maintenance of such a web site.
- 3) We recommend that the Quad Agency team also collaborate with consumers, parents and the Minnesota Disability Law Center to develop, sponsor and offer self-advocacy training for deafblind consumers and their family members and that this be done from existing state agency budgets.
- 4) We recommend that the Quad Agency team collaborate with consumers and families and the Minnesota Commission Serving Deaf and Hard of Hearing People (MCDHH) to study and recommend how to best institute a system of deafblind case management specialists and/or ombudsman services for deafblind adults, using existing state resources, that would offer the type of case management services that deafblind consumers have requested. Options to accomplish this might include (a) re-assigning Deaf and Hard of Hearing Services Division Regional Office staff, (b) re-configuring the job duties of some State Services for the Blind (SSB) self-sufficiency counselors, or (c) training county social

workers (if counties become responsible for serving deafblind people).

- 5) We recommend that the Quad Agency team explore ways to support deafblind Minnesotans who need computers, brailers, jaws, and other adaptive equipment in their homes, including in-home training regarding the use of such equipment, in order to access information to support either their ability to make more informed decisions or to maintain their self-sufficiency.
- 6) We recommend that the Quad Agency team develop and offer yearly training for any professional (state, county, non-profits, etc.) who works occasionally with deafblind persons. Such training should include information about the unique, communication, language, learning and other needs of deafblind individuals. Again, this should be done from the existing agency budgets.

For DHS, SSB and DCFL

- 1) To assist in gathering data needed to plan for and ensure the most effective and efficient use of state resources for deafblind Minnesotans, we recommend that the Department of Children Families & Learning, State Services for the Blind, and the Deaf and Hard of Hearing Services Division of the Minnesota Department of Human Services develop a “data

base,” within the parameters of the Minnesota Data Practices Act, that may include data such as:

- a) the number of unduplicated deafblind people identified in each county,
 - b) the number of deafblind people receiving services in each county,
 - c) type of services provided,
 - d) customer satisfaction rating of services received,
 - e) financial resources allocated to serve deafblind customers, including information about the source of the funding,
 - f) department staff training regarding deafblindness (number trained, hours of training and type of training, area of state),
 - g) training provided for professionals and paraprofessionals (number trained, hours of training and type of training, area of state)
 - h) legislative initiatives carried out by departments that were included in recommendations.
- 2) We recommend that each state agency serving deafblind individuals be required to give to their deafblind consumers and family members an understandable statement of (a) services that are available from the agency for deafblind individuals, (b) services to which they are entitled, (c) appeal procedures, (d) information about how to locate consumer and legal advocacy services and (e) information about other services available to deafblind individuals.

3) We recommend that the Department of Children Families & Learning and the Divisions of State Services for the Blind and Rehabilitation Services establish “best practices” stating that if a student or client has either vision or hearing loss, he/she should be periodically evaluated (not just screened) for loss of the other sense.

For the Minnesota Commission Serving Deaf and Hard of Hearing People (MCDHH)

1) We recommend that MCDHH create a steering committee, comprised of members of this Task Force, for the purpose of monitoring and advocating for the implementation all recommendations contained in this Report. We also recommend that MCDHH serve as the “clearinghouse” for future inquiries as to the status of recommendations contained in this Report.

Appendix A

Complete Listing of All Task Force Recommendations

Recommendations related to Policy Direction #1:

Develop strategies to ensure that deafblind people are identified as having a dual sensory loss.

- 1) We recommend that in 2003 the Legislature direct the Minnesota Department of Children Families & Learning to revise the state special education rules to:
 - (a) increase the likelihood that deafblind children are labeled deafblind rather than deaf, blind, developmental delayed, early childhood education, or anything else,
 - (b) instruct school personnel to use the criteria for deafblindness whenever a child has either a “primary” vision or hearing loss and a “secondary” loss in the other sense,
 - (c) ensure that when an infant is identified as having a hearing loss (through Universal Newborn Hearing Screening or otherwise), recommendations are also made for a complete eye examination.

