Issue

Many individuals with intellectual and developmental disabilities (IDD) have not been included in decisions about their supports and services. Too often, they do not have power in the system and with their service providers. When they have given input, they have not been listened to. Many people with IDD do not have informed choice or control over how to improve supports.

This has been the consistent experience of people with IDD who participated in surveys and interviews like those done through the Minnesota Regional Quality Council system, the National Association of State Directors of Developmental Disabilities Services, and the Human Services Research Institute.

Availability, cost, and predetermined outcomes often shape decisions about supports and services. The self-interests of the funder and service provider affect decisions as well.

Currently, Minnesota does not formally monitor the quality of our system as a whole. They review minimum standards rather than individual outcomes. Some supports do not even meet minimum standards.

Position

In high-quality services and supports, the decisions of people with IDD are placed at the center, with input as needed from trusted individuals of their choice.

High-quality services meet each person's needs, help them achieve their goals in life, and are based on individual outcomes. These outcomes should address the social determinants of health in areas of:

- education
- food
- health care
- transportation
- social community
- neighborhood and environment
- economic stability

People with IDD should have informed choice and control in how their services are improved if they are not high quality, not meeting their needs, or resulting in poor outcomes.

The State of Minnesota must also have an independent process of monitoring service quality. This should measure both individual and system-wide outcomes.

This system should:

- Focus on the needs, goals, and informed decisions of each individual
- Be structured with a co-leadership model that centers persons with IDD
- Engage partners with diverse experiences and skills
- Provide an ongoing review process for all levels of the system
- Focus on continuous improvement in services, supports, and outcomes for each individual rather than punitive response measures
- Advance service quality beyond the minimum standards required in licensing

Quality Supports and Services

- Result in independent recommendations to state agencies and the Minnesota legislature, based on feedback from people accessing services and supports

Reviewed and approved by The Arc Minnesota Public Policy Committee on 10.26.2020