Position on Self-Determination of People with Developmental Disabilities

Adopted April 2013, Revised October 2013

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 to achieve those goals. Unfortunately, people with developmental disabilities face a daily struggle to express the fundamental right of self-determination. The Louisiana Developmental Disabilities Council believes that the service system, family, and friends should support the right of individuals with developmental disabilities to make decisions about their lives and support them in those decisions. The Council believes an individual should be in charge of their own life to the maximum 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 their services. The self-direction service option 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 still can achieve self-determination in their lives if providers respect the wishes of the individual and support them in making decisions. Friends and families 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 make one's own choices regarding where and how they live, learn, work, vote, play, and otherwise relate to each other, their families, and their communities. (2) Whether through the self-direction service option, the traditional service provider model, or natural supports, 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 option in its waivers for people with developmental disabilities.

- 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 OCDD of the development of individual plans;
 - Monitoring by Support Coordinators to ensure follow-through with the individual's plan.

References:

- 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://www.tucollaborative.org/comm_inclusion/self_determination.html.