- 2) We recommend that the Department of Children Families & Learning and the Divisions of State Services for the Blind and Rehabilitation Services establish “best practices” stating that if a student or

client has either vision or hearing loss, he/she should be periodically evaluated (not just screened) for loss of the other sense.

- 3) We recommend that the Quad Agency team collaborate with the DHS Aging and Adult Services Division and the Minnesota Board on Aging to develop a plan to (1) earmark specific resources to address the needs of senior citizens who have a combined hearing and vision loss and (2) provide information to all senior citizens about the need for regular testing of both hearing and sight and the resources available to people with a hearing and/or vision loss.

Recommendations related to Policy Direction #2:
Maximize the ability of deafblind Minnesotans to become more self-sufficient.

- 1) We recommend that in 2003, the Legislature appropriate funds to allow for the further development and availability of specialized job placement and supportive employment services for deafblind people throughout Minnesota.
- 2) We recommend that the Department of Human Services set aside a portion of state allocations for services to deafblind adults for a two-year pilot program to pay for transportation needed to enhance the self-sufficiency and independence of deafblind adults. We also recommend that DHS determine the

amount of money to set aside for this purpose and the priorities for its use by consulting with the Minnesota Commission Serving Deaf and Hard of People (MCDHH) and the Minnesota Deafblind Association (MDBA). Finally, we recommend that this money only be used as a “payor of last resort.”

In addition, we recommend that the Quad Agency team study other possible long-term solutions to the unmet transportation needs of deafblind adults, especially those in Greater Minnesota and that the self-advocacy training that they sponsor for deafblind individuals (see Recommendation #3 for the Quad Agency team) include information about other existing resources to pay for needed transportation.

- 3) We recommend that in 2003, the Legislature appropriate additional grant funding for support services for deafblind children and adults if the MA/MA Waiver and CSSA recommendations contained in this Report are not implemented.

Recommendations related to Policy Direction #3:
Enhance the ability of deafblind individuals and family members to make more informed decisions.

- 1) We recommend that each state agency serving deafblind individuals be required to give to their deafblind consumers and family members an understandable statement of (a) services that are available from the agency for deafblind individuals,

(b) services to which they are entitled, (c) appeal procedures, (d) information about how to locate consumer and legal advocacy services and (e) information about other services available to deafblind individuals.

- 2) We recommend that the Quad Agency team coordinate and support the development and maintenance of a comprehensive web site for deafblind consumers, family members and professionals with information about deafblindness, resources, issues, etc. We also recommend that the Quad Agency team seek corporate sponsorship for the development and maintenance of such a web site.
- 3) We recommend that the Quad Agency team also collaborate with consumers, parents and the Minnesota Disability Law Center to develop, sponsor and offer self-advocacy training for deafblind consumers and their family members and that this be done from existing state agency budgets.
- 4) We further recommend that the Quad Agency team collaborate with consumers and families and the Minnesota Commission Serving Deaf and Hard of Hearing People (MCDHH) to study and recommend how to best institute a system of deafblind case management specialists and/or ombudsman services for deafblind adults, using existing state resources, that would offer the type of case management

services that deafblind consumers have requested. Options to accomplish this might include (a) re-assigning Deaf and Hard of Hearing Services Division Regional Office staff, (b) re-configuring the job duties of some State Services for the Blind (SSB) self-sufficiency counselors, or (c) training county social workers (if counties become responsible for serving deafblind people).

- 5) We recommend that the Quad Agency team explore ways to support deafblind Minnesotans who need computers, brailers, jaws, and other adaptive equipment in their homes, including in-home training regarding the use of such equipment, in order to access information to support either their ability to make more informed decisions or to maintain their self-sufficiency.

Recommendations related to Policy Direction #4:
Develop and align systems to support high quality services with good outcomes that are available throughout Minnesota.

- 1) We recommend that in 2003, the Legislature appropriate additional staff and training funds for the Deafblind Technical Assistance Project of the Department of Children, Families and Learning so that they can address more of the educational issues identified in this Report, including the need for more training for interveners.

