Final Report of the Task Force on Advocacy

To Members of the

Ohio Developmental Disabilities Council

February 29, 2020

<u>Introduction</u>

In May 2018, the Ohio Developmental Disabilities Council (ODDC) addressed the needs for individuals with developmental disabilities to have expanded access to opportunities for self-determination. The ODDC established a Task Force for Advocacy through the grantee, the Ohio Statewide Independent Living Council (OSILC), to bring together the two primary networks in Ohio that create opportunities for individuals to increase their advocacy skills.

The purpose of the Task Force is 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. The Task Force is to prepare a final report of the findings and activities to ODDC. The goal of this report is to assist the ODDC in determining potential grant projects in future state plans, as well as opportunities to better reinforce the empowerment of individuals with developmental disabilities. (See attachment A)

The 14-member Task Force includes nine individuals with disabilities (64%) from all four quadrants of the state. Almost half of the membership reside in rural areas and consist of an equal number of male and female members. Fourteen percent of the Task Force is racially diverse. (See attachment B)

In this report, you will first learn the history of and advances in the developmental disabilities and independent living movements, including the evolution of self-determination. The report concludes with a series of recommendations from the Task Force.

<u>Task Force Member Observations</u>

Over the last 16 months, the Task Force has met 11 times. During the course of those meetings, the Task Force had lengthy discussions determining what is self-determination and the current state of self-determination in Ohio. Those discussions included how members of the Task Force learned to advocate for themselves, other people or issues. One common thread which ran through many of these discussions was that it wasn't necessarily the formal system of services and supports which gave them the needed education and skills to advocate for themselves or others, as much as it was having a positive self-image, family members who helped them create a positive self-image, and a broad set of life experiences. Members of the Task Force were able to find their voice despite the

"system". They did this by being encouraged to take risks and if necessary, to fail in order to learn and gain experience. As stated by several members "the dignity of risk in not a negative thing but a positive and potentially life changing opportunity. There is a need to educate service providers, parents, and siblings on the dignity of risk." People who are "over them" or working with them are not encouraging the dignity of risk. Staff want to keep them "under control or protected."

Members stated there is a 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 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. Involvement in this Task Force of members from the IL system demonstrated how the IL model and structure helps to accomplish many of the goals for greater self-determination and empowerment.

History of Independent Living

The history of IL has its roots in the civil rights movement and various social movements like deinstitutionalization, de-medicalization, and self-help. Each of those movements helped inform and define the independent living movement.

The IL movement located problems or deficiencies in society, not an individual. People with disabilities were not the problem, the answers were to be found in changing and breaking down attitudinal barriers and work to change laws. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional.

The 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 citizens 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. (History of Independent Living, by Gina McDonald and Mike Oxford, IL 201: History and Philosophy of the Independent Living Movement)

Adolf Ratzka of Sweden reflecting on the roots of the independent living movement in the United States said:

"Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.

Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else.

To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.

As long as we regard our disabilities as tragedies, we will be pitied.

As long as we feel ashamed of who we are, our lives will be regarded as useless.

As long as we remain silent, we will be told by others what to do." (Adolf Ratzka, 2003, cited from: http://www.independentliving.org)

Federal Law and Independent-Living

The ideal that individuals with disabilities should have the same range of freedom, control and IL is best exemplified in the federal Rehabilitation Act. This law, among other things, 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.

Moreover, 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. When individuals work with centers, it is through a model that empowers individuals to take control of their lives and decide what independence means to them. The centers do not tell individuals how to live their lives. Rather, they mentor and guide them through the process of achieving their self-identified goals. This model also allows for the dignity of risk, as the individual has the right to develop the goals that matter to them. Every center provides these core services:

- **Information and referral** – Connecting individuals to the services and supports needed in their community;
- **Peer support** – Mentoring and supporting individuals with shared experiences create empowerment and independence;
- **Independent living skills training** – Teaching individuals the skills needed to be more independent and have greater control over their lives;
- **Systems and individual advocacy** – Helping individuals stand up for themselves and access the supports they need. This includes the elimination of barriers and the improvement of systems for individuals with disabilities;
- **Institutional transition** – Assisting individuals in an institutional setting, such as a nursing facility, to transition to community-based living;
- **Youth transition** – Assisting youth with disabilities to prepare for adult life. This can consist of education, employment, or community participation; and,
- **Diversion services** – Critical services aimed at keeping individuals with disabilities from having to enter an institution and remain in the community (See attachment C)

The DD System and Self-determination

Some of the ideals of IL can be found in the DD system. In fact, there have been numerous individuals who have adopted some of the ideals of IL but used different ways and words to express it, most notably through the use of the term called "self-determination."

Tom Nerney, a visionary and pioneer in the field of DD, moved forward the principles of self-determination. He led a movement to reform the system of support for people with developmental disabilities. Those reforms were based on the belief that individuals with disabilities experienced an almost total loss of basic freedoms. He argued that people will not achieve full citizenship without the adoption of "quality standards" based on "universal human aspirations." This movement was named "self-determination." The original principles included:

- **Freedom:** the restoration of those decisions that go to the heart of leading rich and varied lives in the community. These include deciding where and with whom to live, how to create income and establishing important community and personal relationships.

- **Authority:** the ability to personally control (with appropriate assistance) a targeted amount of publicly funded long-term care dollars.

- **Support:** the arrangement of these resources in ways that are unique, meaningful to the person and built on his/her individual preferences.

- **Responsibility:** the use of these public resources in ways that are wise and cost effective and contribute to one's community.

- **Confirmation:** the recognition that individuals with disabilities must be part of the public policy changes necessary to implement self-determination and recognition that families and individuals with disabilities must be included in all re-design issues.

Tom Nerney wrote one of the first monographs in the United States on self-determination specifically relating to people with developmental disabilities.

> "All communities have as members people with disabilities. They are people of worth and value. They belong to family and neighborhoods. They are citizens, fellow workers, customers, and parishioners. They are one of us. Members of our families, our churches, our neighborhoods, people with disabilities who are our friends, our co-workers, our customers, are unwittingly being harmed. People with disabilities have historically lived in isolation from the wider community. Funding for services and supports was out of their control. People with disabilities were not truly respected for their capabilities and in fact, have been treated like commodities. But, we have a choice. We could let the isolation continue, but now that we know the simple truths, the harm would continue with intent. Or, we can start a revolution. A revolution to design community mutual support and common cause. A revolution for self-determination! The time has come to fundamentally re-structure human services for individuals with developmental disabilities. What endures as the goal of self-determination from its origins is simply the ability of a person with a disability to craft a meaningful life in the community, overcome the pernicious effects of enforced poverty and experience deep and lasting relationships."
> (https://www.riddc.org/news/2018/03/27/tom-nerney-respected-visionary-advocate-and-revolutionary-thinker-1941-2018/)

Simply stated, self-determination recognizes the struggle to overcome isolation, stigma and segregation that has existed across disability. It is a struggle for equality and full citizenship.

The philosophy of self-determination assumes goals and standards which reflect universal human aspirations which should be the foundation of quality in the lives of people with disabilities:

- A place to call home with control over who enters for any purpose;

- Real membership in the community;

- The preservation or development of strong relationships; and,

- Planning to avoid or emerge from personal impoverishment.

Ohio Law and Self-determination

Even Ohio law suggests a DD system which is founded, in part, on the principles of self-determination. Section 5123.67, states that the Department of Developmental Disabilities should "liberally interpret" all of Chapter 5123 of the revised code to accomplish the following:

(A) To promote the human dignity and to protect the constitutional rights of persons with developmental disabilities in the state;

(B) To encourage the development of the ability and potential of each person with a developmental disability in the state to the fullest possible extent, no matter how severe the degree of disability;

(C) To promote the economic security, standard of living, and meaningful employment of persons with developmental disabilities;

(D) To maximize the assimilation of persons with developmental disabilities into the ordinary life of the communities in which they live;

(E) To promote opportunities for persons with developmental disabilities to live in surroundings or circumstances that are typical for other community members;

(F) To promote the right of persons with developmental disabilities to speak and be heard about the desired direction of their lives and to use available resources in ways that further that direction.

Riding the Third Wave

The field of intellectual disabilities has developed along three "waves", according to a paper entitled "Riding the Third Wave: Self-Determination and Self-Advocacy in the 21st Century." The authors state that at the dawn of the 20th century, the field of intellectual disabilities was, essentially, a medical discipline in which medical professionals "held all the cards and all the power," one in which people with disabilities lead powerless lives and were viewed as menaces and "objects to be feared and dreaded." This was a period when programs of segregation and sterilization were common. At the height of the First Wave, "professionals defined the issues and created the then-new discipline of mental retardation as separate from the fields of medicine, psychology and education." Parents and the general public assumed that because of their education and social status they knew what was best for their sons and daughters.

During the middle of the 20th century, a Second Wave emerged: the parent movement. Advances in science and medicine changed the way disability was perceived. There was an emphasis on rehabilitation and training. The earlier stereotypes of disability were replaced with "more humane, though still, debilitating stereotypes." People with disabilities were viewed as victims to be fixed, cured and pitied. Parent groups were formed to provide support for one another. These organizations, like The Arc and the United Cerebral Palsy Association, matured and began to advocate for themselves and their children. This movement gained political clout and was a period of great change in services and legislative advocacy.

The Third Wave of the disability movement, the self-advocacy movement, emerged during the 1970s and 1980s. This period was underscored with the principal of normalization, which paved the way for self-determination. "It is, in essence, the story of a people who were powerless finding their voice and demanding control over their lives." The authors conclude that it is clear people with intellectual disabilities will be more in control of their own lives and as a group will be more influential in the planning and monitoring of the services they use. However, self-advocacy as a "social or civil rights movement" will need to resolve issues such as people with disabilities assuming the mantle of power, group identity, the long-term role for people who are not disabled, and "never to confuse the importance of developing and enhancing skills with the need to move ahead and turn over power and control to people with disabilities". (See attachment D)

<u>The value of Leading Self-Determined Lives</u>

The members of the Task Force have stated that to be self-determined means nothing more than to make things happen in their own lives; not to have others do things for them that they can do themselves; and to know what they want and how to get it. They make or cause things to happen that improve the quality of their lives.

Beginning in the late 1990s, researchers began to study the connection between individuals who are leading self-determined lives and post-school outcomes. They learned that students with "higher self-determination scores" when they left high school were more likely to express a preference to live outside the family home, have a savings or checking account, and be employed for pay one year after school. Among those who were employed after completing school, youth in the high self-determination group earned significantly more per hour than their peers in the low self-determination group. In a follow-up study, employed young adults scoring higher in self-determination made statistically significant advances in obtaining job benefits, including vacation and sick leave and health insurance.

More recently, in an article published in 2018 in the Journal of Vocational Rehabilitation, entitled "Promoting and Enhancing Self-determination to Improve the Post-School Outcomes of people with disabilities," authors suggested that – after controlling for other factors – enhanced self-determination leads to more positive post-school outcomes.

This study, building on the early research, explored the impact of actively teaching and creating opportunities for self-determination in adolescents and young adults with disabilities on in-school and post-school outcomes. The research found that teaching self-determination skills can lead to increased academic performance, attainment of academic goals and transition goals as well as greater access to the general education curriculum for adolescents with disabilities in secondary school. Researchers also found that increased self-determination in adults is linked to enhanced recreation and leisure participation, to increased choice opportunities, and to enhanced quality of life in adults with disabilities.

In one of the few longitudinal studies examining the relationship of promoting self-determination in adolescents and longer-term early adulthood outcomes, results indicated that self-determination status at the end of high school, which was impacted by exposure to self-determination interventions in secondary school, predicted significantly more positive employment outcomes, including increased

wages, benefits, and opportunities for career development. The young adults also showed increased community integration outcomes, including access to social networks and supports, transportation, and other critical factors to successful employment and community participation. In essence, this study provided evidence that promoting self-determination while youth are in secondary school results in enhanced self-determination in early adulthood, and that enhanced self-determination in early adulthood results in more positive adult outcomes, including employment and community participation.

Overall, the research suggests the importance of taking a lifespan approach to promoting self-determination, which can be a critical element of promoting positive outcomes, particularly in the context of system-wide activities to support persons with disabilities have more input in the decisions that affect their lives, including decisions about integrated employment and community engagement school and post-school. (See attachments E and F)

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

The Task Force believes there is a need to adopt IL as a way of life in the DD system. Despite Nerney and the attempts of others to alter the way services are delivered to people with disabilities through self-determination, these attempts did not generally take root and are not a typical way of life for people with developmental disabilities. Even the codification of Ohio law has failed to accomplish the necessary results and changes needed for Ohio's DD system to reflect the fundamental tenants of IL. The DD system continues to toss individual and systemic obstacles in the direction of individuals with disabilities despite its best efforts and many times unintentionally and unbeknownst to them. The result is that individuals with disabilities realize only a small fraction of their true human potential and value to society.

Additionally, too few people in the DD system are familiar with IL. They don't understand that it is both a philosophy and a way of life. It is a movement of people with disabilities **who work for self-determination, equal opportunities and self-respect**. They don't realize that every person, regardless of the severity and type of disability, has the potential and the right to exercise individual self-determination.

Furthermore, the Task Force contends the DD system has not generally embraced the IL movement nor has there been a push for consumer control. Individuals with disabilities are not listened to, easily dismissed and too often pacified by the system. This is particularly alarming when all the individual wants or needs is "the

same choices and control in their everyday lives that everyone else takes for granted. Individuals with disabilities want the same freedom to try, and fail, and learn from their failures. They want to grow up in families, go to the neighborhood school, use the same bus as their neighbors, work in jobs that are in line with their education and abilities, and start families of their own. They want to be in charge of their lives, to think and speak for themselves. They want to support and learn from each other. They want to organize themselves and work for political changes that lead to the legal protection of their human and civil rights. (Adapted from Adolf Ratzka, http://www.independentliving.org; cited from https://www.lifecil.org/about/philosophy/)

Recommendations

The Task Force on Advocacy strongly believes the DD system must change its culture, vision, values, re-align itself to the tenants of IL and incorporate more of the ideals of IL. It is with this in mind that the Task Force is making the following recommendations:

1. Continuation of the Task Force on Advocacy

The continuation of the Task Force beyond the end of the grant period has been discussed by members on several occasions. The members feel strongly that the Task Force should continue beyond the end of the grant period. Through the Task Force, members have created a forum and environment where they can express their opinions, thoughts and experiences about the service system without any negative ramifications. Members agree a re-constituted Task Force should be located in a place where it can conduct its work independently, without constraint or interference, or controlled by an outside entity. Furthermore, members feel the Task Force, if not an independent entity, should be housed within an organization whose mission is one of consumer control and self-determination.

The members recommend the Task Force either continue in its present form or be constituted as an independent task force. The primary purpose of the Task Force would be to implement the recommendations of this report and to continue to keep IL and self-determination issues in the forefront of any policy deliberations.

2. Leadership Role of the ODDC, DRO and UCEDDs

The purpose of the federal Developmental Disabilities Assistance and Bill of Rights Act is to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports and other forms of assistance that promote self-

determination, independence, productivity and integration and inclusion in all facets of community life". The law clearly affirms that ODDC, Disability Rights Ohio (DRO) and the University Centers on Excellence in Developmental Disabilities (UCEDDs), commonly referred to as the DD network, to assist and support people with developmental disabilities to lead lives that are self-determined.

The Task Force strongly recommends the DD network take a leadership role in creating a paradigm shift from the current system to one which adheres to the tenants of IL, especially as it pertains to consumer control. This will require the DD network to lead by example and to change their own culture and manner of operation to one which individuals with disabilities take a governing majority within their respective organizations to the extent allowed by federal law. The DD network is uniquely positioned to do so. The DD network can make this shift by placing people with disabilities in leadership positions on their governing boards, advisory councils and planning committees. Furthermore, by creating an organizational structure where individuals with disabilities are a majority of the members on such boards, councils and planning committees, the DD network can make this shift to consumer control.

The IL network, consisting of the OSILC and the CILs, has shown this can be done. The DD network must follow suit and replicate their efforts. Or, at the least, find new and innovative ways to create meaningful collaboration between the two networks.

3. IL/Self-Determination /Scholarship Grant

The Task Force on Advocacy acknowledges the importance of empowering individuals with disabilities through IL education, skill development, and participation in training events. On several occasions, the Task Force discussed how to create such opportunities, being particularly concerned that travel expenses and other costs associated with such opportunities is prohibiting many individuals from pursuing them.

The Task Force is recommending the ODDC establish an IL/self-determination/scholarship grant to enhance the skill sets of individuals with disabilities. The Task Force suggests the initial program can be a demonstration program and piloted for several years. One that will improve independence, productivity and inclusion of people with disabilities in community life. Thereafter, the grant should be a component of the ODDC's five-year plan and be

administered and maintained by a third-party grantee in order to alleviate any issues with match requirements.

The attached recommendation includes key activities of relevant parties. The Task Force did not recommend a specific funding level for this activity, as initial demand for this opportunity may be limited, due to the systemic restrictions individuals with developmental disabilities have faced in enhancing their own self-determination. (See attachment G)

4. <u>Establish a peer mentoring program on self-determination and an independent living apprenticeship program</u>

Peer mentoring is a process through which a more experienced individual encourages and assists a less experienced individual to develop his or her potential within a shared area of interest. The Task Force recommends the establishment of a peer mentoring program where the "peer relationship" is focused on IL/self-determination. This could be especially advantageous to people with developmental disabilities.

The Task Force maintains this can be initially conducted as a pilot with a few CILs and the County Boards of Developmental Disabilities in that CIL's region. The pilot can focus on creating a formal peer-mentorship with individuals in the DD systems that have been receiving services, have exited residential facilities, or are utilizing the SELF Waiver. Individuals participating in the pilot project can be evaluated to see how the mentoring has impacted their ability to live a more self-determined life.

Prior to piloting such a program, the Task Force suggests the review of a document developed by the National Mentoring Resource Center. The Center has examined current research on mentoring for youth who have a disability. The review concludes with insights for practitioners to consider when developing and implementing a mentoring program. (See attachment H)

The Task Force also recommends another approach to establishing peer-mentoring services. Peer-mentoring and self-determination instruction could be included as a home and community-based waiver service option, allowing an individual to identify the need for this service in their plan when working with the County Board of DD staff. Through this mechanism it would empower individuals to include their desire for greater self-determination in their service plans and create a formal structure for the integration of the CILs into the DD system of service.

Furthermore, an IL apprenticeship program in which staff trained in the IL philosophy would mentor individuals served in the DD system could be a way to integrate the two systems. In addition, it would create a means for individuals with DD to gather experience, by shadowing or through formal education, in IL and self-determination.

5. <u>Establish a guiding philosophy and standards/principles for self-determination</u>

The Task Force recommends that the DD network, in conjunction with the Ohio Department of Developmental Disabilities, establish standards and principles for self-determination. These standards/principles should include: lessons learned from the independent living movement; the role of normalization in living a self-determined life; self-determination as a means to obtain an improved quality of life; self-determination as a life-long process; terminology and a definition of self-determination across all systems; and the difference between self-determination and self-advocacy and the types of self-advocacy.

This should also include establishing standards/principles/practices for County Board administration and staff conducted as part of the state certification process.

6. <u>Greater involvement in, and consumer control of, the county boards of DD by individuals with developmental disabilities</u>

The Task Force recommends 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 each one adheres to the principles of IL and self-determination. Moreover, the review should include strategies to provide individuals who are receiving services greater input and control over their services and establishing a service system to better meet their needs.

On numerous occasions, the members of the Task Force engaged in lengthy discussions on how individuals with developmental disabilities should have greater involvement in and control of the operations of a county board of DD. The discussions encompassed the need to review the role of the SSA and ISP process from a self-determination perspective, to modify the accreditation process with a greater emphasis on self-determination, to undertake a comprehensive review of

the county board strategies for promoting self-advocacy, to provide reliable and individualized transportation services, and to train direct care staff in what it means for individuals with developmental disabilities to lead self-determined lives.

7. Survey of County Boards of DD

The Task Force, in conjunction with the ODDC, asked county boards of DD whether or not they currently have a person with a developmental disability on the county board of DD. Of the fifty-eight (58) county boards that responded, only six (6) counties indicated they have a person with a developmental disability on the board.

While the response rate from the county boards of DD was outstanding and the information helpful as a starting point, the Task Force on Advocacy developed a more detailed survey instrument in an effort to obtain additional information about the appointment process.

On December 2, 2019, the Task Force invited the county boards of DD to participate in a survey using Survey Monkey. The Ohio Association of County Boards of DD also provided support by sending two follow-up notices to the boards on December 20, 2019 and January 6, 2020. The survey was officially closed on January 10, 2020.

