

Protection and Advocacy Advisory Board
Meeting Minutes
October 16, 2008

Present: Rachel Bogartz, Margarita Torres, Eileen Furey (Chairperson), Walt Wetmore (PAIMI Chairperson), Arthur Quirk, John Clausen, and Phyllis Zlotnick attended via telephone.

Absent: Walter Pelensky, Suzanne Liquermann, Sheila Mulvey, Peter Tyrrell, Heidi Mark and Christopher Knapp.

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

- 1) **Call to order** at 4:07; quorum is present.
- 2) **Review of Minutes:** several corrections – spelling of Rachel’s last name, add Peter Tyrrell to the absent listing, and ICL changed to CIL (Corporation for Independent Living). Walt made motion to accept minutes, Art seconded, minutes accepted with noted corrections. Under state statute the minutes are posted to our website within seven days of the board meeting and the agenda is posted not less than 24 hours before the meeting.
- 3) **Ground Rules for Meetings.** We will follow the agenda and have added a New Business section for Board Members to bring requests for new information or to discuss topics not listed on the agenda.
- 4) **Priorities:** Based on the discussion at the previous meeting, Jim presented a draft list of priorities for 2009. As suggested by Board Members, most of the issue areas are the same as were identified in 2008, but greater emphasis will be given to calling public attention to problems people are having securing the supports necessary to live as members of their communities, and to matters related to employment discrimination. Board Members commented on the specific areas identified as follows:

a) Protect rights, identify barriers, and increase awareness of benefits related to community inclusion of people with disabilities.

- i) Eileen requested that the terms “DMR” be changed to “DDS”; and, “mental retardation” be changed to “persons with intellectual disabilities”.
- ii) Rachel strongly believes that educating policymakers regarding barriers to living and working in the community is very important. Jim explained that public hearings would be useful to gather necessary information and then to write a persuasive report about the findings.
- iii) The Access Board has two main responsibilities. They advise on policy questions that arise as a result of requests for waivers of the accessibility provisions of the State Building Code; and advise on positions to take with respect to proposed regulatory (e.g. code) and legislative changes that potentially affect accessibility.

b) Safeguard the rights of persons with disabilities living in institutions or at risk of institutionalization.

- i) Protection of rights for people is a good priority to continue. John asked if the Mansfield (CARC v. Thorne) Consent Decree, and implementation plan, “Hello, my name is Jenny”, are still in effect. Jim explained that the State has never sought nor been released from the provisions of the Court’s “Final Order” in CARC v. Thorne, but that the “Jenny” document described a specific plan that was completed. Conditions at Southbury Training School (“STS”) improved as a result of the USA v. Connecticut (Justice Dept.) Consent Decree and subsequent enforcement action. However, in its recent decision in the class action case (Messier v. O’Meara), the Court found that people at STS were being denied their rights to be considered for community placement. STS has 495 people and OPA advocates for approximately 40 clients. Because it is the single largest concentration of people with developmental disabilities in the State, P&A needed to have a presence there. The judge found that Teams were routinely deferring to guardians and parents, who often didn’t really have any options to consider. The Judge said that they needed to be shown concrete, specifically developed alternatives. A DDS PRAT (planning and resources allocation team) is assigned to allocate resources, but usually just says that nothing much is available. The Judge said DDS needs to affirmatively create placements. The problem for the State is that the cost of operating the institution is high, Majority of the West Region’s funds goes to keep STS running.
 - ii) In response to discussion about what the term “institution” means as used in the priorities, Jim said that it means congregate facilities, like regional centers, state hospitals, prisons and jails, nursing homes, residential care homes (board and care homes), and STS. It does not mean small community residences, apartment programs, supported housing, etc.
- c) *Increase awareness of abuse and neglect*
- i) The number of reported allegations of suspected abuse and neglect are significant. It is very important that we continue to get the word out, most people did not get into this field to hurt people, but it happens.
- d) *Protect educational rights of children with disabilities.*
- i) Schools should know what the law expects from them regarding special education. The mandate is to begin with the presumption for including each child with a disability in typical schools and classrooms, and to use separate approaches only when it has been shown that the regular environment won’t work even if the child is provided with specialized instruction, curricula, services and modifications. The effort to identify a student’s special education needs is very individualized. When kids are placed in special education settings they are often thought of as fundamentally different by their peers and teachers. OPA receives calls when something is not working out well and we have very limited advocacy and legal staff to address each individualized situation. We try to take on issues that will make a larger systemic change for the improvement of these services.
 - ii) The services provided vary from district to district. We are trying to change things on larger issues. Two groups, PAP & AFCAMP put their focuses on building groups of parents to advocate for their kids. We have also contracted with CLS to take on some

special education cases. Given the budget problems in government today, we focus on educating and changing widespread problem areas where the most good will result.

- e) *Educate individuals with disabilities about employment rights and support options that help secure employment.*
 - i) Employment discrimination cases are expensive cases for lawyers because there is a great deal of discovery required. We have assisted a number of people with filing Commission on Human Rights and Opportunities (CHRO) complaints. Americans with Disability Act (ADA) law is the primary federal non-discrimination law and the Equal Employment Opportunity Commission (EEOC) deals with employment. The ADA Restoration Act re-establishes the law, and provides a congressional override of Supreme Court rulings. There are some differences between State and Federal laws that prohibit discrimination of people. The State says that an employer of three people and federal law says fifteen are covered.
 - ii) We will try to provide legal representation to at least two individuals who have experienced employment discrimination. Our managing attorney has been given directions to pursue alliances with pro bono counsel. John - What about law schools? We have employed interns before, the difficulty is they are on an academic schedule and finish up by the end of the semester. However, we will look again.
- f) *Housing*
 - i) Essentially this priority if unchanged from last year.
- g) *Health care*
 - i) We have removed dental care for people as DDS has hired a Dental Care Coordinator. She appears very committed and has met with the UCONN clinic and is pursuing different options.

