

Thank you very much for this opportunity to provide ADD with our recommendations on amendments to the P&A program portions of the regulations implementing the Developmental Disabilities Act. We have a number of critical recommendations, which are highlighted immediately below. We also provide specific suggested language to address these concerns – and a range of others – that we strongly recommend be incorporated into a notice of proposed rule making. Also included are detailed explanations for the various recommended revisions. As noted below, assuming ADD agrees with our recommended revisions, the accompanying explanations might be included in the interpretative guidance contained in the regulations' preamble. These recommendations, based on extensive input from the P&A network itself and our Legal Committee, reflect the practical concerns and needs of the network.

### Primary Areas for which Regulatory Amendments are Needed

*Guidance on New P&A Program Provisions Resulting from the DD Act of 2000* – The regulations, of course, must be amended to reflect the changes – and to provide relevant guidance – concerning the P&A System's new mandates and administrative requirements resulting from the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. 15001 et seq. Thus, new regulatory provisions should be included relating to governing board requirements, access to service providers and records of individuals in order to investigate potential abuse and neglect, and the provision by the state of information on the adequacy of health care and other services to persons served under the home and community based waivers. These are the major new P&A provisions reflected in the Act (other provisions contained in the prior version of the statute were carried forward without substantive change.)

For instance, the regulations should provide clear guidance on the liberal rights established with regard to accessing service providers and records without consent of guardians or other third parties to investigate or monitor relating to abuse or neglect:

- Clarification must be provided that P&As shall have unrestricted access to individuals with developmental disabilities in any "location in which services, supports, and other assistance are provided." 42 U.S.C. 15043(a)(2)(H). The regulations currently make reference to access to "facilities." See e.g., sections 1386.22(f) and (g). This should include a clarification that access is mandated with respect to non-residential public schools. There have been an ever increasing number of reports of restraint and seclusion in public schools, and P&As' authority to investigate this and other forms of abuse in these settings must be clarified.
- The regulations must incorporate the enhanced provisions in the statute regarding access to records of individuals with developmental disabilities: the 2000 Act provides that no consent of a third party is required to access records in the case of any death of an individual with a developmental disability or where the P&A is investigating an immediate threat to health or safety, and that such

access must be provided within 24 hours of a written request. In all other matters, access to records must be provided within 3 days of a written request. 42 U.S.C. 15043(a)(2)(J). Also, an amendment is needed to reflect that where there is probable cause regarding “general” abuse or neglect or a complaint, the P&A need only attempt to gain consent. Section 15043(a)(2)(I)(iii).

- Moreover, it should be clarified that, in the case of an inquiry regarding a death (unlike inquiries concerning other incidents), the P&A need not assert that it has probable cause or that it is in receipt of a complaint (nor need it make any other showing) in order to obtain access to the records. This is the clear intent of the relevant statutory section – 42 U.S.C. 15043(a)(2)(J)(ii)(II). This conclusion is supported by a reading of the language itself and by a comparison of the language in that section with the language in the provision immediately preceding it: Compare subsection (a)(2)(J)(ii)(I), which states that access must be provided if the P&A “determines there is probable cause” regarding a risk to health or safety, with subsection (a)(2)(J)(ii)(II), which provides that access must be provided “in any case” regarding a death.

*Conform Interpretative Guidance with that for PAIMI Act Regulations* – ADD should include in its regulations extensive interpretative guidance on access authority and other issues, which is consistent with the helpful guidance contained in the PAIMI Act regulations. We also ask ADD to work with CMHS to assure that CMHS’ PAIMI Act regulations themselves are revised to conform, as much as possible, to the DD Act regulations. (Of course, the PAIMI regulations also should be revised to reflect the amendments to the PAIMI Act enacted in 2000.) A consistent approach is compelled by Congress’ intent that the parallel provisions contained in the DD and PAIMI Acts be applied in a uniform manner.<sup>1</sup>

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<sup>1</sup>The legislative history of both the Acts makes clear that Congress intended that the parallel provisions in the Acts be applied in a consistent manner. See, e.g., S. Rep. 454, 100th Cong., 2d Sess. 10 (1988); S. Rep. 109, 99th Cong., 1st Sess. 3 (1986); S. Rep. 113, 100th Cong., 1st Sess. 24 (1987); Alabama Disabilities Advocacy Program v. J.S. Tarwater Developmental Center, 894 F. Supp. 424, 428 (M.D. Ala. 1995) (stating that the “legislative history suggests that the record access provisions of the [DD and PAIMI] acts are meant to be consistent”), aff’d, 97 F.3d 492 (11th Cir. 1996). Moreover, the preamble to the PAIMI Act’s regulations states that it is the goal of the Department of Health and Human Services “to ensure that all facets of the P&A system administered by the Department [PAIMI and DD Programs] are subject to the same requirements.” 62 Fed. Reg. 53549 (Oct. 15, 1997). Regulatory guidance issued with respect to one program may be controlling with respect to the interpretation of a sister program – and should be consistent. See Iowa Protection and Advocacy Services, Inc. v. Res-Care Premier, Inc., No. 4-02-CV-10012 (S.D. Iowa July 8, 2002), which ruled that the DD Act regulations “are applicable with equal force to a protection and advocacy system operating under [the PAIR Program].” Slip op. at 4.

*Posting of Notices* – the regulations should require public and private service providers to post notices regarding the services provided by the P&A in the state or territory and information on how to contact the agency. Additionally, service providers should be required to provide such a written notice to persons with developmental disabilities and their guardians, as appropriate, upon becoming involved with a program providing supports, services or other assistance. This would be consistent with other notice requirements imposed by HHS on various health care providers.

*Case Law on Access to Investigate Abuse and Neglect* – We believe it is important to incorporate directly into the regulations and the regulatory guidance in the preamble discussion of the positive rulings adopted by the courts in the last few years on the broad scope of P&A access authority. For instance, the regulations should clarify that P&As shall have access to all records of an individual, including records concerning peer reviews or “quality assurance.” This would adopt the holding of the Third Circuit Court of Appeals in *Pennsylvania Protection and Advocacy, Inc. v. Houstoun*, 228 F.3d 423 (2000). In that case, the court found that the PAIMI Act preempts state laws restricting access to peer review records, and invalidated the PAIMI Act regulation which provides that such state laws are not preempted. The DD Act regulations currently contain an identical provision.

### **Specific Recommended Regulatory Amendments**

In much of the following, we provide specific suggested language for revisions to existing regulatory language, as well as suggestions on entirely new provisions. We also provide an explanation of the basis of these recommendations (except for suggestions which are self-explanatory such as those based directly on new DD Act provisions or on grammatical concerns). **We strongly suggest, assuming ADD agrees with such explanations, that the substance of these explanations be included as interpretative guidance in the regulations’ preamble.**

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Similarly, the case law interpreting one P&A program's access provisions is equally applicable with respect to the interpretation of the counterpart provisions in a sister program. *Advocacy Inc. v. Tarrant County Hospital District*, 2001 WL 1297688 (N.D. Tx. 2001), at \*2, fn 4 (Because the acts are virtually identical and further the same goal – protecting the rights of vulnerable individuals – judicial interpretation of provisions in the DD Act are useful for questions raised under a comparable provision in the PAIMI Act); *Advocacy Center v. Stalder*, 128 F. Supp. 358, 360 fn 2 (M.D. La. 1999) (“case law under the DD Act is helpful to the court in determining right to access under the [PAIMI] Act.”). Therefore, guidance contained in case law developed under the PAIMI Act may be adopted in these regulations for purposes of interpreting parallel provisions of the DD Act (as in the case of authorities to access individuals and records to investigate abuse and neglect).