A total of 50 responses were received covering 58 counties, a response rate of sixty-six percent. There was a total of 16 questions asked. Almost 66% of the survey questions were answered by all of the respondents. A general summary of the county board responses, the written comments received and a state map indicating which counties responded to the survey are attached to this report. (See attachment I)

The Task Force believes the information from the survey should be used to identify additional steps to enhance the participation of individuals with developmental disabilities within the county board structure. Such steps should include further follow-up with the counties boards about certain aspects of the survey and developing an outreach campaign targeted at educating county commissioners, probate judges, and superintendents about the importance and value of appointing individuals with developmental disabilities to the county boards. Moreover, it may be necessary to make a concerted effort to recruit, educate and support, as needed, any individual with a developmental disability who might be interested in serving on a county board.

The Task Force recommends the Public Policy Committee of the Ohio Developmental Disabilities Council review and study the survey responses and work with the Task Force, the DD network and the Association of County Boards of DD 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.

8. <u>Legislative effort to appoint individuals with developmental disabilities to the county board of DD</u>

The Task Force reviewed the statutory criteria for how a person is appointed to a county board of DD. The Task Force found that state law does not preclude a person eligible to receive services from a county board from being appointed to a county board, but neither does it mandate or require the appointment of a person with a developmental disability. Furthermore, the Task Force researched past legislative efforts to expand the county board membership from seven to nine members by adding two individuals with developmental disabilities. While those efforts took place over a decade ago and were unsuccessful, the members of the Task Force believe another legislative effort is in order and should be undertaken to require that individuals with developmental disabilities be appointed to the county boards of DD.

The Task Force recommends state law be changed to require the appointment of four individuals with developmental disabilities to the county boards of DD. This approach is consistent with the principle of consumer control. The Task Force is well aware that it will take time to transition to the new board structure and has included in the draft legislation temporary language to delay the effective date of the bill for one year after its passage into law. (See attachment J)

The Task Force also recommends that the DD Council through the Public Policy Committee, convene a group of interested parties (i.e. individuals with disabilities, the DD network, county board representatives, DODD officials, county commissioners, probate judges, etc.) to determine the most viable approach to increasing the number of individuals with disabilities on a county board of DD in a timely fashion, and to assess if a legislative approach is needed to do so.

The Task Force also discussed other ways that individuals with developmental disabilities could be more actively involved in the operation of a county board of DD. The establishment of a group of individuals with developmental disabilities to

comment on the strategic planning efforts of a board, or to work with the Ohio Association of County Boards of DD to arrange sessions and tracks at their conferences and trainings, are a few of the examples where individuals with developmental disabilities could provide a valuable perspective on the services and programs of a county board.

9. Involvement of the Ohio Department of Education

The Task Force reviewed material on a project funded by the Virginia Department of Education which focuses on providing direct instruction, models and opportunities to practice skills associated with self-determined behavior. The Task Force believes this project could have considerable merit and should be evaluated to determine whether replicating it in Ohio's education system is warranted. The project facilitates youth, especially those with disabilities, to undertake a measure of control in their lives, helping them to set and steer the course rather than remaining the silent passenger. (See attachment K)

10. Pre-Employment Transition Services Program

The Task Force has discussed a program administered by the Opportunities for Ohioans with Disabilities (OOD) called the Pre-Employment Transition Services (Pre-ETS) program. The Task Force believes this program has the potential to expose younger students to the principles of IL/self-determination through the "instruction in self-advocacy" service. These services are available to students with disabilities, including students with developmental disabilities, who are potentially eligible for vocational rehabilitation services. This service can be used to introduce and enhance the understanding of individuals with developmental disabilities to the principles of self-determination and self-empowerment.

OOD reports their authorization guidance for "instruction in self-advocacy" is authorized for an initial 4-hours of service for students. If the student completes those hours and the provider requests additional hours, vocational rehabilitation (VR) staff may determine on a case by case basis whether to authorize for additional services and/or discuss opening a VR case, if the student doesn't have an open VR case. The Task Force recommends that OOD re-evaluate the "instruction in self-advocacy" component of the program to allow for ongoing, continuous instruction and be provided on a program-wide basis based on the preferences and needs of the student and not on a case-by-case basis. Furthermore, OOD should work with the DODD and the county boards of DD to publicize this

program and to ensure the availability of this service to students in the DD system. (See attachment L)

11. <u>Promoting IL in the Home</u>

The Task Force recommends that a family focused training on IL and self-determination be developed. The purpose of such a program is to better educate the families of individuals with developmental disabilities on ways they can promote more self-determination in the home. While the Task Force understands that family members are not making decisions and taking protective steps to limit or prevent independence of individuals with developmental disabilities, this program can assist in educating them on how to better understand the needs to empower their family members.

The National Gateway to Self-Determination, a consortium of University Center for Excellence in Developmental Disabilities, in partnership with a National Self-Determination Alliance has developed ten parenting approaches that families can use to play a critical role in teaching their son or daughter to be self-determined. The Task Force suggests these ten parenting approaches be incorporated into a family focused training on IL and self-determination. The 10 parenting approaches can be found in attachment M of this report. (See attachment M)

12. <u>Creation of a self-determination self-assessment checklist</u>

The University Centers on Excellence in Developmental Disabilities (UCEDDs) have created a self-determination self-assessment checklist for its members. The purpose of the checklist is to provide an agency or provider a straightforward tool and process to determine the degree to which its policies, practices and personnel, are promoting self-determination for people with intellectual and developmental disabilities. Currently, no such assessment is in place in Ohio.

The Task Force recommends that a checklist be adopted in Ohio. Using the UCEDD checklist as a model, it can be modified to assess other types of agencies and providers, especially the county boards of DD to better ensure they are creating a service and structure that incorporates the input of individuals with developmental disabilities. (See attachment N)

13. <u>Develop statewide research recommendations</u>

In 2015, at the National Goals Conference in Washington, DC, a group of invited

participants established a list of research goals for self-determination. Those recommendations included research necessary to identify the most effective intervention strategies and to demonstrate that practices can be successfully implemented in multiple settings to assure that all people with disabilities, including those with extensive support needs, will be self-determining.

Other research goals include: a technology goal to assure that individuals can advocate for themselves using existing and emerging technologies in an online environment and to identify the most effective tools; strategies and features to teach and support technology used to enhance self-determination; and, the need for research to assure that people who provide support across the lifespan understand and enhance opportunities for self-determination.

The Task Force recommends that ODDC develop a policy research grant(s) as part of the next five-year plan to replicate the work of the National Goals Conference in Ohio. (See attachment O)

14. <u>Recommend that a survey instrument be created to gage the satisfaction levels of individuals participating in a self-advocacy group</u>

The RIOT at the Human Services Research Institute (HSRI) has developed a survey for people with disabilities who are a member of a self-advocacy group. The survey asks questions about the self-advocacy organization, the purpose of the group, what issues are important to the group, how well the group is listened to, how happy or satisfied the person is with the advisor, facilitator, and who is really leading and in charge of the group.

The Task Force supports such a survey to assess the strength of current self-advocacy organizations. The Task Force asserts that such a survey can be a useful tool for planning purposes and direction setting.

Furthermore, the Task Force believes incorporating such a survey into the current and future ODDC funded projects on self-advocacy and self-empowerment should include a standard follow up survey for participants to assess the effectiveness of the programs and give the programs a means to address the input of individuals with developmental disabilities. These surveys would be reported to the ODDC with any standard grant reporting, as well as providing explanation on how they have incorporated the survey input into the programs funded. (See attachment P)

15. <u>Establish overarching goals and joint strategies to strengthen the ties between self-advocacy organizations, the DD system and IL networks</u>

The Task Force believes there is a need for self-advocacy organizations, the DD and IL networks, state and local agencies to work together in a more coordinated and systemic fashion to support and strengthen IL and self-determination in Ohio. The goal of which would be to create a strong and vibrant system where IL and self-determination are the basic tenants of the system.

The Task Force recommends the ODDC, or a third party grantee, convene an initial meeting of all parties to establish overarching goals and joint strategies in the areas of training, mentoring, leadership opportunities, infrastructure and funding, as well as identifying areas of collaboration to better serve and represent the community of individuals with developmental disabilities.

16. <u>Develop goals and strategies to improve communication between self-advocacy organizations</u>

There are several well-established self-advocacy organizations in Ohio that could benefit from improved communication between their memberships. Strategies like joint conferences, forums, and websites could increase coordination and communication among groups. Furthermore, strategies to use social media and technology, such as Facebook, Skype, blogs, listservs, webinars, video conferencing and online resource libraries can strengthen and build stronger links among groups.

The Task Force recommends the ODDC sponsor an annual meeting with self-advocacy organizations to discuss strategies to improve communication and reduce barriers to communication faced by these organizations and individuals with disabilities.

17. <u>Identification of self-advocacy programs in Ohio</u>

The Task Force on Advocacy, on several occasions reviewed a listing of advocacy organizations in Ohio developed by the Ohio Self-Determination Association (OSDA). While the Task Force feels the information contained in the document would be of benefit to people with disabilities, self-advocacy organizations, and state agencies, it will only be of benefit if the advocacy organizations demonstrate that they are providing self-determined activities that increase the skills and knowledge of people with disabilities. Furthermore, the information must be kept

up-to-date, readily accessible and expanded to include additional organizations. The Task Force believes this is a prudent first step to determine if there exists an actual "system of self-advocacy organizations" in Ohio in which to build upon.

The Task Force recommends that ODDC gather additional data through its formal grant process. The grant should identify all of the local, regional and statewide self-advocacy organizations in Ohio using as a starting point the listing developed by OSDA. The Task Force believes that additional data must be collected on the type of services provided, the regions covered by such organizations and the populations served by such organizations. Moreover, the initiative should seek to determine what type of leadership training opportunities are available through self-advocacy organizations. (See attachment Q)

18. <u>Recommendation to review Home and Community Based Service (HCBS) waivers to fund self-advocacy services, self-determination training and skill reinforcement activities</u>

The Task Force considered the implications of a national study around the HCBS waivers as a potential source of funding for providing self-advocacy services. The study looked at seven states to determine the use of waivers as a way to provide self-advocacy services to individuals with developmental disabilities. Findings revealed approximately half of waivers provided self-advocacy services; however, less than .01% of waiver spending was projected for stand-alone self-advocacy services. The study concludes by suggesting "states need to significantly increase the provision of self-advocacy services, especially as they redesign their waiver program in response to the person-centered requirements of the Medicaid final settings rule." (See attachment R)

In Ohio, "adult day support" activities include "skill reinforcement" and "training in self-determination" in all three of the HCBS waivers administered by DODD. It's unclear how many individuals might be using "adult day support" for either of these purposes. The Task Force is fully aware the SELF waiver provides some reimbursement through the "participant directed goods and services." The Task Force supports the reimbursement, however, it's the Task Force belief, this service is underutilized, too complicated, and people with developmental disabilities are not aware of the potential for this service to support them in leading a self-determined life.

In addition, the Task Force met with representatives from the Ohio Self-Determination Association and the Services for Independent Living to discuss,

among other things, the education and training efforts of those organizations. While the Task Force was impressed with the training undertaken by them, a one-time training does not afford a person with a disability the opportunity to live a self-determined life. The lack of any ongoing opportunities for education and training is due, in part, to a lack of a viable funding source.

The Task Force recommends 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 Task Force believes such services, activities and training should be individualized, based on the individual's personal preferences and readily available across the life spectrum.

The Task Force further recommends that an easy-to-read "user-guide" be developed on how to access self-advocacy services, skill reinforcement and training in self-determination activities through the HCBS waivers.

Closing Message to ODDC

The Task Force on Advocacy wants to thank the ODDC for establishing this grant and thank them for their leadership in elevating the importance of self-determination in Ohio. However, in many ways the creation of this Task Force has proven to be just one step in a longer path to true self-determination of individuals with developmental disabilities.

The Task Force has made many significant, systemic recommendations to ODDC in this report. The ODDC should work to address those recommendations as quickly as possible. Furthermore, the ODDC should broadly distribute these recommendations to the Department of Developmental Disabilities, other state agencies and policymakers, including members of the General Assembly.

It is important that the ODDC, through and by its leadership, affirm a commitment to the equal rights of people with disabilities to live self-determined lives. The Task Force encourages the ODDC to address these recommendations in the broadest way possible in order to meet the needs of all Ohioans with disabilities. The members of the Task Force stand ready to assist the ODDC in any way possible in this endeavor.

ATTACHMENT A

TASK FORCE FOR ADVOCACY

GOAL: Ohioans with developmental disabilities will have an increased united, diversified voice that is recognized and respected by elected official, stakeholders, policy makers, and people with developmental disabilities and their families.

OBJECTIVE AND IMPACT OF PROJECT: Adolescents and adults with developmental disabilities will have an increase in leadership and self-advocacy skills and opportunities.

BACKGROUND, RATIONALE AND SCOPE OF PROJECT:
Disabilities Council address these three areas:

    (I)   establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities;

    (II)   support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

    (III)   support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership

The ODDC will fund the Task Force on Advocacy with the OSILC as the grantee to assist ODDC in addressing the above areas. The purpose of the Task Force for Advocacy will be to identify 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, as well as a means for participating advocacy organizations to work collaboratively and learn from each other. The Task Force will report the findings and activities to Council. This will assist Council in determining potential grant projects in future state plans.

The core group of the Task Force will be representatives from advocacy organizations across the state. At a minimum, this group will consist of the Ohio DD Network (Ohio

DD Council, Disability Rights Ohio, and the two University Centers for Excellence in Ohio which are Nisonger Center at The Ohio State University and the University of Cincinnati UCEDD), Ohio Statewide Independent Living Council (OSILC), ODDC Leadership Development Committee grantees, as well as other organizations as determined by ODDC and the grantee.

This core group of representatives will begin initial discussions to work toward the purpose of the Task Force and will add other members (such as people with disabilities, families) and special advisors (professionals) as the Task Force feels necessary. The grantee's report, which includes recommendations for specific activities of the Task Force, will be used to guide the work of the Task Force.
The grantee will be responsible for:

- Convening the core group to commit to the Task Force;
- Designating the chairperson(s);
- Schedule and host meetings;
- Provide stipends or reimbursements to people with disabilities who are attend meetings; and
- Report final interim actions to Council at the Council meeting in February 28, 2019.
- Submit a final report to Council of the Task Force's findings by April 30, 2019.

KEY ACTIVITIES:
- identify current self- advocacy efforts across Ohio,
- determine overarching, systemic issues and current gaps,
- develop methods to increase the number of self-advocates and their skills,
- participating advocacy organizations to work collaboratively and learn from each other.
- Set of recommendations

OUTPUTS: IFA 1.1 The number of people with developmental disabilities who participated in council supported activities designed to increase their knowledge of how to take part in decisions that affect their lives, the lives of others, and/or systems: 200

SHORT TERM OUTCOMES: Individuals with developmental disabilities and their families have improved self- advocacy skills and knowledge

LONG TERM OUTCOMES: Individuals with developmental disabilities and their families are effective self-advocates and leaders in their communities.

RESOURCES TO BE INVESTED:
*Federal	$ 25,000
Matching Funds:	$ 8,333.33
	$ 33,333.33

FUNDING METHOD:
Non-Competitive Allocation

GRANTEE:
Ohio Statewide Independent Living Council

ATTACHMENT B

Members of the
Task Force on Advocacy

Shari Cooper
Dayton, Ohio

Mike Denlinger
Cincinnati, Ohio

Carolyn Knight
Columbus, Ohio

Linda Kunick
Cincinnati, Ohio

Lisa M. Marn
Euclid, Ohio

Jeremy Morris
Gahanna, Ohio

Leslie Paull
Columbus, Ohio

Michael Richards, Chair
Greenfield, Ohio

Mark Seifarth
Columbus, Ohio

Robert Shuemak
Cincinnati, Ohio

Tim Tobin
Gahanna, Ohio

Dara Walburn
Athens, Ohio

Kraig Walker
Hillsboro, Ohio

Renee Wood
Toledo, Ohio

ATTACHMENT C

Ohio SILC
Ohio Statewide Independent Living Council

OHIO'S INDEPENDENT LIVING PROGRAM

What is Independent Living?

Independent Living isn't defined by where people live, where they are employed, or how active they are in their community. These are all parts of how people choose to live independently and make the decisions that matter to them.

We believe that individuals with disabilities have the right to make their own choices about their lives, live and work in the settings they choose, and have the same rights as any other Ohioan.

Independent Living Philosophy believes that:

- Individuals with disabilities are the best experts of their own needs.

- Individuals should be empowered to make their own decisions.

- Individuals deserve the dignity of risk and to learn from their life experiences.

- Our communities should be inclusive of all disabilities.

Many of us take the small things in life for granted. We drive where we want. We live in neighborhoods of our choosing. We find employment that suits our desires. Through the work of the Ohio Statewide Independent Living Council and the Centers for Independent Living, we want those same choices available to the 1.6 million Ohioans with disabilities.

Individuals should not be limited in their choices or independence because of a disability.

What is SILC?

The Ohio Statewide Independent Living Council (SILC) is a statewide, cross-disability board that is mandated by federal law. The governor of Ohio appoints the Council, most of which is made up of individuals with significant disabilities. We work with the governor to find individuals in the disability community across the state who will help provide leadership and be part of the voice that leads the Independent Living Program of Ohio.

The Ohio 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.

Part of our role is to coordinate the development of the State Plan for Independent Living, a three-year strategic plan that guides the services and funding for the Independent Living Program. The SILC monitors the effectiveness and progress made toward the goals of the State Plan and works with partners for the alignment of our mutual goals.

The Council meets regularly and has committees dedicated to furthering the mission of the SILC and goals of our State Plan. Through our work, we aim to promote the independence, empowerment, and inclusion of people with disabilities across the state and be a voice to represent all members of the disability community.

What is the State Plan?

The State Plan for Independent Living is a three-year plan jointly developed by SILC and the Centers for Independent Living (CIL) of Ohio. This plan incorporates the input and thoughts of people with disabilities across the state to gain perspective and help direct our collective efforts.

This plan also helps direct funding for Independent Living Services for individuals and serves as a way for the Independent Living Program to identify and meet the needs of the community.

WHAT IS COMMUNITY LIVING? At Ohio SILC, we strive to provide individuals with disabilities – regardless of age – with the same opportunities as everyone else. They should: **Choose** where they want to live; **Choose** where they want to work; **Lead** the lives they want; and **Make decisions** about their lives.

History of SILC

In 1993, Gov. George Voinovich signed an executive order creating the Ohio Statewide Independent Living Council, which is more commonly known as Ohio SILC. The move followed a federal mandate that each state create a Council to serve as a voice for individuals with disabilities for the Independent Living Program.

Our Council is composed of 19 members, all appointed by the governor. A majority of Council members have a significant disability and represent diverse backgrounds.

SILC leads the development of the State Plan for Independent Living, a three-year strategic plan that works toward common goals and initiatives. This plan helps guide the direction of the services and funding of programs that increase the independence of Ohioans with disabilities across the state.

We also work to coordinate with our statewide partners, including the state agencies that have members appointed to the Council. This includes Opportunities for Ohioans with Disabilities, the Ohio Department of Developmental Disabilities, the Ohio Developmental Disabilities Council, the Ohio Department of Transportation, and the Ohio Department of Job and Family Services.

> **SILC plays a vital role in our society. As we seek greater inclusion and independence for Ohioans with disabilities, there is not a better organization to lead the charge than SILC.**
>
> *– Carolyn Knight*
> *Executive Director,*
> *Ohio Developmental*
> *Disabilities Council*

Centers for Independent Living

Ohio is home to 12 Centers for Independent Living (CILs). The centers are non-residential, community-based organizations run by and for individuals with disabilities. The law requires that a majority of the board members and staff of the centers be individuals with disabilities, giving them the unique ability to provide resources and advocacy based on first-hand experience.

When individuals work with centers, it is through a model that empowers individuals to take control of their lives and decide what independence means to them. The centers do not tell individuals how to live their lives. Rather, they mentor and guide them through the process of achieving their self-identified goals. Every center provides these services:

INFORMATION AND REFERRAL – Connecting individuals to the services and supports needed in their community.

PEER SUPPORT – Mentoring and supporting individuals with shared experiences to create empowerment and independence.

SKILLS TRAINING – Teaching individuals the skills needed to be more independent and have greater control over their lives.

SYSTEMS AND INDIVIDUAL ADVOCACY – Preparing individuals to stand up for themselves and access the supports they need. This includes the elimination of barriers and the improvement of systems for individuals with disabilities.

INSTITUTIONAL TRANSITION – Assisting individuals in an institutional setting, such as a nursing facility, to transition to community-based living.

YOUTH TRANSITION – Assisting youth with disabilities to prepare for adult life. This can consist of education, employment, or community participation.

DIVERSION SERVICES – Critical services aimed at keeping individuals with disabilities from having to enter an institution and allowing them to remain in the community.

Centers for Independent Living

Ohio has 12 Centers for Independent Living, which provide services to individuals with disabilities. Centers can be contacted directly for more information on their respective services.

