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Report of the Stakeholder Working Group to Review the Current and Future Needs of Maine's Residents Who Are Blind or Visually Impaired, January 2010

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**Report of the Stakeholder Working Group
to Review the Current and Future Needs
of Maine's Residents Who Are
Blind or Visually Impaired.**

Transmitted to:

Joint Standing Committee on Labor
and
Joint Standing Committee on Education and Cultural Affairs

By:

Laura A. Fortman, Commissioner
Maine Department of Labor

January, 2010

As Required by Resolve Chapter 39

“Resolve, To Establish a Working Group of Stakeholders to Review
the Current and Future Needs of Blind and Visually Impaired Individuals
and to Establish Long-term Solutions to Fund Those Needs”

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Compiled by:
John Mc Mahon, Director
Division for the Blind and Visually Impaired

Introduction

At the conclusion of the first session of the 124th Legislature, L.D. 564 "Resolve To Establish a Working Group of Stakeholders To Review the Current and Future Needs of Blind and Visually Impaired Individuals and To Establish Long-term Solutions To Fund Those Needs," was passed and signed by the Governor on June 2, 2009. This resolve required the Commissioner of Labor to establish a work group to explore the current and future needs of persons in Maine who are blind or visually impaired and to recommend long-term solutions to address these needs, as well as to look at the proposed oversight of the Division for the Blind and Visually Impaired (DBVI). The Commissioner established the required working group and allocated staff resources to convene, facilitate and participate in its deliberations.

In addition to a representative of the Department of Labor (DOL), and the Director of the DBVI, the Resolve designated membership to include representatives from the Department of Education, Catholic Charities Maine, the Iris Network, the Disability Rights Center, and other interested parties. The DBVI Director worked to ensure that diverse stakeholder representation and high participation of consumers who are blind or visually impaired was incorporated into the membership of this work group. The work group was comprised of the following 23 members, including those stakeholder entities specified in the resolve.

Jill Duson, Director of the DOL Bureau of Rehabilitation Services (BRS)
Lauralee Raymond, Legislative Liaison, Commissioner's Office of the Department of Labor
John Mc Mahon, Director of the BRS Division for the Blind & Visually Impaired
Andrea Bickford, DBVI Vocational Rehabilitation Program
Bill Ward, DBVI Orientation & Mobility Instructor
Jean Small, Catholic Charities Maine, Education of Blind Children Program Director
Lee Ann Ward, current Teacher of Visually Impaired Children and former student of the
Education of Blind Children Program of Catholic Charities Maine
Todd Winship, Catholic Charities Maine
Bud Lewis, past Director of DBVI
Ruth Mlotek, The Iris Network Rehabilitation Program Director
Janna Gregory, Child Development Services
Jim Phipps, CEO/President of The Iris Network
Patty Sarchi, Consumer representing dual sensory impairment
Brad Strause, ALPHA ONE
Mel Clarrage, Disability Rights Center
David Stockford, Department of Education, Low Incidence Program Director
Lynn Duplesis, Pine Tree Guide Dog Users
Carson Wood, American Council of the Blind of Maine
Jill Adams, Maine Association of Directors of Special Educators
Jeff Jones, DBVI Education Consultant
Debra Hannigan, Child Development Services Director
Steve Sawzen, National Federation of the Blind of Maine
Representative Tim Driscoll, Labor Committee

The group met on four occasions to discuss the three main programs of the DBVI, and explore and identify the various needs of consumers specifically related to each of these programs. These programs include the Education of Blind Children, Vocational Rehabilitation, and Independent Living for Older Blind. The dialog from these meetings, as well as an agreed upon list of identified needs, are the content of this report.

The work group also held a public hearing to solicit feedback to a draft version of this report, as well as to hear additional comments regarding the challenges of Maine residents who experience blindness or visual impairment. This hearing was convened on January 20, 2010 at multiple sites simultaneously. The main location was at the DOL administrative offices located in the Commerce Center in Augusta. Other sites were hooked in electronically via an interactive video system, and included Career Centers in Portland, Bangor, and Presque Isle.

Background

The Division for the Blind and Visually Impaired (DBVI) is a comprehensive blindness agency that administers rehabilitation and education programs for any resident of Maine who is blind or has a severe visual impairment significant enough to affect their daily functioning. For us to review DBVI's three main programs first requires a basic understanding of the impact that blindness can have on the individual and the uniqueness of the needs associated with that impact, as well as the size of the issue.

The challenge of delivering comprehensive, high quality services to children and adults in Maine who are blind or have severe vision impairment can be divided into two main categories. They are the uniqueness of the needs of the individual resulting from the visual impairment, and the sheer numbers of persons in Maine living with blindness or visual impairment.

In terms of numbers, national statistics from the American Foundation for the Blind indicate that there are now around 40,000 people with severe visual impairment in Maine. This number is projected to double by the year 2020. This dramatic increase is due, in part, to the fact that most eye diseases are age-related and the baby boomers are coming of age. As a result, the demand for low vision and vision rehabilitation services is increasing.

