

EXECUTIVE BOARD
COMMISSION FOR THE BLIND AND VISUALLY HANDICAPPED

May 21, 2009

MINUTES

In attendance were:

EXECUTIVE BOARD

Co-chairmen

Alan R. Morse, JD, PhD

Charles Richardson

Members

Carena Collura

Tara Cortes, RN, PhD

Christina Curry,

Karen Gouragey, EdD

Cantor, Dr. Mindy Jacobsen

Luis Mendez, Esq.

Julie Phillipson

COMMISSION FOR THE BLIND AND VISUALLY HANDICAPPED

Brian Daniels, Associate Commissioner

Peter Crowley , Assistant Commissioner

Joseph Nye, Liaison to the Board

Absent were:

John Bartimole

Maria Garcia

Tom Robertson

David Stayer, LCSW

The meeting was called to order at 8:30 AM.

Alan asked Carl to demonstrate the KNFB READER MOBILE by reading his Bio sketch which was to serve as an example of the biographical pieces being requested by the Governor's Office to accompany our final report. He wanted them by Friday, May 29,

2009. They were to be concise, approximately ½ to 1/3 of a page, or 200 words in length, and to exclude experiences not relevant to this Board.

Our annual report is being edited for inconsistencies and to ensure that the executive summary includes all topics in case some readers choose to read only as far as the end of it. Although the governor's office was pleased with the report, they would like to see it edited for inconsistencies and redundancies, so Alan and Ben Cady, the writer from Governor Paterson's office, are doing that and hope to have the completed report ready by next week. Much of the editing involves moving data around as opposed to changing it. In answer to the concern of several board members, they feel that, since this is our first report, its quality is more important than its timeliness.

FUTURE DIRECTIONS

The first idea posited was that we take a chronological approach – reporting on the causes and incidents of blindness in infants and youngsters, and recommending changes to the current system and service delivery.

There was also some inclination toward continuing to address some of the prevalent concerns of the blind community – transportation, mobility and quiet cars. One suggestion was to submit recommendations throughout the year as we have enough information so our constituents know that we are here and representing them. Another was to circulate resolutions to the legislature periodically, as we believe them necessary.

Another thought posited was that we report on one issue that affects each of the groups within our constituency—infants, children, teens, working age people, and seniors.

Focusing on diagnosis and intervention, as they affect our population, from infancy to seniors was another suggestion. If we could find ways of building a strong bridge between the Department Of Health, and education and rehabilitation in the blind service community, we would be doing a great service to our field.

MEETING SCHEDULE

It was decided that, in an effort to keep moving forward and keep to time deadlines we set for ourselves, we will meet several times, during the year, via 90 minute conference calls. Meeting more often will assist us with the follow-up we need. We will also change the location for some of our meetings. The calls will take place at 4:00, in order to accommodate those whose work schedules don't allow for mid-day meetings.

Alan will email us confirmation on the dates, but as of this writing, they are as follows.

July 23, 2009

September 10, 2009

February 11, 2010

May 13, 2010

In person meetings will be held:

October 28, 2009, Albany

December 16, 2009, New York City, THE JEWISH GUILD FOR THE BLIND

March 24, 2010, Albany

June 16, 2010, Albany

In answer to a query from the board, Joe Nye told us that, when our meetings are well publicized, there are 40 or 50 hits, but if it isn't publicized only ten to fifteen people access our webcast. It was agreed that if, for some unforeseen reason, we are unable to broadcast live from the Guild on December 16, the webcast will be posted, without fail, the next day.

THE QUIET CAR RESOLUTION

Mindy Jacobsen offered a rough draft resolution that we might use regarding quiet cars that Luis will edit and email to us for our approval. Alan will then begin to circulate it, where possible, to the legislature.

Mindy's motion that the Executive Board accept a resolution concerning the dangers presented by quiet cars, and, subject to the editing of Luis to comport with normal procedures and standards and legal language, that it be publicized throughout the state was carried unanimously.

A discussion then ensued regarding the priorities for the Board's next report.

Prevention of debilitating loss of capacity to work and accomplish tasks of every-day living is a high priority with Screening and identification of vision loss across the age span at its top. The board suggests that in our next report, prevention be defined, not only as a health concern, but on a second level, a psycho/social issue including the need to maintain functionality. Tara pointed out that when people lose vision, they often think they can't see at all because they seem unable to perform the activities of daily life, but in many cases, there is often some residual vision that they need to learn how to use. In conjunction with some O & M and vision rehab instruction confidence and functionality can be restored..