THE ABILITY CENTER OF GREATER TOLEDO

419-885-5733 | abilitycenter.org

Counties served:
Defiance, Fulton, Henry, Lucas, Ottawa, Williams, Woods

LINKING EMPLOYMENT ABILITIES AND POTENTIAL (LEAP)

216-696-2716 | leapinfo.org

Counties served:
Cuyahoga, Erie, Geauga, Huron, Lake, Lorain, Medina

INDEPENDENT LIVING CENTER OF NORTH CENTRAL OHIO

419-526-6770 | ilcnco.org

Counties served:
Ashland, Crawford, Huron, Knox, Morrow, Richland

ACCESS CENTER FOR INDEPENDENT LIVING

937-341-5202 | acils.com

Counties served:
Clark, Greene, Montgomery, Preble

CENTER FOR INDEPENDENT LIVING OPTIONS

513-241-2600 | cilo.net

Counties served:
Adams, Brown, Butler, Clermont, Hamilton, Highland, Warren

MID-OHIO BOARD FOR AN INDEPENDENT LIVING ENVIRONMENT (MOBILE)

614-443-5936 | mobileonline.com

Counties served:
Franklin
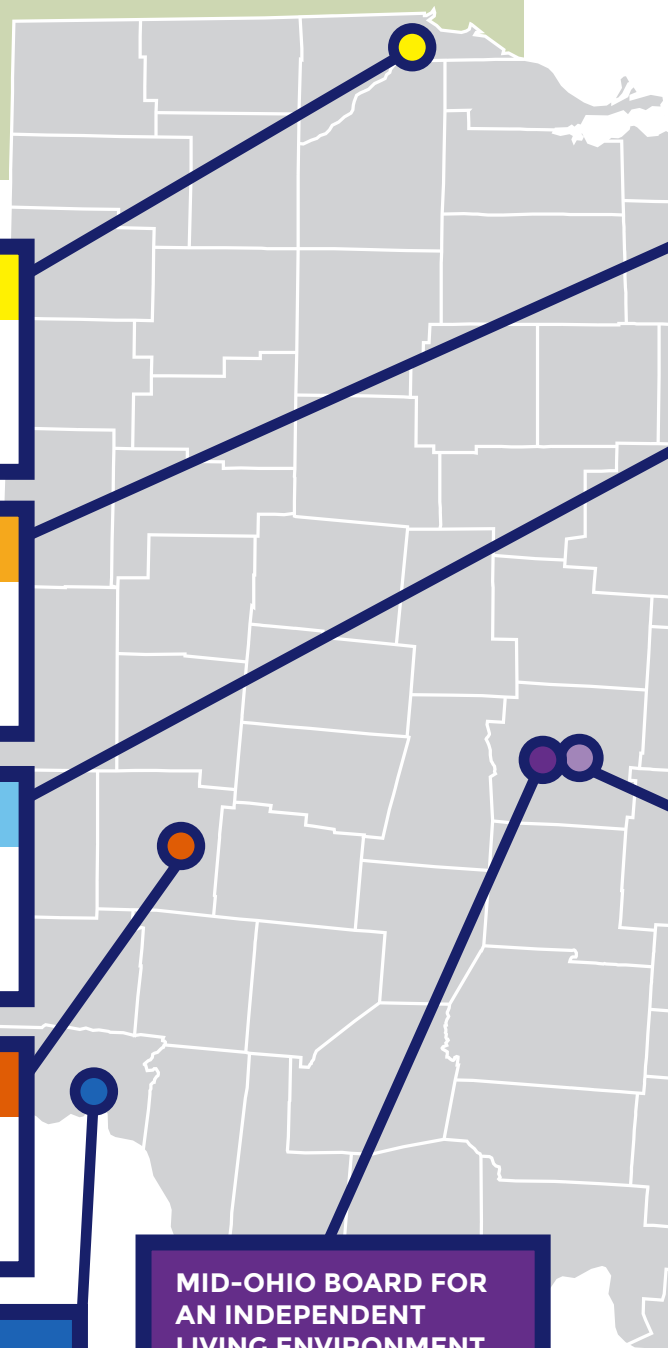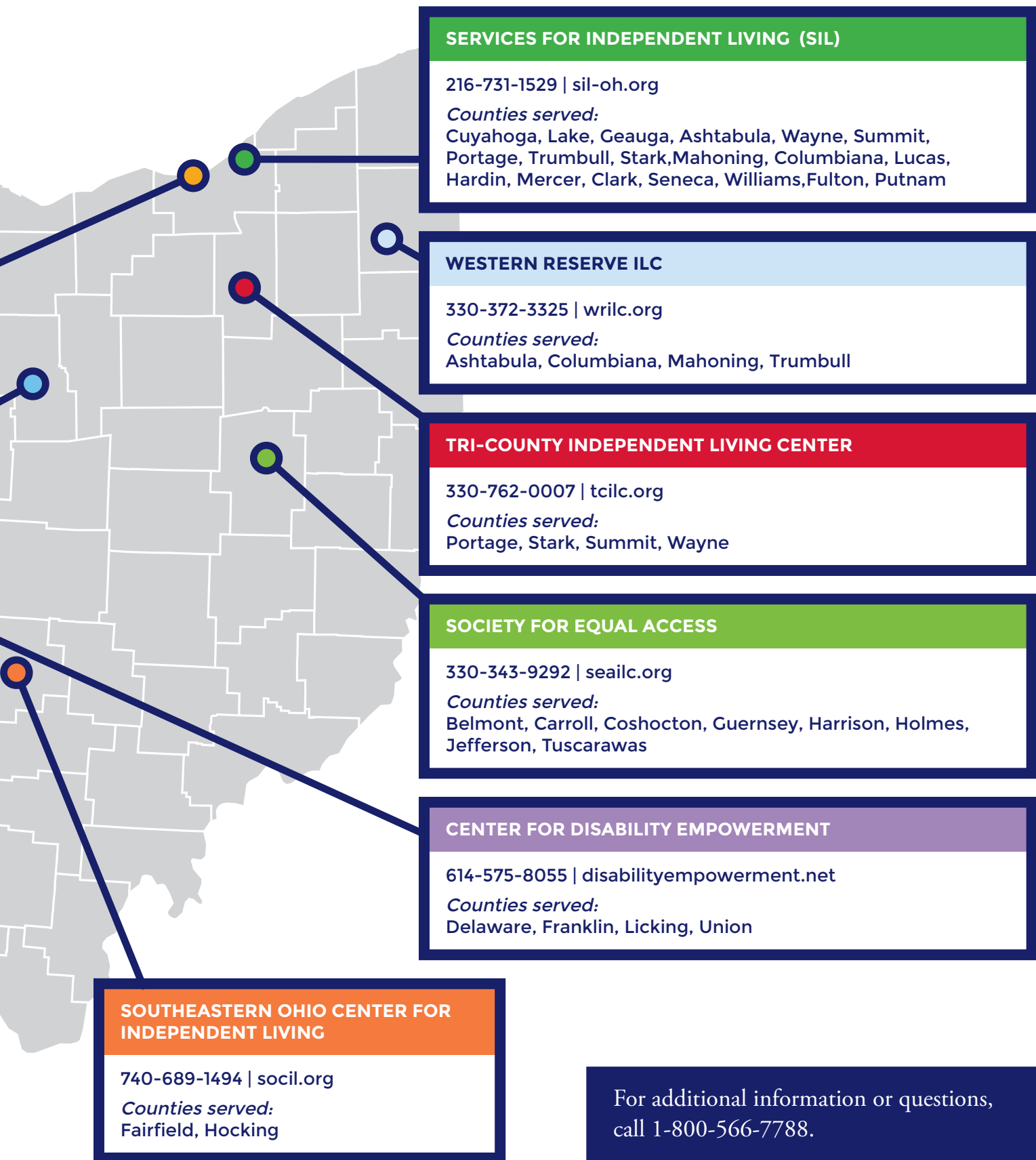
SERVICES FOR INDEPENDENT LIVING (SIL)

216-731-1529 | sil-oh.org

Counties served:
Cuyahoga, Lake, Geauga, Ashtabula, Wayne, Summit, Portage, Trumbull, Stark,Mahoning, Columbiana, Lucas, Hardin, Mercer, Clark, Seneca, Williams,Fulton, Putnam

WESTERN RESERVE ILC

330-372-3325 | wrilc.org

Counties served:
Ashtabula, Columbiana, Mahoning, Trumbull

TRI-COUNTY INDEPENDENT LIVING CENTER

330-762-0007 | tcilc.org

Counties served:
Portage, Stark, Summit, Wayne

SOCIETY FOR EQUAL ACCESS

330-343-9292 | seailc.org

Counties served:
Belmont, Carroll, Coshocton, Guernsey, Harrison, Holmes, Jefferson, Tuscarawas

CENTER FOR DISABILITY EMPOWERMENT

614-575-8055 | disabilityempowerment.net

Counties served:
Delaware, Franklin, Licking, Union

SOUTHEASTERN OHIO CENTER FOR INDEPENDENT LIVING

740-689-1494 | socil.org

Counties served:
Fairfield, Hocking

For additional information or questions, call 1-800-566-7788.

Ohio SILC

Ohio Statewide Independent Living Council

670 Morrison Road, Suite 200
Gahanna, Ohio 43230

614-892-0390 (V/TTY)
1-800-566-7788 (TOLL FREE)

ohiosilc.org

ATTACHMENT D

Riding the Third Wave:
Self-Determination and Self-Advocacy in the 21st Century

Michael Wehmeyer, Hank Bersani, Jr., and Ray Gagne

The importance of self-determination and self-advocacy to the field of mental retardation has become increasingly evident. This article examines the three "waves" of the disability movement: the professional, parent, and self-advocacy waves. From the perspective of both professionals and a person with a disability, we examine the current circumstances for people with disabilities in relation to control and choice in their lives, examine the development of the self-advocacy movement, and, finally, identify issues that will be important to address in the future.

In the last quarter of the 20th century, there was increased attention to the importance of self-determination and self-advocacy in the lives of people with mental retardation. Bersani (1996) labeled this as the third wave of the disability movement: the self-advocacy movement. This article examines where we have been and where we are now, and provides our opinion as to where we need to go in the future in these areas. Unlike other articles, we use two voices to describe this history and vision. The first is the voice of professionals and advocates who have worked to achieve self-determination for people with mental retardation and to promote self-advocacy. The second is the voice of experience—a look at the past, present, and future of self-advocacy and self-determination through the life of someone who experiences a significant disability and whose life experiences better describe the importance of self-advocacy and self-determination than any historical literature review. These voices will be interchanged throughout the article. In

his autobiography, Ray Gagne (1994) characterized the phases in his life in which he either lived in an institution for people with mental retardation or in the community as times of "power" or "no power," respectively. Such headings capture the experience of the 20th century for many people with mental retardation: It is a century of movement from a lack of power to increased opportunities for control and self-determination. The headings in this article mirror the imagery of power as ways to portray the historical and current status in this area.

Powerless Lives

At the dawn of the 20th century, the field of mental retardation was, essentially, a medical discipline in which medical professionals held all the cards and all the power. Bersani (1996) described this as the First Wave of the disability movement, one of *professionalism*. Professionals were not interested in the rights of people whom they called "clients," "re-

tardates," or "the mentally deficient." Indeed, far from a focus on humanity and human rights, in the late part of the 19th century and the early part of the 20th century, people with mental retardation were viewed as menaces and linked with crime, poverty, promiscuity, and the decline of civilization. They were seen by professionals and society as subhuman ("vegetables") or as objects to be feared and dreaded.

Goddard (1912) summarized his study of the Kallikak family as follows:

> We find on the good side of the family prominent people in all walks of life and nearly all of the 496 descendants owners of land or proprietors. On the bad side we find paupers, criminals, prostitutes, drunkards, and examples of all forms of social pest with which modern society is burdened. From this we conclude that feeble-mindedness is largely responsible for these social sores. (p. 116)

Goddard concluded that what needed to be done about "feeble-mindedness" was create a program of segregation and sterilization. He stopped short of recommending eugenics, recommending instead further study of the mechanisms of heredity. By 1926 Goddard had dropped his hesitation over implementing eugenics, which he defined as a science and equated with race betterment, recommending a program of segregation and sterilization to control the spread of feeble-mindedness and concluding that

feeble-mindedness is sufficiently prevalent to arouse the interest and attract the attention of all thotful [sic] people who are interested in social welfare; that it is mostly hereditary; that it underlies all our social problems; that because of these facts it is worth the attention of our most thotful [sic] statesmen and social leaders; that much of the time and money and energy now devoted to other things may be more wisely spent in investigating the problem of feeble-mindedness; and that since feeble-mindedness is in all probability transmitted in accordance with the Mendelian Law of heredity, the way is open for eugenic procedure which shall mean much for the future welfare of the race. (Goddard, 1926, pp. 589–590)

Although not all professionals shared Goddard's enthusiasm for eugenics, there was essentially no opportunity for people with mental retardation to exert control in their lives. Leaders and decision makers in the field were physicians and, to a lesser degree, humanitarians. At the height of the First Wave, professionals defined the issues and created the then-new discipline of mental retardation as separate from the fields of medicine, psychology, and education. They made decisions on their own, and parents and the general public assumed that, because of their education and social status, professionals knew what was best. The emphasis was on diagnosis and, particularly with the growing popularity of intelligence testing, in determining who would benefit from treatment (or not). A person labeled with mental retardation had no basic civil rights, from education to the opportunity to enlist in the military service.

As the country approached the mid-point of the 20th century, a Second Wave emerged in the disability movement: the *parent* movement. After World War II, advances in science and medicine changed the way disability was perceived and greatly increased the life span of people with disabilities. Influenced by the large number of veterans disabled in World War II, which spurred an emphasis on rehabilitation and training, and by successes in developing vaccines for diseases like polio, which offered hope for greater cures for disabling conditions, the earlier

stereotypes of disability were replaced with more humane, though still debilitating, stereotypes. People with disabilities came to be viewed as objects to be fixed, cured, or rehabilitated, and simultaneously pitied; they also came to be viewed as "victims" worthy of charity. Shapiro (1993) described this phenomenon when discussing the emergence of the poster child as a fund-raising tool:

> The poster child is a surefire tug at our hearts. The children picked to represent charity fund-raising drives are brave, determined, and inspirations, the most innocent victims of the cruelest whims of life and health. Yet they smile through their unlucky fates . . . no other symbol of disability is more beloved by Americans than the cute and courageous poster child. (p. 12)

Within this stereotype, people with mental retardation were viewed as "holy innocents" (special messengers, children of God, etc.) and thus incapable of sin and not responsible for their own actions. Based at least partially on the prevalent use of mental age calculated from intelligence scores, people with mental retardation came to be perceived as "eternal children"; although no longer feared and blamed for all social ills, they needed to be protected, pitied, and cared for.

Concurrent to the economic boom post–World War II, there was the now-infamous baby boom. The dramatic increase in the U.S. birthrate meant not only that more babies were being born but also that more children with disabilities were being born. The changing attitudes toward disability just described led more and more families, particularly families of children with mental retardation and families of children with cerebral palsy, to band together and form their own groups. At first, the goal of these organizations was simply for members to support one another. Later, as these organizations matured, parents began to advocate for themselves and their children. Out of this emerged the parent movement, including organizations like The Arc and the United Cerebral Palsy Associations. Slowly, professionals joined in the parent rebellion and recognized the importance of parents in the decision-

making process. This movement gained political clout and, from the 1950s through the 1970s, radically and unalterably changed the face of the disability movement. This was a period of rapid growth in services and legislative protection. It was also critical to the emergence of self-determination and self-advocacy. Early in the Second Wave, parents and family members told professionals that they were the consumers of services and that they spoke for their sons or daughters. As these sons and daughters aged and the movement matured, so too did this emphasis change. Parents and family members, along with professionals, began to recognize that people with mental retardation could, in fact, speak for themselves. The Third Wave of the disability movement, the *self-advocacy* movement, emerged during the 1970s and 1980s.

Several factors contributed to the emergence of this Third Wave. In the early 1940s the field of personality psychology began to form as a means to better explain and predict human behavior. One of the central questions in this young discipline was the question of determinism—that is, to what degree is human behavior determined by internal versus external forces? To describe circumstances under which human behavior was conceptualized to be internally determined, theorists co-opted a term from political science—*self-determination*. The earliest conceptualizations of self-determination within the personality literature used the term as it related to the determination of one's own fate or course of action without compulsion.

However, issues of self-determination were not discussed in relation to the right of people with mental retardation to govern their own lives until the early 1970s. Nirje (1972), in Kugel and Wolfensberger's classic text on normalization, authored a chapter titled "The Right to Self-Determination" and, in the opening paragraph, stated,

> One major facet of the normalization principle is to create conditions through which a handicapped person experiences the normal respect to which any human being is

entitled. Thus the choices, wishes, desires, and aspirations of a handicapped person have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one's family, friends, neighbors, co-workers, other people, or vis-à-vis an agency is difficult for many persons. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. But in the end, even the impaired person has to manage as a distinct individual, and thus has his identity defined to himself and to others through the circumstances and conditions of his existence. Thus, the road to self-determination is both difficult and all important for a person who is impaired. (p. 177)

Although the language referring to disability dates Nirje's quote, his concepts remain relevant. His was a call for self-determination or self-governance for people with mental retardation. Nirje (1972) identified making choices, asserting oneself, self-management, self-knowledge, decision making, self-advocacy, self-efficacy, self-regulation, autonomy, and independence as important to promoting self-determination.

The perception of people with mental retardation as being eternal children or holy innocents was antithetical to the idea that people with disabilities were self-determined, self-sufficient, and competent human beings. Adults with "the mind of a 3-year-old" were not expected to hold a job, make decisions, or live independently. Holy innocents were not expected to learn about sexuality and human relationships. Recipients of pity and charity were to be helped but not accepted as colleagues, friends, or neighbors. Dybwad pointed this out as early as 1961, stating,

The community at large and public officials in the states have heard so much of the mentally retarded as having the mentality of children—of well-meaning but so misleading labels as "eternal children" or "the unfinished child"—that there remains considerable hesitancy to recognize the retarded as adults, let alone as adults capable of sustained productive effort. (p. 159)

In short, the way in which people with disabilities were perceived needed to change

before Nirje's call for self-determination could be realized. Blatt and Kaplan's (1966) exposé of the conditions of institutions in the United States, *Christmas in Purgatory*, starkly illustrated how far we had to go to achieve Nirje's vision. The last two decades of the 20th century proved to be a time during which old stereotypes and perceptions were slowly replaced by the perception of people with mental retardation as competent and worthy of respect and dignity. These changes occurred largely as a result of the growth and implementation of the normalization principle, the emergence and growth of the independent living movement, increased civil rights protections for people with disabilities, and the emergence and maturation of the self-advocacy movement.

Raymond Gagne's Story: The Institution

My name is Raymond J. Gagne. This is my story about my life and why self-advocacy and self-determination are important to me. I was born on January 10, 1945. I am a person with cerebral palsy.

I lived with my mother, grandmother, uncle, two brothers, and a sister in a large house in Attleboro, Massachusetts. My mother felt there was something wrong with me. She took me to many doctors and hospitals to see if they knew how to help me. They told my mother I would never walk.

When I lived at home, I used to sit in a rocking chair next to a yellow window. I would sit there for hours watching people and cars go by. When my family went out, they put me in my baby carriage and usually included me in the activities. My brothers and sister went to school. At the time, there was no school for me. I stayed home with my grandmother, who took care of me. She had her hands full. I could not walk, talk, feed myself, or dress myself. She had to carry me upstairs each time I had to

go to the bathroom. I crawled on the floor to get around. When I was 8, my mother told me I was going away. She put my name on my clothes and packed my new suitcase. I remember the night before I left. I was bathed and my fingernails and toenails were cut. On February 19, 1953, two ladies picked my mother and me up for the drive to a state school. I didn't know where we were going. My mother had just told me I was going away and that I would be better off.

After arriving at the state school, I was put in Building 7. An orderly brought me to a ward. He put me in a bed and took all my clothes off. He put a johnny on me. My mother left, and I didn't see her any more that day. I was scared because I didn't know where I was or why I was there. I had arrived early in the afternoon. The rest of the day and night I was in bed. The bed was different from mine at home. The ward itself was drab. The windows were high with white shades. There were no curtains or decorations on the wall, not even a clock or calendars. There was a radio. The first song I heard was "Pretend You're Happy When You're Blue." It made me sad to hear it. I cried for 3 days.

Later, I was moved to Building 15. They put me on the floor. The other patients stepped all over me. I cried all day because I wanted to go back home. That evening they gave me a group bath with five other boys. The bathtub looked like a bird bath. There were water sprayers all around the inside of the bath. I was put to bed after the bath. At midnight, the attendants woke everybody up to go to the bathroom. I hated that, but I went. Every morning we would wake up at 6:00 a.m. An attendant would help me put on the clothes he had laid out the night before. I didn't have any say about what I wore. What they put on, I wore. Sometimes they wouldn't put underwear on me.