This means that the number of Maine people with significant vision loss is projected to expand from around 40,000 today, to approximately 80,000 by 2020. The programs of DBVI provide services to approximately 1,600 persons annually, with around 900 being individuals who are newly diagnosed with severe vision loss. If the number of people confronting blindness grows by 40,000 during the coming decade as projected, then our capacity to serve the increasing number of new clients will need to expand to serve at least an additional 900 new clients annually; bringing the number of persons served to 2,500 per year.

In addition to this increase in overall numbers, we are also seeing dramatic increases in related subgroups such as more complex secondary disabilities among children with visual impairments (for example, autism or brain injury are common), an increase in the prevalence of persons living with the combination of vision and hearing impairment, and an influx of refugee

and immigrant groups dealing with vision loss who need costly interpreter services in order to access and benefit from vision rehabilitation services.

Blindness education and/or rehabilitation is broader in scope than are general education practices and the medical model of rehabilitation, and require very specialized services in order to address the specific communication, mobility, and vocational needs unique to blindness or visual impairment. This set of specialized skills is similar across all ages and across all DBVI programs. In other words, the alternative skill one needs to access print when he or she cannot read it visually, are much the same for any person who is blind, whether they are a student in school, an adult looking to obtain or maintain a job, or an older person who desires to remain independent in their home.

This basic premise also holds true for things like traveling safely within their environment, being able to store and access information, being able to write the printed word or numbers in an accessible way, and being able to effectively accomplish ordinary day-to-day tasks. Each specialized service we provide under this philosophical umbrella is linked with the others, with the overriding goal of providing to the person the web of tools they need to take or regain more independent control of their life.

Without the above noted interventions, people who are blind are unlikely to arrive at the same place in life with the same opportunities as their sighted peers. Furthermore, children with blindness need the same type of groundwork laid so they too can obtain a Free Appropriate Public Education, enabling them to become viable, successful members of the workforce. And for them, the programs administered through DBVI are currently the only game in town from which to receive these specialized services.

This uniqueness of needs, the increasing numbers of persons being diagnosed with severe vision loss, and the complexity related to the existence of secondary disabilities, combined with the rural nature of our state and its large geographic size, supports the manner in which services are delivered in Maine. Our present system has been able to use the synergistic energy of its three component agencies (DBVI, Iris Network, and Catholic Charities Maine) and highly trained specialized professionals to provide a more vigorous and flexible service than any of the agencies or professional disciplines could accomplish individually.

Our history demonstrates that the centralized oversight of the entire blindness system through the DBVI provides an effective, cost-efficient manner of delivering individualized services directly to consumers, as well as countless hours of public education and support to families, employers, schools, and social service agencies.

Achieving this high level of societal inclusion and a cultural belief in the capability of persons who are blind to live their lives at the highest level of independence is one of the overriding guiding principles for any blindness system. This is true because of the dominance of the stereotypes surrounding blindness driven by the fear demonstrated by a recent national poll conducted by the American Foundation for the blind which indicates blindness being surpassed by only cancer and AIDS in terms of the amount of fear each condition produced. In Maine, this cultural belief in the capability of people who are blind is achieved by the BRS Division for the

Blind and Visually Impaired through administration of its three major programs: Education of Blind Children, Vocational Rehabilitation, and Independent Living for Older Blind Adults.

Historical Overview

Although services for persons who were blind in Maine began around 1905, formalized state sponsored programs began in 1941 with the creation by statute of a Division for the Blind within the Department of Social Services. This occurred when the blindness community demonstrated to the legislature two important facts. The first was that the existing state vocational rehabilitation program was not serving any blind people, and the second was that people who are blind required very specialized services in order to address specific communication, mobility, and vocational needs unique to blindness or visual impairment.

Over time, the legislature recognized that these same specialized services were also required by children in order for them to succeed in local school programs (Maine has never had a residential school for blind children), and were further required by older individuals who were blind and wished to continue living independently in their own homes and communities. This resulted in the division being given authority in law to support local schools in educating blind children, to assist adults to learn adaptive skills in order to get and keep good jobs, and to teach older blind individuals the special skills necessary to continue living independently.

Although the vocational, educational, and independent living objectives were all distinctly different, the same adaptive skills needs applied to each population, cost-effectiveness argued that these services be delivered by a single organization dedicated to serving blind people of all ages.

This combination of DBVI program objectives makes it difficult to establish the perfect departmental location within state government for the division. DBVI could be (and has been at different times) housed within the Dept. of Health and Human Services, the Dept. of Education, and currently, the Bureau of Rehabilitation Services within the Dept. of Labor.

After many years at Human Services, blind consumers convinced the legislature in 1994 to move DBVI to Education, only to have the King administration determine in 1996 that Labor was a better home.

So it was understandable that during the most recent session some members of the Committee on Labor questioned why they were hearing testimony on the educational needs of blind children. The conversation that followed reflected these broad statutory responsibilities of the division and the inevitable confusion of DBVI appearing somewhat out-of-place in any one department.