2) We recommend that the Quad Agency team develop and offer yearly training for any professional (state, county, non-profits, etc) who works occasionally with deafblind persons. Such training should include information about the unique, communication, language, learning and other needs of deafblind individuals. Again, this should be done from the existing agency budgets.

3) To assist in gathering data needed to plan for and ensure the most effective and efficient use of state resources for deafblind Minnesotans, we recommend that the Departments of Children Families and Learning, State Services for the Blind, and the Deaf and Hard of Hearing Services Division of the Minnesota Department of Human Services develop a “data base,” within the parameters of the Minnesota Data Practices Act, that may include data such as:

- a) the number of non-duplicated deafblind people identified in each county,
- b) the number of deafblind people receiving services in each county,
- c) type of services provided,
- d) customer satisfaction rating of services received,
- e) financial resources allocated to serve deafblind customers, including information about the source of the funding,
- f) department staff training regarding deafblindness (#s trained, hours of training and type of training, area of state),

- g) training provided for professionals and paraprofessionals (#s trained, hours of training and type of training, area of state) and
- h) legislative initiatives carried by departments that were included in recommendations.

- 4) We recommend that the DHS Deaf and Hard of Hearing Services Division consider moving its regional offices further west in Southern Minnesota so that deafblind persons in Southwestern Minnesota have closer access to these offices.
- 5) We recommend that the Rehabilitation Council for the Blind establish a deafblind committee, including representatives from MCDHH, to examine and make recommendations regarding how State Services for the Blind (SSB) can improve their services for deafblind individuals. This study should include an examination of the possible use of protocol for SSB counselors to use when they work with deafblind consumers.
- 6) We recommend that SSB provide all of their counselors with training regarding the service needs of deafblind individuals and “best practices” for working with deafblind consumers.
- 7) We recommend that specialized staff positions be created or preserved for SSB counselors who work with deafblind adults who can communicate directly with deafblind consumers and who understand the

specific rehabilitation needs of consumers who have congenital or acquired deafblindness. We also recommend that SSB seek whatever funds necessary to create these staff positions.

Recommendations related to Policy Direction #5:
Maximize the use of existing state appropriations and resources by amending existing reimbursement systems.

A. Regarding Current Legislative Appropriation Language for Deafblind Services

- 1) Concerning the current legislative appropriation language granting money for deafblind services, we recommend that the Legislature:
 - (a) remove all references to specific service providers in current state grant appropriation language for services to people who are deafblind,
 - (b) remove all reference to specific services for deafblind individuals so that the appropriations can be used for any service that addresses needs related to the consumer's deafblindness,
 - (c) include language so that the appropriations can be used either for grants to organizations or for consumer directed services.

- 2) We also recommend that the Legislature direct the Departments of Human Services, Children, Families & Learning and State Services for the Blind to meet

with deafblind citizens, parents of deafblind children and the Minnesota Commission Serving Deaf and Hard of Hearing People and determine which agency can most efficiently and effectively develop and administer a pilot consumer directed service program to deliver needed services to deafblind adults, children and their families. The Department of Human Services should also be required to transfer appropriations for such a pilot program to the state agency determined best able to implement the pilot program.

- 3) Finally, we recommend that the Legislature direct these state agencies to implement such a pilot consumer directed service program using existing state appropriations as soon as possible after July 1, 2002 but no later than September 1, 2002.

Note: Current legislative appropriation language for deafblind services can be found at:

- Laws of Minnesota for 1985, Chapter 9, Article 1, First Special Session
- Laws of Minnesota for 1991, Chapter 292, Article 1
- Laws of Minnesota for 1997, Chapter 203
- Laws of 1998, Chapter 407, Article 1
- Laws of Minnesota for 1999, Chapter 245, Article 1, Section 2
- Laws of Minnesota for 2000, Chapter 245, Article 9, Section 29

B.Regarding Medical Assistance (MA) and MA waivers

- 1) We recommend that the Legislature amend the Medical Assistance (MA) and all MA waiver benefit sets to allow payment for:
 - a) sign language interpreters
 - b) interveners
 - c) support service persons (SSPs)
 - c) orientation and mobility (O & M) services, and
 - d) rehabilitation teaching services.

