



# Vision for Equality

Serving People with Disabilities and Their Families



14-543-10  
5/22/23

May 21, 2023

TO:  
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 ([3364PRO.pdf \(state.pa.us\)](#))**

Dear Mr. Macdaid,  
The mission of Vision for Equality is to assist and empower people with disabilities and their families to seek quality and satisfaction in their lives as well as equal access to supports and services. We believe that all people have a right to live a happy and meaningful life. The human rights of individuals with intellectual/developmental disabilities and autism are often abrogated formally and informally by being persistently subjected to abuse and neglect and further victimized through the reporting and investigation processes that fail them. This issue is so important and so overlooked that Vision for Equality strives to bring enhanced attention to this critical issue: [Abuse & Neglect - Vision For Equality](#)

### General Comments

Vision for Equality supports regulations to implement and augment the statutory requirements of the Adult Protective Services Act (Act 70), which are long overdue. There has been a significant delay in this process as we have waited for over 10 years to advance these regulations, a further demonstration of how the most vulnerable who are victimized are also victimized by the systems unwillingness to provide appropriate supports and uphold individual rights.

One generalized comment is a critical acknowledgement that the origins of the Protective Services Acts were originally limited to older adults in Pennsylvania. There are many changes between the inception and present day. 1) This Act provides protection for individuals with disabilities including those with ID/DD and Autism, individuals at home, individuals in state centers, and individuals in residential placement. Regardless of settings, the intent of this Protective Services Act has to be first and foremost to protect the physical and emotional well-being of the individual for whom a report has been filed. All must be managed with appropriate

trauma support and protocols, and this must be enhanced by increasing trainings for Investigators.

2) Specific inclusions and references need to be made to ensure equity and address disparities. We know that these are systemic and specific efforts to root out systemic disparity which must take place. 3) Attention needs to be paid across the code to the explicit inclusion of assistive technology for mobility as well as communications as these foster autonomy, self-determination and inclusion. 4) A general statement should be made that whatever supported decision-making tools might be in place for an individual (SDM plan, guardianship, power of attorney, etc.) they must be followed throughout the process, and if there is a conflict of interest, that has to be specifically addressed. Other specific recommendations are itemized below.

### 15.2 Definitions

Term	As Currently Defined	Proposed Changes	Comments
Abandonment	“The desertion of an adult by a caregiver.”	Propose a change to “desertion or willful failure, without just cause, of a caregiver to provide care and protection of an adult for any period of time.”	If an individual has a service plan, the “period of time” is defined in the plan. So, if a person receives supports to go into a mall, restaurant, or other community location and their support person, supposed to be supporting them in their purchases, safety, or other activity, leaves the individual to go to another store or elsewhere – this is abandonment.
Abuse	The occurrence of one or more of the following acts: (1) The infliction of injury, unreasonable confinement, intimidation or punishment with resulting physical harm, pain or mental anguish.	Add to (1): “Psycho-social wellbeing.” Add the following types of abuse “verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology. Willful, as used in this definition	<a href="#">SOM - Appendix PP (cms.gov)</a> Note that below we have recommended specifically adding a definition for seclusion and restraint as its own category. Also, it should be noted that withholding mobility aids and

	<p>(2) The willful deprivation by a caregiver of goods or services which are necessary to maintain physical or mental health.</p> <p>(3) Sexual harassment, rape or abuse as the term is defined in 23 Pa.C.S. § 6102 (relating to definitions).</p> <p>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.</p>	<p>of abuse, means the individual must have acted deliberately, not that the individual must have intended to inflict injury or harm.”</p>	<p>communications devices should specifically be considered abuse/confinement</p>
Agency	<p>A local contracted provider of protective services.</p>	<p>Clarify “free of conflict of interests” of any direct service provision.</p>	<p>The text (p18) clearly indicates that “an agency shall be separate from entities providing direct services to adults, county mental health and intellectual disabilities service providers.”</p>
Conflict of Interest		<p>This seems to have disappeared from the text and should be reinstated.</p>	<p>The Regulations should reflect Act 70. The Act clearly states, “the Department shall</p>

