



Idaho Council on Developmental Disabilities

By Ryan Locke

The Idaho Council on Developmental Disabilities, or the DD Council for short, is an Idaho state organization established in 1978 and a partner to the Center on Disabilities and Human Development on multiple projects. Its mission is directed by the federal Developmental Disabilities Act (DD Act) and the state Idaho Council on Developmental Disabilities Act. The DD Act requires every state to have a triad of organizations: a University Center for Excellence in Developmental Disabilities (UCEDD), a Developmental Disabilities Council, and a Protection and Advocacy (P&A) organization. The CDHD is Idaho's UCEDD and Disability Rights Idaho is the state's P&A.

Christine Pisani, Executive Director of the DD Council, says the organization works to fulfill its mission by taking direct feedback from adults with intellectual developmental disabilities (I/DD) and families of children with developmental disabilities about what services best meet their needs in order to improve service systems like the Developmental Disabilities Service System or the Vocational Rehabilitation Service System.

The role of the DD Council as mandated by these laws is work in three areas: Advocacy for and with people I/DD and their families; Capacity Building to improve access to needed services for children and adults with I/DD, and intellectual and improve the communities ability to meaningfully include people I/DD; and Systems Change, providing innovative strategies in creating services that best meet the needs of people with I/DD to improve independence, choice, control, flexibility, and participation in their home communities.

One program the Council has sponsored since 1997 is Idaho Partners in Policymaking. This leadership development program has over 200 graduates who have served in many leadership roles in communities across Idaho. It is an intensive program that requires eight months of training. The Council selects 25 people from around the state. Half of the class is made up of adults with

developmental disabilities and the other half is made up of parents who have young children with developmental disabilities. Students attend two-day monthly sessions in Boise for eight months of best practice and skill development training. Examples of these skills include: How to be most effective at meeting your child's needs in an Individualized Education Program (IEP) meeting, How to run your own Individual Service Plan meeting, what quality person-centered planning looks like, how the Idaho state legislative process works, and opportunities to connect with key policy makers in Idaho. One of the benefits of hosting this program is that all three of the DD Network organizations have benefited from having leaders come out of this program and serve on all of their boards, councils and advisory committees.

Last year, the DD Council worked with the CDHD on a statewide study of adults with I/DD who were using Home and Community Based Services through the Adult DD Waiver. The study provided an understanding of the perceptions of adults with I/DD about how well service providers were meeting the new federal Centers for Medicaid and Medicare (CMS) Rules. The information gathered through the study provided a baseline to understand about what adults with I/DD felt about the services. After the rules are implemented in 2019, the organizations will go back and interview the same people to see if there's any change in their responses as a result of the implementation of these rules.

Another project managed by the DD Council and the DD Network is the Statewide Policy Coalition, whose core members includes adults with I/DD and parents who have children with I/DD who are working together to influence public policy in Idaho. Through the fall and winter, the Eastern Idaho coalition members worked to educate adults with I/DD and families about the ABLE Technical Assistance and Protection of Benefits act that was passed by the Idaho legislature this year. The work of the Coalition members had a direct impact on the passage of the legislation as they were able to help influence state legislators about why it was important in their own lives. Currently, the Coalition in Eastern Idaho is working to inform Idaho congressional delegates about how block granting Medicaid, as proposed in the American Health Care Act, could harm people with disabilities. The DD Network will also be host a leadership summit this July for core members to further their leadership skills and determine a policy agenda for the coming year.

An ongoing goal of the Coalition is the improvement of services for Idaho's Spanish-speaking families who experience I/DD. One of the things that the council is also involved in is working to address a disparity between Spanish-speaking families English-speaking participants in access to services and quality of services in programs. The Council has been working to understand some of these disparities and has learned that while all who access services may occasionally experience access or quality issues, the Latino community face additional obstacles due to lack of information provided in Spanish. Specifically, documents such as the assessment tools used to determine eligibility for DD programs, IEP's, service plans, and student reports are non-existent or difficult to access in Spanish. Over the next five years, The DD Council will be working to eliminate these identified barriers.

As the DD Network works to create the Statewide Policy Coalition, the Coalition as a whole will begin to understand the disparities experienced by Idaho Latino communities. The role of the Coalition as their understanding evolves, will be to speak as an ally for their Latino Coalition members in addressing the elimination of these identified barriers.

Pisani says the Council is excited about these innovative approaches to engage adults with I/DD and families statewide and says this will result in improved policy as a result of the significant involvement by the people themselves who access the service.