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June 3, 2008

Dr. Patricia Morrissey, Commissioner
Administration on Developmental Disabilities
Administration for Children and Families
370 L'Enfant Promenade, S.W.
Mail Stop: HHH 405D
Washington, DC 20447

Re: HHS, Developmental Disabilities Program Proposed Rule, 73 Federal Register, April 10, 2008

Dear Commissioner Morrissey:

The American Health Care Association (AHCA), together with the National Center for Assisted Living (NCAL) is committed to performance excellence and Quality First, a covenant for healthy, affordable, and ethical long term care. AHCA/NCAL represents nearly 11,000 non-profit and for-profit providers dedicated to continuous improvement in the delivery of professional and compassionate care for our nation's frail, elderly and physically and developmentally disabled citizens who live in long term care facilities, including intermediate care facilities for individuals with mental retardation (ICFs/MR) and Medicaid waiver funded group homes for individuals with developmental disabilities (henceforth referred to as group homes.) AHCA appreciates the opportunity to comment on this proposed rule.

Executive Summary

This proposed rule clarifies and proposes new requirements to implement the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act of 2000, Pub. L. 106-402), herein referred to as "the Act." The purpose of the Act is:

"to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs..." including (1) State Councils on Developmental Disabilities; (2) Protection and Advocacy Systems in each state; (3) University Centers for Excellence in Developmental Disabilities Education, Research and Service; and

(4) Funding for [national initiatives and technical assistance...]

The Act directs the Secretary of Health and Human Services to implement an accountability process to monitor program grantees that receive funds under the Act; this accountability system and new reporting requirements form the substantive basis of the proposed rule. AHCA is focusing its comments on Section 1386 of the proposed rule as that section significantly impact clients of ICFs/MR and group homes, as well as their providers.

AHCA's major concerns regarding this proposed rule are:

- 1) The revised definitions in section 1386 do not appropriately identify the thresholds used to define them;
- 2) Aspects of the rule do not recognize the rights of individuals with developmental disabilities (DD) to reside in ICFs/MR and leave ICFs/MR vulnerable to inappropriate closure;
- 3) The rule proposes overly broad access by State Protection and Advocacy Systems (P&As) to individuals with DD, their records, and to service providers, which include ICFs/MR and group homes; and
- 4) Service providers are not guaranteed the right to be parties at hearings that address allegations of their alleged poor care of individuals with DD.

AHCA/NCAL Recommendations

- 1) AHCA recommends that, to prevent individuals with DD, or their families/guardians/representatives, from being unwilling participants in a class action lawsuit, the Administration on Developmental Disabilities (ADD) should require that the P&A communicate directly with ICF/MR clients and, as designated, their legal representatives before lawsuits are filed. Specifically, P&A's should be required to:
 - (1) Notify ICF/MR residents, families and, where appointed, their legal guardians/representatives at least 90 days in advance of filing a class action lawsuit against an ICF/MR.
 - (2) Provide residents and, where appointed, their legal guardians/representatives, with the right to opt out of the lawsuit by notifying plaintiffs' counsel within 90 days after receiving notification.
- 2) AHCA recommends that ADD change the definition of "abuse" to "the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish."
- 3) AHCA recommends that ADD revise the definition of "complaint" to indicate that an individual's residential placement, if not related to quality issues, does not constitute a complaint issue.

- 4) AHCA recommends that ADD change the definition of “neglect” to “the repeated failure to provide goods and services necessary to avoid physical harm, pain or mental anguish.”
- 5) AHCA recommends that ADD revise the definition of “probable cause” to assure due process for DD residential services providers. In addition, we recommend that ADD include in the body of the rule the following statement: “The definition [of probable cause] is not intended to affect the authority of the courts to review the determinations of P&As of whether probable cause exists.”
- 6) AHCA recommends that ADD delete 138.625(b)(1) as it provides inappropriate access to records and replace it with 1386.25(b)(2), which provides more appropriate access to records as the items identified as accessible, e.g., “reports prepared by a federal, state or local governmental agency....with the responsibility for overseeing human services systems.... such as licensing and certification agencies....” directly relate to the alleged issue of sub-optimal care.
- 7) AHCA recommends that 1386.27 clarify that P&A access to service providers and recipients must be based on substantiated allegations of wrongdoing and will only involve individuals with DD that are the subject of wrongdoing.
- 8) AHCA recommends that ADD clarify that an institutional employer is not the responsible party under Subpart D and is not responsible for finding or guaranteeing alternative employment for displaced employees should individuals with DD that reside in the ICF/MR be transferred to alternate community settings, resulting in decreased staffing needs in the ICF/MR or facility closure.
- 9) AHCA recommends that ADD require that affected parties addressed in a hearing are guaranteed admission to the hearing, as well as the right to testify on their own behalf.