		<p>“The conflict which may exist when the investigator of a report of the need for protective services has a personal or financial interest in, is responsible for, or is employed by others responsible for, the delivery of services which may be needed by an older adult to reduce or eliminate the need for protective services. A conflict of interest may also exist if an investigator has a specific <u>personal</u> or financial motivation to recommend services delivered by a specific agency or to allow referrals or case dispositions to be inappropriately influenced by the investigator’s knowledge of agency staff, resource limitations or by agency constraints which affect agency staff or resource allocations.”</p> <p>Any investigation must be conducted conflict-free. The Agency must take concrete steps to avoid any conflicts</p>	<p>establish by regulations procedures to ensure no conflict of interest in the provision of adult protective services.” This is the only way to ensure transparency and the integrity of the process.</p>
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		between investigators and service delivery functions. The entities must be clearly separate.	
Consent/Informed Consent	Consent obtained for a proposed course of protective service provision. The consent shall be based on a reasonable attempt to provide information which conveys, at a minimum, the risks, alternatives and outcomes of the various modes of protective service provision available under the circumstances.	<p>Consent is obtained to gain agreement to a course of ACTION which may or may not result in protective service provision.</p> <p>We strongly recommend enforcement and explicit protections regarding communications to achieve informed consent... ensuring appropriate trained translation services are available, for individuals without or limited verbal /audible communications a communications intermediary is provided which may include assistive technology. Time should be provided for the individual to digest the information provided and consider their chosen course of action. They should not be pressured to provide an immediate response.</p> <p>(2) Further, the individual should not have to request</p>	For consent to be valid, it must be: 1) voluntary and without influence or pressure, 2) informed by relevant information about benefits, risks, alternatives, rights, consequences, and in appropriate language with all parties having access to communications of choice, 3) made with capacity – therefore if an individual has power of attorney, guardianship, or another decision-support plan, their representative in supported decision-making should be available,

		<p>additional information. “Nothing about us without us” – any information germane to the harm of an individual should be freely given without requirement of a separate request.</p>	
<p>Missing: Guardian (and or an identification of ANY tool used to support an individual’s self-determination – SDM plan, power of attorney, guardianship etc.</p>		<p>If there is a guardian for the individual, to support their informed consent, the guardian should be privy to the investigatory process.</p> <p>A guardian’s most basic responsibility is to see that provisions are made for the support, care, comfort, health and maintenance of the individual. The guardian must secure the services, training and education that will maximize the individual’s self-determination, choice, and opportunities.</p> <p>The guardian must seek a clear understanding of the issues and options at hand, encourage and support the individual in understanding the choices and maximize his/her participation.</p>	<p><u>NCEA Fact Sheet: Role of Guardian Standards in Addressing Elder Abuse (acl.gov)</u>  Guardianship under our present contractor has become a critical concern. In the 6-7 years they have been contracted to provide APS services they have adjudicated incompetent between 600-700 people to full guardianship. They have had the court appoint guardians that have upward of 80 or more people to oversee. In our estimation the guardianship has been excessive and have insufficient reporting and oversight. Stripping someone of their civil rights for the rest of their life rather than finding</p>

		<p>The guardian must identify and advocate for the individual’s goals, needs and preference. The guardian starts by asking the individual – and helping the individual to express – what he or she wants. Only when the individual’s goals, needs and preferences cannot be determined may the guardian make a decision in the individual’s “best interest.” This process, clearly outlined in the Standards, promotes self-determination. Guardianship Petitions should demonstrate that the less restrictive alternatives were considered first and why they were found insufficient. Also, when guardianship is the only alternative, it should be narrowed in scope, limited in duration, and used only as the last resort. Guardianships should have vigorous oversight and supervised by the Department.</p>	<p>the many alternatives that exist robs an individual of a lifetime of freedom, the right to control and live their own lives. This was never what Protective Services was meant to do. The Department should investigate the guardianships under the current vendor to determine if people with ID/DD and Autism have been disproportionately impacted.</p>
Freedom from Involuntary Seclusion and/or Restraint		Add a definition: a) “Freedom from an individual from other residents or from	

		<p>her/his room or confinement to her/his room (with or without roommates) or another space against the resident’s will. This may include removal of an individual’s mobility aides.”</p> <p>b) Ensure that the resident is free from physical or chemical restraints imposed for purposes of discipline or convenience and that are not required to treat the resident’s medical symptoms.</p>	
Least restrictive alternative	The least intrusive service or environment that can effectively and safely address the adult’s needs and preferences.	<p>Reinstate part of the previous definition and aligns with settings definition:</p> <p>“The appropriate service or environment which least intrudes upon the personal autonomy, rights, and liberties of the adult. Provides for options for services/environments made. available without discrimination, selected by the individual care recipient (from among the options). Affords and ensures dignity, respect, and freedom</p>	<a href="#">HCBS Settings Rule   ACL Administration for Community Living</a>



