



14-543-5
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PADDC
PA Developmental Disabilities Council



Brian MacDaid
Bureau of Human Services Licensing
Department of Human Services
Office of Administration
Health and Welfare Building
625 Forster Street, Room 631
Harrisburg, PA 17120

Sent via email to: RA-PWOLTLRegsPubCom@pa.gov

Re: Regulation No. 14-543 Protective Services for Adults

May 19, 2023

Mr. MacDaid,

The Pennsylvania Developmental Disabilities Council (PADDC) engages in systems change, advocacy, and capacity building to improve the health, educational, social, and economic well-being of all people with developmental disabilities and their families. Established by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and Governor's Executive Order, the Council is both a planning group and a funding body. We empower individuals with developmental disabilities and their families to help shape policies that impact them.

We write to provide comment on the "Protective Services for Adults" proposed rule. PADDC has an obligation to actively support public policies that promote the purpose and advance the goals outlined in the DD Act. In the DD Act, Congress finds that: "individuals with developmental disabilities are at greater risk than the general population of abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights." Further, it states: "The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to— **...live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights.**"

General Comments

Overall, PADDC supports the regulations drafted to implement the Adult Protective Services Act (Act 70). We are concerned about the long delay in moving the regulations forward. The input from community members was solicited between January 2011 and September 2015. Since 2015, years of experience with implementation and the knowledge gained during that time need to be considered



before finalizing these regulations. We hope that the comments offered now will be given significant weight.

We have some specific suggestions for improvements to the language of the regulations which we believe will provide better outcomes and protections for adults with disabilities who are at risk of abuse, neglect, exploitation, and abandonment.

Definitions

We support the inclusion of the statement “The term does not include environmental factors which are beyond the control of an adult or a caregiver, including, but not limited to, inadequate housing, furnishings, income, clothing or medical care.”

We suggest improving the following definitions:

Informed Consent - We recommend revising this definition to ensure that individuals who are receiving protective services are provided effective communication. As drafted, “a reasonable attempt to provide information” is unclear. Using the standards in the Americans with Disabilities Act will provide guidance and examples of how to ensure communication access to obtain consent for individuals involved in the protective services system. Only when communication is understood, can permission or agreement be truly informed.

Least restrictive alternative – it is unclear what least “intrusive” means. We suggest language that states a “course of action that allows the individual to live, learn, and work in a setting that places as few limits on the individual's rights and personal freedoms as appropriate to meet the needs of the individual.”

Most integrated settings – merely interacting with people without disabilities is not sufficient. We recommend “A setting that supports full access to community resources to the same degree as individuals without disabilities, enables active participation in community activities, and promotes regular engagement with individuals without disabilities.”

In the section about screening and referral of reports received, it is unclear what happens to individuals who are not Commonwealth residents. Is there any obligation to refer to another state or entity in these situations? Are those individuals valued and in need of protection? We recommend directives or instructions to protect the health and welfare of all people, whether they are residents of Pennsylvania or another state, territory, or country. All people deserve protection.



Investigations and reports

We support the high standards for investigators and tight timelines for completing investigations. It is important to have qualified personnel available 24 hours a day, 365 days a year, to respond to reports of abuse, neglect, abandonment, and exploitation. PA must have a system in place to provide protection and ensure the health and well-being of adults with disabilities.

In section 15.12, there are clear standards outlined to separate the agency that investigates from entities providing services, and county mental health and intellectual disabilities service providers. It also prohibits the agency from investigating reports if there is a case where there is a professional, personal, or financial affiliation with the subject or perpetrator and/or an appearance of a conflict of interest. This is important to maintain objectivity and trust; we support this regulation.

However, it is permissible (section 15.45) to allow the State-licensed and operated facilities to conduct investigations on reported cases within their settings, and the APS investigative agency “maintains general responsibility.” This practice continues to concern individuals and families who recommend a completely conflict-free investigative process across all settings.

We recommend that records of unsubstantiated reports be maintained for longer than 1 year. There may be situations where multiple reports involving an individual are filed over time, that may not be substantiated, but indicate a pattern of problematic issues that need to be addressed. Only if records are kept for longer timeframes, can past instances be accessed to uncover a history of abuse or neglect reports. Electronic records should be maintained for up to 5 years and be searchable.