In order to facilitate matters, and clarify our specific suggested revisions, we have reprinted portions of the relevant current DD Act regulations and directly incorporated into those provisions our suggested changes; these changes are noted in bold text. Revisions which we believe are necessitated by the new requirements of the DD Act of 2000 are underlined (as well as bolded), and suggestions which are offered to conform the regulations to those implementing the PAIMI Act are italicized (as well as bolded). Some of the revisions, as discussed below, are necessitated by persuasive decisions issued in recent years by the courts concerning P&A authority to access records and individuals in order to investigate abuse and neglect. The regulations should reflect this important guidance as well, so that P&As can avoid needless disputes concerning this authority.

### **Section 1386.1 Definitions**

As used in Secs. \_\_\_\_ of this Part, the following definitions apply:

*Abuse* means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes ***but is not limited to*** such acts as: Verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue. ***In addition, the P&A may determine, in its discretion, that repeated and/or egregious violations of an individual's statutory or constitutional rights amounts to abuse, such as in a case where an individual is subject to significant financial exploitation which may prevent the individual from providing for his or her basic needs such as food and shelter.***

Explanation: This suggested change is consistent with the interpretation of the term "abuse" contained in the preamble accompanying the PAIMI regulations, at 62 Fed. Reg. 53551 (Oct. 15, 1997). That discussion provides (emphasis added), in relevant part, that

[S]everal commenters [on the proposed PAIMI regulations] requested that the term "violation of rights" be added whenever the terms "abuse" and "neglect" are mentioned in the regulation. Some respondents contended that complaints regarding rights violations such as unlawful restraint, inappropriate medications, and denial of communication rights, freedom to practice religion, access to the electoral process, or freedom of association, should be included as specific examples. The Department believes it necessary to clarify the distinction between "abuse" and

“neglect” and “violation of rights” because the statute draws a distinction between them granting to the systems the power to investigate “abuse” and “neglect” and to protect and advocate on behalf of the rights of individuals with mental illness. The Department believes that when an individual’s rights as defined in the Bill of Rights for Persons with Mental Illness established by the President’s Commission on Mental Health (Title II of the Act) are repeatedly and/or egregiously violated, this constitutes abuse. While the Bill of Rights provides useful guidance, it should not be considered full or limiting as to types of rights violations. It is not necessarily true, however, that every violation of a person’s rights is in and of itself “abuse” as defined in the Act. The Department declines the opportunity, however, of defining the threshold at which a violation of an individual’s rights constitutes abuse, leaving that decision to the systems which will have intimate knowledge of the situation based on its monitoring of facilities and its discussion with individuals with mental illness.

*Complaint* includes, but is not limited to, any report or communication whether formal or informal, written or oral, received by the system including media accounts, newspaper articles, telephone calls (including anonymous calls), from any source, **relating to the status or treatment of an individual with a developmental disability.** ~~alleging abuse or neglect of an individual with a developmental disability.~~ **A P&A may not be compelled to disclose the details of the complaint to third parties.**

Explanation: see discussion below relating to “probable cause.” The same reasoning applies here to the latter suggested change regarding disclosure.

*Designating Official* [retain without change]

~~*Facility* includes any setting that provides care, treatment, services and habilitation, even if only “as needed” or under a contractual arrangement.~~

~~*Facilities* include, but are not limited to the following:~~

~~Community living arrangements (e.g., group homes, board and care homes, individual residences and apartments), day programs, juvenile detention centers, hospitals, nursing homes, homeless shelters, jails and prisons.~~

Explanation: the term “facility,” which is used in the current regulations, and which arguably imposes a limit on the scope of the DD Act’s coverage and P&As’ authority, should be omitted from the revised regulations, in light of the DD Act of 2000. The Act no longer refers to “facilities,” but instead refers to “a location in which services, supports, or other assistance are provided to” an individual with a developmental disability. See 42 U.S.C. 15043(a)(2)(H) (access authority) and 42 U.S.C. 15043(c) (definition of “records”). The Act’s use of this phrase confirms that P&As may serve persons residing in community settings. However, this does not represent a substantive change in the Act (as the overall structure of the predecessor Act supported this authority), but only provides a

clarification on the issue. Accordingly, the regulations should use, in place of the term “facility,” the “location in which services,” etc. terminology. As suggested below, this should be accomplished in the context of a new definition for the term “service provider.”

*Full Investigation* means access to **service providers facilities, individuals with developmental disabilities** clients and records authorized under these regulations, that is necessary for a protection and advocacy (P&A) system to make a determination about whether alleged or suspected instances of abuse and neglect are taking place or have taken place. Full investigations may be conducted independently or in cooperation with other agencies authorized to conduct similar investigations.

Explanation: the term “individuals with developmental disabilities” should replace “clients,” as the Act, its case law and the regulations themselves (elsewhere) contemplate access to all individuals whether or not a client relationship is established. Indeed, one purpose of the Act is to ensure that all eligible persons have access to P&A services.

*Legal Guardian, conservator and legal representative* all mean an individual appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, persons acting only to handle financial payments, attorneys or other persons acting on behalf of an individual with developmental disabilities only in individual legal matters, or officials responsible for the provision of treatment or habilitation services to an individual with developmental disabilities or their designees.

*Neglect* means a negligent act or omission by an individual responsible for providing **services, supports or other assistance** ~~treatment or habilitation services~~ which caused or may have caused injury or death to an individual with developmental disabilities or which placed an individual with developmental disabilities at risk of injury or death, and includes acts or omissions such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); **assure that services, supports or other assistance is provided in the least restrictive appropriate setting or location**; provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; **or** provide a safe environment, which also includes failure to maintain adequate numbers of trained staff.

Explanation: The language on “least restrictive setting” would be helpful in clarifying that P&As can use their access authority to investigate potential violations, based on the *Olmstead* decision, regarding the ADA’s mandate to provide integrated, community-based services to persons with disabilities.

*Probable cause* means a reasonable ground for belief that an individual with

developmental disabilities has been, or may be, subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect. **The P&A shall have sole discretion in making a determination about whether probable cause exists, and shall not be required to disclose to any third party any details regarding the basis of that determination.**

Explanation: The first clause of this recommendation, relating to P&As' discretion regarding the probable cause determination, is taken directly from the rulings of a number of courts. It is critically important, as service providers continue to dispute the basis of a P&A's probable cause and use such disputes to withhold records or physical access needed to investigate abuse or neglect. The leading cases on this issue are Arizona Center for Disability Law v. Allen, 197 F.R.D. 689 or 19 NDLR para. 233 (D. Az 2000) (the P&A is the "final arbiter" regarding the probable cause determination); and Maryland Disability Law Center, Inc. v. Mount Washington Pediatric Hospital, Inc., 664 A.2d16 (Md. Ct. of Spec. Apps.1995). Other cases following Allen and Mount Washington include Advocacy, Inc. v. Tarrant County Hospital District, 2001 WL 1297688 (N.D. Tx. Oct. 11, 2001), at \*4; Iowa Protection and Advocacy Services, Inc. v. Gerard Treatment Programs, L.L.C., 152 F. Supp. 2d 1150, 1172 n.1 (N.D. Ia. 2001); Iowa Protection and Advocacy Services, Inc. v. Res-Care Premier, Inc. (S.D. Iowa March 22, 2002), Slip op at 7-8; and The Legal Center for People with Disabilities v. Earnest, 2002 WL 288340 (D. Co. 2002) at \*3.

