

Protection and Advocacy Advisory Board
Meeting Minutes
March 22, 2012
Conference Room B

Attendees: Art Quirk, Chairperson, Ray Elling, Vivian Cross, and John Clauson, via conference call: Muriel Tomer, Chad Sinanian, Rachel Bogart, and Joyce Peters.

Absent: Sheila Mulvey

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

Call to Order: The meeting was called to order at 4:05. Quorum noted.

Review of Minutes: Minutes will be sent to Muriel for review, approval considered at next meeting.

Consolidation update and next steps:

It was announced in January that the Office of Protection and Advocacy for Persons with Disabilities and the CHRO would be joined to form a new department, the Department of Human Rights, Protection and Advocacy. The proposed budget zeroed out P&A's state funding as a stand-alone agency and included implementing language that would have removed OPA's authority to make independent hiring, budget preparation and expenditure decisions. There were two hearings on these bills before the Appropriations Committee. The good news, OPA had a lot of support at the hearing. PAIMI Council Chairperson, Muriel Tomer, organized a Change.org petition and also spoke to the Committee; Jim has sent out over 50 thank you notes. The Commissioner, Sharon Lewis, from the federal Administration on Developmental Disabilities (ADD) sent a letter to OPM regarding requirements of federal law. The letter states that the state cannot re-designate a P&A system without good cause, and that any change in the existing governance structure would be considered as an attempt to re-designate. Ray has discussed with his representative that this was a very bad idea. Other Board members contacted their legislators and/or testified. On-line petition on www.Change.org contains over 500 signatures against any consolidation, each time it is signed an e-mail goes to the Governor and all the members of both houses. Change.org contains many excellent comments; Muriel did a legendary job on this. Appropriations Committee Members are hearing a lot about the already dismal results from the initial group of consolidations done last fiscal year. Last minute deals, negotiated in the final hours may still harm the agency's independence, we must remain diligent in keeping our representatives in the know about the loose of funding resulting from any merger that redesignates the P&A without just cause or going through the required public hearings, etc. The consolidation does not create any savings, just numerous problems.

Joyce felt that there would not be sufficient protections for vulnerable populations if this merger moved forward. Board Members backed starting a committee to study the future of P&A.

Jim explained that other organizational platforms from which P&As in other states operate include private non-profit corporations and quasi-governmental agencies/authorities (similar to current structures in Virginia and North Dakota). The community would have to have input, and all the correct steps would need to be followed for a “friendly” re-designation. If the Legislature does enact the proposed consolidation, the feds would likely conduct a review and find us out of compliance. Then there would be a big scramble, probably producing a radical change and not necessarily a positive one. There is a major trend across the country for state-agency P&As to be re-designated as private non-profits. The non-profit platform has much to recommend it. However, the Connecticut P&A has operated as a State agency for many years and done so effectively. P&A’s Abuse Investigation Division operates pursuant to State statutory authority to conduct investigations and is an integral part of the State’s system for protecting people with intellectual disability (ID) from abuse and neglect. In addition, the most important asset, and the value we contribute to people with disabilities in CT is tied to the experience and expertise of the staff. If the agency is privatized, we would likely lose the bulk of the staff members, and that would be a real loss for people with disabilities.

Based on a Board – sponsored “stake holder group” initiative, a 2013 legislative proposal strengthening the independence and structural integrity of the agency could be developed and presented for consideration. Long-term, OPA needs a better structure for the agency to make it less vulnerable. Ray pointed out that the time and energy that must be spent protecting the independence and capacity of the agency diverts resources away from real advocacy and safeguarding issues.

Discussion about DDS eliminating their program review committee, nothing concrete. OPA needs to retain its independent watchdog abilities for the protection of DDS clientele.

News from the National P&A System (NDRN), current projects:

- 1) real employment initiative;
- 2) special education transition focus;

National P&A System News (NDRN) - Jim attended CEO meeting in Washington. There are a number of initiatives; one being encouraged is to remove sheltered workshops, which are allowed to pay workers a fraction of the prevailing wage. A lot of the work done at these “workshops” is pretty meaningless. They are a form of exploitation, and need to be transformed into real employment opportunities.