The first time I had a visitor was a month after being left at the state school. My mother came to visit me. I cried all the time she was there. I told

her I wanted to go home. During this visit, she asked me about taking me home for a 1-day visit. When the visit was over and they got ready to take me back, I acted up. I hit and bit my mother. I also hid underneath the bed so she couldn't get me. She finally returned me to the state school.

As I look back on my childhood, I realize that I have been on my own since I was 8 years old. Some people would disagree and say that I was taken care of for many years. However, I felt as though I had no love or understanding from anyone.

That spring, I went to the dentist for the first time ever. The dentist pulled out eight teeth. He did not use any Novocain or any pain killers. I tried to be brave and not cry.

On Sunday afternoons in the summer, I used to spend the day lying on the floor of the ward waiting for company. No one ever came. Once I waited a full day for my mother to come and pick me up. I had to wait on a bench all day because the attendants didn't know when my mother was coming. During my visit, my grandmother fell down the steps and had to be hospitalized. A few days after I returned to the state school, my grandmother died. I wasn't told until Christmas day, 5 months later.

Looking back, I feel my strength and stubbornness helped me to survive these years of my life when I had so little control. Once I went to Building 5 and saw that people had more freedom there. I asked the staff if I could move to this building. In the new building, I could go to bed at 9:30. I never actually had my own personal bed. It made me think that, even in prison, you at least have your own cell. At the state school, I didn't have any living space of my own.

The staff who worked at the state institution were insensitive and cruel. There was one attendant who would take me to a back room and beat me up. Other times, he would hit me right in front of everybody. Another attendant hit the residents on the head with his keys.

The staff never seemed to prepare me for living outside the institution. They didn't seem to think I would make it on my own. I never had support, role models, or mentors to guide me in growing up. Very few of the staff ever assisted me in developing my identity, creativity, or self-esteem.

When I was 19, I started to work in a workshop. I worked in the workshop for 1 year. We put nails in boxes and then sealed the boxes. I got paid $30 a week. This was the first real money I had to call my own. Within a year I was promoted to the position of supervisor. I learned good work habits such as being on time, doing good work, responsibility, and getting along with others. Although I learned some good things at the workshop, many basic skills were never taught. These included budgeting skills, personal grooming skills, and most any other skills that a person needs to live outside an institution.

When I was in the institution, sometimes I went home for a visit. I didn't want to go back so I would act up. I didn't know it, but even then I was advocating for myself. At that time, there were no self-advocacy groups like there are now. I wish there had been, so someone could speak up for me. There I was, only eight years old. It is very important that people learn to speak up for themselves.

Scheerenberger (1987) suggested that no single categorical principle has had a greater impact on services for people with mental retardation than normalization. In conjunction with the independent living movement, whose influence was felt most heavily by people with physical and sensory impairments, the normalization principle paved the way for self-determination. Nirje (1969) explained that the normalization principle had its basis in "Scandinavian experiences from the field" and emerged, in essence, from a Swedish law on mental retardation that was passed on July 1, 1968. In its original conceptualization, the normalization principle provided guidance for creating services that "let the men-

tally retarded obtain an existence as close to the normal as possible" (Nirje, 1969, p. 363). Nirje stated, "As I see it, the normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 363). Nirje identified eight implications of the normalization principle:

1. Normalization means a normal rhythm of day.
2. Normalization implies a normal routine of life.
3. Normalization means to experience the normal rhythm of the year.
4. Normalization means the opportunity to undergo normal developmental experiences of the life cycle.
5. Normalization means that the choices, wishes, and desires of the people with disabilities themselves have to be taken into consideration as much as possible, and respected.
6. Normalization also means living in a bisexual world.
7. Normalization means normal economic standards for those with disabilities.
8. Normalization means that the standards of the physical facility should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens.

Scheerenberger (1987) noted that "at this stage in its development, the normalization principle basically reflected a lifestyle, one diametrically opposed to many prevailing institutional practices" (p. 117), as was aptly illustrated by Blatt and Kaplan (1966). In fact, the ideas forwarded by Nirje in 1969 remain, to a significant extent, the philosophical basis for exemplary services almost 30 years after their original presentation.

Nirje (1969) expanded on these ideas. A "normal rhythm of the day" means that people with disabilities should go about their day in much the same way as most people do: getting out of bed, getting dressed, eating under normal circumstances in typical settings, going to bed at times comparable with peers', and

having opportunities for personal time and relaxation. A "normal routine of life" means that people with disabilities should live in one place, work or attend school in another, and have leisure activities in various places. A "normal rhythm of the year" means that people with disabilities should experience holidays and family days of personal significance, including vacations.

Much of the emphasis of normalization is on people with disabilities experiencing the rich stimulation of being involved in one's community, living with family members, and experiencing friendships. The normalization principle stresses that contact with people without disabilities, and people from both genders, is important across all age ranges. Economic self-sufficiency is also highlighted. Finally, it is evident that self-determination is critical to the normalization principle, as Nirje went on to describe in subsequent writings (Nirje, 1972). At a time when most professionals viewed people with disabilities as patients, when public education was not available, and when public opinion portrayed them as charity cases and eternal children, Nirje stressed the importance of choice and the need to respect the preferences and dreams of people with mental retardation. In a later chapter on the normalization principle, Nirje stated, "Normalization also means that normal understanding and respect should be given to the silent wishes or expressed self-determination" of persons with mental retardation (p. 176).

Self-advocacy as a movement has its roots in these same early activities. In the United States, the origins of the self-advocacy movement are usually attributed to a small group of people with mental retardation in Salem, Oregon, who are credited with formulating the phrase "We are people first" (Edwards, 1982). However, the roots of that movement actually lie in Sweden in the late 1960s and 1970s. Beginning in 1965 in Sweden, Nirje (1969) described the use of social clubs called *flamslattsklubben* to promote training in Sweden for adolescents with mental retardation. This training was embedded within Nirje's development of the normalization principle.

Within only a few years, reports on the training for the social groups included instruction in parliamentary procedure (Nirje, 1969).

From those humble beginnings, the self-advocacy movement gained ground rapidly. Within 5 years of the formation of the Oregon self-advocacy group, there were 1,000 members in Oregon alone, with sister groups in 3 states and requests from 42 states for assistance in starting similar organizations (Edwards, 1982). The first self-advocacy conference took place in October 1974 in Otter Crest, Oregon. Edwards described one moment from that historic meeting: "The earth moved just a bit when Valerie Schaaf, first president of People First, stepped onto the podium and spoke clearly into the microphone: 'This, the first People First convention, is officially called to order!' " (p. 10).

This movement, from Oregon to Nebraska to New York to Tennessee, has a rich history (see Dybwad & Bersani, 1996, for a comprehensive look at the movement). It is, in essence, the story of a people who were powerless finding their voice and demanding control over their lives. The power of this movement is elegantly captured in Ray Gagne's description of his life after the institution—his self-described "life of power."

Lives of Emerging Control: The 1990s

There has been considerable progress in promoting self-determination and self-advocacy, particularly in the 1990s. Federal policy related to disability increasingly emphasized the importance of self-determination. For example, in the 1992 reauthorization of the Rehabilitation Act, the findings of Congress [Section 2 (29 U.S.C. 701)] were as follows:

1. Millions of Americans have one or more physical or mental disability and the number of Americans with disabilities is increasing;
2. Individuals with disabilities constitute one of the most disadvantaged groups in society;

3. Disability is a natural part of the human experience and in no way diminishes the right of individuals to: (a) live independently; (b) enjoy self-determination; (c) make choices; (d) contribute to society; (e) pursue meaningful careers; and (f) enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society . . . ; and
4. The goals of the nation properly include the goal of providing individuals with disabilities the tools necessary to: (a) make informed choices and decisions; and (b) achieve equality of opportunity, full inclusion and integration into society, employment, independent living and economic and social self-sufficiency, for such individuals.

The significant change reflected in this conceptualization is that disability is no longer seen as aberrant, outside the norm, or pathological but instead is recognized as a part of being human. Within this conceptualization, all human abilities and experiences exist on a continuum, and disability is a part of, not outside, that continuum. Whereas Nirje's (1972) call to self-determination came before such a conceptualization of disability was in place, the demands of people with disabilities today for more control and choice come at a time when changing stereotypes of disability—coupled with progress in education, rehabilitation, and legislative protections—ensure that people with disabilities—including the most significant disabilities—can with adequate support work competitively, live independently, and become contributing members of the community.

Two major national initiatives have focused attention on self-determination in the disability services community. The earliest was the U.S. Department of Education, Office of Special Education's self-determination initiative, which from 1990 to 1996 funded 26 model demonstration and 5 assessment development projects to promote self-determination for youth with disabilities (Ward & Kohler, 1996). These projects and other

education-related efforts resulted in numerous frameworks within which the term *self-determination* was defined and activities developed (Abery, 1993; Agran, 1997; Field & Hoffman, 1994; Martin & Marshall, 1996; Mithaug, 1996; Powers et al., 1996; Sands & Wehmeyer, 1996; Wehmeyer, Agran, & Hughes, 1998).

The second major initiative has been the Robert Wood Johnson–funded self-determination projects (Nerney & Shumway, 1996; O'Brien, 1997). The intent of this initiative was to create state agencies that would have the authority to implement changes in state policy and enact system change reforms based on the principles of self-determination. Projects funded under this initiative must engage in activities such as implementing individual budgets to be spent according to decisions made by people with disabilities and their families, or helping service-providing agencies retrain employees to enable self-directed service brokerage. These ongoing projects address political or collective self-determination, focusing attention on systemic and overarching changes and reforms to support and enable individual control and choice.

As a result of these initiatives, schools and service providers across the country have begun to examine how what they do affects self-determination and to put into place mechanisms to promote self-determination.

The self-advocacy movement also came of age in the last decade. There are now in excess of 700 self-advocacy groups across the country, not to mention hundreds more across the world; and a relatively new national organization of self-advocates, Self-Advocates Becoming Empowered, is providing direction for the movement as a whole. The People First convention held in Anchorage, Alaska, in April 1998 was the fourth international conference bringing together self-advocates from around the continent, with previous conferences in Tennessee, Virginia, Oklahoma, and Toronto. These gatherings draw as many as 1,500 people to network, learn, and celebrate self-advocacy. In two states, self-advocacy organizations were the lead

plaintiffs in class action lawsuits that eventually closed state-run institutions for people with mental retardation. People-first language has become widely adopted by professionals and advocates alike, and, locally and nationally, self-advocates are spearheading efforts to change organizational names and labels. For example, in 1991 the Association for Retarded Citizens of the United States (ARC-US) changed its name to The Arc of the United States (with lowercase letters to indicate that the name is no longer an acronym). This name change had support from professionals and families alike but was particularly important to and advocated by people with mental retardation.

Self-advocacy groups have affected areas other than language. Many self-advocates actively campaign against congregate settings, such as nursing homes, and advocate for social justice. The group Advocating Change Together, in Minnesota, has launched a campaign to raise funds to place headstones on the graves of people with mental retardation who died while living in a Minnesota institution, both in respect for those powerless people and as a statement of social justice. In addition, self-advocacy groups have become the training ground for leaders, enabling people with mental retardation to assume leadership positions. Self-advocates now sit on visible boards and committees, including the board of directors for organizations like The Arc, the American Association on Mental Retardation, and TASH, as well as serving on the President's Committee on Mental Retardation and the President's Committee on the Employment of Persons with Disabilities.

Ray Gagne's Story: After the Insitution

The day I moved from the institution to an apartment that I shared with two other men, some staff told me I would be back in a month. They may still be waiting for me to come back. I lived in an apartment for 3 years on my SSI income and the income from

my job at the institution's workshop. The institution did not have professionals coming to help make the move easier. To be honest, I only saw my social worker a week before I moved. If I had a question, I had to call the halfway house.

After I had shared an apartment for 3 years, the staff asked me to move into a halfway house to help five men move out on their own. While I was working in the halfway house, I met an employee named John. After he was hired, we broke all the rules in the book. One night he allowed beer into the house. Another night he took my friend and me to a bar. The bartender refused to serve me because he thought I was drunk. John paid the bill and walked out. This was one of the first times that I felt I was important.

That same year I went on a vacation to Washington, DC, by myself. This was the first time I had ever done this.

One day I asked John where I could get a different job. John referred me to a state vocational rehabilitation agency. They wanted me to go to a workshop that I did not want to attend. Even John and I had a fight over this. Within that year, I finally agreed to go to the workshop. It was boring. After 4 months I quit. They told me either I stayed at the workshop or I could stay at home and do nothing. I stayed home.

During that fall I moved to my own apartment after a counselor at a camp for people with cerebral palsy told me she thought I could. I did well in living alone for 3 years. After living alone for 3 years, I decided to move near the city where my sister lived. While there I began to volunteer with a local chapter of the United Cerebral Palsy. While there I learned about Section 504 of the Rehabilitation Act and helped found an advocacy group named the Massachusetts Coalition of Citizens with Disabilities. I learned the skills of leadership, advocacy, consumer organization, and assertiveness by watching people, par-

ticipating in group meetings, and asking questions.

After 4 years, I moved twice more. I continued to learn new skills and became more involved in self-advocacy and consumer advocacy. I moved to New Bedford, Massachusetts. I was interviewed by the ARC directors and was hired as a public information coordinator. Unlike the staff at the institution, the human service professionals I met at this job treated me with respect. They gave me a chance to contribute my input and feedback, and believed in many of my ideas. My colleagues also adapted the working environment to help me communicate with them. After several years I became the staff liaison to a self-advocacy group of adults with mental retardation. I worked at this job for 6 years.

When I moved to New Bedford, I wanted to open a checking account. I went over to the bank and I gave the $10 to open the account and asked them if there would be a problem. They said no. But, when I went back a couple of days later, they said they couldn't understand my signature. I thought about this and I realized that I had a checking account before I moved, and that had worked fine. The next morning, I put on a suit and tie and went down to the main branch. I asked to see the bank president. They told me he was at a meeting. I told them I would wait. I waited for about two minutes and he came out. He brought me into a room and asked me what the problem was. I told him. I also brought my canceled checks and showed him that I had an account before. He apologized, and I got my checking account.

Through my job I met many people who have become friends. I began to get involved in national issues. In 1988, I was selected to be the National Chairperson of the Self-Advocacy Advisory Committee for the National Association of Retarded Citizens (now The Arc). I helped coordinate a successful voting rights campaign and assisted in promoting self-

advocacy initiatives. I also lectured on these issues at Harvard University.

After 6 years, I decided to look for another job. I was hired as a training specialist in Harrisburg, Pennsylvania. My duties include providing self-advocacy and social skills training to over 200 people at residences for people with mental retardation. My colleagues at my present job treat me well and have made adaptations so I can do a better job.

Lives of Power and Control: The 21st Century

The Self-Advocacy Movement

It is clear that people with mental retardation and other disabilities will be more in control of their own lives as we settle into the 21st century, and that, as a group, people with disabilities will be much more influential in the planning, operating, and monitoring of the services they use. However, self-advocacy as a social or civil rights movement will need to resolve several issues. These issues were premature at the end of the 20th century, but, given the success of the movement to this point, a second generation of issues now emerges for the future.

Assuming the Mantle of Power. What does it mean to be "powerful" as a self-advocate or as a self-advocacy organization? Many advocates are uncomfortable discussing the concept of their power. However, as there is a growing appreciation on the part of parents and professionals of the importance of self-advocacy and self-determination, so too is there growing interest from all quarters in self-advocates and their organizations, and this interest presents challenges to the self-advocacy movement. Self-advocacy groups and group members are now regularly approached to participate in grant applications, sit on boards of directors, and speak on panels. These requests will likely outstrip the movement's ability to respond before too long. Leaders will have to be selective in their alliances and examine their relationships

with professional or parent organizations carefully. There is a fine line between receiving the kind of support that a fledgling organization needs to become established and the overbearing "support" that might be used to keep a radical element "in its place." Self-advocates and self-advocacy groups will need to thoughtfully consider requests from various associations, other advocates, and service providers while acknowledging the reality that progress will likely occur through equal partnerships and collaborations with these stakeholders. By definition, self-advocates' increasing power challenges the power of these other groups. The need in the 21st century is to define opportunities for collaboration and to occasionally agree to disagree, rather than creating hostile opposition that precludes collaboration.

Group Identity. Who is a self-advocate? At least two issues related to this question present challenges to the movement. First, does the term apply only to people with mental retardation, or can someone with a developmental disability other than a cognitive impairment also be considered a self-advocate? Historically, the terms *self-advocacy* and *self-advocate* have referred to entities organized by people with mental retardation or to members of such organizations. There are other self-help organizations organized and run by people with disabilities, but *self-advocacy* typically has referred to the mental retardation–linked organizations. That said, there are many people with cerebral palsy and other disabilities who are exemplary advocates and, in some quarters, they too are known as self-advocates. However, some of these advocates say that they find the term offensive because it makes them sound like they have mental retardation. Certainly, no one needs to accept a label he or she finds offensive, but this concern seems to needlessly heighten the between-group differences. Just as progress will likely stem from meaningful collaborations with parent and professional organizations, so too will progress in the self-advocacy movement in this century likely rely on collaborations with other disabil-

ity self-help organizations. Issues regarding the stigma associated with the term *mental retardation* are real and will not likely go away soon, but there is a very real need to address the underlying stereotypes and beliefs that lead to such stigma, even among and between people with disabilities and the organizations that serve them.

Second, in some places the term *self-advocate* has become just the latest euphemism or politically correct term for referring to a person with mental retardation. People say that they "saw a self-advocate down at the mall," or that they "provide support for three self-advocates." In many of these cases, quite frankly, the individuals being described have shown no real advocacy efforts. Clearly, there is some benefit to expecting individuals to "earn their stripes" before calling them self-advocates. Just as not all minority group members are civil rights activists, not all people with disabilities are self-advocates.

The Long-Term Role for People Who Are Not Disabled. Sometimes called the "temporarily able-bodied" by disability activists, many nondisabled activists (present company included!) have become less secure in their roles as the movement has matured. (Indeed, it is with some trepidation, and the recognition that we cannot speak for or to the self-advocacy movement, that we address future issues!) The issue of the role of people without disabilities in the self-advocacy movement is difficult. It is perhaps most difficult on the front lines—the role of the adviser to the group. It seems evident to us that in far too many circumstances, group actions are based primarily on the will of the adviser. Conflicts between advisers who are employed by agencies that, in turn, provide services to the group members are real and, perhaps, unavoidable. Many self-advocacy groups have established guidelines and deal with potential threats to the groups' power effectively, whereas others remain powerless to initiate needed changes because of the power balance between the group and the adviser and support agency.

As with other social movements (Bersani, 1998), there is some value to groups in clearly identifying themselves. Even if they seek social integration, there may be a role for "formative segregation," that is, conducting group-only events in order to form a self-identity. As Bersani (in press) pointed out,

Those of us who consider ourselves allies of the movement may be tempted to feel that we have earned the right to be involved in the future because we have been supportive in the past. However, part of being supportive is knowing when to stand back. Ultimately, we must realize that the decision is not ours to make. We may not agree with the decisions that self-advocates make, but we must respect them or belie our beliefs.

Leadership as the Legacy of the Self-Advocacy Movement. There is an ongoing need in virtually any volunteer, social, or civil rights movement for the continued development of leaders who can replace current leaders in the organization. This is as true for The Arc as it is for the NAACP, Civitans, or Disabled People's International, and it is no different for the self-advocacy movement. Without concentrated focus on the development of new leaders for self-advocacy groups at all levels, the movement will founder. The formation of Self-Advocates Becoming Empowered was an important step in the process of ensuring ongoing leadership, and there are already efforts coming from self-advocates, like the work of Tia Nellis at the University of Illinois at Chicago, to develop leadership development models, materials, and supports. With a maturing base of leaders, the movement can begin to address the issues that challenge them in the coming century.

Self-Determination

As we previously noted, there have been two major initiatives that have, in some sense, programmed self-determination in the disability arena. These initiatives, one launched by the U.S. Department of Education in the early 1990s and the other by funding from the Robert Wood Johnson Foundation in the mid-1990s,

have taken self-determination from a psychological or political construct to a set of actions that attempt to enable people with mental retardation to achieve greater independence and control. When examined within the context of the entire 20th century, it seems evident that these initiatives are genuinely in their infancy. As a field of service providers, whether educators or adult service providers, we have a half-century history of wielding power "on behalf" of people with mental retardation, but only a half-decade history of trying to enable people with mental retardation to take control over their own lives.

