

**§ 1326.28**

(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