The special education report “*School is Not Supposed to Hurt*” discusses restraint and seclusion in public schools. The second follow-up report features a picture of the Middletown parents’ public meeting where the “Scream Rooms” were discussed. P&A is working with the Office of the Child Advocate to produce a joint report on the Middletown “Scream Rooms”. National legislation has been proposed to eliminate the use of seclusion. Jim met with Rosa DeLora’s office on this matter.

Legislative Update – status of bills currently before the General Assembly

- 1) The Legislative Program Review and Investigations Committee made recommendations that died in committee because Dr. Macy is already implementing those recommendations. The information is available on the P&A website www.ct.gov/opapd Legislative Section.
- 2) Bill on Unionization of PCAs, died in committee. In the Labor Committee it appeared as an amendment on another bill. Muriel Tomer said the union vote is taking place next month. The union received a list of PCAs and made several attempts to contact them to determine who would be interested in unionizing. The Gov. Exec. Order mirrored the legislation from last year and the previous year, there are some legal challenges to his authority to create this type of Executive Order.
- 3) Proposed Senate Bill 452 on outpatient commitment about people with psychiatric disabilities. The probate court can commit someone to a hospital if they are a danger to themselves or others. The issue, *can you force people to take medication while living in the community, when they do not rise to the danger level?* Judge Killian will make the argument for outpatient commitment by the Probate Courts.
- 4) Discussion on State Buildings’ inaccessibility and what was being done to improve the situation. Edith Prague congratulated Beth Bye on her work in this area.
- 5) A proposed bill to give a disabled person who is living at home a priority status in having their electricity turned on first following service interruption due to severe weather. Individuals would have to self-identify that they needed this status, it did not move forward. But, electric companies have to file a regular plan for vulnerable populations.

Special Education issues:

- 1) There is an attempt being made by CAFE, the superintendents’ group and lawyers who represent districts to change the “burden of proof” in Due Process hearings. This is the latest battle in an ongoing war between the school administrators and the parents’ advocacy groups. In a Due Process hearing for special education under the

current regulations, the Local Education Authority (LEA) must show that the program proposed for the child is appropriate. The State Board of Ed is feeling pressure from the districts to change pending regulations.

- 2) (Rachel) Why don't the law firms representing schools donate some pro bono attorneys for parents? They are making lots of money off of the school systems. Also of concern in the regulations the "response to intervention" delays, Federal Special Education laws require attempts at intervention (e.g. alternative teaching strategies) before automatically referring a child who is struggling to learn for special education. But that requirement is not intended to delay evaluations and special education services for children who are manifesting evidence of learning disabilities. Letters have been issued clarifying this, but the practice of delaying much needed special ed. referrals continues.

Lead Poisoning Awareness:

- a. There are compliance issues with the 2009 law that was passed in 2007 regarding mandatory lead testing of children. So what do we do about getting pediatric care providers to comply? Kids' rights are being violated. Dr. Vivian Cross approached the judiciary chair, as a result of the forum on lead poisoning to recommend that guidelines need to be developed; the Center for Public Policy and Social Research of Central CT will take this on as a project.
- b. Commission on Human Rights and Opportunities (CHRO) have agreed to take on the issue of ensuring that children are screened for lead levels. Presently there are many towns, in fact, most towns in Connecticut that are non-compliant with ensuring that children are screened. A simple finger stick is all that is required. Right now, towns have Ds and Fs, coastline towns have Fs. Senator Harp participated in a Legislative Informational Forum called: "A Call to Action to Eliminate a Preventable Contributor to the Achievement Gap: Childhood Lead Poisoning." In a press release Senator Harp stated: "To begin with, we must work to improve BLL screening rates and redouble our efforts at prevention and early detection of lead poisoning in Connecticut's children."

Ray shared that the CC=A secured funding through Mary Beth Bruder, as part of a grant, to hold a 5/16 forum/discussion from 5 to 9:00 p.m. regarding action goals for Farmington for Access and Inclusion.

Adjournment - mMotion to adjourn made John Clausen, seconded by Ray Elling, meeting adjourned 6:10.