

**Suffolk County Disabilities Advisory Board
May 27, 2009 Meeting Minutes**

Corrected & Approved

A meeting of the Suffolk County Disabilities Advisory Board was held on May 27, 2009 in the Conference Room of Building 158, North County Complex, Hauppauge at 2:13 pm, Chairwoman Beverly Cody presided.

PRESENT:

GROUP A

Frank Krotschinsky, Esq.	Representing County Executive Steve Levy
Jack Caffey	Representing Legislature Presiding Officer William Lindsay
Linda O'Donohoe	S.C. Department of Social Services
Tedd Godek	Representing S.C. Department of Public Works, Design & Construction Division

GROUP B

Beverly Cody	Member, Secretary & Acting Chair
Kleo King, Esq.	Member, United Spinal Association

GROUP C

Teresa Strum	Member, Western Suffolk BOCES
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GROUP D

Mitchell Shapiro	Member
Roy Probeyahn	Member

GUESTS: Douglas & Erin King

STAFF: Heidi Zeitler, Senior Clerk Typist, Suffolk County Office of Handicapped Services

EXCUSED: Leg. Kate Browning, Judy Record, Joseph Sanseverino, Valerie Lewis, Terry Maccarrone, Glenn Campbell, Ingo Gloeckner, Paulette Bartunek, Alice Young, Barbara Falkman, Debbie Epple, Jim Sorrentino

APPROVAL OF MINUTES OF APRIL 29, 2009: Beverly asked if there were any changes to be made to the minutes as distributed. There were none. Jack made a motion to accept the minutes as distributed and Mitch seconded the motion. All were in favor and the minutes were unanimously approved.

CORRESPONDENCE: Frank had nothing new on correspondence to report.

CHAIRPERSON'S REPORT: Beverly brought along an article from yesterday's Newsday about the iBOT stair-climbing wheelchair. The iBOT cost \$22,000 each and Medicare only covers \$6,000, so they are halting production because they are too costly. One gentleman in the article said, "If I ever had to get out of this chair, I really don't know if I'd want to live anymore, to be honest with you." This gentleman is paralyzed from the chest down and on his second iBOT. Beverly wanted to know if there was anything the SCDAB board might be able to do. It also mentioned how Medicare pays tens of thousands of dollars for hip replacements to keep the elderly walking pain-free but a 70 year old who can't undergo that operation must become too impaired to care for them selves easily at home before being approved for a basic electric wheelchair. Jack suggested that committee's such as ours and other advocacy groups send letters to their congress, senators and to the President of the U.S. to make them aware of these problems. Kleo mentioned United Spinal has a campaign going on right now for what is reimbursable for just the basic wheelchair. Kleo said she has some sample letters available for drafts that we can use.

SCDAB

May 27, 2009

Page 2

Mitch added, this is just one of many issues which needs to be addressed including hearing aids, which are not covered by insurance or Medicare. This is why Mitch started the "Help America Hear Program." He has been getting inquiries from around the country because people can't afford hearing aids and there is no resource for them. Mitch feels we need to talk about the bigger picture, which is, more assistive tools are needed to help anyone who is disabled, not just one sector. Frank said it seems a bit arbitrary, what insurance companies cover and don't cover. Insurance companies don't want to cover the cost of an iBOT but in other instances will cover a prosthetic leg which cost \$100,000. Jack said unless you're really involved in the situation yourself no one really knows what is covered and what isn't covered and the public should be educated about it. Jack suggested SCDAB write a letter to our Legislators and also the County Executive requesting they pass a resolution on behalf of the people of Suffolk County and in the letter, include the information we talked about and tell them our committee is concerned that the iBOT is going to be discontinued. We advise that the Legislature and the County Executive to proceed with a resolution to the state government and governor to also have them do a resolution introducing Legislation. Mitch wanted to know if there was such a thing as a Fiscal Disability Education Day where people from different walks of life who have physical disabilities give demonstrations to all the Legislators on what its like to be in a wheelchair, blind, deaf etc.... Jack said he doesn't believe they do, but said you can go to the Legislature monthly and testify to present your concerns to them. Jack made a motion that SCDAB write a letter to the sub-committee chairperson, regarding iBOT being discontinued because it's too costly and also the lack of coverage available to people needing hearing aids. Also requesting they pass this on to the full legislature and offer to present this issue in person. Roy seconded the motion and all were in favor to write the letter and the motion was passed.

COMMITTEE REPORTS:

Architectural Barriers – Tedd Godek had nothing new to report.

Community Partnership – Frank had nothing new to report.

Education – Teresa mentioned in a past report that the Center for Medicare and Medicaid Services (CMS) was looking to stop reimbursing school districts for transportation services but now they are looking to rescind that regulation. At this time, the current ruling is to no longer support transportation reimbursement. The CMS is looking to reverse this. There is a 30 day comment period and a final decision should be made by June 30th. If it goes through, the regulation will be that they will reinstate reimbursement for transportation.

Housing - Vacant.

Legislation - Frank reported that every year in the Legislature, in Albany, they have a Disability Awareness Day where a significant amount of legislation is proposed that affects people with disabilities. Frank has the list if anyone is interested. Frank also mentioned the Air Carrier Access Act which affects the airlines has been amended, effective May 13, 2009 and has a lot of good changes in it. Frank has the summary but its several pages long if anyone is interested in taking a look at it.