What was clear throughout all these discussions was the principle that, for compelling reasons of cost and effectiveness, DBVI needed to continue to manage all three major programs within one comprehensive blindness agency. There was nothing to gain, and much to be lost, in separating the programs.

Education of Blind Children Program

DBVI provides a program of specialized teaching services to blind children, primarily in the form of assistance to local schools in meeting the special needs of approximately 300 students who are blind or visually impaired in local classrooms throughout Maine. These teaching services are comprised of instruction in independent movement and travel (Orientation and Mobility), as well as in the teaching of specialized techniques and compensatory skills necessary for the child to access their school curriculum. In addition, assistance is also provided to school staff and families to create and adapt learning strategies specifically related to a student's vision impairment.

These teaching services are provided by Teachers of the Visually Impaired (TVI) and Orientation and Mobility Instructors (O&M), who are highly qualified specialists in teaching the adaptations pertinent to blindness and visual impairment. These specialists are available via FTE's within DBVI for the O&M Instructors and a long-standing contract with Catholic Charities Maine for the TVI's.

Vision is fundamental to learning, but visual impairment limits the ability to receive information from the world around us and its effects can be far-reaching. The impact may include an effect on a child's ability to understand concepts, learn language, move about freely and confidently, and develop in a variety of other ways that may have a detrimental impact on the student well into adulthood. Furthermore, approximately 80% of what we learn comes from visual observation, and for children with vision impairment this means they are unable to learn, model from, perceive, or access 80% of the information, opportunities and experiences that occur in the world around them. These same experiences and concepts are casually and incidentally learned by sighted students as they visually observe them, but for students with visual impairments, such things must be intentionally, systematically, and sequentially taught, and the more severe the visual impairment, the more complex the deficits can be. For these reasons, early intervention becomes critical, which is why comprehensive services for children and families begin as soon as a child is identified as blind or visually impaired.

Educational services provided by DBVI are delivered anywhere in the state, and can take place in a child's school, home, or community. In addition, these services are extremely flexible and can cover the student even if he/she moves from one school district to another in the middle of the school year. In this manner, the instructional professionals can be provided to local school districts as a no-cost service to the school.

Data from the end of the 2009 academic year indicates that services were provided to approximately 300 students in over 200 Maine schools. Of these, 50 were pre-school, aged birth to 5 years old, 21 were Braille learners, and 22 were deafblind. Both of these last two subgroups require significantly more instructional time due to the severity of their functional and academic needs, and have a tremendous impact on the size of caseloads of the TVI's and O&M Instructors. For example, caseloads per TVI varied from 8 to 31 depending on the complexity of the issues of the students and their geographic distribution. In Maine, TVI's averaged 17 students per teacher, while the recommended national average is 12.

TVI's supplement local school education planning and instruction by providing direct instruction in the areas of Braille reading and writing, adaptations and modifications of curriculum/materials, techniques related to learning with low vision, use of specialty equipment and other skills as determined in the student's individualized plan (IEP). They additionally provide Consultation to the school staff and family. Consultation consists of things like detailing the implication of the student's learning style, seating arrangements; textbook and paperwork print-size assessment, and use of adaptive equipment.

Vocational Rehabilitation Program

The Vocational Rehabilitation program is a federal- state partnership which has the objective of assisting Mainers who are blind or visually impaired to gain and maintain the highest level of employment possible for that individual. The DBVI VR Program encompasses the essential transition planning for youth with vision loss, comprehensive blindness rehabilitation services for adults with vision loss, and an overall understanding that vision loss does not mean loss of ability to live, work and engage in our community.

A strong Vocational Rehabilitation program is extremely important if we hope to get more than 30 percent of blind adults (the current national employment rate for persons with visual impairment) into our workforce. Having a strong VR program dedicated to meeting the unique needs of persons who are blind will not only assist the individual's personal economic status, but will also have a positive impact on Maine's overall economy by reducing the number of people who depend on public assistance programs, while increasing the number of tax-paying residents.

When considering the adults who are trying to navigate the world without the benefit of vision it is imperative that comprehensive blindness rehabilitation services be readily available in Maine, and provided in the manner to best meet the individual's needs specifically related to their visual impairment. These services need to be available in a full range of delivery systems, including training done in a person's home, in their school (if transitioning from high school into the workforce), in short-term small group settings, or in a residential-based immersion model. These specialized services need to include the acquisition of the skills needed by persons who are blind or visually impaired to live as independently as possible; everything from maintaining one's home, interpreting the environment and traveling safely within one's community, using computer assistive technology, and opportunities to apply all this training in a real-work or real-life setting which will allow for the self confidence and experience that is essential for anyone to have a quality life. Having this full range of services available right here in Maine will increase the opportunities for folks who are blind to get or keep a job that affords them the chance to earn a livable wage and live independently within their community.

States that have separate state VR programs for persons who are blind understand that such separate programs are more effective in meeting the unique needs of their clients. The foundation of the "unique needs" rationale is the fact that DBVI is the place where people come when they need to begin the process of rehabilitation resulting from vision loss, especially those who are newly blinded. The following scenario is used to underscore this point.