Discussion

Supplementary Information Section- Discussion of Notice of Proposed Rule Making (NPRM)

On page 19709 of the proposed rule, ADD seeks public comment on whether the current process involving class action lawsuits provides adequate protection for individuals with DD; specifically, “what criteria should be applied or clearance process followed to include an individual as a member of a class?”

AHCA is pleased that ADD acknowledges the importance of informed consent in class action lawsuits to “protect the rights of individuals who may choose to be or not to be members of a potential class.” Too often, individuals who reside in ICFs/MR and their families are swept into class action lawsuits, initiated by P&As, without notice to the individual or family and without consent. For example, In *Capitol People First v. California Department of Developmental Services*, filed in 2002, twelve plaintiffs

represent a class of over 6,000 people consisting of “all Californians with developmental disabilities who are or will be institutionalized, and those who are or will be at risk of institutionalization in either public or private facilities, including but not limited to, the Developmental Centers, skilled nursing facilities, intermediate care facilities [ICF/MRs], large congregate care facilities, psychiatric hospitals or children’s shelters.”

Notably, since 1966, every P&A lawsuit has been filed primarily to remove residents from their ICF/MR home to obtain “community integration;” the quality of care provided at the targeted ICF/MR was not at issue in these cases.

While improving facility conditions stands to benefit every DD client in residence equally, community placement is not universally beneficial or clinically appropriate. ICF/MR clients are among the most clinically complex of the DD population; many have extremely impaired cognitive capacity and are dependent upon staff 24 hours a day for feeding, toileting and bathing. Therefore, transitioning these residents from ICFs/MR to “community settings,” such as an apartment or private home where continuous, skilled staff may not be available, without the individual or their guardian’s approval, infringes on the rights of these individuals to receive the level and quality of care that they desperately need. In addition, ICFs/MR nationwide have decreased in size to a median of 6 beds per facility (ICF/MRDD OSCAR survey report, October 2007;) the supposed “warehousing” of individuals with DD, often used as an argument to close down ICFs/MR, is not today’s reality.

Notably, ICFs/MR provide “active treatment” to their residents to help them obtain optimal functioning, and ICFs/MR are surveyed annually by CMS to evaluate compliance with state and federal regulations. Many ICF/MR residents enjoy living in these facilities, where they have the benefit of 24-hour staffing, active treatment, recreational activities and companionship. The ICF/MR is the community of choice for many individuals with DD; thus, to prevent these individuals, or their families/guardians/representatives, from being unwilling participants in a class action lawsuit that could lead to the eventual closing of their home of choice, i.e., the ICF/MR, we recommend that the way P&A pursues a lawsuit must change. Specifically, ADD should require that the P&A communicate with ICF/MR clients and, as designated, their legal representatives before lawsuits are filed. This communication must be in a format so that individuals with DD or their representatives can review it (e.g., written text, audio version, etc.) and in comprehensible language to ensure understanding of the lawsuit. Such requirements would assure that there is informed consent, which is in keeping with the Act, which states:

“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(2000) (*Policies*). Therefore, AHCA provides the following recommendation:

AHCA recommends that ADD require P&A to:

- (1) Notify ICF/MR residents, families and, where appointed, their legal

guardians/representatives at least 90 days in advance of filing a class action lawsuit against an ICF/MR; and

- (2) Provide residents and, where appointed, their legal guardians/representatives, with the right to opt out of the lawsuit by notifying plaintiffs' counsel within 90 days after receiving notification.

Proposed Rule 42CFR 1386- Formula Grant Programs

Subpart B, Protection and Advocacy of Individual Rights, 1386.19 Definitions

In this section of the NPRM, ADD revises the terms and definitions that apply to Parts 1386.20-1386.21, 1386.24-1386.25, and to subpart C. AHCA has the following comments about these revised definitions:

- 1) Definition of "Abuse:" The proposed definition of abuse is unclear and too broad, and it would leave P&As as the final arbiter of what constitutes "abuse" of an individual with DD. This renders DD residential services providers vulnerable to P&A's entirely subjective interpretations of abuse; subsequent inaccurate conclusions can lead to inappropriate P&A inspections and potential ultimate closure of ICFs/MR, especially as the accused provider is not guaranteed admission to resultant hearings on alleged abuse-related issues.

In 1998, the Center for Medicaid State Operations held an "Abuse Initiative" meeting, at which time the following definition for abuse was drafted:

"Abuse:" The willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish.

