D R A F T

P&A Board Meeting Minutes
March 25, 2013
2:00 – 4:00 p.m.
Conference Room B

Attendees: Art Quirk, Chairperson; Sheila Mulvey, Ray Elling, John Clausen, Commissioner Donald DeFronzo, via conference call: Chad Sinanian; and Jerilyn Newsom, Vice-Chair, PAIMI Council.

Absent: Rachel Bogartz.

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

Guests: Beth McArthur

- **Call to order**: 2:10 p.m.

- **New Business:** Items identified for discussion as new business: Hartford Courant articles; Steering Committee update; and, schedule of meeting times.

- **Approval of minutes from January 19, 2013 meeting**: One correction: John Clausen's name misspelled, so noted. One addition: Marissa and Jerilyn attended the January P&A Board Meeting. Ray Elling made motion to approve as corrected, Sheila Mulvey seconded. All present voted in favor. Motion passed and amended minutes approved.

- **Priorities:** Copies of agency priorities with amendments suggested at the Board's last meeting had been distributed for further review prior to the meeting. There was a brief discussion about the implications of loss of federal funding due to sequestration, and the inability to refill state-funded positions for the agency's ability to pursue all the goals and tasks identified in the statement of priorities. Jim reported that the chief impact would be on the agency's ability to accept cases for representation. With fewer advocates, the agency will need to place increased reliance on Information & Referral and collaborative advocacy strategies, and less on direct advocacy representation. We already have to say, "no" to a lot of people with very worthy cases. Jim is looking for adoption of a final set of recommended agency priorities towards the end of this meeting.

- **Agency Budget and Effects of Sequestration cuts in federal programs**. The agency budget has two components, personal services (PS - payroll) and other expenses (OE) – 2/3 comes from the state, 1/3 from federal formula grant programs. Each one assumes the others will continue. The federal government is operating under a sequestration, a reduction of approximately five percent in our federal grant monies during this federal fiscal year. (We still do not have the exact numbers.) The Social Services Block Grant will be reduced by 8% in Connecticut. This grant is used to supplement legal services for

qualified clients, and for adult protective services, including an abuse investigator who follows up on protective service plans and legal services. There is a continuing resolution in effect, which means no federal government shutdown. If the sequestration issue is not resolved, however, additional cuts will be made next year and in future years. The cumulative effect of annual reductions could ultimately total 50% of our federal grant income over the next five years.

The Department of Administrative Services (DAS) business staff met with Jim and Gretchen and, due to the gradually increasing costs of salaries and fringe benefits the State is charging to federal grants, OPA is going to have to move staff from one grant (PAIMI) to another. We believe we can live with these reductions for the balance of this fiscal year without resorting to layoffs. If it goes into next year, we have no guarantee that there will not be layoffs. The Protection and Advocacy for Beneficiaries of Social Security (PABSS) program was eliminated last year; but NDRN now is getting strong signals that Social Security Administration might re-establish this program.

On the state funding side, the good news is that we are not fighting for our lives. However, the Governor's proposed budget calls for some reduction in our personnel services funds. We have vacant positions due to retirements. OPM did not reduce our position count, but, the vacant positions are not funded. We have 31 state-funded positions but only 28.5 are filled at this time. DAS Business Office projects, if the budget goes through as projected, we will not be able to fill those positions the first year. It is very tough to operate with those positions vacant. All staff loses are in the Case Services (Advocacy) Unit. It is impossible to take as many cases. Although increasing use is being made of our website, many of those who contact us need time and personal discussion in order to derive benefit from our services. Personal contact is important in order to properly and completely understand and explain what a caller or client needs. Every other agency and most P&As are experiencing the same problems. Other agencies are being told to provide, "only essential services" John Clausen asked: what is essential and not essential in this agency? He felt that protective services are not necessarily being done within the DDS system. What is statutorily covered? He sees real competition for resources amidst competing goals. It is a very difficult picture.

Jim McGaughey commented that the agency has seen a slight increase in the number of clients who have had multiple substantiated abuse/neglect cases. This seems to occur more frequently in the private provider agencies, which conduct their own investigations and are generally subject to fewer protective services plan requests. While this suggest we might address this trend by increasing our insistence on having protective service plans in those cases, we suspect that would only lead to increased paperwork. Much of what we suspect is happening is the community service system has been slowly starved of resources over an extended period of time. Providers cannot hire the people they need and the training is not what they need.