We support the strong confidentiality requirements included in the regulations and the enforcement measures outlined.

ADD Section on Service Plan

Access to timely services

Services available through the Department of Human Services, especially home and community-based waiver programs may be essential for adults in need of protective services to remain safely in their own homes and communities. We suggest the regulation require that DHS identify point persons within its Office of Developmental Programs, Office of Long-Term Living, Office of Mental Health and Substance Abuse Services, and Office of Medical Assistance Programs who the APS agency can contact and will be available to promptly assist the agency to identify and secure services for an adult in need of protective services, including expediting such services when necessary.



Rights, Legal, and Guardianship Issues

Individuals should have the right to written, oral, and other forms of communication in a language and means that they understand. They have a right to an interpreter or translator if needed. This should happen during all processes in the notification of a report, during the investigation, legal proceedings, and notice of appeals.

Individuals who need protective services should be supported to stay in their own homes. In situations where the suspected perpetrator lives in the same location, all efforts should be made to keep the person who is the victim in the home safe and to remove the offender.

Individuals should have the right to the most inclusive and integrated setting possible and exhaust all options prior to consideration of institutional placement. A direct connection to the offices that provide community-based services must be available to the agency, with accelerated enrollment processes to enable services to begin promptly.

PADDCC supports appointing legal counsel to protect the rights of individuals, at no cost to them, at all proceedings.

Guardianship should only be obtained as a last resort. Regulations should require alternatives to guardianship, such as Supported Decision Making, powers of attorney, health care representatives, and representative payees to be exhausted before subjecting individuals to guardianship. Losing the freedom and authority to make decisions is life-altering and has long-lasting implications. Training for the agency in understanding those options must be provided. Professional guardians have a financial interest at stake. It should be mandated that individuals facing guardianship be provided legal representation to protect their rights and represent their interests. Consideration of less restrictive alternatives, narrowing the scope or duration of the guardian's authority, and rigorous oversight and supervision by the courts is needed to prevent unnecessary loss of rights and autonomy. Reports available indicate that significant numbers of individuals have lost their rights due to APS interventions resulting in guardianship. This is alarming and must be considered a top priority for all concerned. A system intended to protect vulnerable citizens is now stripping rights away from them. And based on the reports, the numbers are increasing. More must be done to prevent this practice. Individuals should have options to reverse these guardianships and periodically have them reassessed once their safety is secured and supports are in place.

Services provided in the plan should never be the financial responsibility of the individual or their family.



Appeals and Hearings

PADDCC supports the right to appeal and fair hearing. It must be clear to the person that assistance is available to them to file the informal complaint. We have concerns with the stated timelines for the complaint process. The timeline to request assistance is 30 days from the date of written notice. And the deadline to file the informal complaint is also 30 days from the date of written notice. So, if an individual requests help on day 29 (which meets the deadline) it is unlikely that the assistance will result in the complaint being filed on time. Therefore, we recommend that the deadline to file the informal complaint be 30 days after the request for assistance to allow adequate time for the agency to provide the necessary support.

Finally, if the proposed resolution to the informal complaint is not acceptable, assistance should be made available to the individual as they proceed to Fair Hearing.

Add Reporting requirements to the regulations

We suggest a new requirement be added to the regulation. The agency or agencies providing protective services should be required to document and report the results of their work. This report will provide legislators, the administration, and concerned citizens with the information needed to evaluate, assess, and identify trends and hopefully formulate ideas for systemic improvements. We suggest an annual report containing the following information be released to the public:

- Number of reports: Substantiated and Unsubstantiated
- Data about the locations, facility type, outcomes, and results of investigations
- Breakdown of victims by age, race, gender, and disability
- Demographics about perpetrators by age, race, gender, role, and relationship
- Category or type of abuse, neglect, exploitation, or abandonment
- Level of injury, harm, or death
- Number of guardianships – by disability, age, race, gender, and location

Thank you for considering our comments. We are focused on ensuring that individuals with developmental disabilities live full lives in the community, with self-determination, and inclusion, and are free from abuse, neglect, and exploitation while maintaining their legal and human rights.

Sincerely,
Lisa A. Tesler
Executive Director