Suppose you are involved in a car accident and acquire a paralyzing spinal chord injury. You are first taken to an acute care hospital like Maine Medical Center for care of the immediate injuries, to get stabilized, and to begin treatments for healing. Once stabilized you would then go to a rehabilitation hospital like New England Rehab. for your rehabilitation treatments and process. There, a staff of specialty doctors like physiatrists, and nurses, physical and occupational therapists would spend several weeks and sometimes several months with you. You would undergo physical therapy that would help optimize your remaining function; occupational therapists would help you learn how to best minimize the impacts of your loss through specialized adaptive techniques and equipment, and physiatrists would help fit you out with a wheelchair, or prosthetics, or any other adapted devices you might need. In addition, you would receive regular counseling to assist with the process of emotional adjustment related to your disability and this new life you are now living. Finally, the medical team would plan a schedule of outpatient treatments and therapies you may need for the next several weeks or months. Your private insurance, or Medicaid or Medicare would pay for the hospital stay, the treatments, the adjustment counseling, and most all of the devices you need.

Now let's return to the scene of the accident, only let's now suppose that your optic nerves have been damaged instead of your spine and you've lost your vision. You would go to the hospital to take care of any acute needs and to get your medical condition stabilized and the healing process underway. Then, still blind, you would be sent home. That's it.

There isn't a single blindness program, professional, or device at New England Rehab. Hospital or at any other rehab. or medical facility which would provide the specialized training necessary for the unique needs of someone who is blind. No Mobility Instructor, no Vision Rehabilitation Therapist, no adjustment counselor. Why? Because insurance programs do not cover any blind rehabilitation therapy, training, or equipment. So you'll be sent home from the acute care hospital with no preparation at all for getting along, beginning the process of adjusting to your blindness, or getting around. You'll need to learn how to move around and navigate again without sight safely and efficiently; how to read, write, and otherwise communicate in a new way in every facet of your life; how to work the phone the TV, the stove, the thermostat, the microwave, the iron, and the washer and dryer. You'll also need to learn new ways to cook, pay bills, shop, do your banking, organize your household and cupboards, clean, shave, and so on. The compensatory or alternative methods, techniques, and equipment are all available, but not at the hospitals.

In Maine, DBVI is the sole source for all of this. There is only one program for supporting the education of children who are blind, one program to assist folks to obtain or maintain employment, and one program to assist those who are older and visually impaired with learning the skills needed to remain as independent as possible in their own community. It is DBVI that funds and manages the systems that employ professional blindness staff and provide the specialized services and devices essential to success with blindness. If these services were not available and you were to lose your vision you would have nowhere to go. You would have

no help in gaining competence in the skills of basic, daily living – let alone the skills needed to search for, secure, and maintain a job.

Without those interventions people who are blind don't arrive at the VR door on equal ground. Others will already have had extensive therapy and rehabilitation through conventional medical models and resources. But for people with vision disabilities, becoming viable, successful members of the workforce depends entirely on DBVI's VR program.

Independent Living/Older Blind Program

Services through this program are geared toward adults in Maine who are over 55 years old, and who are not interested in gainful employment, but want to remain as independent as they can in their own homes. The services offered through DBVI funding are predominantly in the areas of Orientation and Mobility instruction, Vision Rehabilitation Therapy, and Low Vision Therapy. Most of these services are offered directly through DBVI, or through the DBVI contract with The Iris Network, and the vast majority of these services are delivered in the person's place of residence.

Generally speaking, the services provided through this program are the teaching of alternative skills that can compensate for visual impairment. This teaching of such alternative skills can touch virtually every aspect of an individual's daily life. In addition to direct teaching of these specific alternative skills, a variety of other areas are also addressed, such as self-advocacy, assistive technology, and the process of adjustment to vision loss.

Maine already has the oldest population in the United States. Due to both the prevalence of age related eye diseases causing vision loss, and the aging of the baby boom generation, the number of Maine people with significant vision loss is going to almost double by 2020. In Cumberland County, for example, the most densely populated area served, data indicates that there are over 4,500 people, 65 years or older, who have serious vision loss.

Vision loss, along with other exclusionary factors associated with as aging, can lead to damaging social isolation. Individual members of this large and growing population are at risk of falling through the cracks of the social network and becoming dependent on public resources, including costly long-term nursing care. With independent living training, and empowerment activities, people who are blind or visually impaired can lead independent and productive lives, while reducing the burden on Maine taxpayers for long-term care.

The potential return-on-investment in these services is compelling. The cost of providing blindness rehabilitation services to this population averages about \$1,000 per person. Contrast this to the \$5,000 average monthly cost of a nursing home bed in Maine and you can see that if only one in 50 of these individuals stay out of institutional care for one year, the entire program has paid for itself. And that return is multiplied by every year that the person continues living independently, in their own home, with their family, in their community, where they truly want to be.

