

**Protection and Advocacy Advisory Board**  
Board Meeting and Forum Minutes  
June 17, 2010

**Present:** Eileen Furey (Chairperson), Arthur Quirk, John Clausen, Phyllis Zlotnick attended via telephone, Sheila Mulvey, Ray Elling, and Salina Welborn, PAIMI Chairperson.

**Absent:** Margarita Torres, Suzanne Liquermann, and Peter Tyrrell

**Staff Members:** James McGaughey, Executive Director; Gretchen Knauff, Assistant Director; Linda Mizzi, Assistant Program Director and Beth Leslie, Legislative Regulations Specialist.

**Call to Order:** 4:05 p.m.

**Introduction:** New Board Member - Ray Elling from Farmington.

**Attendance letters** went out to frequently absent Board members. Margarita Torres unable to continue because she is employed by BRS. Christopher Knapp and Heidi Mark are unable at this time to continue due to family obligations and have resigned. New letter to be sent to Suzanne Liquermann. Motion to send a letter to the Governor's office regarding the resignations was made, Art made the motion and Sheila seconded the motion, all in favor. Motion passed.

**Minutes and Conflict of Interest Policy:** John made a motion to accept the minutes and the Conflict of Interest Policy that had been discussed at the previous Board Meeting, Art seconded it. Seven yes votes; zero no votes, no abstentions. The motion passed. At the first meeting of the calendar year, the Conflict of Interest Policy and self-reporting form will be handed out.

### **Public Forum Guests**

**Ellen Wright:** requested information on the Hartford Transition Learning Academy (HTLA), now called "2550 Main Academy." Jim explained that P&A was completing an investigation and the State Department of Education (SDE) also did a report because of the continuous problems at 2550 Main Academy. This is the second time this has come to our attention and we intend to make a referral to the Office of Civil Rights (OCR) and possibly to the State Dept. of Education, probably toward the end of next week.

**Carlos Colon:** a self-advocate Coordinator in the DDS North Region. He wished to bring to our attention the lack of adequate transportation and employment opportunities. It is very difficult to get back and forth to work, if you can find a job.

**Melinda Montovani & Ruth Anne Graime:** (BIA of CT) Consumers with traumatic brain injury (TBI) have issues living in the least restrictive environment (LRE). Many people are confined to skilled nursing facilities (SNF). If a facility cannot handle the difficult behaviors, some persons with TBI exhibit, then they are removed from that home and placed in a home that is often on a watch list. They are not given adequate assistance in this setting, but the home takes them because they want to fill the bed. Or, they send people out of state if they have been rejected here, making it extremely difficult for family members/friends to visit. The number of SNFs not accepting people with brain injuries is growing. Homes dealing with people who have behaviors use punitive measures, restraints or isolation, moving them to an Alzheimer Unit. There are very few specialized programs available for persons with

TBI in Connecticut and it is a fast growing group. Money Follows the Person (MFP) is not really relevant, as the funds that people must ultimately live on are capped at a level insufficient to meet costs.

**Merva Jackson:** (AFCAMP) What are we doing for the youth in the juvenile justice system? At Manson Training School the situation they are in is a major problem. What can we do for the youth with learning disabilities (LD) and mental illness (MI), what can we do to help those youth with disabilities? We have worked with that population and we see education failure, evaluations that are not appropriate. We need to make advocacy for youth with special education needs and mental health treatment needs a priority somehow.

**Sheila Harris:** How many people on the ABI waiver and how many people does DSS have on the current list? Consultants' list for people on the ABI waiver get paid very well. There are other people who don't have any services. The ABI waiver is supposed to increase independence, but it is helter/skelter. Supportive housing for people in the DDS and Mental Health system, there is just no housing. Also asked if there is a premium program – a really good program in CT? If so, that should be the model. Also, P&A is the “best kept secret” in urban communities – OPA should do more public education/outreach.

**Merva Jackson:** We need to provide more information, culturally and linguistically, to our neighbors. We do a lot of work with children and their parents, who do not know their rights under ADA. They must know their rights to be independent, and then are able to access services for their children.

**Georgiana Felix:** (PAP) Padres Abriendo Puertas. The present educational system is the big monster. The economic crisis has hurt the children with disabilities more. Even though we have been able to train parents for their children; the schools are not providing adequate services to these children, they need assistance. The families have been going through due process to try and solve these issues. There are limited resources for legal support to parents. With IDEA 2004, parents must pay for the legal piece to be represented in due process. The legal support is very important for the educational system. P&A should prioritize getting a lawyer who can do special education cases.

**Kristen Giantonio:** Parent of a child with disabilities, advocates closing a loophole in the ADA. If you are an employed parent you are not covered by requirement for “reasonable accommodation” from employers, such as schedule modification or extra time off to take your kid to doctors' appointments. Only the person with the disability can get reasonable accommodations (although you cannot be discriminated against because of your child's disability). It's the same with the FMLA. There is a significant increase in numbers of children with disabilities and especially autism. She is on a waiting list for a speech therapist for her daughter. But, the appointments are dictated to you, so you have to take time off from work. Parents should be able to take your child for a medical appointment without fear of losing your job.