The second clause, relating to disclosure of the basis of the P&A's probable cause determination, follows logically from the rule about P&A discretion in making the determination. That is, if P&As are the final arbiter of what amounts to probable cause, as all courts which have considered the issue have found, then they should not be required to engage in a debate with service providers about the specifics of their findings. Moreover, disclosing specifics about the findings may compromise the P&A's investigation or put informants at risk. It should be sufficient if, for instance, the P&A informs a service provider that it has observed an incident which the agency concludes may constitute abuse or neglect or result in future abuse or neglect.

***Service provider* refers to any individual (including a family member of an individual with a developmental disability), or a public or private organization or agency that provides, directly or through contract, brief or long-term services, supports or other assistance to one or more individuals with developmental disabilities. Service providers, include, but are not limited to, locations such as group homes, board and care homes, individual residences and apartments, day programs, **public and private residential and non-residential schools (including charter schools)**, juvenile detention centers, hospitals, nursing homes, homeless**

shelters, and jails and prisons, **which provide either specialized assistance addressing the needs of persons with developmental disabilities or more general assistance such as the provision of vocational training, transportation, education, or shelter, food or clothing.**

Explanation: See discussion above regarding omission of the term “facility.” This new definition borrows from the definition of “facility” in the current regulations, and expands it somewhat to clarify, for instance, that non-residential schools may be covered. This is an important clarification, as a number of P&As have learned of significant abuse in schools, including improper restraint and seclusion, and have met with considerable resistance when attempting to investigate, based on schools’ assertions that they are not covered “facilities.” The clarification that services provided may be of a general nature, not necessarily targeted to persons with developmental disabilities, is consistent with the interpretative guidance in the PAIMI regulations with regard to the definition of the term “care and treatment” in the PAIMI Act. See 62 Fed. Reg. 53551.

### **P&A Access Authority**

Introduction/Explanation: Similar to the PAIMI regulations, these provisions should be set forth in a separate subpart of the regulations, given their importance and level of detail. Many of our suggestions simply reflect the new access authority language contained in sections 15043(a)(2)(I) and (J) of the DD Act. Again, the current DD Act regulations (at section 1386.22) are set out below with revisions which we believe are necessitated by the new requirements of the DD Act of 2000 underlined (as well as **bolded**). Suggestions which are offered to conform the regulations to those implementing the PAIMI Act are *italicized* (as well as **bolded**).

### **Subpart X – Access to records of individuals with developmental disabilities.**

Sec 1386.10 Access to records.

(a) **Pursuant to sections 143(a)(2)(I) and (J) of the Act**, a protection and advocacy (P&A) system, **and all of its authorized agents**, shall have access to the records of individuals with developmental disabilities **under the following circumstances:**

(1) **If authorized by an individual** who is a client of the system, or one who has requested assistance from the system, or by such individual’s legal guardian, conservator or other legal representative.

(2) **In the case of** an individual, including an individual ~~who has died~~ or whose whereabouts **are** unknown, to whom all of the following conditions apply:

(i) The individual, due to his or her mental or physical condition, is unable to authorize the system to have access;

(ii) The individual does not have a legal guardian, conservator or other legal representative, or the individual's guardian is the State (or one of its political subdivisions); and

(iii) With respect to whom a complaint has been received by the system or the system has probable cause (which can be the result of monitoring or other activities including media reports and newspaper articles) to believe that such individual has been **or may be** subject to abuse or neglect.

(3) **In the case of** an individual who has a legal guardian, conservator, or other legal representative, with respect to whom a complaint has been received by the system or, **as a result of monitoring or other activities, the system has determined that there is probable cause to believe that such individual has been or may be subject to abuse or neglect**, whenever all the following conditions exist:

(i) The system has made a good faith effort to contact the representative upon receipt of the representative's name, address and **telephone number (and such information must be provided within one business day of a written request)**;

(ii) The system has offered assistance to the representative to resolve the situation; and

(iii) The representative has failed or refused to **consent to the release of the records (including the situation where the representative's refusal may be based on a good faith belief that such denial is in the best interest of the individual)**.

Explanation: This addition is based on the ruling in Disability Law Center v. Reil, 130 F. Supp.2d 294 (D. Ma. 2001).

**(4) In the case where the system determines that there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in any case of the death of an individual whom the system believes may have had a developmental disability, and in such cases, the system shall have access without the need to seek consent from another party.**

(5) Pursuant to paragraphs (a)(2), (3) and (4) of this section, access to records of a group of individuals with developmental disabilities, as well as to their identities, and to the identities, phone numbers and addresses of their guardians, conservators or other legal representatives, shall be provided to the P&A where the P&A determines that the probable cause or complaint referenced in those paragraphs relates to conditions which may impact generally on the status or treatment of individuals in such group.

Explanation: This revision, clarifying that P&As may access the records of groups or classes of persons with developmental disabilities in order to investigate abuse or neglect potentially impacting them generally, is consistent with multiple provisions in the PAIMI regulations, as well as its interpretative guidance and several recent case decisions. See, e.g., section 51.31(g) of the PAIMI regulations, which provides that the P&A's "determination of 'probable cause'

may result from P&A system monitoring or other activities, including observation by P&A system personnel, and reviews of monitoring and other reports prepared by others pertaining to individuals with mental illness or to general conditions affecting their health and safety." (Emphasis added.) Similarly, the preamble to the PAIMI regulations states that P&As, based on a complaint or probable cause, may act on "behalf of an unnamed client or on behalf of a class of people." 62 Fed. Reg. 53551. It is critical to clarify this authority in regulation for purposes of consistency with the PAIMI regulations, and because the authority is an indispensable tool in addressing systemic abuse and neglect, including practices such as dangerous restraint and seclusion, which may result in death or serious injury to numerous individuals. The additional provision regarding disclosure of service recipient/guardian identities is also critical, because in many cases, the P&A cannot readily determine their identities for purposes of seeking consent to access their records.

These provisions are clearly compelled by the rulings of the courts. Perhaps the most notable case on this issue is Georgia Advocacy Office v. Borison, 520 S.E.2d 701 (Ga. Ct. of Apps.1999). In that case, the Georgia Court of Appeals affirmed the right of the Georgia P&A (GAO) to access, under specified circumstances, the identities of numerous persons with disabilities (and their guardians) who had been the subjects of fraudulent clinical drug studies. After reading newspaper accounts of these studies, GAO sought the names, addresses and records of study participants in order to investigate potential abuse and neglect. A court-appointed receiver which had custody of the records of study participants, citing their confidentiality interests, refused to provide this information without signed releases furnished by the individuals.

The court ruled that, based on the information reviewed by the P&A, and the fact that the physicians leading the studies were indicted and one had pled guilty, GAO clearly had "probable cause," within the meaning of the PAIMI and DD Acts and the PAIR Program, to investigate further. Without access to the names of study participants, the court noted, the P&A could not determine which are covered under the P&A statutes; nor could it obtain their authorization for the release of their records. Accordingly, the appellate court ordered the lower court to devise a plan to ensure the expeditious review of the records to determine which of the study participants are covered under the statutes and were subjected to abuse and neglect. Id. at 784. See also Iowa Protection and Advocacy Services, Inc. v. Gerard Treatment Programs, L.L.C., 152 F. Supp 2d 1150, 1176 (N.D. Ia. 2001) (affirming Iowa P&A's right to access records of all residents of a children's residential psychiatric facility in connection with the P&A's investigation of abusive restraint and seclusion practices, finding that the P&A has "sufficiently alleged that probable cause exists as to the potential for serious abuse of all of the residents of [the facility] to justify [the P&A's] request

for access to all such residents and their records”); Pennsylvania Protection and Advocacy, Inc. v. Royer-Greaves School for the Blind, 1999 WL 179797, at \*8, Fn 11 (E.D. Pa. March 25, 1999) (“where a P&A receives complaints of serious widespread abuse against numerous residents, or has probable cause to suspect that the health and safety of numerous residents is in serious and immediate jeopardy” such facts “could warrant a P&A to have more generalized access to all of the records to properly investigate”); Cramer v. Chiles, No. 98-43-Misc.-T-26A (D. Fla. September 1, 1998) (the P&A has authority to gain access to the records of a class of individuals potentially affected by abuse and neglect – as well as to their identities and the identities of their guardians).

