



January 2009

Abuse/Neglect Reports Are Up

For the six month period leading up to November, 2008, P&A's Abuse Investigation Division (AID) experienced a notable increase in the number of instances of suspected abuse and neglect being reported. AID implements a State mandated program that responds to reports of suspected abuse and neglect of adults with intellectual disabilities. (The statute under which AID operates still refers to the term "mental retardation".) Most reports come from employees of the developmental disabilities service system (public and private) and other professionals who are statutorily mandated to report suspected abuse and neglect to P&A. Reports are also made by family members and concerned community members.

Over the last five years AID has experienced an overall increase in referrals as follows:

2004 - 1061 referrals
2005 - 1029 referrals
2006 - 1105 referrals
2007 - 1179 referrals
2008 - 1191 referrals

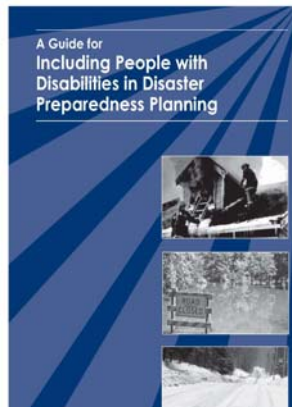
These numbers reflect an increase in monthly average reports from 88 per month in 2004 to 99 per month in 2008. But, for the six months leading to November, 2008, the average number of monthly intake referrals was 107. Both the overall trend and the recent six month jump have significant implications for our investigative caseload. They may also point to as yet unidentified dynamics affecting client safety and protective service needs. Although we have experienced episodic spikes in the past, the recent increase seems to be more than a temporary phenomenon. Previously published research studies have found correlations between stressful economic conditions and increases in abuse and neglect. But, we don't yet know for sure what is going on. In an attempt to better understand what is happening, a detailed review of AID's intake records is being initiated.

Disaster Preparedness

Ever since the devastation wrought by Hurricane Katrina, considerable energy has gone into emergency planning for people with disabilities. This is a good thing. Many people with disabilities were left behind during the evacuation of New Orleans, or were separated from their families, support groups, service animals and mobility equipment. Some died, and many more were dislocated, left homeless and wound up in nursing homes. Similar things had happened in earlier disasters, but the vivid images from Katrina really opened our eyes.

Urged on by our P&A colleagues from Gulf coast states, for the past three years OPA has been actively partnering with other agencies to develop workable approaches for including people with disabilities of all ages in disaster preparedness and emergency response planning. Part of the effort involves carrying the message of personal preparedness and local involvement to disability and senior groups around the State. We have co-hosted emergency preparedness forums in four of the State's planning regions, and plan to co-host the fifth one in Waterbury in April. In addition, we worked with DD Network partners and representatives from the Red Cross, the Department of Emergency Management and Homeland Security (DEMHS) and other interest groups to develop and promote the concept of Universally Accessible Shelters. This approach, which borrows from the principles of Universal Design, represents a major step forward from the days when people thought about having separate shelters for the "general population" and those with "special needs". (The term "special needs" is vague and misleading. As our population ages and more people with disabilities of all ages are living in their own homes, community demographics have changed. Both as a matter of law and to ensure realistic planning, towns and cities need to prepare for everyone.)

Although detailed guidance on Universal Access has been posted on the DEMHS website for over a year, (<http://www.ct.gov/demhs/cwp/view.asp?A=1928&Q=386804>) most towns and cities appear not to be using it. In an effort to more effectively promote the concept, P&A staff is piloting a technical assistance effort in several locations. See, checklist www.ct.gov/opapd/cwp/view.asp?a=1756&q=432946. In addition, I am also visiting each of the five Regional Emergency Preparedness Teams in the State to spread the word about including people with disabilities in all phases of planning – not just sheltering. This means ensuring that warning messages and other communications are issued in accessible formats, that evacuation plans include accessible vehicles and facilities, and that the needs of people who depend on PCAs, home healthcare or other in-home supports are known and addressed. This last issue will be especially important in a “shelter-in-place” scenario (e.g. when officials instruct people to stay in their homes, possibly alone and without power for an extended period).



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I have also been participating on a committee hosted by the Department of Public Health that is working on “supportive care shelters” for people who will need more support or equipment than they can get from, or bring to, a shelter – even an accessible one. The idea is that Supportive Care Shelters will be staffed by medical personnel and have various medical supplies readily available. So far, no one has figured out exactly where these resources would come from or which agency or level of government would be responsible for managing them. While there is a real need to develop “supportive care” sheltering, the effort must be integrated with plans to develop Universally Accessible Shelters. If we are not careful, people could assume that “supportive care” means the same thing as the old-fashioned “special needs”, and, in the event of an emergency, people with disabilities will be unnecessarily sent to a “special” place, away from their friends, neighbors and home communities. At the same time, we have to acknowledge that resources will be limited in a disaster situation. If we don’t develop realistic emergency plans for people who genuinely need caregivers to provide “wellness care supports”, we will be putting their health at risk and increasing the likelihood that they will end up in a health care institution.