There is a compelling need to link these two initiatives, which addressed this issue from different ends of the spectrum in several ways: who is served (students vs. adults) and what the focus of the intervention is (individual vs. corporate or political self-determination). A number of false dichotomies continue to plague our capacity to effectively enable people to assume control over their lives. One such dichotomy is the skills-versus-opportunity debate. This is reminiscent of the nature–nurture debate in psychology and will likely be resolved in the same manner. Napoleon Bonaparte stated that ability is of little account without opportunity. Thus, an overemphasis on skills development seems destined to fail if there are no opportunities for people to exercise choice and control. Additionally, an undue focus on skills development emphasizes that the "problem" is with the person, not the system. On the other hand, opportunity is wasted without capacity. There are a great many adults with mental retardation who simply have not had the experiences that could enable them to take control over their lives, even if they are given the chance. One aspect of "supports" for all people, disabled or not, is enhancing capacity.

We need to better listen to self-advocates when debating what is or is not self-determination. On its Web page, Self-Advocates Becoming Empowered defined *self-determination* as

speaking up for our rights and responsibilities and empowering ourselves to stand up

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for what we believe in. This means being able to choose where we work, live, and our friends; to educate ourselves and others; to work as a team to obtain common goals; and to develop the skills that enable us to fight for our beliefs, to advocate for our needs, and to obtain the level of independence that we desire. (http://www.sabeusa.org/)

This definition recognizes that skills and opportunities are equally important. There is a need to begin to take a lifespan approach to self-determination by better understanding the role of families and schools in the development of a personal self-determination and by implementing models and strategies, like personal budgeting and person-centered planning, that lead to enhanced opportunities for adults to take control over their lives.

It is important to continue to emphasize that there is a reciprocal nature to providing opportunities to take control over one's life (be it chairing an educational planning meeting, deciding one's own educational goals, or choosing one's own service provider) and the increased capacity to take control. That is, we must never confuse the importance of developing and enhancing skills with the need to move ahead and turn over power and control to people with disabilities. A skills development approach is not equivalent to a flow-through model in which a person is not allowed to take control until he or she has a prerequisite set of skills. Instead, it is through the interaction of capacity building, opportunities to exercise choice and control, and provision of supports that the goal of enabling people to achieve self-determination is accomplished.

The challenges for the next century are real and many. How does one provide brokerage services that do not fall victim to the old perils of case management? How does a teacher enable students to become self-directed learners? The programmatization of self-determination introduces many threats to the continued focus on this issue. Already too many schools think that promoting self-determination means merely that a student serves as a chairperson (often in a

token role) in a planning meeting. Likewise, some adult service providers think that conducting a person-centered planning meeting to which the individual is invited constitutes a self-determination program. And, almost predictably, we have heard professionals and others proclaim that self-determination is not for this person because he could not lead his meeting, or for that person because she could not make independent medical decisions.

What we need to emphasize in this new century is that self-determination is about control over one's life and one's destiny. All people have the right to such control, have the right to an education that supports their capacity to take greater control, and deserve the supports that enable them to assume greater control. There is much we do not know about how to make that a reality, but we do know that it is the right direction in which to head and, as a field, must remain diligent and stay the course. It does seem almost inevitable to us, given the strength of the self-advocacy and self-determination movement in the last third of the 20th century, that the 21st century will witness increased power and control for people with disabilities, so perhaps the charge most appropriate for the field was one proclaimed, appropriately, by Burton Blatt. Commenting on *Christmas in Purgatory* (Blatt & Kaplan, 1966) and referring to the reception that this book, which pictorially documented the deplorable conditions of institutions for people with mental retardation in the United States, received among some professionals in the field, Blatt noted,

In spite of those who protest this presentation, there will be no turning back. Once seeds are sown, one only has to wait for the crop to harvest. It has been said that, when the bellman is dead, the wind will toll the bell. So hurry, wind! Or revive yourselves, noble bellringers. (Blatt, 1971, p. 360)

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Workforce Investment Act of 1998, 20 U.S.C. § 9276.

ATTACHMENT E

Promoting and enhancing self-determination to improve the post-school outcomes of people with disabilities

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Abstract. This article re-affirms the call for attention to the development of self-determination skills and opportunities for people with disabilities. Recent data on rates of participation in postsecondary education and employment are reviewed, highlighting the ongoing disparities in post-school outcomes for people with disabilities. Next, research on the relationship between self-determination and post-school outcomes is reviewed as is research on effective strategies to promote self-determination. Implications for the field are highlighted.

Keywords: Self-determination, post-school, transition

1. Introduction

In 1988, the Office of Special Education and Rehabilitative Services (OSERS) began an initiative on self-determination focused on system-wide activities to enable persons with disabilities to have more input in the decisions that affect their lives. In the preliminary stages of the OSERS' initiative, Ward (1988) referred to self-determination as both "the attitudes which lead people to define goals for themselves and the ability to take the initiative to achieve those goals" (p. 2) with the understanding that defining goals was about making choices and having access to multiple options from which to choose. Ward proposed this as a working definition and other definitions were encouraged along with efforts to develop interventions and assessments to promote self-determination. Between 1990 and 1996, OSERS funded more than 26 model demonstration projects on that focused on self-determination theory development, assessment, and intervention (Ward & Kohler, 1996).

Since this time, the field has significantly expanded theoretical frameworks for the development of self-determination and multiple evidence-based practices exist to teach and create opportunities for the development of self-determination in the context of the transition for adulthood for adolescents with disabilities.

The attention directed to self-determination in the early 1990s was part of an effort to improve a range of post-school outcomes and to support youth with disabilities in taking more control over every aspect of their lives (e.g. employment, independent living, community participation). Since the mid-1980s, there have been numerous state-wide and national studies following special education students who completed high school over a period of time (most notably, the National Longitudinal Transition Study 1 & 2). The results of all these studies have indicated that the post-school outcomes of those with disabilities in terms of education, employment, and other aspects of community participation are far bleaker than for the general population. Recurring research has suggested that the outcomes for people with disabilities in all areas have remained stagnant over the past 30 years. The purpose of this article is to first review recent data on rates

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of participation in postsecondary education, employment, SSI, and poverty for people with and without disabilities that suggest the ongoing persistence of this discrepancy and the need for continued attention to the role of self-determination in enhancing post-school outcomes. We will follow this with a review of existing research on the relationship between self-determination and post-outcomes as well as research on effective strategies to promote self-determination, re-affirming the call that originated in the 1990s for attention to the development of self-determination skills and opportunities for people with disabilities.

2. Recent data on post-school outcomes

In this section, we will review data from two recent sources, the CIRP Freshman Survey (Eagan et al., 2017) administered by the Higher Education Research Institute and the Disability Status Report (Erickson, Lee, & von Schrader, 2016) published by Cornell University's Yang-Tan Institute on Employment and Disability. Unfortunately the definition of 'disability' is different in the two data sets and therefore, comparisons cannot be made between them as well as with other common disability counts (e.g. Part B under IDEA). Furthermore, both data sources are based on self-reported disabilities and the accuracy cannot be verified.

The most recent CIRP Freshman Survey data are based upon self-reported responses from 137,456 first-time, full-time students who entered 184 U.S. colleges and universities of in the fall of 2016. Select items related to demographic characteristics and self-determination from the CIRP Freshmen Survey allow for comparisons of the initial college experiences of students with disabilities with those without disabilities. Freshmen participants in the survey were asked to identify as having with any seven disability categories (attention deficit hyperactivity disorder, autism spectrum disorders, chronic illness, learning disability, physical disability, psychological disorder, other disability). Approximately 16.0% of the incoming 2016 class identified as having only one disability with an additional 4.3% selecting two categories and another 1.6% choosing three or more for a total of 21.9% identifying as having at least one disability. The percentages for the total reporting disabilities and for most categories have increased in recent years. For example, 14.6% freshmen reporting one or more disabilities in 2010 compared with 21.9% in 2016,

a 50% increase. This increase was highest for the psychological disorder category. In 2010, a total of 3.6% reported with 2.3% males and 4.7% females reported a psychological disorder while in 2016, a total of 10.7% reported with 6.1% males and 14.5% females. This is over a 300% increase in the total number of freshmen reporting this disability. Perhaps this is encouraging in relation to self-determination as it is possible that students are more comfortable disclosing their disability and are self-advocating for the services and accommodations they need to be successful. However, more research is needed to examine the relationship between disclosure, advocacy and self-determination particularly as survey items do not ask whether students had an IEP/504 Plan in high school or intend to request disability support services from their college.

The CIRP Freshmen Survey asks many items about freshmen's high school experience as well as activities they intend to pursue in college. Two items that particularly relate to self-determination are whether freshmen expect to communicate regularly with professors and whether they expect to get tutoring help. While approximately 90% of all freshmen, including those with disabilities, indicate there is some chance or a very good chance that they will communicate with their professors, it is concerning that about 11% of freshmen with learning disabilities indicate that there is very little or no chance of such communication. We know that many of these students may need support in accessing course content and must disclose to their professors to get support services and accommodations. Therefore, one would hope that almost 100% of this population would be self-advocating for what they need to succeed in specific courses.

Similarly, about 85% of freshmen with learning disabilities indicate that there is at least some chance of getting tutoring help. This means that the remaining 15% do not plan on requesting tutoring help. Again, we know that many in this population will need additional tutoring help to pass their courses. However, there is evidence that for a variety of reasons, including the belief that the need for special education ends with high school (Lightner, Kipps-Vaughan, Schulte, & Trice, 2012; Marshak, Van Wieren, Ferrell, Swiss, & Dugan, 2010), that most college students do not disclose their learning disabilities, which is the first step in obtaining needed accommodations and support services. The chances of successfully completing college is drastically reduced for those students who do not seek these supports.

Data on employment, participation in the Supplemental Security Income (SSI) Program, and poverty for persons with disabilities was examined using the 2015 Annual Disability Status Report published by Cornell University's Yang-Tan Institute on Employment and Disability. This report, based on the American Community Survey (ACS) administered by U.S. Census Bureau, provides a summary of the most recent demographic and economic statistics on the non-institutionalized population with disabilities. Comparisons can be made to people without disabilities and across disability types. This report indicates that the prevalence of disability among non-institutionalized people of all ages was 12.6% or almost 40 million. Among the six types of disabilities identified in the survey (ambulatory, visual, hearing, self-care, independent living, and cognitive) the highest prevalence rate was for ambulatory disability - 7.0%. The lowest prevalence rate was for visual disability - 2.3%.

The employment rate of working-age people with disabilities in 2015 was 35.2% while the employment rate of people without disabilities was 78.3%. This is a gap of 43.1 percentage points. Among the six types of disabilities, the highest employment rate was for people with a hearing disability - 51.8% - while the lowest employment rate was for those with a self-care disability, 15.8%. As indicated by Fig. 1, trend lines for the recession beginning 2008 through 2015 indicate that at the start of this period, the employment rate for people without disabilities was 79.9% and for people with disabilities, 39.5%. Both of these

rates are relatively high. As the recession deepened and those in the general population became unemployed, people with disabilities lost employment at a comparative rate suggesting that when there are an abundance of jobs and a scarcity of workers, people with disabilities are more likely to be hired. However, when the overall unemployment rate is high, diverse populations, including people with disabilities, experience even higher rates of unemployment. In 2015, the employment participation rate of persons with disabilities was about 35%, the same rate it has been for at least 20 years.

The percentage of working-age people with disabilities who received Supplemental Security Income (SSI) payments in 2015 was 19.3% or about 3,801,100. About one in five adults with disabilities participating in this cash payment program including 29.7% of people with an independent living disability. During the same year, the poverty rate of working-age people with disabilities in the U.S. was 27.0% while the rate of poverty among people without disabilities was 11.6% with a difference of 15.4 percentage points. An estimated 31.8% of people with an independent living disability were living below the poverty line. Using readily available information, the poverty level in 2017 for a 1-person household is $12,060 while the maximum monthly SSI benefit for an individual is $735 or an annual income for person on SSI is $8,820. This suggest that more than one-fourth of people with disabilities live in poverty on an on-going basis. Although many on SSI rely on Medicaid to pay for their healthcare and other necessary
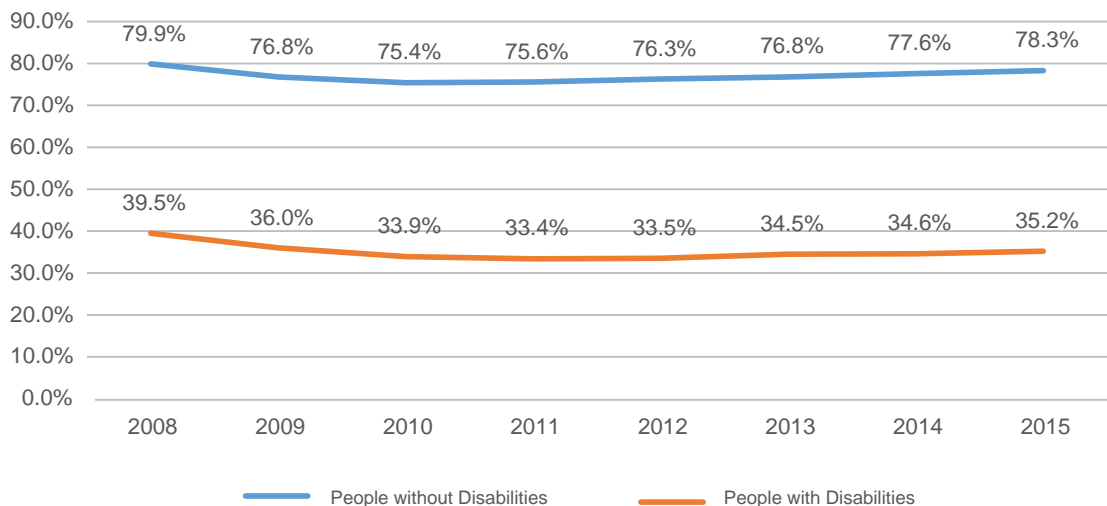
Fig. 1. Employment rate of people with and without disabilities (ages 21-64) 2008-2015. Based on the 2015 American Community Survey (ACS) data (Erickson, Lee, & von Schrader, 2016).

long-term support, less than 1% of those who enroll in this program ever become financially self-sufficient enough to end their dependence on these benefits (Ticket to Work and Work Incentives Improvement Act of 1999). This is unfortunate because an annual income of less than $9,000 creates significant barriers to an independent, self-determined lifestyle.

3. Relationship between self-determination and post-school outcomes

Beginning in the late 1990s, driven in large part by the OSERS initiatives, researchers began to explore the connection between the self-determination of young people with disabilities and post-school outcomes. This research has consistent suggested that – after controlling for other factors – enhanced self-determination leads to more positive post-school outcomes. This research suggests that promoting self-determination is a critical factor to consider along with other systemic changes in the design and delivery of supports and services to enhance post-school outcomes. For example, Wehmeyer and Schwartz (1997) measured the self-determination status of 80 students with intellectual or learning disabilities in their final year of high school and then one year after high school. Students with higher self-determination scores when they left high school were more likely to have expressed a preference to live outside the family home, have a savings or checking account, and be employed for pay one year after school. Among school-leavers who were employed, youth in the high self-determination group earned significantly more per hour than their peers in the low self-determination group. Wehmeyer and Palmer (2003) conducted a second follow-up study, examining the adult status of 94 young people with intellectual or learning disabilities one and three years after graduation. These data replicated Wehmeyer and Schwartz' (1997) earlier study and also found employed young adults scoring higher in self-determination made statistically significant advances in obtaining job benefits, including vacation and sick leave and health insurance, an outcome not shared by their peers in the low self-determination group.

Building on this early research suggesting a correlational link between self-determination and outcomes, researchers have explored the impact of actively teaching and creating opportunities for self-determination in adolescents and young adults with

disabilities on in-school and post-school outcomes. For example, research has found that teaching self-determination skills can lead to increase academic performance (Konrad, Fowler, Walker, Test, & Wood, 2007; Raley, Shogren, & McDonald, 2017), attainment of academic goals (Agran, Blanchard, Hughes, & Wehmeyer, 2002; Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) and transition goals (Devlin, 2011; McGlashing-Johnson, Agran, Sitlington, Cavin, & Wehmeyer, 2003; Shogren et al., 2012; Wehmeyer et al., 2000; Woods & Martin, 2004), as well as greater access to the general education curriculum (Agran, Wehmeyer, Cavin, & Palmer, 2008; Lee, Wehmeyer, Palmer, Soukup, & Little, 2008) for adolescents with disabilities in secondary school. It is hypothesized that these positive in-school outcomes will lead to more positive post-school outcomes. In addition to findings with adolescents, researchers have found that increased self-determination in adults is linked to enhanced recreation and leisure participation (Dattilo & Rusch, 2012), to increased choice opportunities (Neely-Barnes, Marcenko, & Weber, 2008), and to enhanced quality of life (Lachapelle et al., 2005; Wehmeyer & Schalock, 2001) in adults with disabilities.

In one of the few longitudinal studies examining the relationship of promoting self-determination in adolescents and longer-term early adulthood outcomes, Shogren, Wehmeyer, Palmer, Rifenbark, and Little (2015) followed students who had participated in a randomzied control trial on the efficacy of self-determination interventions (compared to a business as ususal control group; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013) for two years post school. To measure adult outcomes, Shogren and colleagues used the Outcome Survey, a survey adapted from Wehmeyer and Schwartz (1997) and Wehmeyer and Palmer (2003), the National Consumer Survey (Jaskulski, Metzler, & Zierman, 1990), and the National Longitudinal Survey (Wagner, D'Amico, Marder, Newman, & Blackorby, 1992). The measure includes questions related to employment, community access, financial independence, independent living, and life satisfaction. Results indicated that self-determination status at the end of high school, which was impacted by exposure to self-determination interventions in secondary school, predicted significantly more positive employment outcomes, including increased wages, benefits, and opportunities for career development. The young adults also showed increased community

integration outcomes, including access to social networks and supports, transportation, and other critical factors to successful employment and community participation. In essence, this study provided evidence that promoting self-determination while youth are in secondary school results in enhanced self-determination in early adulthood, and that enhanced self-determination in early adulthood results in more positive adult outcomes, including employment and community participation.

Overall, the research suggests the importance of taking a lifespan approach to promoting self-determination, which can be a critical element of promoting positive outcomes, particularly in the context of – as noted in the original OSERS' funding-initiatives – system-wide activities to support persons with disabilities have more input in the decisions that affect their lives, including decisions about integrated employment and community engagement school and post-school.

4. Interventions to promote self-determination and post-school outcomes

Beginning with the OSERS' initiatives in the early 1990s, and bolstered by the ongoing data suggesting continued poor post-school outcomes as well as the increasing data suggesting the role of promoting self-determination in addressing poor outcomes, researchers have directed significant attention to the development, evaluation, and implementation of self-determination strategies. Much of this work has focused on adolescents with disabilities in the context of secondary transition services (Test et al., 2009) as required under the Individuals with Disabilities Act, although other research groups have begun to focus on promoting self-determination in the context of the design and delivery of adult services and supports (Heller et al., 2011). Researchers have found that multi-component interventions (i.e., those that target multiple self-determination skills – goal-setting, problem solving, decision making, choice making, self-advocacy simultaneously) tend to be the most effective (Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009), perhaps because of the focus on multiple skills and their application across environments.

Central to implementing interventions to support self-determination is a theoretical framework to guide intervention implementation and evaluation. On the-

ory, developed by Shogren, Wehmeyer, Palmer, Forber-Pratt, et al. (2015) is Causal Agency Theory. Causal Agency Theory is an empirically-validated model that provides a theoretical framework for developing and enhancing supports to enable people with disabilities to develop greater self-determination by engaging in agentic action to set and go after goals. It builds on the functional model of self-determination (Wehmeyer, 1992, 1998, 2003) and defines self-determination as a "dispositional characteristic manifested as acting as the causal agent in one's life" (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015, p. 258). A dispositional characteristic is an enduring tendency that develops over time, with appropriate supports and opportunities. The importance of contextual factors is a central element of Causal Agency Theory. Contextual factors (e.g., personal, family and community, and systems and policy factors) shape opportunities for the development and expression of self-determination, necessitating consideration of the implementation of interventions to teach skills associated with self-determination, such as self-advocacy, goal-setting, problem-solving and decision-making skills, across supportive systems.

Causal Agency Theory provides a framework to assess, develop, implement, and evaluate interventions to promote self-determination. For example, researchers have developed curricula to teach and create opportunities for students with disabilities to take leadership roles in the transition planning process, engaging adolescents in the goal setting process and with advocating for their future. Martin et al. (2006) conducted an randomized control trial (RCT) study of a student involvement curriculum, called the Self-Directed IEP, and found that students with disabilities who received instruction using the SDIEP increased their participation in IEP meetings, engaged in more leadership activities during the meeting, and were better prepared to express their interests, strengths, and support needs. Wehmeyer, Palmer, Lee, Williams-Diehm, and Shogren (2011) conducted an RCT study of the impact of another student involvement curriculum, Whose Future is it Anyway?, on self-determination and transition knowledge and skills, finding that instruction using the WFA resulted in significant, positive differences in self-determination when compared with a placebo-control group, and that students who received instruction gained transition knowledge and skills.