(b) **Information and individual** records to which P&A systems must have access under Section 143(a)(2)(l) **of the Act** (whether written or in another medium, draft, **preliminary** or final, including handwritten notes, electronic files, photographs or video or audio tape records) shall include, but shall not be limited to:

(1) **Information and individual** records prepared or received in the course of providing intake, assessment, evaluation, education, training and other ~~supportive~~ services, **supports or assistance**, including medical records, financial records, and monitoring and other reports prepared or received by a ~~member of the staff of a facility that is providing care and treatment~~ **service provider. This includes records stored or maintained at sites other than the service provider.**

(2) Reports prepared by a **Federal, state or local governmental agency, or a private organization**, charged with investigating incidents of abuse or neglect, injury or death occurring at a **service provider**. **The reports subject to this requirement include, but are not limited to, those prepared or maintained by agencies with responsibility for overseeing human services systems, for instance, the foster care, developmental disabilities and prison and jail systems; criminal and civil law enforcement agencies such as police departments; state and federal licensing and certification agencies; and private accreditation organizations such as the Joint Commission on the Accreditation of Health Care Organizations**, that describe any or all of the following:

- (i) Abuse, neglect, injury, death;
  - (ii) The steps taken to investigate the incidents;
  - (iii) Reports and records, including personnel records, prepared or maintained by the **service provider facility** in connection with such reports of incidents; or,
  - (iv) Supporting information that was relied upon in creating a report, including all information and records which describe persons who were interviewed, physical and documentary evidence that was reviewed, and the related investigative findings; and
- (3) Discharge planning records.

Explanation: The language regarding reports available to the P&A is based on

Congress' intent to ensure the widest possible access to records to promote the System's authority to investigate abuse or neglect and ensure the protection of rights. (The language regarding access to investigative reports of licensing and certification agencies is supported by Iowa Protection and Advocacy Services, Inc. v. Rasmussen, 206 F.R.D. 630 (S.D. Iowa 2002), where the court ordered P&A access to such reports.) This broad interpretation of available records and reports is also consistent with the guidance contained in the PAIMI regulations. See the preamble to those regulations (at pages 54559-60), which states in relevant part, that

It is argued [by comments on the proposed PAIMI regulations] that without an opportunity to review information from various sources, there can be neither a full investigation nor a determination of whether the investigation of another agency or facility was sufficiently thorough. The Department agrees that any or all of the above-named records may be considered relevant on a case-by-case basis, and that they all be considered under the current meaning of "records." The Department has incorporated a number of items which clarify the intention that all records are to be accessible, but it has not included every single example.

(c) Information in the possession of a **service provider** facility which must be available to P&A systems in investigating instances of abuse and neglect under Section 143(a)(2)(B) (whether written or in another medium, draft or final, including hand written notes, electronic files, photographs or video or audio tape records) shall include, but not be limited to:

(1) Information in reports prepared by individuals and entities performing certification or licensure reviews, or by professional accreditation organizations, as well as related assessments prepared for a facility by its staff, contractors or related entities, **including records produced by peer review committees or medical care evaluation or quality assurance committees.** ~~except that nothing in this Section is intended to preempt State law protection records produced by medical care evaluation or peer review committees.~~

Explanation: As noted in the introduction, the amendment in paragraph 1 is compelled by the very persuasive opinion of the Third Circuit Court of Appeals in *Pennsylvania Protection and Advocacy, Inc. v. Houstoun*, 228 F.3d 423 (2000). In that case, the court found that the PAIMI Act preempts state laws restricting access to peer review records. The court ruled, reading the plain language of the PAIMI Act, which is substantially identical to the DD Act, that P&As are authorized to access "all" records of an individual. Peer review records constitute such records, the court determined, since they satisfy part of the definition of records (contained in both the PAIMI and DD Acts), i.e., reports prepared by service providers concerning care. The court rejected a PAIMI Act regulation, which is substantially identical to the current DD Act regulation above, providing

that the PAIMI Act should not be interpreted as preempting state laws regarding disclosure of peer review records. The court found that this regulation, which was based on a brief passage from a single congressional committee report (which did not relate to any particular amendment to the Act), does not represent a reasonable interpretation of the statute.

Peer review committees are comprised of medical professionals who evaluate the care given by other professionals. The committee attempts to evaluate errors in systems of care and make recommendations regarding necessary improvements to those systems. Records of this type provide extremely valuable information about care and instances of abuse and neglect. It is critical that P&As in every jurisdiction have access to this type of record to effectuate their primary mandates under the DD Act to monitor treatment, to investigate incidents of abuse and neglect and to take appropriate action to ensure the protection of the rights of persons with developmental disabilities. Indeed, access to peer review program records must be assured so that P&As can evaluate the integrity and effectiveness of the peer review process itself. Further, these records are pertinent for uncovering evidence concerning inadequacies relating to the overall administration of a service provider that are not discoverable through individual staff interviews or the review of other records. The DD Act regulations themselves require P&As to maintain the confidentiality of records. Thus, allowing P&A access would cause no disruption to the goals of the peer review process, which are to foster candid reviews of deficiencies in health care systems and develop courses of action for improvement without the threat of exposure to civil liability.

(2) Information in professional, performance, building or other safety standards, demographic and statistical information relating to a **service provider, facility and policy and procedures manuals.**

Explanation: As noted above, the Act and language in the interpretative guidance for the PAIMI regulations in its preamble support broad access to all records relevant to an investigation. The PAIMI regulations' preamble expressly references "policy and procedures manuals." 62 Fed. Reg 53559-60 (Oct. 15, 1997). Such manuals are an important source of information for P&As when conducting investigations, and thus they should be referenced in the regulations.

**(d) In the case where the system determines that there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in any case of the death of an individual whom the system believes may have had a developmental disability, access to the records referenced in paragraphs (a), (b) and (c) of this section shall be provided (including the right to inspect and copy records as specified in paragraph (e) of this section) to the P&A within 24 hours of receipt of the P&A's written request for records. In all other cases, access to records shall be provided to the P&A within three business days**

**after the receipt of such a written request from the P&A. In the case of an inquiry regarding a death, the P&A need not assert that it has probable cause to suspect abuse or neglect or that it is in receipt of a complaint (nor need it make any other showing) in order to obtain access to the records.**

Explanation: As stated in the introduction to these recommendations, the above revisions are required by new authority contained in the DD Act. For instance, the third sentence, which relates to access of the records of a deceased person without any showing of probable cause, is based on the plain language of 42 U.S.C. 15043(a)(2)(J)(ii)(II). Also, it is supported by a comparison of the language in that section with the language in the provision immediately preceding it: Compare subsection (a)(2)(J)(ii)(I), which states that access must be provided if the P&A “determines there is probable cause” regarding a risk to health or safety, with subsection (a)(2)(J)(ii)(II), which provides that access must be provided “in any case” regarding a death.

