

Protection and Advocacy Advisory Board
Meeting Minutes
June 16, 2011
Conference Room B

Attendees: Art Quirk, (Acting as Board Chair), Eileen Furey, Ray Elling, Joyce Peters, Vivian Cross, and John Clauson; via conference call: Chad Sinani and Phyllis Zlotnick.

Absent: Peter Tyrrell, Muriel Tomer, and Sheila Mulvey

Staff Members: James McGaughey, Executive Director; Gretchen Knauff, Assistant Director; Peter Hughes, AID Program Director; Bruce Garrison, PAIMI Assistant Program Director; and, Beth Leslie, Legislative Regulations Specialist.

Call to Order & Quorum: The meeting was called to order at 4:05, and the presence of a quorum was noted.

- 1) **Consideration of minutes:** Art noted that OPA Advisory Board Minutes are on the P&A Website. No changes were suggested. Eileen made a motion to approve, Phyllis seconded, all approved. Minutes of the March 17, 2011, meeting were approved.
- 2) **Legislative Report** (Beth Leslie)
 - a) Beth is writing the 2011 Legislation annual report regarding the bills affecting people with disabilities. Highlights:
 - i) Bureau of Rehabilitative Services (BRS) looks something like the old Bureau of Rehabilitation, but is no longer a program of the Department of Social Services (DSS), although it will use the DSS business and personnel offices for administrative purposes. The new BRS will include Board of Education for the Blind, all old BRS services and programs, Department of Motor Vehicles (DMV) driver training program, and Workers Compensation;
 - ii) Electronic recording of custodial interrogations (when people are arrested and charged with major crimes) passed; but it becomes effective in 2014 in order to let police agencies have time to acquire equipment;
 - iii) Department of Developmental Services (DDS) Sexual assault bill approved (allows person who is paid to take care of people with Intellectual Disability to be prosecuted for sexual assault even if the claim is made by both perpetrator and victim that the sexual conduct was consensual);
 - iv) P&A was put onto the State Department of Education's (DOE) Statewide Advisory Council for Special Education. P&A and BRS were added by statute.
 - v) Act making revisions to DMV – no more disability license plates was passed;
 - vi) An act concerning review of the cost of mandated special education services; this is a study (and bears watching);
 - vii) Respectful language bill by DDS passed (Bill #6279) effective May 24, 2011, replacing the term “mental retardation” with “intellectual disability”. (Note: singular or plural it is

“intellectual disability”). Art requested the P&A Website be updated to reflect the respectful language law.

viii) Beth does not know if Sen. Bye’s bill No. 720 passed regarding vulnerable pedestrians.

3) **PAIMI Council Update Report by Bruce Garrison** – Murial Tomer was unavailable to attend. New council members bring the Council to 15 individuals; a very dedicated group. The Council continues to work on the goals and objectives set last year.

- a) Staff have been conducting and writing reports on a number of investigations into serious injuries related to restraint and seclusion (R&S). Initial reports are received from state oversight agencies that are required to report serious injuries to P&A. We see that children are being injured; we want to ban the use of R&S in all but true emergencies, there are alternative strategies that are more effective and less dangerous. Positive intervention supports need to be included in Individual Education Plans (IEPs). Eliminating reliance on R&S is a leadership issue. We have been in contact with DCF and DOE, meeting with leadership regarding the behavioral health needs and what is needed educationally. A child who has both going on needs coordinated approaches in both residential treatment and school environments. Dr. Cross questioned if it is an issue of non-compliance with the current program the child has in place; the IDEA says individualized programs, functional behavioral assessment should be included as part of the process. At some point, you must demand that they bring the correct people to the PPT. Developing the curriculum to empower parents is vital to success.
- b) A public forum was held to discuss medical and mental health issues. Poor medical care for chronic physical disorders and illnesses has long been a feature of the mental health care system. This is especially problematic as so many of the psychotropic medications prescribed for people with mental illness have major consequences for physical health.
- c) Another PAIMI AC work group is focusing on parent training. That group is charged developing a curriculum to help parents understand their child’s mental health and education rights.
- d) Council members are doing assessments to measure a inpatient facilities’ level of respect for patient rights; they are going to Bridgeport, Hospital of Central Connecticut, and Midstate Hospitals.