- 2) We recommend that the Department of Human Services (DHS) amend the assessment tools for MA Home Care services and for all MA waivers that determine eligibility based on how a person's disability affects their activities of daily living (ADL) to take into account the unique needs of persons who are deafblind.

- 3) We recommend that DHS (a) develop and distribute to all counties a policy directive regarding the "Checklist for Related Conditions Eligibility" that provides guidelines for the appropriate assessment of whether a person who is deafblind has "adaptive behavior similar to that of persons with mental retardation" and (b) provide guidelines for the appropriate assessment of whether a person who is deafblind has "substantial functional limitations in three or more of the named life activities (i.e. self

care, understanding and use of language, learning, mobility, self direction and capacity for independent living).

4) We recommend that DHS provide training and written materials to all counties regarding the unique needs of persons who are deafblind, including information about how to assess their eligibility for MA and MA waiver services. Also, that DHS designate and train a “point person” within the MA Division who can serve as a resource person for county personnel who have questions about working with persons who are deafblind.

5) We recommend that DHS work in coordination with representatives of persons who are deafblind to monitor the effectiveness of the legislative recommendations herein concerning amendments to the MA and MA waiver benefit sets and by November, 2003 determine whether a specific Deafblind MA waiver is needed in order to effectively address the unique needs of persons who are deafblind individuals.

C.Regarding the Community Social Services Act (CSSA)

- 1) We recommend that in 2003 the Legislature amend the Community Social Services Act (CSSA) to include deafblind persons as a population that counties must serve within their budget limitations.

Recommendations for “Keeping the Vision”

- 1) We recommend that MCDHH create a steering committee, comprised of members of this Task Force, for the purpose of monitoring and advocating for the implementation all recommendations contained in this Report.
- 2) We also recommend that MCDHH serve as the “clearinghouse” for future inquiries as to the status of recommendations contained in this Report.

Appendix B

Purpose: The purpose of appendix is threefold, and includes:

- 1) Definitions of terms used in the main body of the taskforce document.
- 2) Additional critical needs and barriers identified by the task force.
- 3) Information on the etiologies of deafblindness.

Definitions

The terms “intervener,” “interpreter,” and “support service provider” (SSP), and orientation and mobility (O & M) specialist are defined as follows:

Interveners are individuals who work with deafblind children and youth in a variety of settings including the home, the community and in education. They provide one-on-one supports in the preferred mode of communication used by the child. Such supports not only assist in learning, but also generally ensure that there is clear and continuous access to information in the child’s environment. It should be emphasized that they work with, but do not replace, the teacher or parent. The intervener should have specialized training.

Support service providers (SSPs) are individuals trained to assist people who are deafblind with a variety of home and community activities. For adults, SSP services are crucial in assisting with daily living tasks such as food shopping, reading mail, paying bills, accessing recreational activities and organizing medications. They may also provide the support of a safe escort.

Interpreters are professionals trained to efficiently convey information to the deafblind individual in their preferred mode of communication. They follow a professional Code of Ethics and are typically used in job

interviews, medical settings, legal proceedings, etc. Most often, however, their training is in providing this service to individuals who are deaf and not deafblind. Additional and specialized training is required for interpreters to be skilled in providing this service to deafblind consumers.

Orientation and mobility specialists are teachers with a background in the education and rehabilitation of individuals with “blindness”. Their specialty is in the training of skills and techniques that allow a youth or adult with blindness or visual impairment to travel safely and independently in the home and in the community.

Additional critical needs and barriers identified by the Task Force

The Need for Support Services. As we have mentioned previously, neither deafblind children nor adults have sufficient access to many needed support services. The following list represents additional concerns not mentioned earlier regarding problems in gaining access to SSPs, interveners, and interpreters:

- Information regarding access and rights to the services is not readily available to consumers and families.
- Services themselves are not necessarily available when they may actually be necessary (i.e. 24 hour, 7 day per week service is desired).