With reference to learning media assessment and preparation for vision loss, The Board recognizes that there is disparity within the field, with some advocating preparation for vision loss and some believing that each degree of vision loss should be addressed as it happens.

The need for Psycho and social aspects of vision loss is often recognized but not addressed as an integral part of a comprehensive vision rehabilitation plan.

We see our major task as the creation of linkages between the health education psycho/social and vocational sides of vision loss, and in so doing, to catch those things

that habitually fall between the cracks – to advocate for and gear our recommendations toward the establishment of a unified system that would address vision loss in New York State.

The board pointed out that one of the problems with providing the governor's office and legislature with citations for the current report is the ability of members to do the necessary research. Mark Leinung said that he would look into obtaining electronic access to the state library for us.

A thread that wanders through all of our discussions is the need to make the public aware of the signs and symptoms of vision loss and the availability of resources that can help. An ad campaign, however, is quite costly, and the report will need to reflect the importance of same, e.g. how many people in the state lose vision due to lack of screening, and thereby early intervention and treatment. What economic burden does that place on state resources?

Although it is not within the Executive Board's purview to initiate an ad or public service campaign throughout the state, we do have the ability to adopt a resolution that could be submitted to the Governor and/or the legislature recommending same. Stated in that resolution might be that a media campaign to create public awareness of the signs and symptoms of blindness, and busting some of the myths concerning it needs to be launched. It might be directed, at first, to ophthalmologists and other health care and education professionals, and teachers who might look for children who are squinting, unable to see things on the blackboard and/or other obvious signs of vision loss,

Alan suggests that a working title for our next report might be THE UNIFIED SYSTEM TO ADDRESS VISION LOSS IN NEW YORK, and that our suggestions, so far, include:.

- Identifying state resources,
- Preventing avoidable vision loss,
- Vision loss and its consequences,
- Screening and identification of vision loss across the age span,
- Psycho-social aspects of vision loss
- The learning mediated assessment
- Functional assessment and access to resources,

In answer to the question of colleges or universities doing some of this research, a discussion followed concerning the need and availability of jobs in the blindness field in the state. There are, apparently only 5 colleges and/or universities left in the state with Rehab Counseling programs -- HOFSTRA, SYRACUSE, U. ALBANY, , UNIVERSITY OF BUFFALO, and HUNTER COLLEGE. The programs at HOFSTRA, SYRACUSE and U. ALBANY, might be closing soon. HUNTER COLLEGE offers free tuition to its students. Despite the fact that there is a need for these services, jobs here don't pay well and are "few and far between". Depending upon the location of the service provider, CBVH funding only pays some 30 to 60 percent of the cost of the service. There is no lack of people needing rehabilitation services, but without funding from sources other

than those already allocated for rehabilitation, it is not possible, either to pay for new instructors, or to increase the overall salaries in the field in order to make it more attractive to prospective practitioners. Vocational Rehabilitation Teachers (VRT'S) and Orientation and Mobility instructors (O and M'S) are being paid approximately \$90 per hour by the VETERANS ADMINISTRATION (VA), and the private agencies for the blind and visually impaired need to keep pace in order to recruit and maintain their employ.

For this reason, several agencies, including the JEWISH GUILD FOR THE BLIND (JGB) THE LIGHTHOUSE and others have turned to the medical and insurance providers. They point to other disabling conditions that do receive reimbursement for rehabilitation, such as coronary disease and joint replacement and see vision loss on the same plain. With the rise of incidents of Diabetes, Macular Degeneration, and the baby boomer generation growing older and experiencing serious vision loss, they contend that the lack of functionality created by significant vision loss necessitates the inclusion of vision rehabilitation in the health care system and should be fully reimbursable. Furthermore, they urge us to consider that while health care reform is still on the table in congress, we might have the opportunity to advocate for reimbursement for rehabilitation services, prosthetics, durable medical equipment, low vision devices, and other assistive technology, which are of paramount importance, yet, not even being considered.

The meeting adjourned at 12:20 PM, for lunch and was reconvened in executive session for the rest of the afternoon.

Respectfully Submitted,
Mindy Jacobsen
Secretary