Mitch thought Disability Awareness Day was for people to become educated about people's disabilities. Kleo said she has been there before and what they do is they try to push various bills that have disability as an issue. Kleo said she thinks the Independent Living Centers organize it and invite different legislators to come support their bills. Linda thought it would be a good idea to bring up the situation regarding the iBOT. Frank said he believes the iBOT issue is already out there because he recalls reading about it when he was at the Abilities EXPO in N.J. Kleo mentioned that there is a coalition of disabled groups and manufactures of those different types of wheelchairs that have been advocating with Medicare and Medicaid to fix the regulations.

SCDAB

May 27, 2009

Page 3

Beverly said she is still a little confused with whom are we asking to help regarding the iBOT. Frank said he thinks the theory is to get local government to put pressure on the Feds but review the funding. Jack suggested we also reach out to advocacy groups to let them know we want to work with them and that we are concerned.

Beverly said she would e-mail Bruce bringing this information to his attention and see what other agencies he would suggest to contact. Beverly asked Kleo if Bruce was involved with United Spinal and if United Spinal was involved with the iBOT. Kleo said they are involved with the whole Medicaid and Medicare funding of different types of medical equipment and said that Bruce is an active member of United Spinal.

Mitch asked if the Suffolk County Disability Advisory Board has a website. Frank replied no, that the S.C. Office of Handicapped is part of the County web-site but SCDAB does not have its own web-site. Mitch feels if we had one it would be a good place to utilize information.

Transportation - Cliff was absent.

Beverly asked if anyone had heard from Valerie lately. Some board members said they received an e-mail from her yesterday regarding her opinions on the Braille Bus stop signs. In the e-mail, Valerie said she reviewed the minutes from the last transportation task force meeting and decided to reach out to other organizations for more information. With the new information she received, the conclusion was that the Braille signs would not be sufficient and suggested the possibility of "talking signs." Jack said the talking sign would probably be more costly and there could be problems with hearing it when there is too much traffic noise. Jack feels with the way the economy is right now and how governments are strapped, to reach out and have something recorded in a way that can't be tampered with, would cost too much. Kleo said Valerie had also reach out to other groups that were blind or had visually disabilities and they were concerned that if the bus stops served more than one route, the signs may not be that useful. Jack asked what if the individual is blind and deaf and you don't have anything in Braille. Mitch said keep in mind, not everyone reads Braille, Mitch doesn't. Beverly said maybe we could start with making the Braille sign and go from there because if we wait to please everyone we won't start with anybody.

Employment – Alice was excused.

COUNTY DEPARTMENTS:

Suffolk County Office of Handicapped Services – Frank went to a meeting at SILO yesterday where they are preparing for the ADA celebration which will be held on August 1st at the Clubhouse in Bohemia. Five or six other agencies are also involved in the planning. Frank encouraged everyone to offer them their support.

Mitch asked Frank if he has set his own personal goals in his new position as director of OHS.

Frank said right now he is observing and learning the functions of the office, what people are doing. OHS does a lot of case work as well improving access for groups of people. Frank said it will be like this for awhile until he gets more familiar with things and as he gets ideas he will develop more of a vision and make the office more of his own. Frank said right now its budget time and it must be completed by June 8, 2009.

Suffolk County Parks - Terry was excused.

SCDAB

May 27, 2009

Page 4

S. C. Department of Social Services - Linda reported CDPAP open cases for April 2009 were 355. Starting in July their department is going to have a refresher training course on the ADA for all Supervisors and Receptionists. They will be visiting the various locations and are calling it, Train the Trainer.

S. C. Office of Public Information - Debbie was excused.

VESID - Ingo was excused.

Old Business - None

New Business – Roy reported that the Office of Mental Retardation and Developmental Disabilities is having a series of public forums. Long Island's public forum will be a video conference and they are combining L.I. with Schenectady and Seneca. It will be from 4-6 p.m. on June 10, 2009 at 415A Oser Ave., Hauppauge. Roy said if you wish to present testimony you need to sign-up. Roy also reported that there will be new Family Support Services money in the amount of \$982,000 this fiscal year, which is a significant increase.

There are a couple areas of concern because of the budget crunch, in the addition to the hiatus in residential development of group homes, there is also a concern regarding the Day habilitation graduating class of 2009, and if there will be adequate placement for those individuals.

Teresa said they have staff that work with their aging out students and they do a very good job of ensuring placement for every child when they leave, she is curious because nothing has ever come her way regarding difficulties placing these students. Teresa said she will try and find out some more information about it.

S.C. Department of Health/Division of Children with Special Health Care Needs – Barbara was excused.

S.C. Department of Public Works/Transportation Division - John retired.

Glenn/SILO - Glenn was excused.

S.C. Human Rights Commission - Paulette was excused.

S.C. Community Development - Joseph was excused.

S.C. Library System - Valerie was excused.

ADJOURNMENT: Roy made a motion to adjourn and Jack seconded the motion. All were in favor to adjourn the meeting. The meeting adjourned at 3:10 p.m. The next meeting will be held Wednesday, June 24, 2009 at 2:00 pm in the conference room, Building 158, Veterans Memorial Highway, Hauppauge.

Respectfully submitted,
Heidi Zeitler