- Number of monthly service hours available for each deafblind person is inadequate.
- Difficulties getting equal access to services because of geographic location, as in the case of deafblind people who live in Greater Minnesota.

The Need for Early Identification of Deafblindness.

Although we addressed the critical importance of early identification of deafblindness previously, the specific issue of Usher syndrome, which is the main cause of deafblindness, deserves some additional mention.

A common example of delayed identification of deafblindness can be seen among those with Usher syndrome. In the pre-adolescent years, the condition of retinitis pigmentosa (RP) may go completely unnoticed, especially as the main early symptoms involve night-blindness, peripheral field loss, and possibly balance problems. Hearing parents of deaf children are often not proficient in sign language and so clear communication between parent and child is often lacking. Periodic visits to ophthalmologists or optometrists are also often wrought with miscommunication, and doctors, unaccustomed to communicating with deaf patients, may be uncomfortable.

When eye doctors do not hear complaints about poor night vision, and do not see the typical “bone spicules” in the retina of the eye, they do not order the special electroretinogram test needed to make an early diagnosis.

As the years pass and the vision deteriorates, the loss becomes so acute that it is finally clinically diagnosed by an optometrist or ophthalmologist. This does not, however, bring resolution to the situation. Usher teens are terrified (as are most deaf individuals) to divulge to others in the deaf community that they have a visual disease, making an educational evaluation and subsequent service provision extremely delicate. At this point, the educational system brings in a “vision teacher” to provide specialized services. A “vision teacher” typically is someone who has been trained only in blindness, with no understanding of either deafness or deafblindness. The result is often an inadequate and incomplete evaluation, followed by a series of inappropriate recommendations, all translating into a postponement of the actual training of needed skills. These students usually graduate without having had the training or supports necessary to succeed as deafblind adults. At this stage, they enter the adult service system, which is itself without expertise in deafblindness, and so a cycle of systemic service gaps unfolds.

In the scenario above, early “comprehensive” screenings would lead to a timely identification of the deafblindness and an opportunity to establish appropriate education programming.

The Need to Empower Consumers and their Families through Computer Access and Training. Parents of

deafblind children, and deafblind individuals themselves, are fighting for the opportunity to become empowered consumers and to exercise the right of self-determination.

For the deafblind consumer, the need to overcome that communication barrier and gain access to information is a clear priority. The obstacles to communication within this community of individuals, however, are tremendous. In fact, even the very access to information that might permit effective advocacy to be pursued is an obstacle.

With that point in mind, it is significant to note that for the first time ever, developments in computer technology now make it possible for deafblind people to overcome the communication barrier, allowing access to information, institutions *and each other*. Applications of this technology can have tremendous impact upon everything from education to employment to personal leisure. However, the need for individualized training to learn and make use of this technology is paramount if individuals are to be given opportunities to overcome the educational, vocational and social obstacles that this dual sensory loss presents.

The Need for High Quality Specialized Services

Housing and Transportation

Deafblind individuals need guidance to secure reasonably affordable, practical, and safe housing. Residences are needed within easy walking distance of stores and transportation and in areas with pedestrian traffic. Once residences are secured, the proper accommodations/modifications required for a deafblind person need to be installed with the support and guidance of a county or state agency.

Cost-effective and reliable transportation is also necessary so that deafblind individuals can have access to community events, and participate in everything from vocational training and work experience, to continuing education, social and leisure activities.

Additional barriers that have been noted by the task force, with regard to housing and transportation needs, are:

Housing:

- Affordable housing is rare, and guidance from agencies in this area is equally rare.
- Individuals who can conduct assessments to identify home equipment and device needs are in short supply.
- Difficulty getting services outside of metro area due to lack of trained personnel in Greater Minnesota.

Transportation:

- Reliable transportation is not consistently available, especially outside of Metro area.
- Funding is not available to support transportation needs, including payment for mileage or drivers.
- Coordination and delivery of transportation services are inadequate.
- Ability to communicate effectively with transportation workers is difficult (bus, Metro Mobility and taxi drivers).