		from coercion and restraint, and optimizes autonomy.	
Most integrated setting	A setting that enables individuals with disabilities to interact with individuals who do not have disabilities to the fullest extent possible.	A setting that is integrated and supports access to the greater community; provides opportunities to seek employment, engage in community life, and control personal resources; ensures receipt of services to the same degree and access as individuals without disabilities or receiving benefits; facilitates choice	<a href="#">HCBS Settings Rule   ACL Administration for Community Living</a>
Protective Services	Those activities, resources and supports provided to adults under this act to detect, prevent, reduce or eliminate abuse, neglect, exploitation and abandonment.	We propose including.  “Supporting the individual to seek justice and pursue their rights through all available avenues including legal proceedings; providing independent representation for the individual; supporting the individuals wellbeing and recuperation from victimization.”	
Serious Injury	An injury that: (1) causes a person severe pain; or (2) significantly impairs a person's physical or mental functioning,	Our concern is with the language of “functionality.”  This should be changed to “physical, mental, emotional wellbeing either	See the DSM/Trauma definition.  For individuals with cognitive disabilities (regardless of cause) pre-existing functional limitations often have been

	either temporarily or permanently.	temporarily or permanently.	used to negate impact. “the individual seems fine/unchanged.” We propose that we should DSM definitions of trauma which includes experience of a stressor (a traumatic event such as violence, treat, injury, etc.) which can create unpredictable emotions, flashbacks, strained relationships, and physical symptoms such as headaches or nausea.
Sexual Abuse	Intentionally, knowingly or recklessly causing or attempting to cause rape, involuntary deviate sexual intercourse, sexual assault, statutory sexual assault, aggravated indecent assault or incest, as defined by 18 Pa.C.S. (relating to crimes and offenses).	We strongly recommend explicit inclusion of “Institutional Sexual Assault”	<b>§ 3124.2</b> <a href="#">Chapter 31. - Title 18 - CRIMES AND OFFENSES (state.pa.us)</a>

Administration

Section	As Currently Defined	Proposed Changes	Comments
§15.23 Receiving Reports	Toll-free public telephone or other	Reporting should also be available via the web or in writing.	

	communication access		
§15.26 Screening and referral of reports	(a)Screening/(1 ) Priority. A report placed in this category shall require immediate attention because specific details in the report indicate the possibility that the adult reported to need protective services is at imminent risk of death or serious injury or serious bodily injury. The person receiving a priority report shall immediately contact a protective services caseworker and provide the caseworker with the information contained in the report.	We recommend that certain classifications of individuals should be given priority status due to their increased risk of harm: individuals with limited or no verbal communications abilities, individuals with intense medical involvement, and individuals with high SIS scores.  Further we strongly recommend that priority and non-priority are more clearly defined by the actions (which may be criminal in nature) are deemed priority/nonpriority.	We use a number of different terms.  1) We use terms that are criminal acts – abandonment, rape, etc.  2) But then we move away from potential criminality and instead move to a degree of physical risk. No other category of individual has to go through a secondary prioritization like this.  3) Finally, we then move to priority/nonpriority/not eligible.  Should we not suggest that someone who is the victim of a potential crime receives priority? If we do not act quickly on a crime the evidence can be lost.
§15.42 Standards for initiating investigations	(i)The investigation of a report categorized as a priority...and	It should be added that if the individual has identified a guardian, power of attorney, or other identified	The Adult Protective Services Act clearly sets forth the standards of an investigation. Consolidating, simplifying or deviating from those

	<p>to the extent feasible, a face-to-face visit shall be conducted within 24 hours.</p>	<p>supports for decision-making and health care, that individual should also be contacted. In the event this individual is implicated in the investigation..... another independent representative (attorney/disability rights pa) should be contacted and present to represent the interests of the individual. The standard for caseworkers should be to ensure the immediate safety of the individual in need of protective services. As proposed here agencies have the prerogative to refer investigations to another agency which may permit the "conflicted" agency to have input into who ultimately does the investigation.</p>	<p>requirements would challenge the credibility of the process. Allowing or accepting the results of a facility's investigations findings so as not to "duplicate" services present serious concerns. Act 70 called for conflict free entities to provide and carry out all matters of protective services, anything less than that defeats the spirit and the intent of the Act.</p>
<p><b>§15.43</b> Resolution of unsubstantiated reports</p>	<p>(a)If the agency determines that the subject of the report is in need of protective services, the report shall be classified as substantiated.</p>	<p>Regarding assessments here and in §15.92.  During any assessment, the individual must have the right to representation, and if they have any supports for decision-making, legal, or health care that individual should be present as well</p>	<p><a href="#"><u>Sexual Assault Victim Rights &amp; Evidence Notification Protocol – PA Office of Attorney General</u></a>  The multidisciplinary team approach cannot and should not supersede human rights protocols for victims of abuse. Victims of suspected abuse have the automatic right to counselors (such as rape</p>

