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Developmental Disabilities, and University Centers for Excellence in Developmental Disabilities Education Research and Service will collaborate with each other and with other public and private entities.

§ 1326.23 Non-allowable costs for the State Protection and Advocacy System.

(a) Federal financial participation is not allowable for:

(1) Costs incurred for activities on behalf of individuals with developmental disabilities to solve problems not directly related to their disabilities and which are faced by the general populace. Such activities include but are not limited to: Preparation of wills, divorce decrees, and real estate proceedings. Allowable costs in such cases would include the Protection and Advocacy System providing disability-related technical assistance information and referral to appropriate programs and services; and

(2) Costs not allowed under other applicable statutes, Departmental regulations and issuances of the Office of Management and Budget.

(b) Attorneys' fees are considered program income pursuant to 45 CFR part 75 and must be added to the funds committed to the program and used to further the objectives of the program. This requirement shall apply to all attorneys' fees, including those earned by contractors and those received after the project period in which they were earned.

§ 1326.24 Allowable litigation costs.

Allotments may be used to pay the otherwise allowable costs incurred by a Protection and Advocacy System in bringing lawsuits in its own right to redress incidents of abuse or neglect, discrimination and other rights violations impacting the ability of individuals with developmental disabilities to obtain access to records and when it appears on behalf of named plaintiffs or a class of plaintiff for such purposes.

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Subpart C—Access to Records, Service Providers, and Individuals With Developmental Disabilities

§ 1326.25 Access to records.

(a) Pursuant to sections 143(a)(2), (A)(i), (B), (I), and (J) of the Act, and subject to the provisions of this section, 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 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 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) The individual has been the subject of a complaint to the P&A system, or the P&A 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 subject to abuse and neglect.

(3) In the case of an individual, who has a legal guardian, conservator, or other legal representative, about 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 the individual with developmental disability has been subject to abuse or neglect, whenever the following conditions exist:

(i) The P&A system has made a good faith effort to contact the legal guardian, conservator, or other legal representative upon prompt receipt (within the timelines set forth in paragraph (c) of this section) of the contact information (which is required to include

but not limited to name, address, telephone numbers, and email address) of the legal guardian, conservator, or other legal representative;

(ii) The system has offered assistance to the legal guardian, conservator, or other legal representative to resolve the situation; and

(iii) The legal guardian, conservator, or other legal representative has failed or refused to provide consent on behalf of the individual.

(4) If the P&A determines there is probable cause to believe that the health or safety of an individual is in serious and immediate jeopardy, no consent from another party is needed.

(5) In the case of death, no consent from another party is needed. Probable cause to believe that the death of an individual with a developmental disability resulted from abuse or neglect or any other specific cause is not required for the P&A system to obtain access to the records. Any individual who dies in a situation in which services, supports, or other assistance are, have been, or may customarily be provided to individuals with developmental disabilities shall, for the purposes of the P&A system obtaining access to the individual's records, be deemed an "individual with a developmental disability."

(b) Individual records to which P&A systems must have access under section 143(a)(2), (A)(i), (B), (I), and (J) of the Act (whether written or in another medium, draft, preliminary or final, including handwritten notes, electronic files, photographs or video or audiotape records) shall include, but shall not be limited to:

(1) Individual records prepared or received in the course of providing intake, assessment, evaluation, education, training and other services; supports or assistance, including medical records, financial records, and monitoring and other reports prepared or received by a service provider. This includes records stored or maintained at sites other than that of the service provider, as well as records that were not prepared by the service provider, but received by the service provider from other service providers.

(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. The organizations whose reports are subject to this requirement include, but are not limited to, agencies in the foster care systems, developmental disabilities systems, prison and jail systems, public and private educational systems, emergency shelters, criminal and civil law enforcement agencies such as police departments, agencies overseeing juvenile justice facilities, juvenile detention facilities, all pre- and post-adjudication juvenile facilities, State and Federal licensing and certification agencies, and private accreditation organizations such as the Joint Commission on the Accreditation of Health Care Organizations or by medical care evaluation or peer review committees, regardless of whether they are protected by federal or state law. The reports subject to this requirement describe any or all of the following:

(i) The incidents of abuse, neglect, injury, and/or death;

(ii) The steps taken to investigate the incidents;

(iii) Reports and records, including personnel records, prepared or maintained by the service provider in connection with such reports of incidents; or,

(iv) Supporting information that was relied upon in creating a report including all information and records that describe persons who were interviewed, physical and documentary evidence that was reviewed, and the related investigative findings;

(3) Discharge planning records; and

(4) Information in professional, performance, building or other safety standards, and demographic and statistical information relating to a service provider.

(c) The time period in which the P&A system must be given access to records of individuals with developmental disabilities under sections 143(a)(2)(A)(i), (B), (I), and (J) of the Act, and subject to the provisions of this section, varies depending on the following circumstances:

(1) If the P&A system determines that there is probable cause to believe that the health or safety of the individual with a developmental disability

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is in serious and immediate jeopardy, or in any case of the death of an individual with a developmental disability, access to the records of the individual with a developmental disability, as described in paragraph (b) of this section shall be provided (including the right to inspect and copy records as specified in paragraph (d) of this section) to the P&A system within 24 hours of receipt of the P&A system's written request for the records without the consent of another party.

