



For people with intellectual
and developmental disabilities



POSITION STATEMENT

Medicaid

Persons with intellectual and/or developmental disabilities¹ deserve the opportunity for a full life in their community where they can live, learn, work, and play. Since many individuals require supports to help them realize their opportunities, the Federal/State Medicaid program must provide funding to ensure that nearly 2 million people with intellectual and/or developmental disabilities have access to health care and or long-term services and supports.

Issue

For almost four decades, Medicaid has been the major funding source for community-based supports for people with intellectual and/or developmental disabilities. Policy makers have attempted to scale down the growth of Medicaid funding through regulatory changes and budget cuts instead of addressing gaps in services. If the Medicaid program does not continue to evolve, it cannot respond to the emerging needs of individuals with intellectual and/or developmental disabilities in the areas of health care and long-term services and supports. Cutbacks would not allow the program to address the underfunding of the direct support service system, including the needs of direct support workers; wait lists and future needs for long-term supports; increased opportunities for self-direction and choice; and complete transition from segregated institutions to community-based services in every state.

Position

To address the present and emerging needs of individuals with intellectual and/or developmental disabilities, we affirm that:

- Medicaid waivers and state plan programs should assist people with intellectual and/or developmental disabilities to live full lives in the community, experience a high quality of life and, as adults, achieve economic security and personal independence to the extent possible for the individual;
- Low income individuals with intellectual and/or developmental disabilities are entitled to a full range of Medicaid-financed health

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care and long-term services across their life span in whatever state or community they happen to live;

- Individuals or their families should not be required to impoverish themselves to receive the basic health and social supports they need to live;
- Services should be received with reasonable promptness and with sufficient quality and quantity to meet their individual needs;
- Services and expenditures should continue to be redirected from institutional care to home and community-based supports;
- Medicaid must afford individuals and families opportunities to design and direct their own services to the extent that they wish and with the assistance they need;
- Services should be portable across states and other political jurisdictions;
- Any effort to change or otherwise reform the Medicaid program must take into account the impact of such change upon individuals with intellectual and/or developmental disabilities in order to prevent unintended harmful consequences;
- The quality and effectiveness of health and long-term services and supports for persons with intellectual and/or developmental

disabilities depend upon qualified service providers with necessary skills and training. Federal and state responsibility for service quality therefore should include assuring sufficient recruitment, retention, and training of, as well as appropriate pay for, the personnel who provide needed services and supports;

- Medicaid-based provider reimbursement systems must provide for living wages and decent fringe benefits to direct support workers; and
- Medicaid reform should address wait lists, the quality of service providers and staff, and increased availability of quality health care services for individuals with intellectual and/or developmental disabilities.

¹“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.

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Achieve with us.