This definition provides more guidance on how to identify potential resident mistreatment. Therefore, AHCA provides the following recommendation:

- *AHCA recommends that ADD change the definition of "abuse" to "the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish."*

- 2) Definition of "Complaint:" The preamble states that "the definition of "complaint" has been revised "... to broader language indicating that the complaint relates to the **status** [emphasis supplied] or treatment of an individual with DD." AHCA is concerned that in light of bias against ICFs/MR in favor of "community" settings, individuals' mere "status" as residents in ICFs/MR could be used to justify a complaint, and that subsequent, potentially inappropriate investigations by P&As can occur. Therefore, AHCA provides the following recommendation:

- *AHCA recommends that ADD revise the definition of “complaint” to indicate that an individual’s residential placement, if not related to quality issues, does not constitute a complaint issue.*

3) Definition of “Neglect:” The preamble states that the proposed rule expands the definition of the individual perpetuating the act of neglect from an individual providing “treatment or habilitation services” to an individual responsible for providing “services, supports or other assistance.” This appears appropriate as individuals with DD receive services beyond traditional treatment and habilitation. However, similar to the definition of “abuse” above, the complete revised definition of “neglect” in the rule (p. 19728) leaves too much room for inappropriate correlation of “risk of injury or death” of an individual with DD with “acts or omissions [by the service provider] such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan),” etc.

Also, similar to the “abuse” definition previously mentioned, AHCA believes that ADD needs to provide more guidance on how to identify potential neglect of an individual with DD. In the previously mentioned 1998 Center for Medicaid State Operations “Abuse Initiative” meeting, a definition for neglect also was drafted. As that definition provides more guidance than the one delineated in the proposed rule, AHCA recommends that ADD use that definition, as follows:

- *AHCA recommends that ADD change the definition of “neglect” to “the repeated failure to provide goods and services necessary to avoid physical harm, pain or mental anguish.”*

4) Definition of “Probable Cause:” The definition of “probable cause” on p. 19728 of the proposed rule states: “The P&A system is the final arbiter of probable cause between itself and the organization or individual from whom it is seeking records.” This fails to provide constitutionally mandated due process to DD residential services providers since it is entirely subjective, could lead to inconsistent applications, and fails to place providers on notice of the actual standards to which they are expected to adhere or with which they are required to comply to remain in compliance. Therefore, AHCA provides the following recommendation:

- *AHCA recommends that ADD revise the definition of “probable cause” to reflect the comments above. In addition, we recommend that ADD include in the body of the rule the following statement which was made in the preamble: “The definition [of probable cause] is not intended to affect the authority of the courts to review the determinations of P&As of whether probable cause exists.”*

This would clarify that the courts are the final arbiter for determining “probable cause,” not the P&As.

Subpart C- Access to Records, Service Providers and Service Recipients (1386.25-1386.28)

In the proposed rule, ADD creates a new Subpart C on P&A access to records, service providers and service recipients as, per the preamble on p. 19715, this will “[support] the P&A system in investigating suspected cases of abuse and neglect.” In addressing key provisions related to P&As’ access to service providers, recipients and/or records, as well as consent issues, the NPRM rationalizes this approach by stating that it is consistent with the DD Act and with the 2nd circuit decision in “State of Connecticut Office of Protection and Advocacy for Persons with Disabilities v. Hartford Board of Education, Hartford Public Schools and Robert Henry, Supt. of School.” In addition, ADD proposes to make the regulation on access to records consistent, where applicable, with Protection and Advocacy for Individuals with Mental Illness (PAIMI) regulation to ensure that all facets of the P&A system administered by the Department are subject to the same legally supportable requirements.

The preamble states that “where we [ADD] exercise discretion [in the rule], we do so in the belief that the proposed provisions are necessary to meet Congress' underlying intent to ensure necessary access to records to promote the System’s authority to investigate abuse and neglect and ensure the protection of rights.”

AHCA believes that although the 2nd circuit decision may set a precedent for access, it is not necessarily appropriate for all circuits. The proposed rule provides P&A with practically unlimited and uncontrolled access to individuals with DD, their records and provider settings; due to strong institutional bias against ICFs/MR, in which client placement in these settings alone (often considered “client status”) has been used as an excuse to close ICFs/MR, this section provides fodder to bolster P&A’s efforts to justify ICF/MR closure. This is evident in several key provisions of this section of the rule, as are discussed below:

- 1) This entire section uses the terms “complaint, abuse, probable cause and neglect.” Our comments about the inappropriateness of these terms are enumerated in the above comments entitled Subpart B, Protection and Advocacy of Individual Rights, 1386.19 Definitions. To promote more reasonable stipulations for P&As to access individuals with DD, records, staff, etc. that are in DD residential settings, AHCA provides the following recommendation:
 - *AHCA recommends that the definitions of “complaint, abuse, probable cause and neglect” in Subpart C **and throughout the rule** be revised as suggested in AHCA’s comments on Subpart B.*
- 2) In sections 1386.25(b)(1-2) of the proposed rule, P&A is given unrestricted access to essentially all client records. This is inappropriate as only records pertaining to the complaint or alleged abuse or neglect (as appropriately defined) should be available to the P&A. Also, unrestricted P&A access to all records related to the individual with DD is duplicative to requirements for providers under CMS oversight, namely ICFs/MR. ICF/MR summary reports to CMS, and CMS survey findings of the DD provider would provide adequate information to the P&A to reflect care provided to the individual with DD. Therefore, AHCA provides the following recommendation:

