



Community Support for People with Developmental Disabilities

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The guiding principles of Louisiana's Act 378 of 1989 clearly state that individuals with developmental disabilities "should be afforded the opportunity to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens" and that children, regardless of the severity of their disability, "need families and enduring relationships with adults in a nurturing home environment."

The Louisiana Developmental Disabilities Council stands by these guiding principles and the abundance of research demonstrating the benefits of community support over the institutional placement of individuals with developmental disabilities.

Research shows that community support offers greater opportunities for individuals with developmental disabilities to make individualized choices and to fully participate in social and economic life than those provided by institutional care.¹ Additionally, people who move from institutions to community settings have experiences that help them to broaden their social networks, improve their adaptive behavior skills and increase their overall quality of life.² Despite compelling research and the transition of hundreds of people from state-run developmental centers, Louisiana still ranks first in the country for the number of individuals per capita living in intermediate care facilities for people with developmental disabilities (ICFs/DD).³ This is primarily due to the large number of people in private residential facilities.

The Council believes that principles, such as those captured in Act 378 of 1989, should drive all community supports and services so that they are designed to maximize success, delivered in the most individualized environment, and enable people with developmental disabilities to exercise self-determination and control over their daily lives to the fullest extent possible. Unfortunately, the current support system sometimes fails to meet this standard; and while it is not the individual who fails, he or she is often the one penalized by losing his or her home. The system needs changing.

Services should be responsive to the needs of the individual and their family members, rather than fitting people into available programs. Furthermore, without the availability of appropriate services, *when* they are needed, many families find themselves in crisis and are left with no other option but to pursue out-of-home placement. Far too many Louisianans with developmental disabilities continue to live in residential facilities providing 24-hour services when they require far fewer hours of support.

Since a stable and quality work force is critical to ensure successful community living outcomes, it is imperative that direct support professionals (DSPs) and support coordinators receive adequate training and technical assistance, particularly related to supporting individuals with challenging medical and behavioral health needs, and receive a competitive, living wage for the work they do.



Community support for individuals with disabilities is cost effective but more importantly it allows for greater quality of life, fuller participation in society, larger social networks, and positive behavioral outcomes. In Louisiana, high quality support in the community should be the standard for serving people with developmental disabilities and all public policy should facilitate that outcome.

Recommendations:

1. Provide adequate funding to build a system of high quality, individualized supports and services in the community for people with developmental disabilities that are available *when* they are needed.
2. Ensure a qualified and stable workforce of direct support professionals (DSPs) and support coordinators who
 - a) demonstrate skill sets necessary to meet individual needs, including the most challenging medical and behavioral health needs, and
 - b) receive appropriate, competitive compensation.
3. Ensure individuals with developmental disabilities and their families will have access to the same level and quality of services across the state.
4. Implement a Money Follows the Person program to allow individuals residing in private ICFs/DD the option to move into the home and community of their choice.
5. Make out of home placement unnecessary by
 - a) increasing the capacity of community providers to serve people with challenging needs through
 - financial incentives, and
 - specialized training, technical assistance and collaboration with other agencies,
 - b) prioritizing the current home and community-based waiver waiting list to serve those with the most emergent needs first,
 - c) enhancing the safety net system for individuals in each region of the state by
 - expanding the number of emergency waiver slots available,
 - implementing a comprehensive crisis prevention and intervention system for individuals in the community including proactive preventive services and coordinated 24-hour crisis response services.
 - d) developing policies to stop adjudications to ICFs/DD.

Many of the above recommendations could be accomplished through implementation of a Managed Long Term Supports and Services (MLTSS) system that includes all Medicaid services and settings. An adequate investment of resources in a well-designed MLTSS system where the Managed Care Organizations are held accountable for quality of life outcomes would provide for:

- a. an expansion of the number of people served
- b. an improvement in the quality and integration of services
- c. an ability to meet needs in a timely fashion
- d. the ability for people (and funding) to move from congregate to individualized, community settings
- e. improved access to providers across the state.



References:

- ¹ Neely-Barnes, S., Marcenko, M. Weber, L. (2008). Does Choice Influence Quality of Life for People with Mild Intellectual Disabilities? *Intellectual and Developmental Disabilities*, 1, 12 – 26.
- ² Kozma, A., Mansell, J., Beadle-Brown, J., (2009). *Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review*. *American Journal on Intellectual and Developmental Disabilities*, 114, 193 – 222.
- ³ In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012, Research and Training Center on Community Living Institute on Community Integration/UCEDD, University of Minnesota, 2014, Table 3.4.