**Sheila Harris:** The Hartford Board of Education is looking at places not programs, kids are losing out; they are not providing therapeutic programming. They keep thinking, “Where am I going to house these kids?” The Parker Memorial Graduation Family Center, in Hartford, is available for educational support. We provide leadership training on IDEA and P&A part is on the ADA. How to help those families?

Time to put the P&A show on the road! Things are not right, there has to be an educational effort. We need to let the school system know that are not taking it anymore.

When P&A decides on the priorities, it needs to include education and training, how do communities organize to get needs met? Ray Elling responded that the community needs to mobilize, to learn its power. Many of members do feel like individuals, because there are no means to organize. Sheila reminded P&A that posting priorities and other things on its website leaves a lot of people who do not have computers out of the loop,

Sheila Mulvey recalled her experiences going to meetings for her son, saying. She felt very much alone in the room with all these professionals saying, 'leave it to us.' It never dawned on me to say I would meet with two people, than you can bring in two more people. It is a stacked deck. It's all driven because of the budget. Anything you craft in the way of a procedural safeguard can be perverted.

**Milagros Vega:** I am mother and grandmother who has been involved in special education for a very long time. A lot of concerns on how the economy is impacting services. My grandson has a very good teacher to help him learn to read. Her concern is that they are going to do away with teachers who have the most experience. Can we provide training in the schools for the parents? (After the forum closed, Ms. Vega approached Jim McGaughey and asked that future forums in Hartford be conducted with wireless interpretation so that she and other Spanish-speaking attendees could understand what other participants were saying.)

**Maria Riveria:** Echoed the concerns about the problems we are having in Hartford, all the reading problems, please do something for our children's reading programs. Thank you.

**Darlene Bourne** – Identified herself as having a son with autism. I am in a battle with the school system about housing for these children; need to develop something for the future. Eighty percent of children with autism are under the age of 21 and there are few, if any, group homes, nothing that was ever set up for the sensory issues that come up for our children. So after we are gone, our kids will need a safe place. Art Quirk suggested calling Corporation for Independent Living

**Merva Jackson** - we are starting to look at the long term and autism. NAIMI did a similar project like that in New Haven, in a subset of housing. Share with them what you want to do. Purchased housing through HUD or a housing unit because this children will outlive their parents. Look for people to join the Autism Group - All Seasons Academy, we are an idea.

**Georgina Felix** - DDS is wonderful but nothing was ever set up for sensory needs, it is so hard. Dr. Steven Becker of HART toured their facility; he is a very good resource.

**Sue Pedersen** – We have a good relationship with P&A. I have spoken with P&A about the use of Video Relay Interpreting (VRI) which is being used extensively in hospitals. The hospitals do not use live interpreters, prefer to use video remote interpreting, sign language differs throughout the US, and the ADA mandates effective communications. An elderly couple contacted her this morning; many frustrations for attorneys will not use interpreters. What is an appropriate accommodation? We had P&A help us and a Consent Decree settled a lawsuit against hospitals. That decree expired; the Hospitals are going back to their old ways, except now they have newer technology but no

understanding of when and when not to use it (or sometimes even how to use it). There are a lot of frustrations. VRI does not do the job, most VRIs are out-of-state personnel. What does the ADA really expect from them?

**Jim Pedersen** – basically share an experience I had at St. Francis Hospital. I went into register for an admission; I would use VRI equipment as long as they have this equipment for triage only, not when I am having a conversation with the Dr. The VRI signed “LW” and it happened again, I asked what it was, she spelled out “living will”. I am thinking of what other patients might have understood this to mean. I was just trying to be unbiased, you cannot make an expectation that they know what LW means.

One other thing, deaf people want to see movies but movie theaters have no captioning, no rear-window captioning. We want to be able to go to the movies with our grandchildren.

**Ray Elling:** getting organized in Farmington in fighting city hall, the Citizen Collaborative for Equal Advocacy approached the post office to install power doors, if we raised the money, both post offices would have power doors, but it is not the answer.

Ray brought a letter from Chris, HR Commission in Farmington, has problems with getting to doctor appointments. The van for transportation is overbooked, is often late to pick people up, making them later for their appointments. There are other problems with the drivers.

Ruth the Chairperson has worked with Chris Palamis and has identified a lot of issues in the Unionville development, the Stop & Shop developments: inadequate curb cuts, in charge of city facilities, and a list of all the problems with doing these services, getting around with a wheelchair. There are traffic problems and infrastructure issues. Some towns the commissions are quite active, are looking for help.

**Minutes.** Minutes from previous meeting were unanimously accepted.

Adjourned: 6:10 P.M.