Final Report of the Task Force on Advocacy

Submitted to Members of the

Ohio Developmental Disabilities Council

On February 29, 2020

EXECUTIVE SUMMARY

Introduction

In May 2018, the Ohio Developmental Disabilities Council (ODDC) established a Task Force for Advocacy through the grantee, 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 to develop methods to increase the number of self-advocates and their

skills, as well as, a means for participating advocacy organizations to work

collaboratively and learn from each other.

Task Force Member Observations

The 14-member Task Force included nine individuals with disabilities (64%) from

all quadrants of the state. The Task Force on Advocacy met eleven times. The Task Force engaged in lengthy discussions about self-determination and the current state of self-determination in Ohio.

Members observed the major difference 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 a consensus of opinion 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 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.

Furthermore, Ohio has 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.

The Need to Adopt IL as a Way of Life in the DD System

The member 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 individual 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.

A Summary of the Task Force Recommendations:

* The members of the Task Force are recommending that the Task Force on Advocacy continue.
* That the DD Act Partner organizations (ODDC, DRO and UCEDDs) take a leadership position and increase the number of governing board members with disabilities to reflect a majority on their boards, or to the maximum extent possible under federal law.
* That the DD Council establish a scholarship grant to increase and empower individuals with disabilities through IL education, skill development, and participation in training events.
* That a peer mentoring program on self-determination be established where the “peer relationship” is focused on IL/self-determination. Furthermore, an IL apprenticeship program in which staff trained in the IL philosophy would mentor individuals served in the DD system should also be established.

* That the DD network, in conjunction with the Ohio Department of Developmental Disabilities, establish standards and principles for self-determination.

* That the DD network, the Ohio Department of DD and the county boards of DD 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.

* That the Public Policy Committee of the DD Council 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.

* That a program of direct instruction, models and opportunities to practice skills associated with self-determined behavior be adopted in Ohio’s education system.

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

* That a self-determination self-assessment checklist be adopted in Ohio to determine the degree to which its policies, practices and personnel, are promoting self-determination.

* That the DD Council develop a policy research grant as part of the next five-year plan to establish a list of research goals for self-determination.
* That a survey instrument be created to gage satisfaction of individuals with disabilities who are participating in self-advocacy groups throughout Ohio.

* That the DD Council 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.

* That the DD Council sponsor an annual meeting with self-advocacy organizations to discuss strategies to improve communication.
* That the DD Council gather more data on self-advocacy programs in Ohio.

* That the 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.

The report has been submitted to the Ohio Developmental Disability Council upon completion of the grant. The project has been extended, and the Task Force is now working on strategies for implementation of the recommendations.

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

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