



For people with intellectual  
and developmental disabilities



# Position Statement Waiting Lists

Waiting lists are unacceptable for those who need services and supports. These lists constitute a major crisis in most states. Individuals with intellectual and/or developmental disabilities must have appropriate services and supports provided when requested and when needed. States must recognize the range of disabilities that result in functional limitations and respond appropriately. Governors and legislators must find the necessary resources to enable state agencies to fund appropriate community-based services and supports.

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## Issue

Individuals with disabilities and their families should not have to experience the death of a parent, a medical emergency or other tragic events to obtain the services they need. Despite new federal laws and regulations, individuals with intellectual and/or developmental disabilities and their families remain on waiting lists for years after requesting necessary supports and services.

If ongoing support is not available to young adults transitioning out of special education services, educational gains will be lost. Many people either accept services and supports that are available, but inappropriate, or receive no services at all. Inappropriate services may end up costing more than an appropriate service or support. Many individuals and families are desperate and experience extraordinary stress. Experts report that at least 700,000 Americans with disabilities are living at home with a caregiver who is over the age of 65. In many states, it takes a decade or more to receive necessary services and supports.

## Position

Needed public services and supports must be funded and made available for our constituents when they need them. To ensure that people can obtain services and supports, the following must occur:

- Each state shall develop an Olmstead [landmark Supreme Court case, "Olmstead v LC" 1999] plan that includes recognition of all individuals with intellectual and/or developmental disabilities that may require assistance through public supports and services. The plan shall include attention to existing populations which are eligible but not yet served; determine other populations that need to be included

in eligibility and determine if existing mechanisms in the community system are sufficient to provide services of sufficient quality;

- Plans should be developed based on the unique needs of the individual and accompanied with measurable goals and annual funding allocations;
- Public systems should actively reach out to individuals and to families to make them aware of the process to obtain services and supports;
- Eligibility determination should occur promptly upon request;
- Any supports or services prioritization shall include a realistic timeline for those individuals not receiving the highest priority;
- Individuals and families should be made aware of community service and support options whether they are readily available or need to be developed;
- Support services should address the needs of the individu-

als and be designed to include them in community life;

- The individual or family should be equal partners in the development of a supports or service plan. Essential Life Planning or similar person-centered process shall be utilized to develop a life plan in partnership with family, friends, independent professional(s), and others who have knowledge of the service system, the individual or the community and are independent from the service provider and the funding agency;
- Individuals or families should be given the option to self-direct their services and assistance to do so;
- Once a service or support option is agreed upon, it should be implemented as soon as possible but not later than 90 days. This timeframe applies to those who require a change in services and supports as well as to those without services and support; and
- In emergency situations, people should receive services and supports within hours.

<sup>1</sup>“People with intellectual disabilities and/or developmental disabilities” refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

Adopted:

Board of Directors, The Arc of the United States  
August 4, 2008

Board of Directors, AAIDD  
August 18, 2008

Congress of Delegates, The Arc of the United States  
November 8, 2008

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