Resolve Findings

Although many of the needs that were identified by the Resolve Work Group are similar across the three main programs of DBVI, the authors decided to outline them individually, and then discuss how they impact the specific program. Additionally, this section also contains subsections related to some specific needs that fall outside of any given program, and subsequently warrant their own stand-alone discussion. Furthermore, emergent patterns related to a variety of the identified needs will also be discussed, as will the secondary directive of the Resolve dealing with where services for persons who are blind in Maine are located within state government.

How Should Services Be Administered

The work group on this Resolve conducted an examination of how services for children and adults who are blind or visually impaired should be administered by the state of Maine.

First and foremost, the work group unanimously strongly feels that the three primary programs of the Division should remain intact in one centralized agency, where one comprehensive and seamless system can deliver direct instruction for children who are blind, Vocational Rehabilitation Services for those who want to gain or maintain employment, and Independent Living services so that individuals can reside in the least restrictive environment possible. The professionals working in the field of blindness are specially trained to address the unique needs presented by visual impairment, and the alternative skills needed are much the same across the age spectrum. This makes our current delivery system the most cost-effective and efficient model for Maine as we don't need to have a completely different set of blindness professionals for each particular age group or program. Thus it is important that a single entity in State government oversee and administer these programs.

As stated previously in this report, services have been overseen over the years in three different Departments; Health and Human Services, Education, and currently Labor. Although in an ideal world it is felt that direct access to the Governor would be the most effective manor to cover the wide range of issues with this low incident group, the current economic environment appears to make this unrealistic at this time. Furthermore, the Department of Labor appears to be providing a solid oversight of the Division within its Bureau of Rehabilitation Services and Commissioner of MDOL has a full understanding of the mission of DBVI.

Based on this, we believe that there is currently no advantage to persons in Maine who are blind for DBVI to leave the Department of Labor. Furthermore, given the great deal of work needed to be done to address ongoing needs for persons who are blind, the work group recommends the energy of the state agency should be focused on this task versus a change in departments.

Access to Immersion, Residential-Based Rehabilitation Model in Maine

There are two basic types of service delivery models for blind rehabilitation: home based and center-based, immersion programs. Currently Maine offers home-based services only and

does not have a center-based nor any other immersion type of program. Therefore, Maine can't provide the many significant advantages inherent in those types of programs that can be critical to effective, efficient rehabilitation to blindness without having to send clients to these type of programs outside of the state.

Both home-based and immersion models have their particular advantages, but neither alone can provide all the elements needed for efficient, effective adjustment to vision loss. A truly effective blind rehabilitation program needs to have both. However, because those experiencing vision loss typically become isolated and cut-off from others and resources quickly, nearly all can benefit substantially, psychologically and practically, from at least some time spent with others in an immersion program regardless of individual goals and situations. This is reinforced by a study at Western Michigan University looking at post rehabilitation performance of skills taught during adjustment training, which found that the skills appeared to be used more frequently and at higher levels by consumers served in centers than by those trained in their homes.

The essential benefits of center-based and other immersion programs include:

1. Provides immediate, comprehensive training and application with a wide variety of fundamental and essential blindness skills and devices.
2. Provides a forum to help with the early establishing of peer and mentor networks which are necessary to help reduce the impact of isolation resulting from visual impairment.
3. Provides people with prolonged, meaningful interaction with blindness professionals, and others in a similar stage and situation, as well as those who have had some success and progress. In addition, the consumer new to blindness can readily see the progress in themselves and others, providing early, effective motivation and inspiration.
4. Establishes a cohesive comprehensive base of initial and essential skills, knowledge, and confidence that can subsequently be refined and expanded upon by home-based rehabilitation services.

Because, we understand that state resources needed to fund services at this level are unlikely to be available in the short-term, we are exploring ways to change the service delivery model to reduce the per-client cost of providing services. We anticipate that as client demand increases, we will endeavor to meet that rapidly expanding need by offering more group classes and centralized programs, while at the same time working toward building a mechanism for immersion programming and center-based training that will be available here in Maine.

Unfortunately, however, currently in Maine we lack the infrastructure needed to deliver group training and center-based services. Today, when we send clients out of state for center-based services (at the Carroll Center in Boston, for example) it costs \$1,500 per week per client. We believe that we can provide comparable services for less cost in Maine, but we need to invest funds to create the infrastructure needed to offer these services. This investment is critical, however, because, not only is local service delivery more cost effective than sending clients to

Boston for vision rehabilitation, but clients newly dealing with vision loss are more receptive to receiving these services in a familiar environment closer to home. Therefore, clients are more likely to accept services; thus, leading to more individuals becoming employed and reducing the high cost of unnecessary institutional care for elders with vision loss who lack the necessary skills to live independently. Furthermore, the adaptive skills needed by clients in rural Maine do differ somewhat from those taught in highly urbanized areas such as Boston where more highly developed transportation services and other support systems are available. Therefore, it is essential for Maine to develop the infrastructure to provide local access to group classes and appropriate center-based vision rehabilitation services.