(2) In all other cases, access to records of individuals with developmental disabilities shall be provided to the P&A system within three business days after the receipt of such a written request from the P&A system.

(d) A P&A shall be permitted to inspect and copy information and records, subject to a reasonable charge to offset duplicating costs. If the service provider or its agents copy the records for the P&A system, it may not charge the P&A system an amount that would exceed the amount customarily charged other non-profit or State government agencies for reproducing documents. At its option, the P&A may make written notes when inspecting information and records, and may use its own photocopying equipment to obtain copies. If a party other than the P&A system performs the photocopying or other reproduction of records, it shall provide the photocopies or reproductions to the P&A system within the time frames specified in paragraph (c) of this section. In addition, where records are kept or maintained electronically they shall be provided to the P&A electronically.

(e) The Health Insurance Portability and Accountability Act Privacy Rule permits the disclosure of protected health information (PHI) without the authorization of the individual to a P&A system to the extent that such disclosure is required by law and the disclosure complies with the requirements of that law.

(f) Educational agencies, including public, private, and charter schools, as well as, public and private residential and non-residential schools, must provide a P&A with the name of and contact information for the parent or guardian of a student for whom the

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P&A has probable cause to obtain records under the DD Act.

§ 1326.26 Denial or delay of access to records.

If a P&A system's access is denied or delayed beyond the deadlines specified in § 1326.25, the P&A system shall be provided, within one business day after the expiration of such deadline, with a written statement of reasons for the denial or delay. In the case of a denial for alleged lack of authorization, the name, address and telephone number of individuals with developmental disabilities and legal guardians, conservators, or other legal representative will be included in the aforementioned response. 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.

[80 FR 44807, July 27, 2015, as amended at 81 FR 35647, June 3, 2016]

§ 1326.27 Access to service providers and individuals with developmental disabilities.

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

(b) The P&A system shall have reasonable unaccompanied access to individuals with developmental disabilities at all times necessary to conduct a full investigation of an incident of abuse or neglect.

(1) Such access shall be afforded upon request, by the P&A system when:

(i) An incident is reported or a complaint is made to the P&A system;

(ii) The P&A system determines that there is probable cause to believe that an incident has or may have occurred; or

(iii) 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.

(2) A P&A system shall have reasonable unaccompanied access to public and private service providers, programs in the State, and to all areas of the service provider's premises that are used by individuals with developmental disabilities or are accessible to them. Such access shall be provided without

advance notice and made available immediately upon request. This authority shall include the opportunity to interview any individual with developmental disability, 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 individual with developmental disability or staff with whom it plans to meet; neither may the P&A be required to justify or explain its interaction with such persons.

(c) In addition to the access required under paragraph (b) of this section, a P&A system shall have reasonable unaccompanied access to service providers for routine circumstances. This includes areas which are used by individuals with developmental disabilities and are accessible to individuals with developmental disabilities at reasonable times, which at a minimum shall include normal working hours and visiting hours. A P&A also shall be permitted to attend treatment planning meetings concerning individuals with developmental disabilities with the consent of the individual or his or her guardian, conservator or other legal representative, except that no consent is required if the individual, due to his or mental or physical condition, is unable to authorize the system to have access to a treatment planning meeting; and 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).

(1) Access to service providers shall be afforded immediately upon an oral or written request by the P&A system. Except where complying with the P&A's request would interfere with treatment or therapy to be provided, service providers shall provide access to individuals for the purpose covered by this paragraph. If the P&A's access to an individual must be delayed beyond 24 hours to allow for the provision of treatment or therapy, the P&A shall receive access as soon as possible thereafter. In cases where a service provider denies a P&A access to an in-

dividual with a developmental disability on the grounds that such access would interfere with the individual's treatment or therapy, the service provider shall, no later than 24 hours of the P&A's request, provide the P&A with a written statement from a physician stating that P&A access to the individual will interfere with the individual's treatment and therapy, and the time and circumstances under which the P&A can interview the individual. If the physician states that the individual cannot be interviewed in the next 24 hours, the P&A and the service provider shall engage in a good faith interactive process to determine when and under what circumstances the P&A can interview the individual. If the P&A and the service provider are unable to agree upon the time and circumstance, they shall select a mutually agreeable independent physician who will determine when and under what circumstances the individual may be interviewed. The expense of the independent physician's services shall be paid for by the service provider. Individuals with developmental disabilities subject to the requirements in this paragraph include adults and minors who have legal guardians or conservators.

(2) P&A activities shall be conducted so as to minimize interference with service provider programs, respect individuals with developmental disabilities' privacy interests, and honor a recipient's request to terminate an interview. This access is for the purpose of:

(i) Providing information, training, and referral for programs addressing the needs of individuals with developmental disabilities, 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. P&As shall be permitted to post, in an area which individuals with developmental disabilities receive services, a poster which states the protection and advocacy services available from the P&A system, including the name, address and telephone number of the P&A system.