Promoting self-determination, however, can and should occur across contexts (e.g., home, school,

and the community) as well as within contexts (e.g., transition planning, employment experiences, core content instruction at school) across the lifespan. Two related interventions, the Self-Determined Learning Model of Instruction and the Self-Determined Career Development Model have been extensively researched with adolescents and adults with disabilities as a means of promoting self-determination and goal-directed action. The SDLMI and SDCDM are models of instruction used by a facilitator (e.g., educator, direct support professional, family member) to design instruction and supports that enable people with disabilities to self-direct goal-setting to enhance self-determination. In implementing the model, people with disabilities are supported to set a goal, develop an action plan, and evaluate their progress. The SDLMI and SDCDM create opportunities for people with disabilities to focus on choice-making, problem solving, decision making, and self-advocacy, with support from a trained facilitator. The differences between the SDLMI and the SDCDM emerge in the focus of the goal and the support provided. The SDLMI can be used generally with any learning goal (e.g., academic, social, behavioral, recreational), including learning goals in the school context and the SDCDM is specific to career development related goals and the supports needed to self-direct career exploration and development activities.

A growing body of research has suggested the impact of the SDLMI and SDCDM on self-determination other school and post-school outcomes. Wehmeyer et al. (2012) reported the results of a group RCT study of the efficacy of SDLMI with over 300 students with intellectual and learning disability. Adolescents in the treatment group reported significantly greater increases in self-determination, with the greatest growth in the second year of instruction suggesting the importance of ongoing exposure to self-determination skill instruction. Shogren et al. (2012) conducted a group RCT of the impact of the SDLMI on access to the general education curriculum and goal attainment, finding that students in the SDLMI group (vs. the control group) made significantly more progress on goals and had significantly greater increases in their access to the general education curriculum than students assigned to the control group, further teachers reported significant changes in their perceptions of student's capacity for self-determination (Shogren, Plotner, Palmer, Wehmeyer, & Paek, 2014). As mentioned previously, Shogren, Wehmeyer, Palmer, Rifenbark,

et al. (2015) followed youth with disabilities, for two years after high school who were exposed to multicomponent self-determination interventions including the SDLMI, finding increased employment and community participation outcomes post-school. Powers et al. (2012) had similar results in school and post-school using an intervention to promote self-determination called My Life for youth in foster care and special education. Shogren, Burke, et al. (2017) reported the results of a state-wide implementation of the SDLMI with transition-age youth planning for the movement from school to integrated employment, and found that one year of implementation of the SDLMI teacher's perceptions of adolescent self-determination and transition-related goal attainment.

With regard to the SDCDM, Wehmeyer et al. (2003) worked with vocational rehabilitation counselors to implement the SDCDM, and found that adults with disabilities who were supported to use the model made progress on self-selected employment goals, and felt that they had gained important skills. Wehmeyer et al. (2009) also used the SDCDM as part of a larger intervention package with young women with developmental disabilities, suggesting that they found the model useful and effective in setting and pursing career development goals. Shogren et al. (2016) examined implementation of the SDCDM with direct support providers as facilitators, examining the impacts on self-determination of adults with intellectual and developmental disabilities served by support provider organizations in the community, finding that the SDCDM influenced self-determination outcomes. However, differences in how the provider organizations supported the SDCDM significantly influenced outcomes, suggesting the importance of the environment and training and supports provided for implementation. Shogren, Dean, et al. (2017) combined the SDCDM with the Discovery process and found impacts on self-determination when implemented with adults with intellectual and developmental disabilities receiving supports for employment from community service provider organizations.

Overall, there is a wide and growing body of research that clearly establishes that people with disabilities can learn the skills associated with self-determination when provided with individualized supports, instruction, and opportunities. While researchers have established that promoting the development of self-determination influences outcomes across the lifespan, including integrated

employment outcomes, there is also a compelling body of evidence that schools and adult support provider organizations too often do not implement evidence-based practices to promote self-determination to improve integrated employment outcomes (Winsor & Butterworth, 2008; Winsor, Butterworth, & Boone, 2011). People with disabilities remain restricted in their opportunities to learn and use skills leading to enhanced self-determination necessitating ongoing targeted and directed attention to embedding opportunities and supports for self-determination across all contexts within which people with disabilities live, learn, work and play (Shogren et al., 2014; Shogren & Shaw, 2017).

5. Future directions to promote integrated employment outcomes

The ongoing disparities in post-school employment and community participation outcomes are well-established and illuminate the ongoing need for the development of interventions and supports that address these outcomes. Given the established relationship between self-determination, employment, and community integration outcomes (Shogren & Shaw, 2016; Shogren, Wehmeyer, Palmer, Rifenbark, et al., 2015; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997), we would argue that self-determination should be at the center of efforts to promote change. Enabling people with disabilities to self-direct their own lives and careers should be a goal of disability supports and services across the lifespan both because of the inherent right all people to be self-determining as well as the clear and compelling evidence that promoting self-determination makes a difference in outcomes. Obviously, systemic changes are needed both to create opportunities for self-determination as well as to address the other factors that restrict opportunities for adults with disabilities to be engaged members of their community and the workforce. Promoting self-determination should be an explicit aspect of all supports and services and all system reforms initiatives. As such, changes are needed in the structure of the systems that organize supports (Shogren, Abery, et al., 2015). Current opportunities, such as those introduced by the U.S. Department of Justice's enforcement of Title II of the Americans with Disabilities Act as interpreted by the U.S Supreme Court in Olmstead vs. L.C in the context of employment supports (United States

District Court District of Rhode Island, 2014) as well as the provisions related to transition in the Workforce Innovation and Opportunities Act create opportunities that must be leveraged for systemic changes.

At the individual level to promote integrated employment outcomes, enabling people with disabilities to make choices as well as set and work toward goals will enable supports and services to be matched to wishes, interests, and capabilities, and, in doing so, will promote greater engagement and motivation (Mithaug, 2005; Shogren, Dean et al., 2017). Making choices and setting goals requires that individuals are exposed to a pool of potentially rich choice options and opportunities that enable the ongoing development of self-determination. If these options are sufficiently rich, the person's goals and choices will become more and more self-determining. This also promotes systems change by shifting the focus from what is available to what is aligned with the person's interests, preferences and needs. During the employment goal setting process, job seekers should participate actively in all job search activities - from determining their interests and career goals to starting a new job (Brugnaro & Timmons, 2007). Self-determined job seekers choose the resources to achieve those goals, are the decision-makers, and are actively involved in all stages of the employment process. They act as the primary source of information, decide the direction of the job search, choose the people to participate, and control the planning that leads to a job. They know, and fully understand, what choices are available. To be self-determining is to be fully engaged in the job selection process as well as the selection of community-based resources and supports which creates feelings of empowerment and motivation.

At the system level, school based transition and employment supports and services need to be coordinated and funded in ways that promote self-determination and provide individualized supports based on identified support needs with the goal of enhanced self-determination and employment and community integration outcomes. To enable self-determined job seekers to create their own personal career goals and to take responsibility for participating actively in determining how these goals will be achieved, supports must be aligned with these goals and training for staff and decision-makers must focus on self-determination across all levels to foster self-determined individuals and valued outcomes.

6. Conclusion

Through persistence and innovation, the field has developed many strategies that enable long-term career and community engagement outcomes of people with disabilities. However, the utilization and the full integration of these strategies into systems of supports remains low. Strategies such as supported employment and entrepreneurship, and their value in finding jobs one person at a time cannot be denied. Further, researchers have shown that efforts to promote self-determination can be fully integrated into these strategies (Shogren, Dean, et al., 2017). Yet with the employment rate of people with disabilities stagnating at about 35%, further systemic change is needed that incorporates best practices in employment, community integration, and promoting self-determination. New and ongoing innovation in federal policy and initiatives, building on the original OSERS' initiatives, is needed across systems. Further, ongoing work is needed to support evidence-based practice at the level of individual, community, and state level supports and services. Exploring ways to innovate, plan with the end in mind, and effectively use evidence-based practice are critically important to break down the stagnation in outcomes and promote real, meaningful, self-determined lives in the community that are driven by the interests, preferences, and values of people with disabilities.

Conflict of interest

None to report.

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Workforce Innovation and Opportunity Act. (2014). Public Law 113-128 (29 U.S.C. Sec. 3101, et. seq.)

ATTACHMENT F

A National Gateway to Self-Determination

funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Self-Determination and People with Intellectual and Developmental Disabilities: What Does The Research Tell Us?

Institute for Human Development, University of Missouri Kansas City

Kansas University Center on Developmental Disabilities, University of Kansas

Center on Human Development, University of Oregon

Department of Disability and Human Development, University of Illinois Chicago

Westchester Institute for Human Development, New York Medical College

Self-Determination and People with Intellectual and Developmental Disabilities: What Does the Research Tell Us?

There exists an already substantive and still growing literature base pertaining to self-determination and people with disabilities. The intent of this slide show is to provide a synthesis of major findings in the area of self-determination pertaining to youth and adults with intellectual and developmental disabilities.

What Does the Research Tell Us About Self-Determination?

- The findings in this slide show come from a comprehensive review of the literature on self-determination published in 2007 in the journal *Exceptionality*, * as well as from a comprehensive review of the research published subsequent to this review.

- Studies included in the review met these selection criteria:

  - The researchers measured global self-determination, as opposed to one component (such as choice making or problem solving only), using a validated measure of self-determination. By measuring "global self-determination," we mean that the research must have actually measured self-determination using a valid measure of self-determination.

  - The studies included in the review had to involve adults/students with disabilities.

    *Chambers, C.R., Wehmeyer, M.L., Saito, Y., Lida, K.M., Lee, Y., & Singh, V. (2007). Self-determination: What do we know? Where do we go? *Exceptionality, 15*, 3-15.

What Does the Research Tell Us About Self-Determination? Caveats and Qualifiers

- This slide show is an attempt to synthesize information from an already large and constantly growing literature base. In essence, it hits the high points about what is known from research and provides representative citations.
- This synthesis focuses on issues of self-determination pertaining to youth/adults with intellectual and developmental disabilities, so does not constitute a synthesis of the literature in self-determination across disabilities.
- The intent of this presentation is to provide a foundation with regard to knowledge obtained through research so as to guide intervention development and implementation and the provision of supports to enable people with intellectual and developmental disabilities to become more self-determined.

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Finding Summary: Self-Determination Status

- Research shows that youth/adults with disabilities are less self-determined than their non-disabled peers.

  - It is important, however, not to assume that this in any way reflects the capacity of people with disabilities to become self-determined. The research clearly shows that people with disabilities have many fewer opportunities to make choices and express preferences across their daily lives.

Representative Studies: Self-Determination Status

Stancliffe, R. J., Abery B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation, 105*, 431-454.

Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *American Journal on Mental Retardation, 100*, 632-42.

Wehmeyer, M. L., & Metzler, C. (1995). How self-determined are people with mental retardation? The National Consumer Survey. *Mental Retardation, 33*, 111 - 119.

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Finding Summary: Factors Contributing to Self-Determination

- Social abilities and adaptive behavior skills are related to more positive self-determination.
- Choice-making opportunity is a strong predictor of self-determination. Research shows that the environments in which adults with disabilities live or work limit opportunities to make choices and restrict personal autonomy.
- Although many people believe that people with intellectual disability cannot be self-determined because of their cognitive impairment, research consistently shows that while SD is positively correlated with IQ, that relationship is generally weak and IQ is not predictive of self-determination status.
  - IQ is predictive* of where one lives/works, which in turn is predictive of self-determination status by virtue of the above-noted findings.

    *By predictive, we simply mean the research shows a statistical relationship between IQ and where one lives/works. This should not be interpreted to mean that IQ must, by any means, be predictive of where one lives or works; it is simply the case at the current time.

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funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Factors Contributing to Self-Determination

Nota, L., Ferrrari, L., Soresi, S., & Wehmeyer, M.L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research, 51*, 850-865.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N. & Lawrence, M. (2007). Examining individual and ecological predictors of the self-determination of students with disabilities. *Exceptional Children, 73*, 488-509.

Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 91-98.

Stancliffe, R. J., Abery B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation, 105*, 431-454.

Stancliffe, R. & Wehmeyer, M. L. (1995). Variability in the availability of choice to adults with mental retardation. Journal of Vocational Rehabilitation 5 319-328

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Representative Studies: Factors Contributing to Self-Determination (continued)

Wehmeyer, M. L., Kelchner, K. & Richards, S. (1995). Individual and environmental factors related to the self-determination of adults with mental retardation. Journal of Vocational Rehabilitation, 5, 291-305.

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with mental retardation as an outcome of moving to community-based work or living environments. Journal of Intellectual Disability Research, 45, 371-383.

Wehmeyer, M. L., & Bolding, N. (1999). Self-determination across living and working environments: A matched-samples study of adults with mental retardation. Mental Retardation, 37, 353 - 363.

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Finding Summary: Self-Determination and Adult Outcomes

- Multiple research studies find that a person's self-determination status predicts higher quality of life.
- Self-determination status is positively correlated with more positive post-secondary outcomes, including employment, independent living, and community inclusion for youth with disabilities.
- Young adults who are more engaged in personally-valued recreation activities are more self-determined, suggesting a reciprocal relationship between recreation activities and self-determination.

Finding Summary: Self-Determination and Adult Outcomes (continued)

- ## Students with cognitive disabilities who leave school as self-determined young people:

  - Are more independent one year after graduation.
  - Are more likely to live somewhere other than where they lived in high school one year after graduation.
  - Are significantly more likely to be employed for pay at higher wages one year after graduation.
  - Are significantly more likely to be employed in a position that provides health care, sick leave, and vacation benefits three years after graduation.
  - Are significantly more likely to live independently three years after graduation.

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Representative Studies: Self-Determination and Adult Outcomes

Copeland, S.R., & Hughes, C. (2002). Effects of goal setting on task performance of persons with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 37*, 40 - 54.

Lachappelle Y., Wehmeyer M. L., Haelewyck M. C., Courbois Y., Keith K. D., Schalock R., Verdugo M. A., & Walsh P. N. (2005) The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research* 49, 740-744.

McGuire, J., & McDonnell, J. (2008). Relationships between recreation and levels of self-determination for adolescents and young adults with disabilities. *Career Development for Exceptional Individuals, 31*(3), 154-163.

Sowers, J., & Powers, L. (1995). Enhancing the participation and independence of students with severe physical and multiple disabilities in performing community activities. *Mental Retardation, 33*, 209 – 220.

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Representative Studies: Self-Determination and Adult Outcomes (continued)

Wehmeyer, M.L., & Palmer, S.B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities, 38,* 131-144.

Wehmeyer, M. L. & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63,* 245-255.

Wehmeyer, M. L. & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33,* 3-12.

Finding Summary: Perceptions of Self-Determination and People with Disabilities

- Adults with disabilities themselves rank self-determination as more important than do professionals and parents/family members.
- Special education teachers report that:
  - they are familiar with self-determination;
  - believe self-determination is an important component of transition planning;
  - believe that student involvement in planning is important;
  - their level of training, students' type and level of disability, and type of teaching placement impact their ratings of the importance of promoting self-determination.
- Parents of school-age students with disabilities perceive promotion of self-determination as important.
  - Report that they do not believe that their sons/daughters receive enough instruction on component elements of self-determined behavior at school.

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Representative Studies: Perceptions of Self-Determination and People with Disabilities

Agran, M., Snow, K., & Swaner, J. (1999). Teacher perceptions of self-determination: Benefits, characteristics, strategies. *Education and Training in Mental Retardation on Developmental Disabilities, 34,* 293-301.

Schalock, R., Verdugo, M., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., & Lachapelle, Y. (2005). Cross-cultural study of core quality of life indicators. *American Journal on Mental Retardation, 110,* 298-311.

Thoma, C. A., Nathanson, R., & Baker, S. R. (2002). Self-determination: What do special educators know and where do they learn it? *Remedial and Special Education, 23,* 242-247.

Wehmeyer, M. L., Agran, M. & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student directed learning. *Journal of Special Education, 34,* 58-68.

Grigal, M., Neubert, D.A., Moon, M.S., & Graham, S. (2003). Self-determination for students with disabilities: views of parents and teachers. *Exceptional Children, 70,* 97-112.

Finding Summary: Efforts to Promote Self-Determination

- Despite wide acceptance of the importance of self-determination, research has consistently found that explicit instruction to promote self-determination during the school years is limited, though more recent studies suggest that this situation may be changing.
  - Goals addressing self-determination are not included on many student's Individualized Education Programs.
  - When efforts to promote self-determination are in place, there are few efforts to systematically assess the effect of those interventions.
- Teachers report that barriers to promoting self-determination include:
  - Their belief about whether the student will benefit;
  - Insufficient time, particularly in context of No Child Left Behind;
  - Insufficient training to and knowledge about promoting self-determination.
  - Insufficient time to plan to integrate instruction to promote self-determination into the instructional day.

Representative Studies: Efforts to Promote Self-Determination

Carter, E.W., Lane, K.L., Pierson, M.R., & Stang, K.K. (2008). Promoting self-determination for transition-age youth: Views fo high school general and special educators. Exceptional Children, 75(1), 55-70.

Eisenman, L.T., & Chamberlin, M. (2001). Implementing self-determination activities: Lessons from schools. *Remedial and Special Education, 22(3)*, 138-147.

Millar, D.S. (2008). Self-determination in relation to having or not having a legal guardian: Case studies of two school-aged young adults with developmental disabilities. *Education and Training in Developmental Disabilities, 43(3)*, 279-273.

Sands, D., Spencer, K., Gliner, J., & Swaim, R. (1999). Structural equation modeling of student involvement in transition-related actions: The path of least resistance. *Focus on Autism and Other Developmental Disabilities, 14*, 17 – 27.

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Representative Studies: Efforts to Promote Self-Determination (continued)

Thoma, C.A., Pannozzo, G.M., Fritton, S.C., & Bartholomew, C.C. (2008). A qualitative study of preservice teachers' understanding of self-determination for students with significant disabilities. *Career Development for Exceptional Individuals, 31*, 94-105.

Wehmeyer, M. L., Agran, M. & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student directed learning. *Journal of Special Education, 34,* 58-68.

Wehmeyer, M. L., & Schwartz, M. (1998). The self-determination focus of transition goals for students with mental retardation. *Career Development for Exceptional Individuals, 21,* 75 - 86.

Zhang, D., Katsiyannis, A., & Zhang, J. (2002). Teacher and parent practice on fostering self-determination of high school students with mild disabilities. *Career Development for Exceptional Individuals, 25,* 157-169.

Finding Summary: Efficacy of Interventions to Promote Self-Determination

- Data exists to support the efficacy of several self-determination-focused intervention models/programs, including:
  - Steps to Self-Determination (Hoffman & Field, 1995)
  - TAKE CHARGE for the Future (Powers et al., 2001)
  - Self-Determined Learning Model of Instruction (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000)
- Meta-analytic (group and single-subject design studies) of existing research show that that students with disabilities can acquire component elements of self-determined behavior (e.g., choice making, decision making, problem solving, goal setting and attainment, self-advocacy, self-regulation, perceptions of efficacy, self-awareness, self-knowledge) if taught.
  - Student-directed learning strategies particularly powerful.

A National Gateway to Self-Determination

Representative Studies: Efficacy of Interventions to Promote Self-Determination

Agran, M., Blanchard, C., & Wehmeyer, M. L. (2000). Promoting transition goals and self-determination through student-directed learning: The Self-Determined Learning Model of Instruction. *Education and Training in Mental Retardation and Developmental Disabilities, 35,* 351 – 364

Algozzine, B., Browder, D., Karvonen, M., Test, D.W., & Wood, W.M. (2001). Effects of intervention to promote self-determination for individuals with disabilities. *Review of Educational Research, 71,* 219 – 277.

Bambera, L.M., & Gomez, O.N. (2001). Using a self-instructional training package to teach complex problem-solving skills to adults with moderate and severe disabilities. *Education and Training in Mental Retardation and Developmental Disabilities, 36,* 386-400.

Browder, D., Wood, W. M., Test, D. T., Algozzine, B. & Karvonen, M. (2001). A map for teachers to follow in reviewing resources on self-determination. *Remedial and Special Education, 22,* 233-244.

Field, S., & Hoffman, A. (2002). *Lessons learned from implementing the Steps to Self-Determination curriculum.* Remedial and Special Education, 23(2), 90-98.

Hoffman, A., & Field, S. (1995). Promoting self-determination through effective curriculum development. *Intervention in School and Clinic, 30(3),* 134-141.

A National Gateway to Self-Determination

Representative Studies: Efficacy of Interventions to Promote Self-Determination

(continued)

Powers, L.E., Turner, A., Westwood, D., Matuszewski, J., Wilson, R., & Phillips, A. (2001). A controlled field-test of Take Charge: A multi-component intervention to promote adolescent self-determination. *Career Development for Exceptional Individuals, 24,* 89-104.