(e) A system shall be permitted to inspect and copy information and records, subject to a reasonable charge to offset duplicating costs; **the charge may not exceed the amount charged to other similar non-profit or state government agencies, which ever amount is less. At its option, the P&A may make written notes when inspecting information and records and may use its own photo copying equipment to obtain copies. Where photocopying or other reproduction of records is performed by a party other than the P&A, such reproductions of records shall be provided to the P&A within the time frames specified in paragraph (d) of this section.**

Explanation: The PAIMI regulations’ regulatory preamble states (at 62 Fed. Reg. 53560, Oct. 15, 1997) that the P&A system may not be charged for copies more than is “reasonable” according to prevailing local rates, and certainly not a rate higher than that charged any other service provider, and that nothing shall prevent a system from negotiating a lower fee or no fee. Many service providers have tried to impose excessive costs on P&As for copies as a means of obstructing access. The above clarifications are necessary to prevent this from occurring. Also the clarification on the time frame during which copies of records must be provided to P&As is necessary to avoid the frequently long delays in this regard. Often it is the service provider and not the P&A which makes the copies of the requested records and the entity has every motivation to delay in producing these materials. Prompt access for the P&A to inspect records is of no assistance in its investigation if copies of the records themselves are not provided quickly.

~~(e) The client's record is the property of the Protection and Advocacy System which must protect it from loss, damage, tampering, or use by unauthorized individuals. The Protection and Advocacy System must:~~

~~(1) Keep confidential all information contained in a client's records, which includes, but~~

~~is not limited to, information contained in an automated data bank. This regulation does not limit access by parents or legal guardians of minors unless prohibited by State or Federal law, court order or the rules of attorney-client privilege;~~

~~(2) Have written policies governing access to, storage of, duplication of, and release of information from the client's record; and~~

~~(3) Be authorized to keep confidential the names and identity of individuals who report incidents of abuse and neglect and individuals who furnish information that forms the basis for a determination that probable cause exists.~~

Explanation: As discussed below, all provisions regarding confidentiality of P&A records should be consolidated into a separate section devoted to this issued. Therefore, the above provisions should be omitted from the revised regulations.

### **Section 1386.11 Access to Service Providers**

Introduction/explanation: Because the corresponding provisions in the PAIMI regulations (42 CFR 51.42) relating to access to facilities contain considerably more guidance than is contained in the current DD Act regulations – and to help ensure consistency with the PAIMI regulations – we use these provisions as a baseline for our recommendations. The PAIMI regulations are reprinted below and changes that we believe are necessary for purposes of the DD Act regulations are indicated in bold and struck out text. (The absence of bold or struck out text indicates that the PAIMI provision is reprinted without substantive change.) Although not indicated in bolding or strikeout, the terms “service provider” and “service recipient,” respectively, are substituted throughout for the terms “facility” and “resident,” which appear in the PAIMI regulations.

(a) Access to service providers and service recipients shall be extended to all authorized agents of a P&A system.

(b) A P&A system shall have reasonable unaccompanied access to public and private service providers and programs in the State ~~which render care or treatment for individuals with mental illness,~~ and to all areas of the **service provider’s premises** which are used by service recipients or are accessible to **them**. **Such access shall be provided without advance notice and immediately upon request.** The P&A system shall have reasonable unaccompanied access to service recipients at all times necessary **(including non-business hours such as evenings, weekends and holidays)** to conduct a full investigation of an incident of abuse or neglect. This authority shall include the opportunity to interview any service recipient, employee, or other persons, including the person thought to be the victim of such abuse, who might be reasonably believed by the system to have knowledge of the incident under investigation. **The P&A may not be required to provide the name or other identifying information regarding the service recipient or staff with whom it plans to meet; neither may the P&A be required to justify or explain its interaction with**

**such persons.** Such access shall be afforded upon **an oral or written** request, by the P&A system when:

- (1) An incident is reported or a complaint is made to the P&A system;
- (2) The P&A system determines there is probable cause to believe that an incident has or may have occurred **or may occur in the future**; or
- (3) The P&A system determines that there is or may be imminent danger of serious abuse or neglect of an individual with a developmental disability.

Explanation: The changes in paragraph (b), relating to times and circumstances under which access shall be afforded, are consistent with the PAIMI regulations' interpretative guidance at 62 Fed. Reg. 53561-62 (emphasis added):

Several commenters [concerning the proposed regulations] suggested that P&A systems should not be required to provide notice to a facility that they are going to come to that facility to investigate an incident, and further, that P&A systems should be able to appear unannounced at a facility to investigate any report that is regarded as an emergency. The Department responds that the regulations do not require notice to be given a facility in advance of an investigation, but that in nonemergency instances such notice is reasonable. The Department agrees that in cases where a system believes that an individual with mental illness is, or may be, in imminent danger of serious harm, the system should investigate as quickly as possible . . . .

Many commenters felt that P&A systems should have the right to access facilities "whenever necessary" to investigate alleged incidents of neglect and abuse. They maintained that reasonable access means access "at any and all times necessary" to conduct a full investigation of an incident, that the determination of "reasonableness" should reside with the P&A system, and the facility should be required to give access on request. If the facility wishes to contest the "reasonableness," they should be authorized to do so only after the access has been granted, not before. The Department does not agree that the P&A system should have access at ALL times, but does accept the argument that access be granted "all times necessary . . ." to conduct a full investigation, and particularly when the system has determined "probable cause" that there is or may be imminent danger of serious abuse or neglect of an individual with mental illness. In addition, 51.42(c) provides for access to facility residents and to programs "at reasonable times, which at a minimum shall include normal working hours and visiting hours." Access should not be limited only to business hours during week-days . . . .

As noted in the above guidance, immediate access is necessary with respect to service providers to permit P&As to uncover situations that may involve immediate threats to health or safety. It is also necessary to prevent service providers from concealing situations involving abuse or neglect or taking actions

which may compromise evidence related to such incidents (such as intimidating staff or service recipients). For instance, one court has ruled that when a P&A has received a report relating to abuse or neglect or has a belief that such incident may have occurred, a facility serving persons with developmental disabilities must permit the P&A “prompt access” to its premises “and to all potential witnesses of the abuse or neglect.” Mississippi Protection and Advocacy System, Inc. v. Cotten, 1989 WL 224953 (S.D. Miss.), *aff’d*, 929 F.2d 1054 (5<sup>th</sup> Cir. 1991). We believe this requirement would not impose any unreasonable burdens on service providers, as they would not be required to engage in any preparation for such access.

The additional revisions, relating to justification for contacts with service recipients and staff, are based on the rulings of the courts. Mississippi Protection and Advocacy System, Inc. v. Cotten, No. J87-0503(L) (S.D. Miss. Sept. 29, 1989), at pp. 3-4, *aff’d*, 929 F.2d 1054 (5<sup>th</sup> Cir. 1991); Robbins v. Budke, 739 F.Supp. 1479, 1489 (D.N.M. 1990). As the court noted in the Cotten case, requiring the P&As to provide identify residents with whom they plan to meet or explain their contact with service recipients would conflict with the right to preserve attorney-client confidences and privileges and to freely obtain witness statements.