One of the major advantages of our present blindness system in Maine is that DBVI has long standing, strong collaborative relationships with its other contracting partners. These partners have been extremely willing to work with DBVI to address any size of identified need. In this regard, the Iris Network has begun a long-term capitol campaign to begin to rebuild some of this infrastructure. In 2001, they embarked on the first phase of a two part project to renovate its facilities in Portland that predominantly serve Cumberland and York counties. Because Portland and surrounding areas of southern Maine are the most densely settled part of the State of Maine, we believe developing group training activities and center-based programs in Portland is likely to be a cost-effective means of serving more clients. The first phase of this project cost \$772,000 in 2001 and renovated approximately one-third of the Iris Network's Ryan Building (originally constructed in 1908 and substantially unchanged until 2001). They are now planning the second phase of this project which will renovate the remaining two-thirds of the space in the Ryan Building to provide space for group classes and some center-based programming. Their current estimates indicate that phase two of the Ryan Building renovations will cost approximately \$850,000. They hope to raise the needed funds to allow completion of the planned renovations to occur in 2012.

The cost of these building renovations is anticipated to be paid through philanthropy, thus minimizing the cost to the State of Maine for developing the physical infrastructure needed to deliver these services. The cost of operating programs and services, however, cannot be funded entirely with philanthropic resources and an investment into providing services in this manner will be essential.

Deafblind or Dual Sensory Impairment

The life of a person with Dual Sensory loss is often best understood through real-life descriptions of day-to-day things that are individual barriers for a person who only has blindness, or only has hearing loss, to live with.

For example, when sight is impaired a person can be taught how to use their hearing to enable them to travel safely and familiarize themselves with the environment around them. The use of the north, south, east, west technique can be used to locate buildings, streets, and facilities in a downtown area, and the clock system is often used to locate things within the body radius. A long cane enables you to feel for changes in walkways or in buildings (like ramps, stairs, or

curbs). In addition, sounds around you help to assure you that you are in the area you want to be in, or location of traffic noise can be used to enable you to cross a street safely,

A person who is deaf or severely hard of hearing doesn't have these same types of issues as this individual can maneuver most anywhere with the use of their sight. Looking around provides them with a wealth of instant information about the world around them. For example, seeing flashing red lights can identify a fire truck is near or that some other emergency vehicle is coming toward them but is still two blocks away. On the other hand, people who have severe hearing impairment have a difficult time with verbal communication. Not only is it hard to simply hear the spoken word for this individual, but also people do not understand communication with a person who does not hear. For example, the person may be able to lip read if the speaker is speaking in the same language, doesn't mumble or run their words together, or have a large beard and/or moustache.

Another clear example is in something as routine as the giving of directions. This task is accomplished with a person who is blind by another person using spoken words to describe things like "two blocks," "turn right," or "one block down and two doors on your left." A deaf person may be able to use these same directions if they can lip-read the person giving the directions, or if they can write it on a paper that the deaf person provides.

Now put the two impairments of hearing and vision together and try to understand how the person with a dual sensory impairment can not listen for the sounds of traffic to be sure they are going straight down the right road and not turn up a side street by mistake and leaving the traffic sounds behind. They are now lost with no ability to access external indicators to reorient themselves. The techniques used for traveling for a person who is blind will not work for somebody who cannot see nor hear.

When a person is both deaf and blind you cannot simply combine the adaptive techniques for blindness and those for the deaf and effectively meet the needs of this individual. The needs associated with this dual sensory impairment are unique and more complex than are those related to either blindness or deafness individually, and the training needed in alternative techniques is also even more specialized. In addition, the training needed by professions who work with this population is even more specialized than those for either blindness or deafness.

At the present time in Maine there are limited services for children who are deaf-blind, and virtually no specialized service for deaf-blind rehabilitation for adults. Adults experiencing both hearing and vision impairment who need this specialized type of rehabilitation are sent to center-based rehabilitation programs such as the Helen Keller National Center in New York. Although this type of program is highly successful, it is quite costly and we do not have the specialty trained personnel in Maine to work with the individual once they return home to Maine.

Even though the prevalence of deaf-blindness is quite low, the extent and intensity of the educational and rehabilitative services necessary are disproportionately high. In years past Maine has had at least one professional specializing in children, and another one specializing in adults with dual sensory impairment. Although we have an effort underway to expand our capacity for children and adults in this population, we are doing so with existing blindness professionals,

which means we will be simply moving their hours of service from one segment of the population to another. This will not increase our actual capacity to effectively address the needs of Maine residents who are deaf-blind. The need is for Maine to invest in having at least two professionals specially trained to meet the unique needs of children and adults who are deaf-blind, and who are compensated at a level that will minimize the risk of losing them to agencies in other states.