4) **Abuse Investigation Division Report by Peter Hughes**

- i) Hired Forensic Nurse Investigator Diana Macomber, who comes with a lot of experience in the field, graduated from the Quinnipiac Masters program in Forensic Nursing. Ms. Macomber is working with investigators and reading reports dealing with medical and death investigations.
- ii) The updated version of Access was installed on 3/29 for the AID database; we believed it would help eliminate the unexplained quirks in the statistics; it did help somewhat, but some of the numbers are still not accurate. Auditors came in May and wanted to know if the figures were being accurately reported now. Although it functions quite well to facilitate individual investigations and as a daily management/assignment system, it falls short in providing accurate overall longer-term management information. At some point we will need to replace the data base – it is quite old.
- iii) Records retention reviews are always large projects and we have recently cleaned up quite a number of older records.

- iv) Department of Developmental Services (DDS) has a new State Police Sergeant in charge of the Division of Investigations, which serves a parallel function similar to P&A; they do investigations as assigned by our program. DDS has a new Commissioner, Dr. Terry Macy.
- v) Met with Kathryn Dupree, DDS Deputy Commissioner, to discuss protective services. We asked the DDS to address the specific services within protective service plans. Deputy Commissioner Dupree was not defensive but committed to getting these cases resolved; she met with the regional directors of the areas.
- vi) Next quarterly Commissioners meeting next month, agenda to be set by Tuesday. Preparing the end of the year 2010 report; some of that is in the annual report.

5) **Executive Director Update, James McGaughey**

- a) Jim has been trying to figure out P&A's role on the Department of Education Statewide Advisory Council on Special Education. A majority of the members are parents. State Representative Carter is also on the Council. At the request of parent members of the Council's Legislation Committee, he initiated legislation to put P&A and BRS on Council, and it passed. DOE does not get to appoint someone from our office, we make that decision. Jim had attended meetings for several months as an ad hoc member, but with passage of the bill he is a permanent member.
- b) Jim met with Terry Macy, new DDS Commissioner, and conversation included incorporating safeguards; Terry expressed belief in individual supports for people and families. He wants to take a cutting edge approach. Jim discussed ways to incorporate the concept of "safeguarding" in these innovative models. The need for this is underscored by recent scandals in New York, and the arrest of a Community Training Home operator in Hamden for multiple instances of abuse. The idea is to build things like support for personal relationships and periodic individual, off-site visits with individuals into each person's plan. Commissioner Macy will come in September for our Board Meeting to describe what he sees as the future of DDS.

How best to make the case for maintaining P&A as an independent agency.

In the fast-changing world of government (state and federal), considerable emphasis is being placed on restructuring, economizing, down-sizing and consolidation. Very few current leaders have any experience with disability rights issues or P&A. How should the agency explain the value of maintaining its independent investigation and advocacy capacity in the face of efforts to consolidate small state agencies, and to eliminate agencies and programs altogether when they are perceived as having been created primarily to make other agencies do the jobs they ought to be doing anyway?

Art felt Jim's letter to Secretary Ben Barnes was a very powerful letter yet very condensed. The idea is to pursue long-term strategies that educate policy makers and other advocates so as to reduce the need for "powerful" letters. In the ensuing discussion two strategies emerged:

- Successfully marketing P&A.
- Mobilizing P&A supporters.

To further both, it will be necessary to figure out who we are targeting, and to find out what they need to know. The community organizing/political action approach could involve systematic outreach to disability groups, soliciting their experiences and success stories about P&A. They could participate in a “how to get the word out” day; learn how to contact legislators, etc.