(c) In addition to access as prescribed in paragraph (b) of this section, a P&A system shall have reasonable unaccompanied access to service providers, including all areas which are used by service recipients, and are accessible to service recipients, ~~and to programs and their residents at reasonable times, which at a minimum shall include normal working hours and visiting hours~~ **(including non-business hours such as evenings, weekends and holidays. A P&A shall also be permitted to attend treatment planning meetings concerning individual service recipients, with the consent of the individual or his or her guardian, conservator or other legal representative; however, such consent need not be obtained if the individual, due to his or her mental or physical condition is unable to provide such consent, and he or she does not have a legal guardian, conservator or other legal representative, or the individual's guardian is the State. Such access shall be afforded immediately upon an oral or written request by the P&A system.** Service recipients **subject to the requirements in this paragraph** include adults or minors who have legal guardians or conservators. P&A activities shall be conducted so as to minimize interference with service provider programs, respect service recipients' privacy interests, and honor a recipient's request to terminate an interview. This access is for the purpose of:

(1) Providing information and training on, and referral to programs addressing the needs of individuals with developmental disabilities, and information and training about individual rights and the protection and advocacy services available from the P&A system, including the name, address, and telephone number of the P&A system.

(2) Monitoring compliance with respect to the rights and safety of service

recipients; and

(3) Inspecting, viewing and photographing all areas of a service provider's premises which are used by service recipients or are accessible to them.

Explanation: The requirement that access to conduct monitoring be provided immediately is consistent with the rulings of the courts. Pennsylvania Protection and Advocacy, Inc. v Royer-Greaves School for the Blind, 1999 WL 179797, at \*6 (E.D. Pa. March 25, 1999) (P&As shall be afforded access to conduct monitoring activities without advance notice); Robbins v. Budke, 739 F.Supp. 1479, 1487-88 (D.N.M. 1990) (the P&A's ability to observe conditions to which patients are subject is "seriously hindered by the requirement that any tours of the facility take place only with advance notice and only with an administrative chaperon"). It is important that immediate access be mandated, consistent with the approach for access to investigate specific suspected incidents of abuse or neglect (and the release of records where the investigation concerns a death or an immediate threat to health or safety). The P&A should have no less rights in the context of its physical access to conduct monitoring, especially given that such prompt access may allow the P&A to detect and prevent conditions which may lead to deaths or which present an imminent threat of harm to service recipients.

We recommend that the regulations clarify that access be permitted to treatment planning meetings (with the consent of the individual or his or her guardian), as such access is needed to assure that service providers are protecting the health and safety of service recipients (such right is not clearly provided for in the current regulations). The limitation related to individual/guardian consent would provide an appropriate safeguard concerning privacy. Such access is supported by the legislative history of the PAIMI Act, which provides that P&As must be afforded "access to meetings within the facility regarding investigations of abuse and neglect and to discharge planning sessions." S. Rep. 454, 100th Cong., 2d Sess. 9 (1988). Based on this statement (and the interest in assuring consistency with the PAIMI Program), the P&A also should be authorized to attend treatment team meetings, which serve some of the same purposes as discharge planning sessions.

Moreover, the DD Act and its case law generally support extremely broad access to individuals to monitor conditions relating to safety and health. These authorities, then, generally support treatment team access, as such access is an important strategy in monitoring the adequacy of health care. While some courts have ruled that P&A monitoring must be limited to minimize interference with treatment and programs, these cases place the burden on service providers to make a persuasive showing that such access would in fact be disruptive. See Pennsylvania Protection and Advocacy, Inc. v. Royer-Greaves School for the Blind, 1999 WL 179797 (E.D. Pa. 1999), at \*3-6, and the cases discussed in that

decision. Accordingly, access to treatment team meetings should be mandated; service providers would continue to have the option (as in other disputed areas relating to access) of raising objections based on a showing that such access would interfere with the meetings.

(d) Unaccompanied access to service recipients shall include the opportunity to meet and communicate privately with individuals regularly, both formally and informally, by telephone, mail and in person. ~~Residents include minors or adults who have legal guardians or conservators.~~

(e) The right of access specified in paragraphs (c) **and (d)** of this section shall apply despite the existence of any State or local laws or regulations which restrict informal access to minors and adults with legal guardians, conservators **or other legal representatives, and despite the objection of such guardian, conservator or other legal representative to such access.** The system shall make every effort to ensure that the parents of minors or guardians of individuals in the care of a service provider are informed that the system will be monitoring activities at the service provider and may in the course of such monitoring have access to the minor or adult with a legal guardian. The system shall take no formal action on behalf of individuals with legal guardians, ~~or conservators~~ **or other legal representatives**, or initiate a formal attorney/client or advocate/client relationship without appropriate consent, except in emergency situations **such as where the P&A determines there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy** ~~as described in Sec. 51.41(b)(3).~~

Explanation: Regarding the first revision to paragraph (e), it is clear that the DD Act does not restrict a P&A from interviewing a service recipient, despite the fact that his or her guardian may object to the interview. Iowa Protection and Advocacy Services, Inc. v. Res-Care Premier, Inc., No. 4-02-CV-10012 (S.D. Iowa July 8, 2002), slip opinion at 7-8. Indeed, such an opportunity is essential to furthering the P&A's mandate to effectively investigate abuse and neglect. Id.

### **Sec. 1386.12 Denial of delay or access.**

If a P&A system's access to service providers, programs, service recipients or records covered by the Act or this part is denied or delayed **beyond the deadlines specified in sections 1386.10 and 1386.11**, the P&A system shall be provided, **within one business day after the expiration of such deadline**, promptly with a written statement of reasons, including, in the case of a denial for alleged lack of authorization, the name, address and telephone number of **individual service recipients and of their legal guardians, conservators, or other legal representatives. All of the above information shall be provided whether or not the P&A has probable cause to**

## **suspect abuse or neglect or has received a complaint.**

Explanation: The above language is based on section 1386.22(i) of the current DD Act regulations, but is set out here as a separate section, as in the case of the parallel PAIMI regulation at 42 CFR 51.43. The revision to the first sentence regarding disclosing the names of service recipients is taken from the rulings of the courts. See the Borison and Cramer cases, which are discussed above in connection with the section on access to records (section 1386.10(a)(5)). P&As must be able to obtain the identities of service recipients from service providers (who have control of this information), as often consent for access must be sought from them rather than guardians. (The confidentiality of such P&A records, of course, would be protected under other provisions of these regulations.)

We recommend a one-business-day deadline for providing the written denial justification in light of the 24 hours/three day time frames for the release of records (contained in the Act) and the immediate access requirement we recommended above concerning service provider premises. This deadline for producing the written justification must occur shortly after the expiration of those deadlines for them to have any meaning. The final revision merely reflects a clarification of the current DD Act regulation, section 1386.22(i). It is based on the holding of the courts (construing that regulation) that access to guardian/legal representative information is available to the P&A in its role as a monitor of health and safety – without any showing of specific potential abuse or neglect. Pennsylvania Protection and Advocacy, Inc. v. Royer-Greaves School for the Blind, 1999 WL 179797 (E.D. Pa. March 25, 1999), at \*9-12. The court stated that the practical result of its ruling “is that all a P&A need to do is [sic] to receive a list of guardians is ask for it.” *Id.* at \*11. The court in Robbins v. Budke, 739 F.Supp. 1479 (D.N.M. 1990), issued a similar order.