Access Technology

People who are blind use a wide variety of assistive technology across all aspects of their daily life. Access technology for persons who are blind incorporates everything from the most high tech devices like computers that read aloud what is written in print on the screen, electronic video magnifiers that magnify print onto a screen, personal notetaking devices that use speech or Braille to read the printed word, printers that can write Braille, all the way to low tech devices such as devices that can tell somebody what color something is, devices that indicate when liquid is reaching the top of a cup or glass, to calculators and wristwatches that talk.

Without a doubt the most important need for this technology is the ability to access print. These types of technologies are of paramount importance for being able to obtain an appropriate education, obtain or maintain suitable employment, or for being able to live at a higher level of independence in one's home. Being able to access print in an efficient manner is critical at all of these levels.

There are currently a diversity of private vendors providing necessary training in the use of a wide variety of access technologies. What does not exist in Maine, however, is a place where anyone with a visual impairment can go to see the various types of access technologies in one place. Being able to have such a type of demonstration center available in Maine for persons with visual impairments would allow for a much more cost effective manner in which to provide the necessary training required for the various technologies. This would happen in two ways. First, individuals could focus their DBVI sponsored training time on the exact pieces of equipment needed to meet their particular need. Secondly, persons who had already completed a comprehensive education or rehabilitative program through DBVI would have a place to access information on newer technologies on their own without having to be referred to DBVI for only this service.

Translators for Refugee Populations

We are also seeing an influx of refugee and immigrant groups dealing with vision loss who need costly interpreter services in order to receive the vision rehabilitation services they need. Many of these individuals are in need of the most basic of skills related to their visual impairment before they can even begin to consider becoming independent and contributing members of our society. Progress is extremely slow due to the various communication issues relevant to the various languages spoken by some of the refugees, many of whom speak very little English. In addition, diverse cultural beliefs also have to be considered when providing education and rehabilitative services to this population.

Documenting Unmet Needs

One key point that became clear in this work group was the current limited documentation of actual needs of students and adult clients. Throughout the proceedings it was clear that what is currently happening across the blindness system is to provide services based on the finite human resources available, rather than what is necessary for the person to obtain the quality education or rehabilitation program required to compete on an equal basis in their world. The current manner of documenting consumer needs is inadequate in terms of describing the true needs of consumers who are blind, and may well lead to a misinformed belief that our blindness system is fully meeting these needs. It needs to change immediately.

Group members agreed that the first step to understanding the extent of the need for additional resources was to document the true needs of our students and clients based on what they really need from our specialized blindness system, and then compare it to what we currently provide. In this manner we can more readily identify any gaps that exist between our present blindness system capacity and what our students and clients truly need.

To accomplish this task, the Resolve work group asked each of our blindness professional specialists to review their entire caseload and describe those instances where their students or clients have identified needs that are essential to their becoming as independent as possible, but that we cannot address in the amount of time available. These professionals were then requested to compile the number of hours per week that it would take to provide this base level of essential services.

The following are what was reported:

1. Teachers of Visually Impaired Children; 15 TVIs reported time differences between what they are presently able to provide to students and what their assessments say the students truly need. The total additional TVI time required to meet actual student needs came to 78.5 hours per week beyond what they are currently able to provide. Also to be considered are 13 students on a Services Pending List. These 13 students each require at least a total of 1-2 hours a week from a TVI. More TVI time is also necessary for assessment of new referrals generally about 1 hour a week for each TVI. No additional travel time nor lesson preparation time was calculated by the TVIs, but a conservative estimate would be an additional 20 hours per week for travel and 16 hours a week for lesson prep time bringing the total additional TVI hours needed to 146.5 hours per week (or 3.5 FTE;'s).
2. Orientation and Mobility Instructors; There are currently nine O&M Instructors. As a group they reported time differences between what they are presently able to provide to student and adult clients and what they believe these consumers truly need. The additional O&M time averaged out to 10 hours per instructor, with the total number of hours needed being 90 per week (or just over 2 FTE;'s).
3. Vocational Rehabilitation Counselors; There are currently eight VR Counselors. As a group they reported time differences between what they are presently able to provide to

transition-aged students and adult clients, and what they believe these consumers truly need. The additional VRC time averaged out to eight hours per counselor, with the total number of hours actually needed being 64 per week (or 1.5 FTE's).

4. Vision Rehabilitation Therapists; There are currently eight VRT's. As a group they reported time differences between what they are presently able to provide to student and adult clients and what they believe these consumers truly need. The additional VRT time needed totaled 54 per week (or 1.5 FTE's).

5. Blindness Rehabilitation Specialists; There are currently three positions in this class. Originally, these individuals provided services that support the entire Education Program, specifically working with schools and families. Two of these positions presently dedicate almost all of their work hours (approximately 70 out of the possible 80) to providing actual VR Counseling services. This equates to a minimum of 70 hours of time needed for these positions to just meet the base need they provide to students in the DBVI Education Program (or 2 FTE's).

6. Personal Adjustment Counselor; There is currently only one professional providing this service across the entire state. The sheer geographical size of Maine makes delivering Personal Adjustment Counseling in this manner quite impossible. The unmet need here is related to residents of Maine living in the northern half of the state as most of the clients served through this program are from Augusta south. The minimal need in this area is for at least one additional professional covering the northern half of the state (or one FTE).