Walt made Motion to accept priorities, as revised, seconded by Art. Full Board voted to accept.

5) **Executive Director Report** – Jim reviewed the Executive Director Report that had been sent to the members. Full report follows at end of minutes.

6) **New Business**

- a) All future Board Agendas will include a section for the PAIMI Chairperson to present a report to the Board on the activities of the PAIMI Council.
- b) John Clauson is a member of the DDS Human Rights Committee and expressed concern over the practice of care providers requesting financial restitution from a client who has a propensity toward breaking or damaging things (i.e., lamps, eye glasses) when they do break something. Discussion included: Should their meager funds be attached? What is the client's ability to comprehend their actions as being wrong or did they understand the punitive act of having to pay for their actions? What is the responsibility of the provider who, knowing full well this client's behaviors, who continues to place the object(s) within breaking distance? Would this be a case by case situation, looking at the overall fundamental problems? Is this a question of rights being violated? Is this something the Board could assist in, by way of writing a letter to the Commissioner?

- 7) **Next meeting** is December 4, 2008, at which time we will set the 2009 Meeting agenda.
- 8) **Motion to adjourn** made by Art is not debatable, all seconded.

Executive Director's Report

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There is a lot going on at OPA

- 1) DAD Upgrade. We have upgraded the case management database we use for our Case Services (advocacy) Unit. This is a web-based system we purchase from our national association (National Disability Rights Network). Called the Disability Advocacy Database (DAD for short), it is set up to easily yield statistics that meet federal reporting requirements. Data from the past 8 years “migrated” to the new system successfully.
- 2) DD and Aging. The Legislative Program Review and Investigations Committee is conducting a study of issues relating to developmental disabilities and aging. This topic is an area of major concern to the agency, as a lot of the fatalities reviewed by our Fatality Review Board involve people who were placed into long term care facilities (nursing homes) because the group homes and other placements (including family homes) were they were living weren't accessible or capable of supporting them as they became older. We met with committee staff in late August, and testified before the committee two weeks ago. They have come out with preliminary findings and will be working on recommendations. We are also co-sponsoring an “interoburst” type of symposium so that people who want opportunities to “age in place” can get together and articulate what that means to them, what kind of supports need to be developed and to adopt some kind of strategy for advancing this issue.
- 3) Choinski settlement. This is the case we brought against DOC to get prisoners with serious mental illnesses out of the Northern “supermax” institution. The settlement agreement expired on Sept. 26. After talking with Commissioner Lantz, I wrote listing the safeguards we think it is important for DOC to maintain as a matter of policy. She has appointed internal committees to study and recommend what should stay and what should change.
- 4) Sign Language Interpreters in hospitals. I continue to be very involved in efforts to maintain the on-call system for sign language interpreters for hospitals. This has led to awareness of a larger problem involving an aging cadre of interpreters approaching retirement age and significant problems with recruitment and training of interpreting students. We are attempting to convene a meeting of leaders from the deaf community and from the educational institutions that could help meet this need. In the meantime, we have cobbled together a back-up mechanism for the hospital on-call system.
- 5) Due to severe budget restrictions I did not go to the April P&A CEO meeting, and will not be going to the October one next week. Using state funds for out-of-state travel has been banned, and we have almost no federal funds for the coming year that will not be needed to pay staff salaries. Missing three meetings in a row is not good – those meetings are where new federal program initiatives and requirements are discussed, as are common operating problems.
- 6) I am exploring a possible linkage with the Connecticut Family Support Network – a parent-driven system for arranging parent-to-parent assistance. Lacking the bureaucratic

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trappings and restrictions of typical organized human services, the parent coordinators do incredible things for families. While they are extremely dedicated and knowledgeable, they are paid peanuts, have no health insurance benefits and the future security of the funding for their positions is questionable. Nonetheless, we will see if there is a way to form an effective partnership.

- 7) We are pursuing an investigation into reports of rights violations in connection with the Hartford Transitional Learning Academy (formerly housed at Tower Ave and Washington St.) This is a follow-up on an investigation conducted 4 years ago. We are also investigating the death of an inmate with mental illness.
- 8) Peter Hughes and I met recently with DDS Regional Directors and Deputy Commissioner Kathryn DuPree to review contents and expectations surrounding our newly negotiated interagency agreement about investigations. As DDS' capacity to conduct investigations has grown, so has the complexity of tracking reports, protective services, etc. A lot of the agreement is just spelling out who does what and in which sequence. However, not all the players from the different regions are on the same page – hence the meeting.
- 9) One of our long time staff members, Amagalis Holloway, lost her 17-year-old son in a tragic accident. The whole Office has come together to support her and each other, but it has been a difficult time.
- 10) We are soliciting suggestions for legislative proposals. We know that one of our proposals will be to try to obtain a Freedom of Information Act exception that protects notes we make about calls we receive from people with disabilities who are seeking our help. While all investigation files are exempt from disclosure, it appears that advocacy and Information and Referral calls are vulnerable, unless the person was seeking legal advice or representation, or was advised or represented by an advocate working under the direction of a lawyer. We are also looking at how we might clarify our internal processes so that we could demonstrate the existence of Attorney-Client privilege when it is appropriate to do so.