## **Section \_\_ Confidentiality of protection and advocacy system records**

Introduction/explanation: Similar to the approach used in the PAIMI regulations (at section 51.45), these regulations should incorporate a separate section devoted exclusively to the issue of confidentiality of P&A records. The regulations currently address confidentiality of such records in subsection (e) of section 1386.22, which deals with P&A access authority. Because the confidentiality provisions relate to a broad range of client information, and not only materials obtained through the P&A’s access authority, it is more appropriate to address the issues in a separate, dedicated section of the regulations. Moreover, for purposes of assuring consistency, the regulation should adopt (with a few clarifications discussed below) helpful clarifying provisions from this part of the PAIMI regulations, which are absent from the current DD regulations. Again, we have reprinted below the relevant language from the PAIMI regulations (section 51.45) and have indicated in bold (or struck out) text the changes that we believe are necessary to those

provisions for purposes of the DD Act regulations:

(a) Records maintained by the P&A system are the property of the P&A system, which must protect them from loss, damage, tampering or use by unauthorized individuals. The P&A system must:

(1) Except as provided elsewhere in this section, keep confidential all records and information, including information contained in any automated electronic database pertaining to:

(i) ~~Clients to the same extent as is required under Federal or State laws for a provider of mental health services;~~

(ii) Individuals who have been provided general information or technical assistance on a particular matter;

(iii) **the** Identity of individuals who report incidents of abuse or neglect or furnish information that forms the basis for a determination that probable cause exists; and

(iv) Names of individuals **who have received services, supports or other assistance** ~~residents~~ and provide information **to the P&A** for the record.

(2) Have written policies governing access to, storage of, duplication and release of, information from client records; and

(3) Obtain written consent from the client, if competent, or from his or her legal representative, from individuals who have been provided general information or technical assistance on a particular matter and from individuals who furnish reports or information that forms the basis for a determination of probable cause, before releasing information **concerning such individuals** to individuals not otherwise authorized to receive it.

(b) **Except as specified in paragraph (c) of this section regarding the disclosure of identifying information**, nothing in this subpart shall prevent the P&A system from ~~-(1) issuing a public report of the results of an investigation which maintains the confidentiality of the individuals listed in paragraph (a)(1) of this section; or -(2) reporting the results of an investigation, in a manner which maintains the confidentiality of such individuals~~ ~~individual service recipients~~, to responsible investigative or enforcement agencies, should an investigation reveal information concerning the **service provider** ~~facility~~, its staff, or employees warranting possible sanctions or corrective action. This information may be reported to agencies responsible for **service provider** ~~facility~~ licensing or accreditation, employee discipline, employee licensing or certification, or criminal **investigation or** prosecution.

(c) **Notwithstanding the confidentiality requirements of paragraph (b) of this section, the P&A may make a report to investigative or enforcement agencies, as described in that paragraph, which reveals the identity of an individual service recipient and information relating to his or her status or treatment under the following circumstances:**

(1) **If authorized by the individual or by his or her legal guardian, conservator or other legal representative;**

(2) **In the case of an individual, including an individual whose whereabouts are unknown, to whom all of the following conditions apply:**

(i) **The individual, due to his or her mental or physical condition is unable to authorize the system to reveal the information;**

**(ii) The individual does not have a legal guardian, conservator or other legal representative, or the individual's guardian is the State (or one of its political subdivisions); and**

**(iii) With respect to whom a complaint has been received by the system or the system has probable cause (which can be the result of monitoring or other activities including media reports and newspaper articles) to believe that such individual has been or may be subject to abuse or neglect;**

**(3) In the case of an individual who has a legal guardian, conservator, or other legal representative, with respect to whom a complaint has been received by the system or, as a result of monitoring or other activities, the system has determined that there is probable cause to believe that such individual has been or may be subject to abuse or neglect, whenever all the following conditions exist:**

**(i) The system has made a good faith effort to contact the representative upon receipt of the representative's name, address and telephone number (and such information must be provided within one business day of a written request);**

**(ii) The system has offered assistance to the representative to resolve the situation; and**

**(iii) The representative has failed or refused to consent to the disclosure of the information (including the situation where the representative's refusal may be based on a good faith belief that such denial is in the best interest of the individual); and**

**(4) In the case where the system determines that there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy, or in any case of the death of an individual whom the system believes may have had a developmental disability (and in such cases, the system need not seek consent from another party).**

Explanation: The revisions to paragraphs (b) and (c) reflect the critical need for P&As to be able to disclose to other investigative and enforcement agencies information about ongoing or potential abuse and neglect and specific individuals affected. Frequently, a P&A will uncover, as part of its own investigation or monitoring efforts, information about abuse and neglect which must be addressed promptly by other agencies with specialized state or federal authority and/or greater resources, such as state licensing and certification agencies, the Department of Justice, and the police. In order for these agencies to act promptly and effectively they must be provided specific information about individuals subject to abuse or neglect and the relevant circumstances.

Under the current regulations, P&As arguably have lesser rights to report to the police and other responsible agencies specific information about individuals subject to abuse (i.e., information that may disclose their identities) than does the public. We have recommended that such information may be disclosed only with significant restrictions – under those circumstances in which P&As are authorized to obtain access to the records of an individual, as set out in the DD Act. This approach should strike an appropriate balance between the interests

that service recipients may have in privacy (and the authority of their guardians concerning decision making issues) versus the interest in safeguarding their health and safety. Also, this approach is consistent with congressional intent, given that it relies on established – and logically applicable – requirements concerning the privacy interests of individuals with developmental disabilities and the role of guardians. Therefore, it would represent a reasonable interpretation of the Act.

### **Posting of Notices on P&A Services**

As mentioned at the outset, the regulations should require public and private service providers to post notices regarding the services provided by the P&A in the state or territory and information on how to contact the agency. Additionally, service providers should be required to provide such a written notice to persons with developmental disabilities and their guardians, as appropriate, upon their becoming involved with a program providing supports, services or other assistance.

This would be similar to the requirement for nursing homes under the Medicaid Act, as amended by the Nursing Home Reform Act, at 42 U.S.C. 1396r(c)(2)(B)(iii), and its regulations, at 42 CFR 483.10(b)(7). The statute and regulation require nursing homes to provide individual notice to residents and to post a notice in the facility. Specifically, the statute states that a nursing facility is required, before effecting a transfer or a discharge of resident, to provide a written notice to the resident and an immediate family member of the resident or legal representative of the address and telephone number of the P&A. And the regulation states that the facility must post the name, address and phone number of the P&A. There is a similar requirement contained in the Centers for Medicare and Medicaid Services' regulations concerning the use of restraint and seclusion in psychiatric residential treatment facilities for persons under 21, at 42 CFR 483.356(d). That regulation requires such facilities to provide incoming residents and their guardians contact information for the local P&A (as part of dissemination of its policy on the use of restraint and seclusion). And at least one court has required a service provider to post a notice regarding P&A services. Robbins v. Budke, 739 F.Supp. 1479, 1489-1490 (D. N.M. 1990).

This notice provision is a critical outreach tool, because the experience of the P&A System demonstrates that most persons with developmental disabilities who may be subject to abuse and neglect, especially those who may be isolated in institutional settings, are unaware of the System and its services. And P&As do not have the resources to reach all locations serving persons with developmental disabilities in order to inform them of their rights and the services available from the P&A. Correspondingly, it seems clear that perhaps a majority of service providers for persons with developmental disabilities are unaware of the system's mandates. P&As are constantly expending their resources in disputes about their authority, including diverting much of their resources to unnecessary litigation concerning their authority to investigate abuse

and neglect or to monitor conditions relating to health and safety. Such a notice requirement would go a long way in helping to educate service providers about the P&A system and its authorities, and thus avoid these unnecessary disputes and wasting of limited P&A resources.

To minimize burdens on service providers, the regulations should provide that the notice may be transmitted to service recipients, and/or an immediate family member or guardian/legal representative, at the time other written information (such as a general notice of legal rights) is routinely first provided to service recipients and/or their family members or legal representatives. The regulations should also provide suggested language for such a notice. We suggest the following language:

If you have a concern regarding the care provided to you by \_\_\_\_\_ [service provider's name] or your legal rights, you may contact the local protection and advocacy agency, \_\_\_\_\_ [name of protection and advocacy agency, address and phone number]. \_\_\_\_\_. [Name of agency] can inform you of your rights to treatment and services and can investigate incidents of abuse or neglect and other concerns you may have about your rights.