These numbers encompass direct instruction and/or provision of service, as well as those activities necessary to support that direct instruction or service (i.e. lesson planning, report writing, and consultation). However, these numbers only reflect the unmet need that we have been able to determine to date. We also know there is a need to reinvest into maintaining current staff by compensating them at a level that will minimize the risk of losing them to agencies in other states.

Conclusion and Recommendations

The need for ongoing state support for program services that promote independence and community integration of Maine people who are blind or visually impaired is essential as we work to design and develop cost-effective methods of delivering necessary services in the 21st century and piece together a patchwork of diversified funding sources to cover the cost of these services. State funding for local access to, and state-wide availability of, these services must be maintained while we make needed investments to support the delivery of services for an increasing number of Maine people with significant vision loss in the decade ahead. Federal matching funds are available if the appropriate investment is made by the State of Maine. This investment will pay dividends by keeping people with vision loss living in their own homes and working in their communities; thereby being productive, tax-paying members of society.

Following a strategy of investing sufficient state resources to leverage the maximum amount of federal funding will ultimately reduce state expenditures by avoiding the high cost of

unnecessary institutionalization for people who are blind or visually impaired. In addition to being the most cost-effective approach for Maine, this strategy has the added benefit of changing our society to one that respects the ability of all people (regardless of disability) to contribute to a diversified productive society. We believe that Maine must make this responsible investment by providing new state resources to the programs of DBVI.

In looking at the identified needs it becomes abundantly clear that we need to reinvest in our human resource for blindness services in Maine to be able to meet the needs as they currently exist, and to build the system in a way that will also meet the needs of the greatly increasing number of additional clients with visual impairment by the year 2020. The above description of the unmet need of our child and adult clients is quite large, however, increasing the funding needed to add the 11.5 FTE's necessary to meet the current level of unmet need can be done if a systematic, sequential reinvestment is planned and followed.

It is important to note that the hours of service of the 11.5 FTE's are not neatly located in any one area of the state, but that the flexible nature of Maine's delivery system for blindness services will allow us to match our human resources to where the most immediate needs arise. Therefore, adding the needed additional human resources in a steady, well planned manner will provide for maximum use of the flexible nature of our blindness system.

The recommendation, then, for addressing the current level of unmet need is to add a minimum of one FTE per year for the duration of the next decade. Just committing to this basic approach will result in the addition of 10 of the needed FTE's. Funding for the remaining 1.5 FTE's can be added at any time there are sufficient revenues available to do so within the time span being discussed. The cost of adding this level of human resource is approximately \$90,000 per position (including salary, benefits and significant travel costs associated with each position). Adding all 11.5 FTE's during the ten year period we've been discussing requires \$108,000 per year.

Further evaluation is needed to continually assess the needs as they change in subsequent years in order to refine our delivery system as the numbers of persons with blindness increases significantly over the next decade. In order to accomplish this task it is recommended that DBVI conduct an annual review on progress and update on current needs, including recommendations and a plan for meeting such needs.

Against this dramatic need for increased services, the resources needed to provide these services have not kept up to the pace of inflation. In fact, the overall inflation rate from 1995 through 2008 increased 38%, while the General Fund expenditures for DBVI have increased only 27%. In addition, the DBVI General Fund Appropriation for both 2009 and 2010 have decreased even more.

We understand that there are not enough financial resources to implement this plan beginning with the current 2010-2011 biennial budget, but if the reinvestment plan begins with the 2012 budget cycle it still affords the ability to implement this systematic reinvestment approach in a responsible manner. The Work Group for L.D. 564 recommends implementation of such a systematic plan to invest in our future by investing in our people.

Respectfully submitted this 29th day of January, 2010

**Stakeholder Working Group
to Review the Current and Future Needs of Maine's Residents
Who are Blind or Visually Impaired**

Appendix A

RESOLVE Chapter 39

First Regular Session - 124th Maine Legislature

**Resolve, to Establish a Working Group of Stakeholders
to Review the Current and Future Needs
of Blind and Visually Impaired Individuals
and to Establish Long-term Solutions
to Fund Those Needs**

Sec. 1. Working group to review current and future needs of blind and visually impaired individuals. Resolved: That the Commissioner of Labor shall establish within existing resources a working group of stakeholders to review the current and future needs of blind and visually impaired individuals. The stakeholder group must include representatives from the Department of Labor, Catholic Charities Maine, The Iris Network, the Division for the Blind and Visually Impaired, the Department of Education, the Disability Rights Center and other interested parties. The group shall assess the current and future needs of blind and visually impaired individuals to determine the costs of those needs and to design a solution that will work to meet those needs; and be it further

Sec. 2. Reporting date established. Resolved: That the Commissioner of Labor shall report the working group's findings, including the proposed oversight of the Division for the Blind and Visually Impaired, to the Joint Standing Committee on Labor and the Joint Standing Committee on Education and Cultural Affairs by January 31, 2010.