		<p>(unless there is a conflict of interest). A private conversation should happen with the individual outside a large group setting. The individual and their chosen supports should have the opportunity for privacy and confidentiality.</p> <p>Per the Pennsylvania’s Sexual Assault Testing and Evidence Collection Act, a victim of sexual offenses has the right to have crime evidence collected. The individual should receive an assessment from qualified individuals following forensic protocols such as doctors. This “multidisciplinary team assessment” should not operate in lieu of proper medical treatment and collection of evidence.</p> <p>Where there is a concern of sexual abuse, medical assessment by a qualified medical provider should include STD, pregnancy, and other sexual health testing.</p>	<p>counselors), evidence collection, etc.</p> <p>Further the law requires victims to be notified related to the status of their sexual assault evidence kit if the victim requests such notification.</p>

<p>§15.46 Law Enforcement Officials</p>		<p>When the police are contacted regarding possible abuse, exploitation, etc. It should be clear that the police are to immediately file a report with APS rather than simply deferring to the service provider agency to manage any reporting.</p> <p>What are the repercussions if the police do not follow up and report to APS?</p>	
<p>§15.61 Access to adults</p>	<p>When access is denied and (2ii) the agency can demonstrate that the adult in need of protective services denied access because of coercion, extortion, or justifiable fear of future abuse, neglect, or exploitation or abandonment.</p>	<p>First, it should be clear that at this point there has been no assessment so the adult is not necessarily in need of protective services – this should be changed to allegedly in need.</p>	
<p>§15.81 Rights of adults reported to need protective services.</p>	<p>(1) The agency shall, to the extent possible, notify the adult privately during the investigation that a report has been made and provide the adult with a</p>	<p>(1) We strongly recommend enforcement and explicit protections regarding communications throughout the process ... ensuring appropriate</p>	<p>Individuals with verbal/written communications limitations should be specifically considered in this policy. We need to ensure a non-discriminatory and equitable process that does not burden nor discriminate against those with linguistic limitations. Individuals must know their rights in the process and the</p>

	<p>brief summary of the nature of the report.</p> <p>(2) As provided under section 306(b)(3), the adult may request, and the agency shall provide additional information contained in the report.</p>	<p>trained translation services are available, for individuals without or limited verbal /audible communication s a communication s intermediary is provided which may include assistive technology or a trusted person with historical knowledge of the person’s communication style/needs. Additional considerations need to be in place to ensure the rights of people who do not communicate in a way others understand are upheld to same extent as that of any human.</p> <p>(2) Further, the individual should not have to request additional information. “Nothing about us without us” – any information germane to the harm of an</p>	<p>rights should be properly and simply explained. Access to all information should be easy and the question of access should be asked as part of their rights/not an exception.</p>
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		<p>individual should be freely given without requirement of a separate request.</p> <p>(3) The individual and their guardian or person with power of attorney for healthcare, if one exists, should be included with the individual throughout the investigatory process. Note that if the guardian is under investigation, then their guardianship, is temporarily stopped an intermediate guardian is in place (is this correct?).</p> <p>(6) regarding legal counsel... the investigatory process is a legal event. The individual victimized should have access to independent representation to ensure their full legal rights are protected and not just a court order.</p> <p>(8) The individual should be supported to stay in their own homes, with continued unrestricted free access of the home. If the individual is at risk for bodily or mental injury, the suspected perpetrator lives in the</p>	
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		<p>same location, that perpetrator should be temporarily removed from the location.</p> <p>Note that restraining, segregating, or isolating an individual/victim for example by restricting them to their room for “safety” is, in itself, a form of abuse.</p>	
<p><b>§15.122</b> Protective Services Staff Training Curriculum</p>	<p>2 - Disability competence including issues and barriers faced by adults with disabilities.</p> <p>15- Experience of Trauma</p> <p>17- Communication skills, including complex communication needs.</p> <p>19- Service Delivery System in the Commonwealth for persons with disabilities</p>	<p>2 -Disability competence including issues and barriers faced by adults with physical, intellectual, and developmental disabilities including autism.</p> <p>15- Trauma Informed Care/Enhanced Trauma Awareness course with a min of 18 hours of course time</p> <p>17- Communication skills including complex communication disorders, non-traditional forms of communication, including but not limited to, echolalia, gestures, stereotypy, and behaviors.</p> <p>19- Service Delivery Systems in the Commonwealth</p>	<p>2 - We strongly suggest adding ID/DD and autism as these disabilities manifest in critically different ways than physical disabilities. Investigators must understand how these disabilities manifest themselves in different individuals and their behavior and communication differences in order to ensure appropriate measures are taken to communicate in a way they understand, maintain their rights, and collect credible evidence.</p> <p>15- The trauma a victim experiences can cause lifelong emotional and physical ramifications. It is imperative that investigators understand the principles of Trauma Informed Care and can apply these principles when supporting a victim, their caregivers, and staff.</p> <p>17- Investigators must understand the behavior and communication differences in</p>

