

Position Statement on Stakeholder Involvement in Service System Redesign

Position Statement

People with intellectual and other developmental disabilities and their families are the consumers of long-term care services and must be involved in all aspects of planning, service delivery, and evaluation of service delivery programs. Stakeholder groups and advisory boards at the local, state, and national level controlling health and human services, education, employment, and housing must include people with intellectual and developmental disabilities and their families. Adequate training and education must be provided to ensure informed participation. Professionals must acknowledge the value of the expertise and knowledge of people with intellectual and other developmental disabilities and their families. This requires new skills and attitudes for both professionals and such consumers.

Service system redesign groups must be accessible for participation in a variety of ways. These include flexible meeting times; sufficient advance notice of meetings; accessible locations; online, video, and phone participation; accommodations for people who are deaf or have other hearing impairments; use of social media; and other methods to increase stakeholder involvement. Individuals participating in state-mandated task forces should receive the necessary supports and accommodations and should be reimbursed for any necessary expenses to ensure their full participation on those committees.

We believe that the following principles must also be followed in designing or redesigning service delivery systems in which people with intellectual and related developmental disabilities and their families will become major stakeholders:

- Self-determination must guide the redesign of the entire system of long-term care. Self-determination means control over a place to call home, real membership in the community, support for long-term relationships with others, and the generation of private income through work. Consumers must have more individual choice over services and control over the funding allotted to them. (See The Arc's Position Statement on [Self-Determination](#).)
- System redesign must seek to create flexibility in regulatory systems to foster the exercise of freedom and responsibility by recipients. System redesign must also seek cost effectiveness, when appropriate.
- While the service system should include internal controls, oversight for the ultimate protection for consumers must remain outside the service delivery system, including consumers, advocates, family members, and guardians.

Issue

The service system for persons with intellectual disabilities and other developmental disabilities and their families is continuously evolving. Stakeholder involvement is essential to redesigning and improving a service system to be both responsive and cost effective. People with intellectual disabilities and other developmental disabilities and their families are the authorities on their individual needs and how to best meet those needs. Therefore, they must be actively involved in all public and private planning and development of systems to better meet those needs.

Collaborative efforts result in greater satisfaction for everyone. People with intellectual disabilities and other developmental disabilities and their families have fresh and valuable insights and observations. They can be visionaries. Their dreams are not tied to bureaucratic limitations and they can provide inspiration and guidance to the boards or committees on which they serve.

Stakeholders demand a stronger emphasis on self-determination and consumer control in the planning and delivery of services. Individuals with disabilities and their families want individual choices and more control of their services and funding rather than program funding categories and regulations which restrict their choices and disregard their individual desires. The present system severely limits the exercise of freedom and responsibility by most recipients of public long-term care supports. Laws and regulations can result in non-productive and limited lives for recipients.

This statement was approved by the Delegate Body at The Arc Minnesota Annual Business Meeting on October 28, 2007.

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