### **State Interference with P&A Authority**

The current regulations provide only limited guidance on impermissible state policies and practices which interfere with the implementation of the P&A's mandates, and these regulatory provisions generally just echo parallel statutory requirements. See sections 1386.21(b) (prohibiting federal allotments to supplant available state funds) and 1386.21(d) (prohibiting state policies that impact negatively on P&A staff or implementation of federal P&A mandates). We continue to receive reports that states are imposing a range of policies that impair the ability of P&As to carry out their federal mandates. Accordingly, we suggest that detailed guidance be included in the regulations regarding specific policies and practices that would conflict with the requirement that P&As retain their independent federal authority.

Specifically, the regulations should incorporate the following clarifications – that states may not establish a policy or practice, which requires a P&A to:

- obtain the state's review and/or approval of the P&A's plans to undertake a particular advocacy initiative, including specific litigation (or to pursue litigation rather than some other remedy or approach), or to contract with outside counsel or an expert witness or other consultants.

- refrain from representing individuals with particular types of concerns or legal claims, or refrain from otherwise pursuing a particular course of action designed to

remedy a violation of rights such as promoting modification or adoption of federal, state or local laws or policies affecting the rights of persons with developmental disabilities.

- investigate certain matters (or restrict the manner of the P&A's investigation), or report to state authorities or other entities the P&A's investigative findings.

### **Providing the P&A Information about the Adequacy of Waiver Services**

The DD Act of 2000 established a new mandatory requirement upon the part of states to provide information to P&As concerning services provided by the state to persons with developmental disabilities under the state's home and community based (HCB) waiver. Specifically, the DD Act provides (at 42 U.S.C. 15043(a)(3)) that "to the extent available, the State shall provide to the system – . . . information about the adequacy of health care and other services, supports, and other assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under [42 U.S.C. 1396n(c)]) receive."<sup>2</sup> Accordingly, the DD regulations must be revised to set forth requirements to implement this new provision.

Under this part of the Medicaid law and its implementing regulations (at 42 CFR 441.301-309), states are required to develop certain information as part of their initial applications for the HCB waiver, as well as for their applications for renewals of the waivers. An application for a renewal may be made three years after the initial waiver is granted, but the information for the renewal application must be developed one year prior to the expiration of the initial waiver for review by the Centers for Medicare and Medicaid Services (CMS). In particular, the states must document the qualifications of providers of care under the HCB waiver and the plan of care for each participant under the HCB, including the scope of services to be provided, and the amount and duration of services.

More specifically, the state Medicaid agency must provide certain assurances concerning the health and welfare of persons to be served under the waiver. 42 CFR 441.302(a). The state must also report annually to CMS on the impact of the waiver on the type and amount of services provided under the state's plan and the health and welfare of recipients of services. 42 CFR 441.302(h). And the state must comply with specified documentation requirements, whereby it must provide, for instance, a description of the safeguards necessary to protect the health and welfare of recipients, and a description of the state's plan for evaluation and reevaluation of recipients.

We recommend that the regulations incorporate provisions requiring the state Medicaid agency and or other responsible state agencies (such as the state developmental

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<sup>2</sup>The DD Act also contains a provision that states are to provide P&As with copies of independent reviews the state conducts of ICF/MRs pursuant to 42 U.S.C. 1396a(a)(30)(C). However that section, 1396a(a)(30)(C), was repealed in 1999, and thus the DD Act requirement apparently no longer has any effect.

disabilities agency) to provide to the P&A all of the above referenced information at the same time it is provided to CMS. This approach would result in minimal additional burdens to the state and will allow P&As to learn about the adequacy of services to persons with developmental disabilities under the HCB waiver, as required by the DD Act.

### **Burden of Proof and Confidentiality of Client Records During Audits of P&As**

Section 1385.9(e)(2) of the current regulations provides that the P&A shall have the ultimate burden of proving compliance with the Act or regulations where HHS has found, during an audit or other investigation, any evidence of non-compliance. We believe that the imposition of this burden on the P&A is clearly at odds with federal due process protections. Clearly, HHS must have the ultimate burden of proof in this regard, especially where the agency may take punitive action such as withholding of funds. Also, this provision is in conflict with the hearing rules at subpart D of the regulations.

The regulation states further that the inability of the P&A to establish compliance because of its failure to disclose to HHS confidential client records will not relieve the P&A of this responsibility. This provision is in direct conflict with the statute at section 15044(c). This section provides that for purposes of an audit or evaluation, the Secretary “shall not require [the P&A] to disclose the identity of, or any other personally identifiable information related to, any individual requesting assistance under [the Act].” If the only means of avoiding a sanction imposed by HHS is to disclose such information, then in effect, the P&A is being “required” to make such disclosure. It is not a sufficient safeguard for P&As that the regulation allows the P&A to obtain a release from persons with developmental disabilities regarding the disclosure of their records. Such a requirement would be viewed as coercive by individuals and/or their representatives, and would violate their attorney-client privilege protections.

We recommend strongly that the requirements contained in this subsection be omitted from the revised regulations.

### **Redesignation of P&As**

The regulation concerning redesignation of P&As for “good cause” (section 1386.20(d) and (e)) do not set forth sufficient guidance on what conduct amounts to “good cause.” Absent such guidance, there is the risk that states will initiate redesignations for arbitrary or retaliatory reasons. The preamble to the final DD regulations (at 61 Fed. Reg. 51145 (September 30, 1996)), but not the regulations themselves, do contain some useful guidance: “We have modified the guidance we included in the NPRM to explain that ‘good cause’ may include, but is not limited to eliminating longstanding or pervasive inefficiency or a substantial breach of section [143] of the Act, or violations of other State and Federal requirements, such as 45 CFR part 74 [administration of grants requirements].” We recommend that this statement be incorporated directly into the regulatory language itself, so that it will be controlling as to redesignation determinations.

Additionally, the preamble for the proposed DD Act regulations included important guidance (at 60 Fed. Reg. 26777, May 18, 1995): “merely technical or minor shortcomings will not support such a finding [of good cause]. Further, in order to qualify as good cause the allegation must be made in good faith, which means that it was not made for the purpose of frustrating the accomplishment of the goals of the Act, these regulations, [the PAIMI, PAIR and Assistive Technology Programs] and any other Federal advocacy program that is administered by the State Protection and Advocacy System.” Again, this clarification should be incorporated into the regulations themselves.

### **Governing Board**

The regulations should incorporate the most significant provisions regarding the operation of P&A governing boards contained in the DD Act (at section 15044(a)), including the new requirements. This is particularly important because the PAIMI Act regulations contain provisions on board member term limitations which are not based on statutory requirements and are in conflict with the DD Act. In particular, the PAIMI Act regulations provide (at 42 CFR 51.22(b)(1)) that the term of board members shall be limited to four years, and that a member may not be reappointed during the two-year period following the expiration of his or her prior term.

Thus, the regulations should clarify that, except for the limitations set out in the Act and the regulations, the board shall be selected by the P&A and subject to such policies and procedures as the P&A may choose to establish, and (as specified in section 15044(a)(3)), the membership of the board shall be subject to term limits set by the system to ensure rotating membership. Other specific requirements in section 15044(a) then should be set out, along with guidance on their implementation, to the extent practicable.