Powers, L.E., Ellison, R., Matuszewski, J., and Turner, A. (2004). *TAKE CHARGE for the future.* Portland, OR: Portland State University Regional Resource Center.

Test, D.W., Fowler, C., Brewer, D., & Wood, W. (2005). A content and methodological review of self-advocacy intervention studies. *Exceptional Children, 72,* 101-125.

Wehmeyer, M. L., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The Self-Determined Learning Model of Instruction. *Exceptional Children, 66,* 439 - 453

A National Gateway to Self-Determination

Finding Summary: Student Involvement and Self-Determination

- Research has shown that students with disabilities are not major players in their IEP/transition planning meetings.
- Research has also shown that students with disabilities can learn the skills to be active participants in their IEP/transition planning meetings.
- Research suggests that student involvement has a reciprocal effect with self-determination. That is, students who are more self-determined are more likely to be involved in their educational planning, but getting students involved in their planning—independent of their level of self-determination—enhances self-determination.

Finding Summary: Student Involvement and Self-Determination (continued)

- Data exists to support the efficacy of the following student—involvement related interventions/programs:
  - Next S.T.E.P. (Halpern, et al., 1997)
  - Self-Directed IEP (Martin, Huber Marshall, Maxon, & Jerman, 1997)
  - Self-Advocacy Strategy (VanReusen et al., 2002).
  - Whose Future is it Anyway? (Wehmeyer et al., 2005).

A National Gateway to Self-Determination

Representative Studies: Student Involvement and Self-Determination

Allen, S.K., Smith, A.C., Test, D.W., Flowers, C., & Wood, W.M. (2001). The effects of Self-Directed IEP on student participation in IEP meetings. *Career Development for Exceptional Individuals, 24*, 107-120.

Arndt, S.A., Moira, K., & Test, D.W. (2006). Effects of the Self-Directed IEP on student participation in planning meetings. *Remedial and Special Education, 27*(4), 194-207.

Halpern, A.S., Herr, C.M., Wolf, N.K., Doren, B., Johnson, M.D., & Lawson, J.D. (1997). *Next S.T.E.P.: Student Transition and Educational Planning*. Austin, TX: Pro-ED.

ATTACHMENT G

RECOMMENDATION ON FUNDING AN IL/SELF-DETERMINATION/SCHOLARSHIP GRANT

The Self-Advocacy Task Force acknowledges the importance of empowering individuals with disabilities through IL education, skill development, training and events. As such, the Self-Advocacy Task Force recommends the Ohio Developmental Disabilities Council (ODDC) establish an IL/self-determination/scholarship grant to enhance the skill sets of individuals with disabilities and to create change that improves independence, productivity and inclusion of people with disabilities in community life. Such a grant should be a component of the ODDC's five-year plan. The grant shall be administered and maintained by a third-party grantee.

KEY ACTIVITIES:

I.   The ODDC shall identify and secure adequate funding for the operation of an IL/self-determination/scholarship grant. Potential sources of funding of a self-determination/scholarship grant may include the state protection and advocacy, University Centers for Excellence in Developmental Disabilities, Ohio Statewide Independent Living Council, state agencies, state and local organizations and other non-profits, etc.

II.   The ODDC shall inform the grantee of any compliance standards applicable to a self-determination/scholarship grant.

III.   The ODDC and grantee shall establish the standards and conditions of an IL/self-determination/scholarship grant, which shall include but not be limited to:

        a. Eligibility;
        b. Restrictions and limitations on receiving funds;
        c. Eligible and ineligible events;
        d. How often the program can be accessed;
        e. The amount of funds that can be accessed;
        f. The application process;
        g. Notice of approval and denial;
        h. Allowable rates;
        i. Proper accounting of funds by the recipient; and
        j. Mechanisms for determining successful outcomes of the grant.

IV.   The grantee shall consult with ODDC staff on establishing an IL/self-determination/scholarship grant.

V.   The grantee shall publicize the existence of an IL/self-determination/scholarship grant and shall make the program easily accessible to individuals with disabilities, including any assistance needed to apply for the grant.

RESOURCES TO BE INVESTED:

Federal $ xxxxx
Matching Funds: <u>$ xxxxx</u>
                             $ xxxxx

ATTACHMENT H

MENTORING FOR YOUTH WITH DISABILITIES

National Mentoring Resource Center Population Review

Sally Lindsay, University of Toronto and Michelle R. Munson, New York University

October 2018

Summary

This review examined research on mentoring for youth (ages 25 and younger) who have a disability, including physical, cognitive, learning, and developmental disabilities, and excluding psychiatric disabilities which have been discussed elsewhere.[1] It addressed four questions:

1. What is the documented effectiveness of mentoring for youth with disabilities?

2. What factors condition or shape the effectiveness of mentoring for youth with disabilities?

3. What are the intervening processes that are most important for linking mentoring to outcomes for youth with disabilities?

4. To what extent have efforts that provide mentoring to youth with disabilities reached and engaged targeted youth, been implemented with high quality, and been adopted and sustained by host organizations and settings?

The review found a total of 40 studies addressing these questions. Benefits of mentoring program participation for youth with disabilities include improved employment and career-related decisions, transitions to adulthood (as well as college and work), postsecondary education goals, and independent living skills.

Although the research in this area is still relatively new, it suggests the following takeaways:

- Potential benefits of mentoring programs for youth with disabilities include several in the areas of academic and career development, employment, psychosocial health and quality of life, transition, and life skills.

- Although various types of mentoring models were used in these studies, it is unclear which formats work best for youth with disabilities.

- Results suggest several potential processes occur between mentoring provision and ultimate outcomes (i.e., mediators), such as self-determination, and some factors could influence, or moderate, the effects of mentoring for youth with disabilities, including gender and ethnicity.

The review concludes with insights for practitioners that highlight a number of factors to consider when developing and implementing mentoring programs for youth with disabilities. This commentary suggests that programs looking to serve youth with disabilities consider accessibility factors that would better enable mentees to participate in activities offered, which may include not only physical access to facilities but also access to program materials in various formats. Furthermore, programs are advised to consider expanding the age ranges of youth they serve in order to meet the needs of youth with disabilities, who often need support during their transitions into adulthood (e.g., transition to independent living).

INTRODUCTION

Worldwide there are an estimated 93 to 150 million children and youth with disabilities. This number is expected to rise given medical advancements that promote higher survival rates and life expectancy.[2] Within the United States, there are approximately 6.7 million students aged 3 to 21 who receive special education services.[3] Thirty-four percent of these students have a learning disability, 20 percent have a speech or language impairment, 9 percent have autism, 6 percent have a developmental delay, 14 percent have other health impairments, and the remainder face other types of physical disabilities.[3, 4]

Young people with disabilities encounter many challenges and barriers to participating in society. For instance, they often experience social isolation and physical exclusion,[5] are at risk of abuse and poor developmental outcomes, and are less equipped with the emotional, social, and cognitive resources to fully achieve positive life outcomes.[2, 5] Many youth with disabilities also lack educational and employment opportunities.[2, 6] For instance, youth with disabilities are underrepresented in higher education and have a lower probability of completing school than children without disabilities.[7, 8] Furthermore, they are at risk of living below the poverty line[9] and are more likely to encounter extreme social and economic disparities relative to youth without disabilities.[4] Negative attitudes, discrimination, lack of resources and supports, and inaccessible environments contribute to these trends.[10, 11]

 The UN Convention on the Rights of Persons with Disabilities aims to enhance inclusion and participation of youth with disabilities toward realization of their human rights.[12] Mentoring is one promising mechanism that could help achieve this goal by enhancing youth's inclusion in society.[13, 14, 15, 16, 17] Mentors can serve as role models and share experiences while helping to support youth in their academic, career, and psychosocial development[5, 15, 18] and in their transition to adulthood. Mentors can help teach or advise youth, offer support and coping strategies, and help them to feel less alone.[19]

....

Mentoring is one promising mechanism that could help **youth with disabilities** by enhancing **youth's inclusion in society**. Mentors can serve as **role models** and **share experiences** while helping to support youth in their **academic, career, and psychosocial development**, and in their **transition to adulthood**.

....

Until recently, most mentoring programs did not include or specifically target youth with disabilities.[14, 20] Therefore, the number of youth with disabilities in the United States who are engaged in mentoring is largely unknown. Studies focusing on mentoring for youth with disabilities show potential benefits on the transition to postsecondary education and employment,[14, 21] self-esteem, social competence,[22] and independent living skills.[23] Having mentors for youth with disabilities also may be important for the development of social capital, self-determination, quality of life, and career and employment goals.[14, 15, 21, 24, 25, 26, 27]

Scope of Review

For this review, disability is defined as follows (using the World Health Organization's definition)[8:] "Disability is an umbrella term covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is, therefore, not just ahealthproblem. It is a complex phenomenon reflecting the interaction between features of a person's body and features of the society in which they live."

Furthermore, the National Mentoring Resource Center defines mentoring as "relationships and activities that take place between youth (i.e., mentees) and older or more experienced persons (i.e., mentors) who are acting in a nonprofessional helping capacity, whether through a program or, more informally, to provide support that benefits one or more areas of the young person's development" (for further details, see [What is Mentoring?](#)).

Studies were included in which:

1. Youth participants are age 25 and under, or the average age of the sample was 18 or under; or findings were delineated by age, with findings outlined for a subsample of youth 25 and under. This target age was expanded from that used in other NMRC reviews because youth with disabilities are often delayed in their transition to adulthood relative to youth without disabilities.[28] We sought to include youth up to age 25 years to capture the "other side" of their transition to adulthood.

2. At least 80 percent of study participants have a disability (using the World Health Organization's[8] definition of disability), or the authors conducted analyses that examine youth with disabilities as a distinct group.

3. The study was a report of quantitative or qualitative empirical research with sufficient methodological detail included to be able to assess study rigor and findings.

4. The study reported findings that bear on one or more of the four core questions for the review and examined either (a) an intentional, structured intervention or program involving mentoring, or (b) natural mentoring relationships occurring with youth with disabilities.

Mental health conditions were excluded as a disability because an NMRC review has already been conducted on mentoring youth with mental health challenges.[1] Temporary disabilities (e.g., cancer and the youth has fully recovered) and chronic illnesses/conditions that are not classified as a disability using the World Health Organization's definition[8] were also excluded. We also excluded chronic illness (e.g., chronic pain, diabetes) because a systematic review of peer support interventions for youth with chronic illness is already reported elsewhere.[29] In addition, we excluded program descriptions and studies that did not have empirical findings.

A literature search was conducted to identify potentially eligible journal articles, book chapters, and other types of reports, including searches of PubMed, ProQuest, PsycINFO, and Google Scholar, using an established set of keywords. Keywords used in the searches included "disability" (and a broad list of various types of physical, developmental, cognitive, and intellectual disabilities), "children and youth," and "mentoring." After two authors independently applied our inclusion criteria, we found a total of 40 studies addressing these questions with most of the studies focusing on youth aged 25 and under.

1. What are the Demonstrated Effects of Mentoring on Youth with Disabilities?

BACKGROUND

There are several reasons to suggest that youth with disabilities could benefit from mentoring relationships. Youth with disabilities are a vulnerable population with unique social, developmental, educational, and vocational needs.[14] Children with disabilities are more likely to report being victims of peer aggression and social exclusion because they often do not have the protective function of friendships.[10, 30] They are bullied at disproportionally higher rates compared to youth without disabilities and are nearly three times as likely to experience social exclusion including limited social integration, fewer friends, and lower levels of friend support.[10, 31] Given that they often encounter social isolation and exclusion, social support is an area of particular need for youth with disabilities. Therefore, mentoring may be a good resource for them to build friendships and other social networks that facilitate their development. Research also suggests that mentoring can improve academic and employment outcomes—areas of need for many youth with disabilities. This section presents findings on the potential benefits of mentoring for youth with disabilities.

RESEARCH

First, we discuss the following broad outcome areas that were explored in this review: academic and career development; employment; psychosocial health, quality of life, and protective factors; and transition and life skills. Next, we describe the types of mentoring models used within the studies found in our review.

Academic and career development. Six studies in this review assessed the benefits of mentoring for academic outcomes and career development. For example, Kolakowsky-Hayner et al.[32] used a pre-post survey to evaluate a community, group-based mentoring program (i.e., Back on Track to Success) to help 131 youth (aged 16 to 26) return to work and school after a brain or spinal cord injury. Participating youth reported that mentoring was beneficial for achieving postsecondary educational goals. In another study using a repeated measures design, Bell[33] explored the effects of an online mentoring program for transition-age youth with blindness and found a significant increase in efficacy to make career-related decisions compared to their efficacy at the beginning of the program. Similarly, Kim-Rupnow and Burgstahler[34] evaluated a community-based online mentoring program using a cross-sectional post-survey design and found a significant improvement in knowledge of

career options. O'Mally and Antonelli[18] used a longitudinal design to explore how a one-on-one career mentoring program benefited college students who were legally blind and found a pattern of improved career adaptability among participants over time. Burgstahler and Chang's[35] study assessed the impact of the Access STEM/DO-IT online program among youth with various types of disabilities. Using a case study design, they found that youth improved their career options (e.g., interest in STEM) over time. Finally, Powers et al.[36] assessed the impact of an online group-based program on youth with various types of disabilities using a RCT (randomized controlled trial) design and reported significant improvements in educational planning among participants compared to controls.[36]

Employment. Six studies in this review found that mentoring was associated with employment-related improvements, specifically improved knowledge of employment services and supports,[37, 38] transition to employment,[32, 37] knowledge of employment preparedness[34] (e.g., the key skills needed to apply for a job), increased job-seeking self-efficacy and assertiveness in job hunting,[18] as well as improvements in employability.[39] Francis et al.[37,38] used a mixed-method design (i.e., surveys and qualitative methods) to evaluate a group mentoring program serving youth with various types of disabilities. They found improved self-rated knowledge of employment services and supports and different types of competitive employment positions.[37, 38] Kolakowsky-Hayner et al.[32] evaluated a community-based group mentoring approach for youth with a brain or spinal cord injury. The researchers used a pre-post survey design and reported that promising numbers of program participants showed progress toward achieving their goals of postsecondary education, employment, and community independence. Another study focusing on youth with various types of disabilities[34] involved an online group mentoring program and found significant improvements in perceived Internet and computer skills, career options, employment preparedness, perseverance, self-esteem, social skills, self-advocacy, and independence. O'Mally and Antonelli's[18] study focused on a one-to-one career mentoring program serving youth with vision impairments. Using a longitudinal design, they found that participants experienced increased job-seeking self-efficacy and career adaptability, and made significant gains in assertiveness in job hunting. Another study[39] found that youth with spinal cord injury participating in an online, phone-based mentoring program experienced significant improvements in student education planning and transition awareness.

> Six studies in this review found that mentoring was associated with **employment-related improvements**, specifically improved knowledge of **employment services and supports**, transition to employment, knowledge of **employment preparedness** (e.g., the key skills needed to **apply for a job**), increased **job-seeking self-efficacy** and **assertiveness** in job hunting, as well as improvements in **employability**.

Psychosocial health, quality of life, and protective factors. Fourteen studies included in this review found positive mentoring outcomes among youth with disabilities in areas which are important protective factors, including self-determination,[25, 40] self-efficacy,[18] social and emotional support,[41, 42, 43] self-advocacy,[25, 34, 42, 44] self-esteem,[34, 45, 46] self-confidence,[16, 47] and sense of community.[39, 47] Studies showing benefits in these areas used a wide range of methods (e.g., quasi-experimental, pre-post, qualitative) and focused on youth with various disabilities including intellectual disability,[40,

[43, 45] vision impairments,[18] pediatric liver transplant,[41] deafness,[42] autism,[46] and various additional disabilities.[34, 44, 48] Studies also included a wide range of mentoring models, such as one-to-one mentoring[18, 41, 43] taking place at a college, out-patient or employment setting; group-based mentoring;[34, 40, 44] e-mentoring;[25, 34, 48, 49] naturally occurring mentoring;[42, 45] and mixed models.[34] We did not note any strong patterns in outcomes based on methodological design, type of disability, or type of mentoring.

Eleven studies showed improvements in quality of life and social connections. Specifically, four studies[41, 46, 50, 51] using various methodological designs (i.e., pre-post, case study, RCT) showed enhanced quality of life among youth with autism, brain injury, pediatric transplants, and other various types of disabilities (i.e., learning, emotional, behavioral). One study found an improved ability to manage their condition[49] among those with juvenile arthritis. Studies focusing on youth with autism that used pre-post designs showed improvements in social anxiety[46] and empathy.[52] A qualitative study further found that role modeling[42] helped youth with deafness. Improvements in social skills,[34] social acceptance,[47] social connectedness,[46, 47, 53] ability to make new friends,[22] and positive attitudes toward disability[33] were seen for youth with autism, developmental disabilities, learning disabilities, physical disabilities, blindness, and other types of disabilities. These studies used survey, pre-post, and qualitative designs.

Transition and life skills. Five studies using a range of designs (e.g., 3 RCTs, pre-post surveys) highlighted that mentoring yielded improvements in skills related to the transition to adulthood and life skills. Specifically, Powers et al.[16, 36, 51] used an RCT design in three separate studies to assess the impact of mentoring programs for youth with various types of disabilities. They found significant differences between the treatment and comparison groups at post-intervention and/or follow-up in transition-related goals and planning, accessing transition services,[51] engagement in independent living activities,[51] and knowledge about strategies to promote independence,[16] as well as significant improvements over time in program participants relative to the control group in transition awareness.[36] Kolowsky-Hayner's[32] evaluation of a community, group-based mentoring program for youth with brain and spinal cord injury used a pre-post survey and found improvements in community independence[32] over time.

Studies within this review also reported on benefits of mentoring for the development of life skills. For example, Powers[16] evaluated an online and in-person mentoring program for youth with physical disabilities, using an RCT design and found significant improvements in daily living skills (i.e., choice management, problem-solving)[16, 54] compared to controls. Kramer et al.[54] similarly found improvements in problem-solving over time for a one-to-one e-mentoring program for youth with intellectual and developmental disabilities. Another study evaluated an in-person, group-based mentoring program for youth with intellectual disabilities using a pre-post design and found significant improvements in self-regulation and assertiveness.[40] Two studies focusing on youth with physical disabilities participating in online mentoring programs found significant improvements in typing skills[55] as well as Internet and computer skills.[34]

Types of mentoring models. Of the studies included within our review, five different types of mentoring models were studied. Two studies involved naturally occurring mentoring,[42, 45] fifteen involved one-to-one mentoring, (see references [17, 18, 22, 24, 26, 41, 43, 46, 50, 53, 56, 57, 58, 59, 60]) and eleven studied group-based mentoring programs(see [13, 16, 32, 34, 36, 37, 38, 40, 44, 51, 52]). Online or e-mentoring

was studied in 21 evaluations (see [13, 16, 25, 33, 34, 35, 36, 39, 47, 48, 49, 51, 54, 55, 58, 61, 62, 63, 64, 65, 66]), revealing both the promise and relevance of this modality given that it helps to address many of the barriers that youth with disabilities often encounter in traveling to meet a mentor. Six studies had mixed models (i.e., combined approaches).[13,16,34,36,51,58] The studies of naturally occurring mentoring focused on youth with deafness and youth with learning disabilities, whereas the one-to-one based mentoring interventions focused on youth with a wide variety of disabilities including intellectual, learning, and developmental disabilities; autism; blindness; pediatric transplants; acquired brain injury; and various other (i.e., mixed) types of disabilities. The group-based models focused on youth with physical and intellectual disabilities, acquired brain injury, spinal cord injury, autism, and various other types of disabilities. Finally, studies using an e-mentoring approach focused on youth with cerebral palsy; spina bifida; intellectual, learning, and developmental disabilities; blindness; spinal cord injury; juvenile arthritis; and various types of physical disabilities.

CONCLUSIONS

1. Research on mentoring programs and interventions for youth with disabilities shows that there are potential benefits of mentoring on academics, employment, psychosocial health and quality of life, and transition-related and life skills.

2. Given the various mentoring formats and disability types included in the studies, it is difficult to draw conclusions about what formats work best for which types of youth.

3. The limited number of RCTs conducted and the various types of outcomes explored in studies to date only allows for tentative conclusions about the effectiveness of mentoring programs for youth with disabilities.

2. What Factors or Conditions Influence the Effectiveness of Mentoring for Youth with Disabilities?

BACKGROUND

The impact of mentoring—both for youth with and without disabilities—can vary due to individual-level factors (e.g., gender, age, level of commitment), relationship-level factors (e.g., parent support), and program factors (e.g., duration).[16, 67, 68] Also, the impact of mentoring has been thought to depend on program practices (e.g., training, supervision, characteristics of the mentor).[69] For example, the impact of a mentoring program may be stronger if the program includes structured training with continued intermittent training and supervision[67] or if it involves mentors who also live with disabilities.[69] The impact may depend on program location and organizational culture and climate.

