



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

February 8, 2016

Department of Health and Human Services
Administration for Community Living
Administration on Aging □
One Massachusetts Avenue NW
Washington, DC 20001

To Whom It May Concern:

Re: Comments on the Administration on Aging – Draft Voluntary Consensus Guidelines for State Adult Protective Services Systems

The organizations signed below, are members the Consortium for Citizens with Disabilities (CCD) Rights Task Force. We thank the Administration on Aging for issuing draft voluntary consensus guidelines for state Adult Protective Services (APS) programs, and to suggest additions to those guidelines. CCD is a coalition of national disability organizations working to promote national public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society.

We have reviewed the proposed guidelines, and think they will be very useful in helping APS programs better meet the needs of individuals with disabilities. We offer the following recommendations:

I. Clarify the standards for “involuntary intervention” and “self-neglect” and make the individual the center of the decision-making process

These guidelines attempt to make APS programs more accessible, more efficient, and more effective at pursuing cases of abuse and neglect on aging individuals and people with disabilities. However, without clear standards for involuntary intervention, these new guidelines also risk establishing paternalistic government interventions in the lives of people with disabilities who neither want nor need such service. While the voluntary intervention clause of Section 5 urges deference in many APS operations to the wishes of the client in many APS operations, there is

also an involuntary intervention clause which allows an APS caseworker to make housing and other life decisions for a client if the caseworker does not feel that the client is competent enough to make those decisions on their own. The involuntary intervention clause may invite APS caseworkers who disapprove of a person's actions to classify those actions as a form of "self-neglect" which warrants coercive intervention. An exploration of the "...ethical issues in the decision to use voluntary intervention" is not enough to ensure that individuals autonomy is appropriately preserved. There must also be a requirement to explore and use less restrictive interventions, including interventions that respond to findings of serious danger to health and safety. Therefore, the guidelines should recommend that states require their APS programs to identify all of the assistance and/or accommodations that a client needs in order to maximize self determination for each individual.

II. Clarify the accessibility requirements for state APS program interviews of clients and witnesses

Section 3 of the guidelines recommends that APS phone data intake processes should be accessible to disabled clients and witnesses by means of TTY services. However, the guidelines do not mention the use of augmentative and alternative communication (AAC) devices, interpreters, or other auxiliary aids and services when interviewing clients and witnesses who permanently or temporarily require these auxiliary aids or services for effective communication. We urge that the guidelines highlight the necessity for state APS programs to make needed accommodations to ensure effective communication with individuals with disabilities. For example, they must provide AAC devices (such as letter-boards and computer tablets pre-installed with AAC applications), ASL interpreters, and other communication supports to these clients and witnesses when collecting information about their experiences. People with disabilities who cannot speak – such as some autistic or deaf individuals, those with developmental or intellectual disabilities, and those with speech impediments – need to understand and be understood by APS workers. If they are not granted accommodations to ensure effective communication, the APS caseworker will not obtain complete information, and may even unfairly question the competency of the person to make a decision. In addition, by means of the psycho-social assessment, the APS worker should determine how the client or witness they are interviewing communicates and use that individual's personal AAC device if possible, to ensure that the person can use the device with which they are the most familiar. This practice ensures that the most reliable method of communication is used.

In the case of someone with a communication disability for whom a form of assistive communication cannot be identified, every effort should nevertheless be made to understand the individual's desires and preferences. These preferences may be expressed through facial expressions, behavior, sounds or signs. APS should consult with those familiar with the individual, who often have important information about how the individual communicates or who can interpret the unique expressions of the individual.

III. Make the client the center of the decision-making process and require section 4's psycho-social assessment to include the identification of necessary decision-making supports

While section 5b suggests that the individual can participate in the decision-making process, we believe that the individual must be central to the decision-making process. In general, the client has a right to make all important life decisions. If the client cannot do that without assistance or accommodation, then the assistance or accommodation that allows them to do that should be provided. Therefore, the guidelines should recommend that states require their APS programs to identify all of the assistance and/or accommodations that a client needs in order to make their own life decisions to the extent possible or desired by the individual. APS programs must identify and offer all the assistance and accommodations that the client needs, but must not provide assistance that the client does not want.

