
Personal Assistance Principles

*Publication #1007 - Adopted 5/21/1994; Amended 12/6/2003;
Amended 6/21/2014, Amended 1/26/2018*

BACKGROUND

Disability Rights California adopted these principles to guide our policy work related to all forms of personal assistance from all sources including, but not limited to, California's In-Home Supportive Services (IHSS) and Waiver Personal Care Services, attendant care services funded through regional centers, and home health aide services through home health agencies. Below, we use the term “people” to mean a person or persons with a disability, regardless of age, and “PAS” to mean personal assistance services or personal assistant.

PRINCIPLES

- a) People, including children and seniors, have the right to receive services in the most integrated setting possible, in a manner which maximizes their personal autonomy and independence.
- b) People who need PAS have the right to select, hire, fire and direct a PAS. They have a right to hire from a competent and stable workforce of PAS. The compensation for PAS should be sufficient to develop and sustain such a workforce.
- c) People have the right to maximum flexibility in managing their services, including participating, if eligible, in programs which enable them to pay their providers directly.

- d) PAS should be available wherever people are during the day, such as home, day program, school and work.
- e) PAS should follow the social model versus the medical model approach.
- f) A parent with a disability should have access to a PAS to assist with parenting tasks such as feeding and diapering.
- g) People should have access to help in the administration and management of PAS, including care management services and help recruiting, screening and training. People should have a way to report abuse or problems. Training or management assistance or complaint processes should be independent of any agency delivering PAS.
- h) PAS should be as available as out-of-home care. Home-based care should be the norm; out-of-home care the exception, provided only when people choose it. People should retain the right to opt for in-home care, regardless of where their care is currently received.
- i) The IHSS program should be maintained and expanded to better meet the needs of people including, but not limited to, people with psychiatric disabilities, intellectual and developmental disabilities, traumatic brain injury and sensory disabilities including low vision and blindness. Allotment of PAS should be based on functional assessments and actual needs, not on assumptions or stereotypes about disabilities.
- j) Eligibility determinations and assessments for PAS should be performed by entities other than those who are delivering PAS. Counties, managed care organizations, or others performing assessments should not have financial incentives to deny certain services or benefit financially if people receive services out of their homes.
- k) People should be told about exemptions and exceptions to publicly funded PAS services including In-Home Supportive Services Overtime Rules/Limitations and their right to review so to ensure that they receive the appropriate number of hours they need.
- l) Secure funding is necessary to ensure stability in PAS programs and to avoid inappropriate or unwanted out-of-home placement.

- m) Every effort should be taken to maximize federal funding, when doing so does not adversely affect peoples' personal autonomy rights and scope of program benefits. Funding allocated to PAS should be sufficient to cover labor costs such as worker pay raises, overtime or benefits, so that these costs do not result in a reduction in the assistance.
- n) Compensation for PAS by family members—and particularly family members who have been excluded from other jobs because of the family member's care needs—has been key to enabling people to remain in their own home and should be maintained.
- o) Personal assistance programs should ensure the involvement of people and their family members in deciding program policy and should have a mechanism for effective communication.
- p) Personal assistance programs should be culturally and linguistically responsive to the diversity of people who need PAS.
- q) Any technology required or used in the delivery of PAS, including Electronic Visit Verification technology, should be consistent with all of the PAS principles herein. In particular, the technology should ensure personal autonomy and independence, maximize flexibility and location of services, enhance federal funding, and involve consumers and caregivers in the development of the system's functionality and implementing policies. Technology should be accessible to all program participants and providers with disabilities.