



Self-determination of People with Developmental Disabilities

Updated and Approved April 2016

The fundamental right of self-determination refers to making meaningful decisions about one's own life and having the opportunity to set goals and to work toward the achievement of those goals. Unfortunately, people with developmental disabilities face a daily struggle to express their right to self-determination. The Louisiana Developmental Disabilities Council believes that the service system, families, and friends of individuals with developmental disabilities should support their right to make decisions about their lives and support them in those decisions. The Council believes individuals should be in charge of their own lives to the fullest extent possible.

One way in which the principle of self-determination is afforded to individuals with developmental disabilities is through self-direction. Using the self-direction model of service delivery provides individuals with maximum decision-making authority over certain services and also gives them direct responsibility to manage those services. Self-direction promotes personal choice and control over the delivery of services, including who provides the services and how services are provided.¹

However, this model is not for everyone, and individuals using the traditional service provider model can still achieve self-determination in their lives if providers respect the wishes of the individual and support them in making decisions. Friends and family also play a key role in supporting the right of individuals with developmental disabilities to make their own decisions and respecting the actual choices they make.

Self-determination for individuals with developmental disabilities includes the freedom to choose where and how they live, learn, work, vote, play, and otherwise relate to each other, their families, and their communities.² Whether through self-direction, the traditional service provider model, or natural support, the choices of the individual should be honored by state agencies, providers, families, and friends. In Louisiana, the right of individuals with developmental disabilities to have power over their own lives must be a central focus of all services for people with developmental disabilities.

Recommendations:

Louisiana should:

1. Increase the availability of the self-direction service delivery option in its waivers for people with developmental disabilities and assure that support coordinators are trained to assist waiver recipients in accessing this option.
2. Require the submission of basic provider data from all Home and Community-Based Waiver providers to be made available on the Department of Health and Hospitals' website with a user-friendly search engine to assist individuals with developmental disabilities and their families in making informed choices.
3. Monitor the state's compliance with Person-Centered Planning requirements in the Medicaid rule for Home and Community-Based Services settings.



4. Encourage individuals with developmental disabilities to make choices and support those decisions. Assure that the choices of individuals receiving services are respected, honored and supported through:
- Training for support coordinators, direct service providers, and families in how to respect and support personal choices and decision-making;
 - Monitoring by the Office for Citizens with Developmental Disabilities (OCDD) of the development of individual plans;
 - Monitoring by support coordinators to ensure follow-through with the individual's plan.

References:

- ¹ Centers for Medicaid and Medicare Services. Self-directed Services. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>.
- ² The Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities. Community Inclusion Issues: Self-Determination. Retrieved from http://tucollaborative.org/comm_inclusion/self_determination.html.