- P&A testified before two subcommittees of the legislature's bi-partisan super committee on gun violence and child safety: the sub-committee on mental health issues and the

subcommittee on school safety. In addition, the agency testified on several related bills before the Public Safety Committee. One bill, which the agency opposed, created the presumption that anyone who was hospitalized could not own a gun, notwithstanding the fact that they might have checked in voluntarily or have been admitted in error and quickly released. While advocates for mental health services see the focus on mental health as an opportunity to expand some services, there is deep worry over the implications that proposals like this will have on the willingness of people to seek treatment, and on the identity and direction of the public mental health system.

- Commissioner DeFronzo asked whether, with all the attention on mental health issues, there was any funding coming to the agency. At this point, there has been suggestion that P&A be provided funding. Ray asked if there was any way for the agency to raise money. It would be a good idea to keep our eyes and ears open. Jim commented that there may be two possibilities: 1) set up an independent foundation that would operate completely independently, but sympathetically; and, 2) utilize our statutory authority to accept bequests and gifts. We decided long ago not to compete for grants against the non-profits who work for people with disabilities. NDRN and some state P&As are doing non-profit fund raising, concept worth exploring further.

- **Legislative Report -** Attempts to address the Newtown shooting are still in the forefront: mental health, school safety and gun control. The Governor has appointed Committees to address each issue and the Legislature has its own Task Forces.

1) Sexual Assault (HB 6641) – the bill that has grown out of the Fortin case looks like it will garner the necessary support to pass this year. Jim testified in support of the bill.
2) HB 5298 An Act Concerning Electroconvulsive Therapy - Proposed bill on involuntary electric convulsive therapy (ECT). The bill originally said this is invasive to people with mental illness, should only be done with the person's informed consent. The Public Health Committee has amended it to allow a probate judge to order the use of ECT. Advocates now want to kill the bill.
3) SB650 – Establishment of a Mental Illness (MI) hot line for parents whose children exhibit MI issues; parents fear that DCF will take their children away if they use this.
4) HB6645 – "Aid in Dying" (more commonly called Physician-Assisted Suicide) Bill would legalize it in Connecticut. Both Oregon and Washington have similar laws allowing a physician to prescribe a lethal does of medicine. However, there are real concerns over both the adequacy of safeguards against abuse, and the long term implications, especially for people with disabilities who are sometimes seen as "terminally ill" even though they may have years of good life in front of them.

   Jim and Beth explained the agency's longstanding position on this issue, which is consistent with that of national disability rights groups. Proponents say assisted suicide is

a private issue between patient and doctor, and that the proposal will limit availability to those with terminal diagnoses who are within six months of death. Some of the objection lies with the fact that the business of predicting timeframes for death is notoriously error-prone, especially when dealing with progressive disabilities such as muscular dystrophy and ALS. Also, many individuals with disabilities go through an adjustment period following a serious, debilitating accident or onset of worsening symptoms of a degenerative process. Especially if they are stuck in a nursing home or other institutional location, people may feel hopelessly trapped – that their lives aren't worth living. The combination of this sense of hopelessness, the desire not to be a "burden" to others, and the willingness of at least some doctors to describe them as "terminal" or in the "end stages" of life, could prove deadly - both for them, and for the disability rights movement's efforts to assert that the lives of people with significant disabilities do, in fact, have value and that people deserve better options for living, not "aid in dying". The history of the disability rights movement is dotted with court battles over people who requested that someone "pull the plug" before they came to see they could still live meaningful, contributing lives. Enacting this proposal starts us down a very real slippery slope. In the Netherlands, which has tolerated physician-assisted suicide for almost 40 years, there is an increasing expectation that you will choose to end your life rather than burden relatives (and society) with your continued presence. (And the "slippery slope" has taken the practice of medicine there to new lows – active euthanasia of newborns with disabilities.) Proponents cite the experience in Oregon as evidence that the practice doesn't lead to abuses. But, in the absence of any oversight, how does anyone know? The Oregon public health department destroys reports of physician-assisted suicide deaths precisely so that no Freedom of Information requests can be made to further investigations or research. However, it does keep certain minimal statistics about the reasons doctors who wrote lethal prescriptions say their patients chose to end their lives. It turns out that fear of dying in pain is not the reason most ask for lethal prescriptions. Rather it is fear of disability; concern over becoming disabled and needing care. More funding should go toward palliative care, Hospice Programs; a person has a right to quality end-of-life care.