Ray and Art disagreed regarding the extent to which this organizing approach was included in the concept of marketing. Nonetheless, there seems no inherent conflict between these strategies – both could be pursued, although Jim pointed out that it is awkward for governmental agencies to invest heavily in marketing or to recruit and organize their own armies of supporters who engage in political action. He said it would probably be better to reach for constituent support through existing groups whose members might support us a part of their “cause”. We also need material that can quickly and accurately brief people about what we contribute “at a glance”. A general discussion of ideas ensued. Suggestions included:

- ❖ Identifying the target market, who do we need to reach?
 - ❖ Identifying supporters
 - ❖ Identifying sources of expertise in marketing
 - ❖ Public service announcements - radio, television, public announcements, the real story, very Sunday morning they talk about issues, constituents.
 - ❖ Tell stories that touch the heart, e.g., what were the benefits that P&A realized for this individual? Perhaps there could be a series of case studies.
 - ❖ Joyce suggested that we invest in issues-oriented training. In this climate there is a possibility of putting people at risk. By offering specific training you not only educate people about the risks to vulnerable people and what can be done to reduce those risks, but you also increase the visibility of P&A. Being involved in the concept of safeguarding around these formats and to put this forward, marketing this as an idea; plant it in people’s minds now and put it in their system. Become identified with that issue.
 - ❖ Plug into some existing coalitions. Don’t assume that everyone understands P&A, like the new administration. You know the things about P&A that brought you into contact with the agency, but often you do not have the full picture of what the agency is about.
 - ❖ A sound bite.
 - ❖ Dr. Cross offered graphic representation she uses to brief people – everyone from Senators to parents – on the effects of childhood lead poisoning, and what can be done about the problem. Similar one or two page graphic presentations could really help; a picture worth a thousand words.
 - ❖ Facebook, when are we going to get a Facebook page? Facebook page goes back to the website.
 - ❖ CTMirror.org, electronic newspaper, did a report on restraint and seclusion; they have a lot of information.
 - ❖ How do you reach out to the Courant? Feed them stories.
 - ❖ There is no one who solely focuses a website.
 - ❖ Fairs and festivals are coming up through the rest of the year.
- Ray Elling felt that Nancy Wyman is a person you can talk with. The essence of the P&A message is the value of independence for the agency, and not being combined into something else. The prevailing ethic is to combine, streamline and not have little silos, and the theory is

that this will generate more efficient government. But Protection and Advocacy only functions if we can call our own shots. We need to tell the world how good we are.

- OSERS statement that LEAs denying services to children, links the achievement gap and scoring poorly because of children with lead poisoning. Data from the CDC shows that 19,400 under the age of 6 that have lead poison. Dr. Cross has been talking about this for seven years. New research from Duke University showed 35,000 children with over 77,000 children that were impacted and put at risk.

Ways to focus public attention on problems involving abuse and neglect.

Much of the work conducted by the Abuse Investigation Division is kept confidential. Even Case Services investigations, which are conducted pursuant to federal P&A authority, are typically not publicized. Nor is the advocacy work that sometimes results. The main reasons for this are: 1) to protect the identities and privacy of people who have been victims of abuse and neglect; 2) to encourage greater cooperation from witnesses, families, etc.; and, 3) to ensure the agency complies with statutory requirements regarding confidentiality. While these considerations are undoubtedly valid, we may be overdoing it. And, in the process, we may be depriving both the public and policymakers of access to information concerning the realities of abuse/neglect. Does the Board have suggestions about how we can reconcile these two competing values?

How do we explain to people? We want to tell the stories but we have to keep information confidential. PAIMI did a report and redacted the name of the facility. The story of what happened to them, the massive scale of putting people into the facilities. It was suggested that we tell personal stories using pseudonyms and also provide overall statistics about the scope of the problem of abuse and neglect. Again, this could be an issue that the public comes to identify us by.

- 6) **New Business & Updates** – Dr. Cross shared an update on Duke University lead poison study that was presented by CTN - the outcomes of Phase 1 of the study. Clearly the data speaks for itself. Thousands of children in special education are there because they have been lead poisoned, between 1997 – 2007; 17,000+ showed elevated levels of lead. Advocates have long suspected that this affects school dropout rates, and even incarceration rates, but the Duke study clearly shows the correlation between lead poisoning and scores on the Connecticut Mastery Tests. Thanks to universal blood lead level screening, we can identify individuals who are at risk of educational and behavioral problems – individuals who need early intervention and special education services. Yet, despite the availability of this information and the overwhelming evidence of the relationship between lead poisoning and special education needs, educators have done nothing to reach out and identify students who need help.

Questions were asked regarding where these children are located, and what can be done. Given the importance of the issue, Art asked that it be included as an item for full discussion on the agenda for the next meeting.

Sept. 16, 2011 – is the next meeting.

Adjournment – 6:15