The Etiologies of Deafblindness

Deafblindness can result from infections, trauma, tumors (or chemotherapy and radiation), chromosome disorders and at least 130 distinct syndromes, most of which are genetic. In addition, some individuals may have combinations, e.g. a genetic hearing loss with vision loss due to retinopathy of prematurity or trauma. The most well known prenatal cause is Rubella, which is now almost eradicated but those born during the epidemic in the 1960s are now deafblind disabled adults. Other prenatal infections include cytomegalovirus (CMV), toxoplasmosis, herpes, syphilis and AIDS may also cause vision or hearing loss or both. Maternal ingestion of certain drugs such as alcohol, cocaine and others occasionally result in combined loss. Complications of prematurity such as neonatal meningitis, retinopathy of prematurity plus medications toxic to the ear are becoming much less frequent.

The most common congenital condition is CHARGE Syndrome, an acronym which involves eyes, ears, cranial nerves, heart and many other organ systems. Since this was first described in 1981, many children and most adults remain undiagnosed. Most carry the label of “multiply handicapped” or “multiple congenital anomalies.” Early accurate diagnosis can mean the difference between growing up as a mentally retarded adult and becoming a productive member of society due to early acquisition of a formal language system and appropriate educational programming. Some syndromes, such as Stickler Syndrome, may have some vision and/or hearing losses present at birth but one or both may progress as the individual grows older

Except for five syndromes that only affect the eyes and ears, all the conditions listed above have physical or mental issues beyond these two organs. Of the five, Usher Syndrome is the most common and accounts for at least half of the referrals to the Helen Keller National Center and half of the membership in the American Association of the Deafblind. People with Usher Syndrome are born deaf or hard of hearing and then lose their vision due to Retinitis Pigmentosa (RP). Intelligence is normal. RP is a disease of the retina characterized by “night-blindness” and an ever-decreasing tunnel of central visual field. It is common for individuals with Usher to become legally blind in adolescence, and then to experience continuously

diminishing visual performance as they become older. In many cases, this leads to total blindness.

Last but not least, deafblindness is also seen in growing numbers among a population that has been typically ignored or overlooked, namely, the elderly. By 2030, one out of every four Minnesotans will be over the age of 65. As life expectancies increase, the numbers of people who experience difficulties with both vision and hearing in these later years also increases. The elderly will undoubtedly constitute the largest group of deafblind individuals in the future.

Appendix C

Deafblind Resources and Demographics

Minnesota offers very limited resources to support its citizens who are deafblind. There are support and financial resources available specifically for people who are deaf as well as support and resources available specifically for people who are blind. However, the needs of people who are **both deaf and blind** are unique and services designed to meet only one of these two sensory needs are ineffective.

The two resources in Minnesota that are dedicated specifically for services to people who are deafblind are:

- The federal Department of Education - Office of Special Education Programs provides \$184,231 annually to the Minnesota DeafBlind Technical

Assistance Project for technical assistance to schools and families of children birth through age 21. These funds are used to support 2.5 staff who provide workshops, in-service programs, individual technical assistance and family support and training.

Minnesota school districts have identified 51 students who are deafblind, however Minnesota's federal census count is 211 deafblind children and youth.

The Project began the third year of a four-year grant in October 2001.

- The Minnesota Legislature has appropriated \$560,000 per year in state grant funding through fiscal year 2003 for services to individuals who are deafblind. However, due to the ongoing nature and degree of services needed, less than 15% of deafblind Minnesotans are able to receive services. The types of services provided include interveners, family support and education, support service providers, orientation and mobility specialist, intervener training, consumer education and capacity building for the deafblind adult consumer organization. Services are delivered by community providers and DHS administers the appropriations.

The grid following the demographic data provides more detailed information about the number of people served and a breakdown of the funding.

