

P&A News



E-MAIL NEWSLETTER FROM JIM MCGAUGHEY
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News from D.C.



Last month I journeyed to Washington, D.C. to attend the National Disability Rights Network's CEO meeting. (Technically, I was on vacation. But that's another story...) The meeting was a chance to hear from our federal partner agencies regarding new initiatives and changing program requirements, and an opportunity to catch up with news from other states' P&As. And there was a lot of news. Here is some of what I gleaned:

1. Congress and the Obama Administration are taking increasing notice of issues related to Restraint & Seclusion (R&S) in the nation's public schools. Federal law requires hospitals and residential programs for children with disabilities to observe certain standards regarding R&S, but there are no federal rules regarding public schools. This may change soon. As I reported in January, NDRN issued a report summarizing the experiences of P&As from different states, including examples where special education students had been seriously injured, and in a few cases had died as a result of inappropriate restraint and seclusion practices employed by their schools. That report was released at a Capitol press briefing hosted by Senator Chris Dodd. Three Connecticut families that had worked with OPA spoke at that event. Following release of the NDRN report, Congressman George Miller (D-CA), Chair of the House Committee on Education and Labor requested the Government Accountability Office (GAO) to investigate the issue and scheduled a hearing before his Committee. GAO released its report on May 19th, the same day as the hearing. It essentially confirmed NDRN's findings, and those of a more recently released report from the Council of Parent Attorneys and Advocates (COPAA). (You can download a copy of the GAO report at: www.gao.gov/new.items/d09719t.pdf) The hearing generated enormous interest and was well covered by national media. Committee members heard compelling testimony from parents (including a foster parent whose child had died while being restrained), from educators and from experts familiar with positive behavioral supports. GAO staff also testified about their findings. It became apparent that school systems' attitudes and policies regarding use of R&S vary widely, that parents are often "kept in the dark" about what is being done to their children, and that teachers and aides are often untrained and unaware of the harm they may cause. Committee members gave assurances of Congressional action. The following day the White House asked NDRN for nominees to participate in a task force the Administration is putting together to develop proposals.
2. In the wake of a scandal involving Henry's Turkey Services, a Texas-based labor contractor, the Social Security Administration is turning to P&As for assistance in tracking down instances of exploitation by Representative Payees. "Rep. Payees" are individuals or organizations that are authorized to receive Social Security payments on behalf of a beneficiary. They are supposed to see to it that the payments are used for the benefit of the recipient. Henry's Turkey Services employed a number of men with intellectual disabilities, contracting to provide their labor to agriculture-related businesses in different states, including a meat packing plant in Iowa. Henry's apparently collected prevailing wages for the work, but paid the workers at sub-minimum wages rates, claiming to be providing them with "sheltered employment". Because they earned so little, the men remained eligible for Social Security benefits. However, you guessed it: Henry's also served as the men's Representative Payee, deducting considerable amounts of the Social Security checks as "rent" for housing, and fees for meals, transportation and other costs. The scandal in Iowa was discovered because the dilapidated building Henry's had rented to house the workers was ultimately condemned by local building inspectors, and Henry's was charged with operating an unlicensed residential program. Officials at the Social Security Administration want P&As to help identify similar scenarios where Representative Payees are also listed as employers and recipients are being exploited. P&As have responded, pointing out that the potential for exploitation is not limited to situations where Rep Payees are employers. In fact, in OPA's experience the greatest potential for abuse arises when minimally regulated residential providers or probate-appointed conservators become Representative Payees. NDRN is currently negotiating with the Social Security Administration to clarify expectations.

3. Federal statutes that establish several of P&A programs are due for Congressional reauthorization. Chief among these are the Developmental Disabilities Assistance and Bill of Rights Act (a.k.a. the "DD Act"), and the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI). Because Congress is currently focusing so much attention on health care reform, it is not clear exactly when these measures will be taken up. However, in anticipation of discussions about the DD Act, the National Council on Disability (NOD) has commissioned a comprehensive review of the three principal DD programs - DD Councils, University Centers for Excellence and P&As. Historically, the reauthorization of P&A programs has been supported by most advocacy and civil rights groups, but has drawn some opposition from defenders of institutions and proponents of compulsory outpatient medication laws.

Retirements Create Worries for Agencies

A number of experienced State human service agency staff members have decided to take advantage of the State's recently announced Retirement Incentive Program (RIP). The Department of Developmental Services expects to lose 338 employees to retirement by July 1; the Department of Mental Health and Addiction Services estimates its number to be approximately 370; and the Department of Social Services (which includes the Bureau of Rehabilitation Services) projects losing 210. Similar numbers are expected at the Departments of Education and Public Health. While those eligible for retirement are generally earning at the top end of their respective pay scales, and the savings associated with their departures will no doubt help ease the State's fiscal crisis, the abrupt loss of their collective experience may prove costly in the long run. Many of those slated to retire are experienced nurses, clinicians, case managers, counselors, sign language interpreters, facility inspectors and program supervisors. Personnel losses on this scale can stress any organization beyond its capacity to meet commitments, ensure quality, and provide necessary oversight; it will be especially difficult to compensate for the loss of so many experienced professionals.



