

Strengthening Self-Determination in Ohio

An Executive Summary of the Final Report to ODDC from the Ohio Task Force on Advocacy

In May 2018, the Ohio Developmental Disabilities Council (ODDC) established a Task Force on Advocacy through a grant awarded to the Ohio Statewide Independent Living Council (OSILC). It was an effort to bring together the two networks in Ohio that create opportunities for individuals with disabilities to increase their advocacy skills.

The purpose of the Task Force was to:

- Assist ODDC in addressing current self-advocacy efforts across Ohio;
- Determine overarching, systemic issues and current gaps; and
- Develop methods to increase the number of self-advocates and their skills, including a means for participating advocacy organizations to work collaboratively and learn from each other.

The 14-member Task Force included nine individuals with disabilities (64%) from all regions of the state. The Task Force on Advocacy met 11 times and engaged in lengthy discussions about self-determination and the current state of self-determination in Ohio. A final report was issued to ODDC on February 29, 2020.

The Need to Adopt the Independent Living Philosophy

Members of the Task Force observed the major differences between how the Developmental Disabilities (DD) and Independent Living (IL) systems have evolved. Members consistently returned to the idea that the DD system must change and adhere to the tenants and ideals of IL if people with developmental disabilities are going to live self-determined lives in Ohio. There was consensus that this will require a new way of thinking—one in which people with disabilities are truly in control of their lives—and a complete restructuring of the way the DD system currently operates.

The members of the Task Force contend that too few people in the DD system are familiar with IL and don't understand the philosophy and a way of life of IL. Professionals in the DD system don't always recognize that every person, regardless of the severity and type of disability, has the potential and the right to exercise self-determination. The members of the Task Force contend the DD system has not generally embraced the IL movement nor has there been a push for

consumer control. Since the DD system has been structured in a paternalistic manner, individuals with disabilities are not always listened to, easily dismissed and too often pacified by the system.

The IL philosophy assumes that people with disabilities are the best experts on their needs, and as a result, must take the initiative to design and promote better solutions. The IL philosophy holds that people with disabilities are citizen's first and only secondarily as consumers of healthcare, rehabilitation or social services. The movement reinforces that people with disabilities have the same right to determination in everyday life that other citizens take for granted.

Federal law requires every state to have a statewide IL Council (SILC) consisting of a majority of individuals with significant disabilities across the disability spectrum. Each SILC is committed to promoting a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy to maximize leadership, empowerment, independence, productivity and to support full inclusion and integration of individuals with disabilities into the mainstream of American society.

Ohio's SILC includes 12 Centers for Independent Living (CILs). It is a federal statutory requirement that a majority of the board members, management, and staff of the centers be individuals with disabilities, giving them the unique ability to provide resources and advocacy, based on first-hand experience. These centers are non-residential, community-based organizations run by and for individuals with disabilities.

Summary of the Task Force Recommendations

The full report was submitted to the Ohio Developmental Disabilities Council upon completion of the grant activities in 2020. The first recommendation was to allow the Task Force to continue its work. ODDC approved to extend the project and the Task Force is currently working on strategies to implement the following recommendations.

Collaboration

- That the DD Act Partner organizations, also called the DD Network, should take a leadership position and increase the number of governing board members with disabilities to a majority of their boards, or to the maximum extent possible under federal law. The partners include:
 - ODDC;

- Ohio's protection and advocacy system (P&A): Disability Rights Ohio; and
 - Ohio's University Centers for Excellence in Developmental Disabilities Education (UCEDD): Ohio State University Nisonger Center and University of Cincinnati UCEDD.
- The DD Network, in partnership with the Ohio Department of Developmental Disabilities, will establish standards and principles for self-determination.
 - The DD Network, the Ohio Department of Developmental Disabilities and the county boards of DD will work collaboratively with the Task Force to complete a systemic review of its structure, programs and services to assure that they adhere to the principles of IL and self-determination.
 - Develop and adopt a self-determination self-assessment checklist to determine the degree to which Ohio's policies, practices and personnel, are promoting self-determination.
 - Create a survey instrument to gauge satisfaction of individuals with disabilities who are participating in self-advocacy groups throughout Ohio.
 - Have the Ohio Department of Developmental Disabilities conduct a comprehensive review of the HCBS waivers in order to make the waivers a viable source of funding for self-advocacy services, skill reinforcement activities and self-determination training.

Education and Training

- Establish a peer mentoring program on self-determination where the "peer relationship" is focused on IL/self-determination. Also develop an IL apprenticeship program in which staff trained in the IL philosophy would mentor individuals served in the DD system.
- Develop and adopt a program of direct instruction, models and opportunities to practice skills associated with self-determined behavior in Ohio's education system.

- Develop an ongoing, continuous instruction in self-advocacy in the Pre-Employment Transition Services (Pre-ETS) program administered by the Ohioans for Opportunities with Disabilities.
- That a family focused training on IL and self-determination be developed.

Support from ODDC

- Establish a scholarship grant to increase and empower individuals with disabilities through IL education, skill development, and participation in training events.
- The Public Policy Committee of the DD Council will review the results of a survey conducted by the Task Force and work with interested parties to establish an informational and educational outreach campaign that will increase the opportunities for individuals with developmental disabilities to serve on county boards of DD.
- Develop a policy research grant as part of the next five-year plan to establish a list of research goals for self-determination.
- Convene a meeting of self-advocacy organizations, the DD system and IL network to establish overarching goals and joint strategies in the areas of training, mentoring, leadership opportunities, infrastructure and funding.
- Sponsor an annual meeting with self-advocacy organizations to discuss strategies to improve communication.
- Gather more data on self-advocacy programs in Ohio.

Be a Part of the Solution

To become part of the work or read the full report, you can contact the Ohio Statewide Independent Living Council at www.ohiosilc.org. You can also contact Jeremy Morris at jmorris@ohiosilc.org or Tim Tobin at ttobin@ohiosilc.org.

NOTE: This would also be where we would put the website and Facebook address information.