NOTE ABOUT OTHER RESOURCES

Other resources are available that could potentially support the needs of deafblind people. However, because these other resources are not earmarked specifically for deafblind people, they cannot be relied upon for predictable or consistent services. These include the following:

- *Minnesota Department of Economic Security, State Services for the Blind* – funding is available for independent living, vocational rehabilitation, and child rehabilitation services for people who are blind but no funding is specifically dedicated for deafblind services. Deafblind people may receive services from SSB but the services are not specifically designed for people with a combined hearing and vision loss.
- *Minnesota Department of Human Services Deaf and Hard of Hearing Services Regional Offices* – deafblind people may use any regional office services that are available but the services are not specifically designed for people with a combined hearing and vision loss.
- *Medical Assistance Waiver Services* – a small number of deafblind children and adults have been found eligible to receive some waiver services. However, the eligibility varies from county to county and caseworker to caseworker. No assessment procedures are in place to evaluate the unique needs

of deafblind people and no guidance is provided to counties on how to apply eligibility criteria to deafblind people. Many services needed by deafblind people are not in the benefit set of services that can be paid for by MA and the MA waivers, including interpreters, interveners and support service providers.

- *County Community Social Services* – while many of the services required by deafblind people are similar in scope and degree to the services provided under CSSA for other disability groups, deafblind people are not one of the mandated groups to be served and therefore are unable to tap into this resource. To our knowledge, only three counties are voluntarily providing services to deafblind residents at the present time.

Demographic Information

A formal census of the number of deafblind people in the United States or in Minnesota has not been done. While many agencies have tried to estimate the number of deafblind people, there is no consensus about which numbers are most accurate.

A reasonable estimate from the Task Force's perspective comes from the federal Rehabilitation Services Administration. According to their demographic information, about .0146% of the population is deafblind. Applying that percentage to

Minnesota's population, we get the following estimate of the number of deafblind Minnesotans:

<u>General population</u>	<u># of deafblind Minnesotans</u>
4,919,469	718
Minnesotans up to age 21: 1,505,169	220
Minnesotans age 21 and over: 3,414,300	498

The estimate for Minnesotans up to age 21 is very close to the federal census of the U.S. Department of Education that lists the number of deafblind children and youth in Minnesota to be 211. However, given the number of new referrals, this is definitely an underestimate.

The actual number of deafblind Minnesotans age 21 and over is likely to be **higher** than the above estimate number as well. The incidence of deafblindness increases in this population due to the progressive loss of vision and hearing in two groups of people, senior citizens and those with Usher Syndrome.

Financial Resources Dedicated to Deafblind People in Minnesota

DIRECT SERVICES	Adminis tering Agency	Per Yr State Grant \$ ¹	Per Yr Fed Grant \$ ²	# of DB Served ³	Hrs of Service Per Yr	% of DB Unservd ⁴
For Children						
Provides dedicated funding for intervenors and family education	DHS	\$255,000	\$0	15 metro 5 Gr MN	3,744	est. 90% unserved
For Adults						
Provides dedicated funding for Support Service Providers (SSP), service management	DHS	\$150,000	\$0	8 metro 30 Gr MN (N.E. MN)	2,056	est. 92% unserved
Combined Children and Adults						
Orientation / Mobility Specialist (funding ends 6/30/03)	DHS	\$60,000	\$0	Varies according to indiv. needs	164	
TOTALS		\$465,000	\$0	58	8,184	Avg. 91% unserved

TRAINING AND TECHNICAL ASSISTANCE	Funding Source	Per Yr State Grant \$¹	Per Yr Fed Grant \$²	Training Events / People Served Per Year
Training for Interveners and SSPs	DHS	\$25,000	\$0	3 / Yr (est.)
Consumer Education, Support Groups and Capacity Building for DB Consumer Organization	DHS	\$50,000	\$0	6 events metro / avg. 15 deafblind per event 24 events Gr MN / avg. 2-3 deafblind per event
DB Technical Assistance Project (training parents and education professionals)	OSEP	\$0	\$184,231	2 conferences/250 ed. prof. and parents 3 workshops/150 ed. prof. and parents 20 inservices/200 people 1 family enrichment weekend/28 families 1:1 training/20 ed. prof. and parents
TOTALS		\$75,000	\$184,231	

- 1 State grant funding included in base budget appropriations; re-allocated on a biennial basis.
- 2 Federal grant funding open for RFP every four years.
- 3 Total numbers of people served are not unduplicated. For example, a deafblind individual may receive SSP services and orientation/mobility services.
- 4 Percentage is calculated based on the prevalence of deafblindness in the general population, using the demographic data on the previous page.