http://www.ct.gov/opapd/lib/opapd/documents/adobe/guide_final.pdf

Interpreters for the Deaf: A Growing Crisis

The shortage of qualified interpreters for the deaf is hitting home in Connecticut. Despite our State’s rich heritage of Deaf education and culture, there has never been an abundance of sign language interpreters. Many experienced interpreters are now reaching retirement age, and educational pre-requisites for certification are increasing. The result: an increasing shortage that impacts deaf peoples’ access to a variety of educational, work and civic environments, and is especially problematic when an interpreter is needed on short notice at night or on weekends. P&A has been working with representatives of the Deaf community, the Commission on the Deaf and Hearing Impaired (CDHI), Family Services Woodfield (FSW), the Connecticut Registry of Interpreters for the Deaf (CRID), the Connecticut Coalition of Organizations Serving the Deaf (CCOSD) and the Connecticut Hospital Association (CHA) to develop a back-up system for after-hours requests from hospital emergency departments. We have also been working with these groups and representatives from institutions of higher education and the State’s Workforce Competitiveness Board to address the larger question of how best to recruit, educate and mentor new interpreters. This problem has been a long time in the making; addressing it will also be a long-term proposition.

Budget Woes Overshadow Legislative Session

Budget concerns are dominating discussions at the State Capitol. (Wow, is that an understatement.) With revenue plummeting and the overall economic picture growing bleaker every week, proposals that involve new spending are not being considered, and many existing programs face significant cuts. Obviously, this is not good news for people who rely on State-funded human services for support, especially those who are waiting for a new, innovative program to “roll out”, or for a slot “open up” on a waiting list. Times like these can also dramatically impact service quality, and, in some cases, the health and safety of people being supported. The fate of non-profit community-based service providers and their clients is of particular concern. Unable to secure adequate funding to meet ever increasing operating costs, Connecticut’s non-profit disability service providers are reporting that their ability to retain qualified staff and to cultivate and renew leadership from within their organizations has been steadily eroding. These dynamics – high staff turnover, strained resources, inexperienced leaders and organizations operating in “survival mode” – will bear watching. If you are not signed up to receive weekly legislative updates from P&A’s Legislative & Regulations Specialist, Beth Leslie, you can do so by contacting her directly at Beth.Leslie@po.state.ct.us.

Restraint & Seclusion Report from NDRN

Taking up a cause that the Connecticut P&A first surfaced in 2006, the National Disability Rights Network (NDRN) has issued a dramatic report on the use of restraint and seclusion in public schools. Citing multiple examples from around the country, including a number of cases where children have been injured and several where children died, the report concludes with a call for action at the national level. On January 13th, Connecticut Senator Chris Dodd hosted a news conference at the Capitol to highlight the report and support the drive for reform. With him were three parents from Connecticut who related compelling stories about how their children with disabilities had been restrained and secluded (and traumatized and, in one case, injured) at school without their knowledge or approval. They had initially told their stories at a forum P&A sponsored in late 2006 to discuss the issue. While Connecticut enacted legislation in 2007 limiting the use of these techniques and requiring parents to be notified, advocates agree that additional safeguards are needed. The NDRN report can be accessed at www.ndrn.org.

Aging and Disability Studies and Policy Initiatives

"Will I still be able to live in my own place as I grow older and my needs increase?" "Will my daughter have to move from her group home if she begins to need more care?" "What happens if I have to go to a rehabilitation facility for a while – will I still have an apartment to come home to?" "We had no choice but to place our brother with intellectual disabilities in a nursing home. Mom and Dad just couldn't take care of him anymore. But when the case manager talked to us, we thought it would just be temporary until DDS reached him on their waiting list. Now we find out that because he is in a "safe" environment, he is no longer considered a priority, and he has lost his place on the list."

The questions, hard lessons and calls to P&A go on and on. The good news is that awareness of the issues affecting people with disabilities who are aging is increasing, and policy makers are beginning to pay attention. Medicare and Medicaid reforms in the late 1980s were supposed to stop unwarranted placements of people with psychiatric and developmental disabilities into nursing homes. However, it seems there are loopholes. In fact, so many of the DDS client deaths investigated by P&A's Fatality Review Board have occurred in nursing homes, that last year the FRB enlisted the assistance of the Forensic Nursing Program at Quinnipiac University to conduct a study. The study, which was hampered by difficulty locating records, found little correlation between individuals' health status and decisions about their admission or length-of-stay in a nursing home. Data and preliminary findings from the study were cited in the Legislative Program Review and Investigations Committee's December recent report on DDS Aging Services (see, www.cga.ct.gov/pri/year2008studies.htm). The FRB hopes the final report, which has yet to be published, will be useful for health professionals, human service planners and other policy makers. Together with momentum generated by an October symposium on "Aging in Place" that was sponsored by the Connecticut DD Network (P&A, DD Council and UCONN Center on Disability), we also hope the study will stimulate advocates to become informed and involved in pushing for policies that meet the needs and respect the preferences of people who are getting older.

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

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