IV. Ensure that there are sufficient APS caseworkers with appropriate expertise concerning the needs of people with disabilities

Section 6 of the guidelines recommends that state APS programs require that caseworkers have at least a bachelor's degree from an accredited university and gives preference to those who have master's degrees in an APS-related field, such as public health, gerontology, or social work. We agree that APS caseworkers must have relevant academic credentials. However, the academic backgrounds of APS caseworkers must be diverse, not only in terms of the caseworkers' fields of study but also in terms of their expertise and experience in addressing the needs of people with disabilities. APS programs must have sufficient numbers of staff who have knowledge of and experience with the needs of people with a range of disabilities to ensure that the APS program effectively serves individuals with disabilities. If staff lacks appropriate knowledge, then outside experts with such knowledge must be brought in to assist when needed.

APS workers should receive continued training on disability rights and the Americans with Disabilities Act, including attendance at disability rights related conferences and use of consultants who have a background in disability from a rights-based perspective.

V. Emphasize the importance of working with State Protection & Advocacy (P&A) organizations and Developmental Disability (DD) Councils

The APS program must ensure that the basic rights of the people it serves are appropriately protected. Pursuant to the recommendation in section one of the guidelines to collaborate with other organizations, we urge that the guidelines require coordination between the APS program and the state P&A and DD council. These organizations are typically the primary state-based advocates for people with disabilities. Working closely with them is essential to ensure that APS programs adequately protect the needs and rights of the clients and witnesses with disabilities.

VI. Clarify the definition of “conflict of interest” so that it includes cases where friends/family and associates of staff members are accused of abuse

According to section 1g, a conflict of interest occurs when an APS employee or contractor is the alleged abuser. This definition is too narrow. It should be broadened to include situations where an APS caseworker is a friend or relative of, or has another personal relationship with, the alleged abuser. Personal relationships between the two can also create unfair biases in favor of the alleged abuser. The law must consider them conflicts of interest to avoid threatening the integrity of state APS programs.

VII. Ensure that state APS programs and the laws regulating them properly respect the Americans with Disabilities Act (ADA)

Throughout the guidelines, Child Protective Services (CPS) are held as a standard by which state APS programs must operate. The HHS Office for Civil Rights along with the Department of Justice (DOJ) recently issued a technical assistance document concerning the ADA obligations of local child welfare authorities toward parents and other caregivers with disabilities. Similarly, the ADA rights of adult care recipients, including the right to effective communication, freedom from discrimination, and community integration, must be fully respected—for example, as noted above, by providing reasonable accommodations to ensure equal opportunity for clients of the APS program, and by ensuring that APS actions do not result in individuals being placed in segregated settings as a protective measure. APS programs that have the authority to serve individuals in institutional settings should ensure that abuse and neglect allegations concerning institutionalized individuals are treated the same as those concerning individuals living in community settings. In addition, the ADA rights of adult caretakers with disabilities must be fully respected. It is imperative that the Administration for Community Living (ACL) pay attention to the technical assistance that HHS and the DOJ are providing in the context of the child welfare system so that it can inform future decisions. ACL must also issue its own technical assistance to clarify the ADA obligations of state APS programs.

Once again, we thank you for the opportunity to submit feedback on these guidelines.

Sincerely,

American Association of People with Disabilities (AAPD)
American Foundation for the Blind (AFB)
The ARC of the United States
Autistic Self Advocacy Network (ASAN)
Bazelon Center for Mental Health Law
Epilepsy Foundation
National Council on Independent Living (NCIL)
National Disability Rights Network (NDRN)
United Spinal Association