Appendix D Cost of Preparing This Report

The following is a summary of the costs of preparing this report:

State staff assistance: \$22,245

Dept. of Children, Families and Learning: \$4,680

Dept. of Economic Security: \$2,520

Dept. of Human Services: \$15,045

Accessibility costs for task force meetings: \$12,270

Interpreting services: \$10,945

Transportation for deafblind participants: \$1,325

Other task force meeting costs: \$1,165

Report preparation: \$5,400

Writing: \$5,000

Printing and mailing: \$400

TOTAL COST: \$41,080

Appendix E DeafBlind Task Force Membership and Meeting Schedule and Others Who Helped

Members of the DeafBlind Task Force

The Department of Human Services would like to thank the following members of the DeafBlind Task Force for their dedication to improving the quality of life for deafblind Minnesotans and for their commitment to making the Task Force successful in its mission.

Kathie Anderson, deafblind consumer, Minneapolis.

Lynette Boyer, president of the Minnesota DeafBlind Association and deafblind consumer, Otsego.

George Failes, hard of hearing/blind consumer, St. Paul.

Mary Hartnett, Executive Director of the Minnesota Commission Serving Deaf and Hard of Hearing People.

Adrienne Haugen, deafblind consumer, Olivia.

Eric Kloos, Department of Children, Families & Learning, Special Education.

Linda Lingen, Department of Economic Security, State Services for the Blind.

Curt Micka, Task Force Facilitator, Department of Human Services Deaf and Hard of Hearing Services Division.

Linda Mitchell, Minnesota State Academy for the Deaf and Minnesota State Academy for the Blind.

Terry O’Kane, parent of a deafblind young adult, St. Paul.

Sally Prouty, Minnesota DeafBlind Technical Assistance Project and parent of a deafblind young adult, Shoreview.

Jan Radatz, Department of Human Services Deaf and Hard of Hearing Services Division.

Susan Shogren Smith, parent of deafblind children, Brooklyn Center.

Wendy Williams, deafblind professional and consumer, Faribault.

Ken and Karen Wojcik, parents of a deafblind child, Woodbury.

Others Who Helped

The success of the Task Force was dependent on the involvement of community partners as well as Task Force members. Their willingness to offer their time and input throughout the process is greatly appreciated.

Dr. Sandra Davenport, DeafBlind Technical Assistance Project.

John Filek, DeafBlind Services Minnesota.

Steve Fischer, DeafBlind Services Minnesota and Vision Loss Resources.

Mark Geiger, Hennepin County social worker.

Nicole Gutowski, Duluth Lighthouse for the Blind.

Diane Lentsch, DeafBlind Services Minnesota.

Beth Ryland-Collova, DeafBlind Services Minnesota.

A special thanks to:

Sean Virnig from the DHS Deaf and Hard of Hearing Services Division for assisting with Task Force meetings and conducting research for the Task Force, and

Joe Cioffi for his assistance in writing the final report and lending us the expertise in deafblindness we were lacking.

Task Force Meeting Schedule

July 30, 2001	10:30 AM – 2:30 PM
September 6, 2001	1:00 – 4:00 PM
September 27, 2001	1:00 – 4:00 PM
November 8, 2001	1:00 – 4:00 PM
November 29, 2001	1:00 – 4:00 PM
December 20, 2001	1:00 – 4:00 PM
January 2, 2002	1:00 – 4:00 PM
January 10, 2002	1:00 – 4:00 PM
January 22, 2002	10 AM – 1 PM