- *AHCA recommends that ADD delete 138.625(b)(1) as it provides inappropriate access to records and replace it with 1386.25(b)(2.)*

1386.25(b)(2) provides more appropriate access to records as the items identified as accessible, e.g., “reports prepared by a federal, state or local governmental agency...with the responsibility for overseeing human services systems.... such as licensing and certification agencies....” These reports may include descriptions of incidents of abuse, neglect, injury or death, steps taken to investigate the incidents, etc. As the report contents directly relate to the alleged issue of sub-optimal care, they are more appropriate for P&A access than the broad array of items proposed in 138.625(b)(1).

3) Section 1386.27, “Access to service providers and service recipients” allows P&As to have “reasonable” unaccompanied access to service providers and to all areas of the premises without advance notice and immediately upon request. As “abuse, neglect, probable cause and complaint” are used throughout this section to justify practically universal access to providers and recipients, it is particularly important that those terms be appropriately defined earlier in the rule. In addition, the following items in particular need to be addressed:

- a. In item (b) of this section, not requiring the P&A to identify the service recipient that it plans to meet with would give the P&A unchecked access to the service setting and service recipients to investigate beyond the scope of P&A’s initial inquiry. This would place individuals, who have nothing to do with the alleged abuse, neglect, etc. subject to P&A investigation, which is inappropriate and could interrupt standard facility operations and specific care of these individuals.
- b. In item (c), there is no rationale for the P&A system to have reasonable unaccompanied access to the service provider under routine circumstances. If there is no apparent abuse, neglect, complaint or probable cause, unchecked access by the P&As is not appropriate.

Therefore, AHCA provides the following recommendations:

- *AHCA recommends that section 1386.27 reflect the appropriate definitions as mentioned in our comments on Subpart B.*
- *AHCA recommends that 1386.27 should clarify that P&A access to service providers and recipients must be based on substantiated allegations of wrongdoing and will only involve individuals with DD that are the subject of wrongdoing. Access under “routine circumstances” when no allegations of misconduct are evident, is inappropriate.*

Subpart D, Federal Assistance to State Councils on DD

In section 1386.33, the rule states that the “State plan must assure fair and equitable arrangements to protect the interests of all institutional employees affected by actions under the plan to provide community living activities... [including] guaranteeing employment and employee training and retraining programs” should an institution be closed. Though it seems obvious that the operators of a closing ICF/MR should not be

responsible for securing jobs for its displaced employees, AHCA would like ADD to clarify to States that the laudable goal of making such arrangements is a State responsibility. Therefore, AHCA provides the following recommendation:

- *AHCA recommends that ADD clarify that an institutional employer is not the responsible party under this section and is not responsible for finding or guaranteeing alternative employment for displaced employees should individuals with DD that reside in the ICF/MR be transferred to alternate community settings, resulting in decreased staffing needs in the ICF/MR or facility closure.*

Subpart E- Practice and Procedure for Hearings Pertaining to State’s Conformity and Compliance with DD State Plans, Reports and Federal Requirements

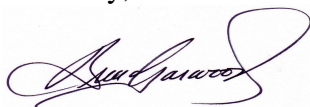
Section 1386.94 (b)(2) of the rule states that “other individuals or groups [beyond ADD, P&As, etc.] may be recognized as parties [in a hearing] if the issues to be considered at the hearing have caused them injury and their interests are relevant to the issues in the hearing.” Not guaranteeing affected parties, such as ICFs/MR and group homes, to be parties in a hearing when such providers have relevant interest is unjust. Therefore, AHCA provides the following recommendation:

- *AHCA recommends that ADD revise this section of the rule to indicate that affected parties addressed in a hearing are guaranteed admission to the hearing, as well as the right to testify on their own behalf.*

Conclusion

The main purpose of the Developmental Disabilities Program proposed rule, as it relates to ICFs/MR and group homes, appears to be to address P&As’ access to individuals with DD, their records, and service providers. AHCA believes that the rule inappropriately expands P&As’ access to service providers based on the P&A’s own subjective interpretation of abuse, neglect, complaint and probable cause, which may provide credence to close ICFs/MR altogether due to individuals with DDs’ “status” as residents in these facilities. Therefore, AHCA recommends that ADD revise the document as delineated in these comments to promote quality care for individuals with DD while preserving their rights to reside in ICFs/MR.

Sincerely,



Bruce Yarwood
President and CEO

cc: Van Moore