- Bill No. 5353 would create statutory requirements for accessibility in State buildings that are open to the public – requirements for entrances and interior access that exceed current code requirements. The bill has made it through committee and is on the way to the full House, but there are concerns over costs. It will require state buildings to have power door openers, accessible elevators and at least one accessible bathroom. Commissioner DeFronzo discussed state building accessibility with the Governor, who has proposed including two million dollars to improve accessibility of State building into the bond act in each of the next two budget years. This was a direct result of the public hearing. This will allow the improvement process to get started.

Adoption of Recommended Agency Priorities for 2013-2015:

Chairman Quirk stated that most of the items being considered have already been discussed at the previous meeting, and called for a motion to accept the amended Statement of Priorities that had been distributed as a result. Ray Elling moved adoption; Chad Sinanian seconded.

There was additional discussion on several items:

Increase awareness of abuse and neglect. DCF, SDE, DHMAS, DDS, OPA, OCA, and the juvenile detention agencies have been meeting monthly to plan on how to reduce and prevent the use of restraint and seclusion in their facilities.

Development of an Informed Consent toolkit., We might need help with this, perhaps a Board Member would work with one the attorneys. In addition, we should contact the Probate Court Administrator and/or elder and health law sections of the Bar Association to see if material is already in existence which could as a starting point.

Pursue employment first initiatives. This is sweeping the nation (or, at least the P&A system). There may be more funding associated with this, we must position ourselves for the future.

To expand community mental health services. We need to watch to ensure that community services expand in a person-centered, recovery-oriented direction – not just that they expand.

Education clinics with other organizations. Ada Suarez a P&A Human Service Advocate does a lot of special education outreach to parent groups, especially with the Latino communities throughout the state. We also think we can work with AFCAMP and CPAC on this initiative.

Medical Transportation. We will need to research the possibility of establishing an effective complaint mechanism for users of medical transportation services, or developing an information package about how to access currently available mechanisms.

Vote on Priorities: All voted favorably. Motion passed and (Revised) Statement of Recommended Priorities was adopted.

New Business:

Hartford Courant Article on Abuse and Neglect in the DDS system over a period of ten years.

> A three-part series ran in the Courant, March 3-5, using information from an OPA/ Fatality Review Board ten-year retrospective report on the Review and Investigation of Individuals with Intellectual Disabilities. Department of Developmental Services sent a response to all the families; but, unfortunately, the article never said what we are doing to make the system better. There is some frustration that certain information was extracted

from the news story to support the view that institutions are a better option than group homes or community living. The reason we do the death investigations is so that we can make things safer, and we definitely have done so. But the problems we are encountering now will require more than new policies or procedural safeguards – they are much more tied to the chronic under-funding of the system, especially the private non-profit sector. Providers need to be able to hire and retain the kind of people you would want taking care of your relatives. Too often they cannot do so. If you starve your community service system, you ultimately get bad results.

It has come to Sheila's attention that DDS is developing a policy to address aging in place as opposed to just making nursing home placements. This is certainly a positive development, but the infrastructure of competent and committed personnel necessary to support such improved policy also needs attention. Long-time case management supervisors and dedicated providers yearn for a return of the open-to-all types of training and conferences that used to be the places innovative ideas were discussed and dedication was renewed.

There are over 7000 employees that are hired, let's start there. Find some real experts to provide training, we could go forward. Jim and Anne Broadhurst have a meeting with the health department. Sheila will discuss the idea of renewing training efforts to see what can be done to improve staff awareness and to support commitment.

2013 P&A Board Meetings: Mondays, 2:00 – 4:00, June 17, Sept. 16, Dec. 16.

Adjournment: 4:10 p.m.