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(ii) Monitoring compliance with respect to the rights and safety of individuals with developmental disabilities; and

(iii) Access including, but is not limited to inspecting, viewing, photographing, and video recording all areas of a service provider's premises or under the service provider's supervision or control which are used by individuals with developmental disabilities or are accessible to them. This authority does not include photographing or video recording individuals with developmental disabilities unless they consent or State laws allow such activities.

(d) Unaccompanied access to individuals with developmental disabilities including, but not limited to, the opportunity to meet and communicate privately with individuals regularly, both formally and informally, by telephone, mail and in person. This authority shall also include the opportunity to meet, communicate with, or interview any individual with a developmental disability, including a person thought to be the subject of abuse, who might be reasonably believed by the P&A system to have knowledge of an incident under investigation or non-compliance with respect to the rights and safety of individuals with developmental disabilities. Except as otherwise required by law the P&A shall not be required to provide the name or other identifying information regarding the individual with a disability with whom it plans to meet; neither may the P&A be required to justify or explain its interaction with such persons.

§ 1326.28 Confidentiality of State Protection and Advocacy System records.

(a) A P&A shall, at minimum, comply with the confidentiality provisions of all applicable Federal and State laws.

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

(1) Except as provided elsewhere in this section, keep confidential all records and information, including in-

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formation contained in any automated electronic database pertaining to:

(i) Clients;

(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 who 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, and who provided information to the P&A for the record.

(v) Peer review records.

(2) Have written policies governing the access, storage, duplication and release of information from client records, including the release of information peer review records.

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

(c) Nothing in this subpart shall prevent the P&A system from 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 reporting the results of an investigation in a manner which maintains the confidentiality of such individuals, to responsible investigative or enforcement agencies should an investigation reveal information concerning the service provider, its staff, or employees warranting possible sanctions or corrective action. This information may be reported to agencies responsible for service provider licensing or accreditation, employee discipline, employee licensing or certification, or criminal investigation or prosecution.

(d) Notwithstanding the confidentiality requirements of this section, the P&A may make a report to investigative or enforcement agencies, as described in paragraph (b) of this section, which reveals the identity of an

individual with developmental disability, and information relating to his or her status or treatment:

(1) When the system has received a complaint that the individual has been or may be subject to abuse and neglect, or 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;

(2) When the system determines that there is probable cause to believe the health or safety of the individual is in serious and immediate jeopardy; or

(3) In any case of the death of an individual whom the system believes may have had a developmental disability.

Subpart D—Federal Assistance to State Councils on Developmental Disabilities

§ 1326.30 State plan requirements.

(a) In order to receive Federal funding under this subpart, each State Developmental Disabilities Council must prepare and submit a State plan which meets the requirements of sections 124 and 125 of the Act (42 U.S.C. 15024 and 15025), and the applicable regulation. Development of the State plan and its periodic updating are the responsibility of the State Council on Developmental Disabilities. As provided in section 124(d) of the Act, the Council shall provide opportunities for public input and review (in accessible formats and plain language requirements), and will consult with the Designated State Agency to determine that the plan is consistent with applicable State laws, and obtain appropriate State plan assurances.

(b) Failure to comply with the State plan requirements may result in the loss of Federal funds as described in section 127 of the Act (42 U.S.C. 15027). The Secretary, or his or her designee, must provide reasonable notice and an opportunity for a hearing to the Council and the Designated State Agency before withholding any payments for planning, administration, and services.

(c) The State plan must be submitted through the designated system by AIDD which is used to collect quantifi-

able and qualifiable information from the State Councils on Developmental Disabilities. The plan must:

(1) Identify the agency or office in the State designated to support the Council in accordance with section 124(c)(2) and 125(d) of the Act. The Designated State Agency shall provide required assurances and support services requested from and negotiated with the Council.

(2) For a year covered by the State plan, include for each area of emphasis under which a goal or goals have been identified, the measures of progress the Council has established or is required to apply in its progress in furthering the purpose of the Developmental Disabilities Assistance and Bill of Rights Act through advocacy, capacity building, and systemic change activities.

(3) Provide for the establishment and maintenance of a Council in accordance with section 125 of the Act and describe the membership of such Council. The non-State agency members of the Council shall be subject to term limits to ensure rotating membership.

(d) The State plan must be updated during the five-year period when substantive changes are contemplated in plan content, including changes under paragraph (c)(2) of this section.

(e) The State plan may provide for funding projects to demonstrate new approaches to direct services that enhance the independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities. Direct service demonstrations must be short-term, with a strategy to locate on-going funding from other sources after five years. Any State desiring to receive assistance beyond five years, under this subtitle, shall include in the State plan the information listed in paragraphs (e)(1) through (3) of this section, and AIDD reserves the right as the overseeing agency to deny the continuation of the demonstration project beyond five years.

(1) The estimated period for the project's continued duration;

(2) Justifications of why the project cannot be funded by the State or other sources and should receive continued funding; and