Equally worrisome is the projected loss of a number of senior administrators who are veterans of numerous policy debates, reform campaigns and economic cycles. Many of them cut their teeth on tasks like closing institutions and developing alternative community services. They are from a generation of government insiders who figured out how to make in-home supports and personal care assistance mechanisms work; who created family-friendly, flexible, individually tailored support programs; who pushed the agenda for supported work opportunities and helped remove employment disincentives that were built into entitlement programs. Along the way they learned a lot about what does and does not work, often by making mistakes and then having to painfully correct them. In some cases their personal journeys parallel the changes in the service systems that employed them: More than a few of these administrators began their careers working in front line jobs, where they found themselves serving – unconsciously and sometimes unwillingly – as accomplices in cumbersome, oppressive systems that functioned as if they were designed to impoverish, dis-empower and devalue the very people they were supposed to be helping. As they assumed greater leadership responsibilities, they carried with them powerful lessons learned from the people they served. Unfortunately, they are taking much of that learning with them, and leaving at precisely the time when, due to the intense fiscal pressures confronting the State, their experience and wisdom would be most useful.

P&A Bills Pass & Signed



As the General Assembly approached its June 3rd deadline for the adjournment, it became increasingly apparent that there would be no State budget, and no action on a number of proposals affecting people with disabilities. However, in the waning weeks of the session two bills affecting OPA did pass: As its title implies, [SB 893, An Act Concerning Notification of the Office of Protection and Advocacy for Persons with Disabilities of Department of Mental Health and Addiction Services Client Deaths](#), requires DMHAS to notify OPA when clients living in its facilities die. OPA sought this legislation to better enable us to conduct monitoring activities and, where appropriate, investigations. DMHAS also supported the bill, as it clarifies that agency's authority to disclose information to OPA. The other bill, [SB 854 An Act Concerning the Office of](#)

[Protection and Advocacy for Persons with Disabilities](#), explicitly includes reference to federal P&A confidentiality requirements in our State enabling statute. OPA sought this legislation to ensure clear notice to all who read our State statute concerning the existence of federal requirements for client confidentiality. Both bills were signed into law by Governor Reil last week. A more comprehensive look at the fate of other bills can be found on P&A's Legislative Update Report at: [Bill Tracking](#)

DDS Announces Cuts in Case Management and Support Grants

"In response to the downturn in the state's economic health and a growing budget deficit, it has become necessary for the Department of Developmental Services (DDS) to make difficult decisions." So begins a May 21st memo to recipients of DDS Individual and Family Support Grants. A week earlier, DDS sent letters announcing that effective July 1st, it could no longer provide DDS case managers for people who were not enrolled in fee-for-services Medicaid, or for people residing in ICF-MRs operated by private providers. A separate communication informs families that respite services will not be available on weekends this summer, because funding is not available to hire sufficient numbers of summer workers to staff respite centers on a seven-day-per-week basis. The terminations and reductions in services represent "final administrative decisions" for which there is no administrative appeal process.

There is no doubt that these cuts will hurt. DDS case managers were once described as being the front line in the State's quality assurance system – the "outside eyeball" or "fixed point of responsibility" assigned to monitor the welfare and coming needs of families, of growing children and of clients served through private sector programs. While previous regional restructuring and ongoing budgetary pressures have taken their toll on the case management system, families struggling to learn about resources often reported that having a "good" case manager – one who is knowledgeable and responsive – has been decidedly helpful. Case managers have also been on the front lines of the State's safeguarding efforts. Over the years, more than a few reports of urgent, unmet needs have been made to OPA by DDS case managers who, in the course of routine family contact, were uniquely positioned to identify and report a serious problem. The cuts affecting respite and flexible funding for families will also hurt. In summers past, week-long respite opportunities allowed families to take much needed vacations. And Family Support Grants, which will now only be available for the "most serious and urgent needs", are considered among the most innovative, relevant and economically efficient forms of assistance that any public agency has yet devised. So, these were difficult decisions indeed.

DDS has posted copies of the letters and answers to frequently asked questions on its website: www.ct.gov/dds/cwp/view.asp?a=2042&q=440430

Olmstead Anniversary Celebration

The Disability Advocacy Network is organizing a celebration event on June 18th, the tenth anniversary of the U.S. Supreme Court's decision in Olmstead vs. L.C. and E.W. L.C and E.W. were plaintiffs in a case that challenged the state of Georgia's practice of confining individuals with intellectual and psychiatric disabilities in institutions, despite the fact that they wanted to live in community-based programs and everyone (including the State's own clinicians) agreed that they could do so. In deciding the case the Court upheld the validity of ADA regulations that prohibit unnecessary segregation in the delivery of governmental services, and suggested that states develop "Olmstead plans" that allow people who want to leave institutional environments to do so in accordance with thoughtful, reasonably paced transition plans. Olmstead signaled a significant change of direction for many state disability service systems. It spurred interest in efforts such as Money Follows the Person and various Medicaid waivers geared toward helping people leave institutions and long term care facilities. The celebration will involve a "walk" (march?) from a long term care facility to the State Capitol, followed by a recognition event and celebration (with music and a cake). "L.C." (Lois Curtiss), one of the original Olmstead plaintiffs will be recognized and will speak.



Atty. Sue Jamieson, Elaine Wilson and Lois Curtiss

Photo courtesy of www.atlantalegalaid.org

Details are available at: www.ct.gov/opapd/cwp/view.asp?a=1782&O=441584&PM=1

This publication will be made available in alternate format upon request.

Comments, questions, or suggestions should be forwarded to: James.McGaughey@po.state.ct.us

James D. McGaughey, Executive Director

Office of Protection and Advocacy for Persons with Disabilities

60B Weston Street

Hartford, CT 06120-1551