

CHILDREN with DEVELOPMENTAL DISABILITIES

The definition of developmental disability generally means a severe, chronic disability that is attributable to a mental and/or physical impairment manifested before the individual attains age 22 that is likely to continue indefinitely and results in substantial limitations in three or more of the following areas of major life activity:

- self care
- receptive and expressive language
- learning
- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency



More than
12,000
persons with
developmental
disabilities are
on the waiting
list for home
and
community
based waiver
services in
Louisiana

A child from birth through age 9 who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria listed above if the child has a high probability of meeting those criteria later in life.

Children with developmental disabilities will need quality supports and services in their homes so they can be active members of their families and communities. These services should be individually planned and available for an extended period of time. Louisiana must commit to the development of an individual and family-centered, comprehensive system, with a coordinated array of culturally competent supports and services designed to promote self-determination, independence, productivity, integration, and inclusion into the community for individuals with developmental disabilities.

The vast majority of children with developmental disabilities live with their families. Experience suggests that most families prefer to keep their children at home, a more cost-effective alternative to residential placement. However, these families need access to quality services in their communities and they should participate in the service design for their children. Instead, Louisiana has a long history of providing institutional care for both children and adults with disabilities, and currently owns and operates 6 residential developmental centers (now called supports and services centers) and 31 community and/or group homes. In addition, the state provides funding for persons with developmental disabilities to live in approximately ten large private facilities and over 400 small private facilities. There are no waiting lists for residential placement. Following the 2005 storms, a state developmental center was closed and the majority of its residents chose community living over another developmental center.

CHILDREN with DEVELOPMENTAL DISABILITIES (continued)

In Louisiana, most home and community-based services for children with developmental disabilities are funded through Medicaid waivers that provide care for a limited number of persons (slots). The state uses the Medicaid waiver process to manage costs and avoid opening the services to everyone that might qualify. There are long waiting lists for these waiver slots and, despite increased funding, the number of children added to the lists each year generally outpaces any increases in slots. There is also a state-supported program that provides family supports and cash subsidies to help families maintain their children at home. This program pays for after school care, respite care, equipment, environmental adaptations, and other needed services for which there is no other means of support. Currently, almost 6,000 children are on that waiting list.

Public policy to address the needs of children with developmental disabilities in Louisiana should include the following:

- require insurance to cover therapies prescribed for children with developmental delays
- expand state funding for the family support and cash subsidy programs to help families keep their children at home
- close and consolidate the state developmental centers in order to align resources with the demand for home and community-based services
- build capacity in local communities to deliver quality services appropriate to individual needs
- provide an adequate pool of emergency waiver slots for persons in emergent situations whose only current alternative is institutional placement
- support specialized extended family/foster care for children with developmental disabilities in the state's custody
- provide adoption subsidies and develop aggressive recruitment strategies to help place children with developmental disabilities with families
- assure that state-supported training for child care center staff includes content related to the care of children with developmental disabilities to encourage acceptance of such children
- provide full support for the Part C-Early Steps program that identifies infants and toddlers with developmental delays and provides services designed to enhance development and prevent long term disabilities

For additional information please go to www.lapartnership.org.

At current funding levels, it will take ten years to reach the last names added to the community based waiver waiting list