		<p>ADD- Person Centered Planning/Thinking</p>	<p>the ID/DD population in order to ensure appropriate measures are taken to communicate in a way they understand, maintain their rights, and collect credible evidence. Without this experience and knowledge a person with these disabilities can be wrongfully detained, unnecessarily adjudicated, and/or manipulated. All these outcomes deny a person of their basic human rights.</p> <p>19- There is more than one service delivery system in the Commonwealth with many differences between them. The Office of Developmental Programs Service Delivery is very different from the services delivered under the Office for Long-term Living. Both deliver HCBS, but very differently.</p>
<p><b>§15.150</b> Right to appeal and fair hearing. Appeals Procedure</p>	<p>An adult who has been found not to be in need of protective services has the right to appeal the decision and to have a fair hearing.</p>	<p>We strongly support the addition of an appeals procedure.</p> <p>This procedure should be in place for individuals for who an investigation took place as well as those who were relegated to the no investigation category.</p> <p>Further the results of the protective service plan, for example if an individual who perpetrated violence</p>	

		has to be removed from his home permanently, there should be the opportunity for appeal as well.	
<b>§15.152 Informal complaints</b>	Prior to arranging for any formal hearing on appeals, the Department requires .... An informal complain process	<p>This 2 stage process is administratively heavy and burdensome especially to an individual who is seeking justice from victimization.</p> <p>A complaint form should merely be the method by which an appeal is initiated – a one stage process.</p> <p>Further the complaint form must be constructed in plain language so that individuals with cognitive disabilities and limited literacy can submit a complaint. An option for an audible form should be accepted.</p>	

**Missing**

Missing from this document are the following:

- A process by which failures by the Agency can be reported. What are the repercussions when the Agency fails to identify a priority case or act within a timely manner resulting in increased harm to the individual -- what happens when the direct actions of the Agency places the individual at further risk or violates the individual’s rights (such as the right to consent)?
- A requirement that all reports and communications be written in “plain language” (per the Federal Plain Language Guidelines). All government information and services should be provided in clear information such that the audience can readily understand the information/report.

- A requirement for reporting (this used to be in miscellaneous provisions? And it does not appear in this document). Annual reporting should be made by the Agency. Reports should be made available to the public. An annual hearing should be made to the Department of Health as well as legislators. The report should be in plain language and include information about:
  - Data including the locations: facility type, outcomes, results of investigations, and geography
  - Number of reports: substantiated and unsubstantiated
  - Priorities and categories
  - Degree of harm, injury, or death,
  - Demographics of victims including age, disability, race, gender, and how they communicate
  - Supported decision making employed (SDM, POA, Guardianship, etc.)
  - Demographics on guardians including personal vs professional,
  - Number of guardianships by disability, age, race, gender, and location,
  - Information about perpetrators including setting, age, race, gender, role, and relationship.

Conclusion

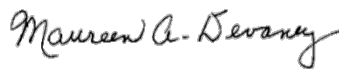
- Our collective interests are the welfare of vulnerable adult populations in the Commonwealth. The Protective Services must be a conflict-free port of entry to reject pervasive abuse and neglect. The system must put the individuals who have been victimized first, responding with trauma-informed support and training for person-sensitive investigations that preserve the dignity and privacy of the individual. And it must provide transparency especially to the individuals themselves. Families fought hard for the establishment of Adult Protective Services for their loved ones. They now look to the Regulations to fill in the necessary parameters that will provide the clarity and transparency needed to assure them their loved ones will be safe under the care and protection of the State of Pennsylvania.

Thank you for considering our comments.

Sincerely,



Audrey Coccia  
Co-executive Director



Maureen Devaney  
Co-executive Director