RESEARCH

Research on children and youth with disabilities has not formally tested moderation (i.e., factors influencing the extent to which youth benefit), but qualitative and small-scale exploratory studies suggest some potential factors.

Demographics and type of disability. For example, in one study of secondary and postsecondary students (n=189) with a university-defined disability (e.g., autism, learning disability), the effects of a virtual mentoring program to keep students involved in science, technology, engineering, and mathematics (STEM) were found to vary by type of disability and race/ethnicity.[25] More specifically, minority students did not experience gains in self-determination that were apparent for nonminority students. Also, students with attention deficit hyperactivity disorder (ADHD) actually decreased in their math-related self-efficacy, whereas students without ADHD made gains in this area.[25] Burgstahler and Chang[61] also found gender differences in the perceived value of a mentoring program for students with disabilities. Male DO-IT program participants reported more interest, or saw more value, in STEM areas of career goals and financial security, while females reported more interest in program areas related to independent living.[61] Thus, although no studies in our review formally examined moderators, these qualitative findings suggest that race/ethnicity, gender, and type of disability may influence program effectiveness and should be prioritized as potential moderators in future studies.

Communication. A small group of studies suggest that communication between mentors and youth may influence the impact of mentoring: stronger communication may foster stronger program benefits. One study involving the DO-IT program found that youth particularly enjoyed "having conversations about their work plans for the future."[61] It was these types of conversations that fostered youth satisfaction and, thus, potentially influenced educational and employment outcomes.[13] One e-mentoring study with a small group of mentoring dyads (n=9)[53] reported that the type of communication style within the mentoring relationship affected its success.[53] Another e-mentoring study found that unsuccessful mentoring pairs used a more formal and distant communication style, whereas successful dyads had mentors who used a more informal and supportive communication style.[64]

> One study involving the DO-IT program found that youth particularly enjoyed "**having conversations about their work plans for the future**."It was these types of conversations that fostered **youth satisfaction** and, thus, potentially influenced **educational and employment outcomes**.

Communication was also highlighted as important in an evaluation of a mentoring program for young adults with intellectual disabilities on a college campus (n=24 participants across three focus groups).[57] One of the main themes in this study was that program effectiveness was perceived to be affected by the strength of communication and collaboration across stakeholders (e.g., with parents and professors).[57] Combined with the findings highlighting the importance of strong mentor-mentee communication, these findings suggest that the effects of mentoring may be strengthened by strong communication on both the dyadic and programmatic levels.

CONCLUSIONS

While the studies within our review did not formally assess factors influencing the effectiveness of mentoring, they suggest some potentially important factors and set the stage for the next phase of research. Next steps for the field should include formally examining the influence of some of these potential moderators.

1. Gender and race/ethnicity of program participants may strengthen or weaken program effectiveness; however, research to understand whether mentoring programs should be designed to target youth with specific types of disabilities or whether a more generic approach could be similarly effective is lacking.

2. Communication (e.g., strength, style) between mentor and mentee emerged as another potential factor that may affect outcomes of mentoring for youth with disabilities.

3. What Processes Are Most Important in Linking Mentoring to Outcomes for Youth with Disabilities?

BACKGROUND

Numerous mentoring conceptual frameworks, models, or theories have proposed possible pathways through which mentoring can benefit youth (see Rhodes[70;] Parra et al.[71]). In the field of mentoring for youth with disabilities, some researchers have begun to apply these theories and others (e.g., relational cultural theory) to their research but, to date, there is no single dominant theory for how mentoring impacts youth with disabilities. The studies reviewed in this section are suggestive of some of the important processes that may ultimately lead to positive youth outcomes, such as work, school, or relationship improvements. Where possible, we group studies together by mediator (i.e., the processes through which mentoring achieves its benefits) and/or type of disability.

RESEARCH

Among the studies within our review, there were no direct investigations of processes through which mentoring may influence outcomes for youth with disabilities. However, a group of empirical descriptive and qualitative studies provide some early evidence for important processes that youth experience in these relationships and that may be key in contributing to program effects. Qualitative data are often a first step in understanding how an intervention, such as mentoring, makes an impact. Future studies will need to test these potential pathways.

Social processes. Mentoring relationships can have effects on social processes and relationships (e.g., improved social skills, improved relationships with parents or peers). In addition, the impact of mentoring on specific youth outcomes, such as employment and college success can be achieved *through* effects on other relationships, making these relationships an important process in linking mentoring with outcomes. For example, using data from the classic Big Brothers Big Sisters evaluation,[68] Rhodes et al.[70] found that the impact of mentoring on academic outcomes occurred, in part, through improved relationships with parents.

One small qualitative study of 22 adolescents with physical disabilities, such as spina bifida or cerebral palsy, were connected with 5 mentors online for 25 sessions over 6 months.[55] Youth's responses to semistructured interviews postintervention suggest that they felt the program increased their social connections with other teens, reduced their feelings of loneliness, and increased their feelings of social acceptance.[47] A second qualitative study with adolescents with

autism spectrum disorders reported that both youth and other stakeholders (e.g., parents, mentors, staff) had improved social connectedness and willingness to take social risks.[46] These social outcomes could certainly foster distal improvements in a wide range of areas.

Learning processes. Another important process that research suggests could mediate the ultimate outcomes of mentoring is knowledge or learning. Two studies suggest that youth learn important information though mentoring. One study examined the use of peer mentors for youth in a cosmetology program and found improvements in work-related performance; one youth reported that a peer mentor provided them an opportunity to learn and "ask questions that[14] they may have been hesitant to ask before working with (their mentors)."[58] There was learning taking place through the provision of the peer mentorship program, which focused on praise, corrective feedback, and demonstrations.[58] These types of processes could then support further positive outcomes.

Another mentoring program, the Family Employment Awareness Training (FEAT), focused on improving competitive employment for youth with disabilities and reported that expectations and knowledge improved through the program.[37, 38] Relatedly, Barnard-Brak and colleagues[24] conducted a study involving 43 high school students attending a one-to-one mentoring program aimed at improving academic outcomes for students with a variety of disabilities. Participation improved youth's attitudes toward help-seeking (e.g., requesting accommodations).[24] As stated earlier, theories have suggested cognitive, emotional, and modeling pathways to ultimate outcomes in mentoring, and some of these preliminary qualitative studies suggest that examining attitude change and enhanced knowledge may similarly inform our understanding of how mentoring influences outcomes for youth with disabilities.

Self-determination. Some research suggests that self-determination is an outcome of mentoring participation. One study further suggests that it also may help to explain how mentoring achieves impacts on quality of life.[51] "Take Charge" is a mentoring program for youth enrolled in special education and involved in the foster care system. An evaluation of this program reported that self-determination partially mediated, or explained, effects on enhanced quality of life for participants.[51] Another study found that e-mentoring was empowering for youth with special needs.[65] While the study did not test empowerment, or self-determination, as a potential mediator, it could be important in fostering other positive outcomes. Although the field of mentoring for youth with disabilities is in its infancy, these two studies together suggest that fostering the process of enhancing self-determination and empowerment may be important; however, research in this area is notably limited.

One qualitative study on youth with hearing impairments reported that **emotional support**, in addition to **advice-giving** and **role modeling**, were important for mentees in achieving **career success**.

Emotional support. Finally, emotional support is a common process that is addressed by mentoring programs for many different groups of youth, as it is a key process in youth development. One qualitative study on youth with hearing impairments reported that emotional support, in addition to advice-giving and role modeling, were important for mentees in achieving career success.[42] Informal mentors provided a foundation for the mentees to break through common barriers to career success (e.g., lack of self-belief) for deaf youth. The relationships assisted these youth by advocating for

additional needed support services and having faith and belief in them as they struggled to move forward in their lives.

CONCLUSIONS

1. Potential areas for formal tests of mediation roughly map onto previous conceptual models of youth mentoring, namely a socioemotional mediating pathway, a cognitive pathway, and a modeling pathway.

2. Overall, the field of mentoring interventions for children, youth, and young adults with disabilities needs to move beyond qualitative research to rigorously test potential mediators that have emerged as important in qualitative studies.

4. Have Mentoring Programs and Supports for Youth with Disabilities Reached Intended Youth, Been Implemented with High Quality, and Been Adopted and Sustained?

BACKGROUND

Studies included in this review focused on mentoring programs designed specifically for youth with disabilities. These programs have shown some evidence of reach through their ability to enroll a targeted number of participants. However, with the exception of the DO-IT program, most of the mentoring programs discussed in this review have not been adopted on a wider scale. Our review indicates that relatively little is known about best practices for setting up a sustainable and effective mentoring program for youth with disabilities.

RESEARCH

Challenges in mentoring youth with disabilities. Several studies in this review highlighted challenges encountered by programs and the mentors they support when serving this population. Some mentors found it difficult to engage youth and to develop a rapport with them,[72] particularly engaging younger mentees in career development conversations. This may have been a result of youth with disabilities often starting to think about employment and careers at a later stage compared to youth without disabilities.[28] Communication style was highlighted in Shpigelman and Gill's[64] study where they noted that unsuccessful mentoring was associated with a more formal style and distant tone. Others similarly reported challenges common to mentoring other populations of youth—for example, that having a mismatch in the values, work styles, or personalities of the youth and mentor, combined with distancing behavior[64] hindered communication. Pham[26] found that building positive mentoring relationships requires sustained rather than time-limited or random efforts. Mentors need to think about communicating in a way that enhances trust and reduces feelings of alienation.[26] This work suggests that additional and/or tailored training and support beyond that which is provided in more typical mentoring programs is needed when working with

this population to ensure that mentors are adequately prepared for the unique challenges that these youth are experiencing.

Other studies highlighted difficulties with the accessibility of the program setting,[73] challenges in arranging transportation,[17, 73] and/or overprotective parents.[73] Other hurdles specific to mentoring youth with disabilities include that there is not a "one-size-fits-all" approach; mentoring programs should be designed specifically for the youth and type of disability that they are targeting.[3] It is also difficult to assimilate persons from diverse backgrounds, needs, and abilities into one mentoring program.[42] Barnfather et al.[55] also noted that the age and ability level of the participants need to be considered when matching them. Others (e.g., Pham[26]) discovered that a program's own evaluation efforts may be challenged given that youth with learning disabilities, autism, and intellectual disabilities had difficulties completing some of the self-assessment outcome measures. Bedell et al.[74] found that youth with acquired brain injury had social participation barriers and fewer strategies for overcoming them compared to youth without disabilities. Because mentoring is an inherently social activity, some youth with disabilities may need support and resources beyond that which is provided by mentoring to help them achieve their goals. Other challenges noted by programs mentoring youth with disabilities include lack of mentor training, length of time for mentoring,[17, 49, 64, 75] difficulty locating mentors,[76] and challenges specific to e-mentoring (e.g., connectivity, security, privacy).[25]

> Other studies highlighted difficulties with the **accessibility** of the program setting, challenges in **arranging transportation**, and/or **overprotective parents**. Other hurdles specific to mentoring youth with disabilities include that there is **not a "one-size-fits-all" approach**; mentoring programs should be designed specifically for the youth and type of disability that they are targeting.

Reach and engagement. Very few studies in this review reported on reach and engagement (i.e., participation in the program). Of those that did, one study reported a mean engagement of 8.53/10 (i.e., participants self-reported on their engagement level with the program).[49] The Kramer et al.[54] study reported that mentees had high rates of attendance (87 percent) in peer mentoring calls and high rates of engagement within these calls, suggesting that mentoring is a promising approach for engaging this population. They also noted that some mentors with disabilities relied on a script to maintain engagement with participants.[54] The highest rates of fidelity were achieved when addressing objectives related to participants' unique interests and strengths or goals.[54]

Powers et al. found that having experiential and hands-on activities (e.g., visiting colleges, shadowing professionals on job sites, touring STEM clubs and organizations, volunteering) helped to increase engagement in the mentoring relationship.[72] Francis et al.[37] further noted that having small group activities helped with engagement of participants. Others[57] reported that clearly articulating the expectations of mentors at the outset helped with participant engagement. Requiring a social component (i.e., meeting face-to-face) is also a catalyst for more frequent, spontaneous, natural interactions, helping to foster a meaningful bond.

Three studies highlighted that e-mentoring can help to reach and engage youth because it uses a convenient format, can reach youth in remote locations, and is anonymous.[15, 25, 77] Gregg et al.,[25, 48] for

example, found that a collaborative use of online learning modules, in which mentors and participants met to complete these modules, was essential to participant engagement (i.e., participation in the program). Another aspect of engagement, noted in two studies,[16, 78] was the importance of having family supports and engaging family members in the intervention.

Quality of implementation. Six studies within this review reported that their mentoring program or intervention was feasible and acceptable to the participants.[17, 22, 46, 54, 66, 74]

Adoption and sustainability. Some studies within this review reported on the adoption and sustainability of mentoring programs for youth with disabilities. For example, Stumbo et al.[15] found that e-mentoring can be used to create and sustain a community that benefits both peers and mentors. These authors argue that engaging youth early on (i.e., beginning of college) can help to sustain their participation in mentoring over the longer term.[15] Francis et al.[37, 38] suggested that their program (FEAT) could be formatted as a professional development program for employment agencies to reach vocational rehabilitation counselors, job coaches, and other employment-related professionals. The authors also highlighted the potential for this program to expand to other states. They argue that expanding into schools would provide a sustainable foundation for teachers to empower their students.[37, 38] Burghstahler and Crawford[77] noted that the steps involved in sustaining an e-mentor community include: establishing goals for the program; selecting appropriate technology for the communication; developing the community structure; developing guidelines for protégés, mentors and parents; standardized procedures for recruiting, screening, and orienting participants; providing supervision and ongoing support of mentors; managing the mentor-mentee discussions; and evaluating the program.

Furthermore, Kramer et al.[54] emphasize that community-based organizations adopting e-mentoring should consider partnering with local colleges or vocational training institutions, which could help provide students with valuable hands-on experience and ensure that they also have access to qualified personnel.[54] E-mentoring could help to sustain the program because of its ease of access.

CONCLUSIONS

1. Several mentoring programs that are designed specifically for youth with disabilities appear to have successfully engaged substantial numbers of youth on a local level; however, most of these programs have not been adopted on a larger scale.

2. Research on the factors influencing the adoption and longer-term sustainability of the programs is lacking.

3. Challenges in mentoring youth with disabilities are similar to those found in mentoring programs for youth without disabilities, with the exception of the accessibility of the program.

IMPLICATIONS FOR PRACTICE

(Mike Garringer, MENTOR: The National Mentoring Partnership and
Genelle Thomas, Partners for Youth with Disabilities)

As noted in the review of the research presented on the preceding pages, there is considerable evidence that mentoring relationships can be beneficial to youth with disabilities in a wide range of aspects of their lives, including their education, careers, engagement with the community at large, and their own sense of identity, direction, and purpose. This evidence is especially important given the high prevalence of disability within the U.S. population. With one in five people experiencing some type of disability, it is a virtual guarantee that all mentoring programs are serving youth with disabilities (even when the program does not proactively recruit youth with disabilities). Therefore, whether a mentoring program explicitly engages youth with disabilities or whether the inclusion of youth with disabilities has occurred in a less intentional way, all mentoring programs should be prepared to adopt an inclusive approach to ensure that youth with disabilities are being served in a meaningful, equitable way.

Despite the evidence of the value of mentoring for youth with disabilities, the review also notes challenges that practitioners can face in providing meaningful mentoring to these youth. Here we attempt to review some of the programmatic and relationship factors that can maximize the benefit of mentoring for youth with disabilities, building on the content of the review to support practitioners in developing inclusive, responsible, and meaningful mentoring services.

1. **FIRST AND FOREMOST, PROGRAMS SHOULD ENSURE THAT THEIR SERVICES ARE ACCESSIBLE FOR YOUTH WITH DISABILITIES IN THEIR DESIGN AND DELIVERY.**

   A number of included studies discussed the challenges mentoring programs encountered with accessibility-related issues. The most foundational step a program can make around disability inclusion is to ensure a physically accessible environment. Program meetings and events should only be held in accessible locations and if transportation is provided, that transportation should be accessible to everyone. Examples of very basic accessibility include accessible bathroom facilities, clear signage, a level entrance to a building, accessible parking, meeting rooms with enough space for wheelchair access, and an elevator if a meeting is held above the first floor.

   Accessibility can also include less obvious (but still important) steps, such as having materials available in alternate formats, asking about and providing reasonable accommodations, and providing a low-stimulus area. To download a no-cost tip sheet and checklist, "Disability Inclusion Tips for Youth Sports and Recreation Programs," go to: https://www.pyd.org/blog/wp-content/uploads/2018/07/PYD-Tips-and-Checklist_Printable.pdf.

   Online or electronically delivered mentoring models also need to pay attention to accessible design. Although they may not have physical spaces that youth and mentors visit in person, they certainly offer virtual spaces that need to be just as accessible. Please see section 5 on

e-mentoring platforms below for further discussion about how virtual mentoring programs can ensure accessibility for all.

In addition to physical accessibility, programs should ensure programmatic accessibility by understanding and using Universal Design for Learning principles. Universal Design for Learning (UDL) is a framework to improve and optimize teaching and learning for all people based on scientific insights into how humans learn. When programs take a proactive approach to developing trainings and activities, all youth participants are more engaged and retain more information. Programs can gain knowledge around UDL through CAST (www.cast.org). Programs and professionals can evaluate their own accessibility by accessing no-cost online inclusion self-assessments on the Partner's for Youth with Disabilities (PYD) Pathways to Inclusion eLearning network. By registering on http://p2i.pyd.org, individuals can measure their individual and organizational strengths and areas for growth in key areas, allowing them to focus on their greatest area of need for future training. Additional training materials can be found at no cost on the PYD website (https://www.pyd.org/guidebooks.php) or through online courses on the Pathways to Inclusion network for a nominal fee. Readers should also note that there are UDL concepts for physical spaces as well, making this a principle that can be woven into all efforts to make a program's physical, virtual, and educational spaces accessible and valuable to all.

2. FOCUSING ON PERIODS OF TRANSITION FOR YOUTH WITH DISABILITIES MAY BE ESPECIALLY BENEFICIAL.

Included in this review were several examples of mentoring programs that intentionally served youth with disabilities at key transition points. This included examples related to educational and career transitions, as well as transitions out of services, such as leaving the child welfare system. Mentors can be tremendous assets in supporting transition planning and in helping mentees navigate other services and acclimate to new environments and routines. This can include transitions that are both sudden (e.g., the Back on Track to Success program[32] that worked with youth who had experienced a spinal cord injury and needed help returning to familiar activities with new limitations), as well as those that are known well in advance (e.g., the work of Powers and colleagues focused on transitions to independent living as youth aged out of juvenile services).[16, 51]

One key point related to transitions that practitioners and program developers should keep in mind is that these transition points often happen at later ages for youth with disabilities than they do for their peers. Due to the Individuals with Disabilities Education Act, some youth with disabilities choose to remain in high school until age 22, which extends their transition period compared to their peers without disabilities. Similarly, there may be delays in entering the workforce, living independently, or in other major life milestones. Programs may want to expand the age ranges they serve so that they can meet youth with disabilities where they are on their progression toward key milestones. Many service providers increase the upper limit of the age range they serve, with some including youth up to age 26 to reflect the reality of the timelines that youth with disabilities may experience. Unfortunately, many youth age out of

"juvenile" services long before they are practically ready, so keep in mind that mentoring that supports these stressful transition points may be very beneficial to these youth.

3. A SELF-DETERMINATION APPROACH CAN BE PARTICULARLY EMPOWERING FOR YOUTH WITH DISABILITIES.

Many youth with disabilities face barriers to making independent decisions. Even well-intentioned supports in healthcare, education, and family life can leave youth feeling like they have little say in how they participate in the world and the paths that are open to them. Mentoring programs, and mentors, may be uniquely positioned to help young people with disabilities think about and strategize about life plans that are important to *them*. The research review offers several excellent examples of this type of programming in action, especially in the Take Charge[36] and My Life[51] programs, which support the transition out of the foster care system. These programs offer intensive transition planning and dogged pursuit of specific goals set by the youth (along with very little coaching from the mentors or staff about what is a "worthy" goal to pursue). Many of the features of these programs are designed to give the mentee the authority to guide activities, seek additional resources, and set timelines and milestones. This type of approach is often a breath of fresh air to youth who are used to authority figures telling them what their experiences will be based on their disability. Unsurprisingly, reports of self-determination predicted, in part, the other outcomes of the Take Charge program,[36] particularly perceptions of overall quality of life.

One simple way that programs can start a self-determination approach is to give youth with disabilities extensive say in who they are matched with. For example, some may want a mentor with a similar disability who can teach them how to overcome the specific barriers that their disability provides. Other youth with disabilities may want a mentor with a specific skill or who can connect them to career opportunities. What is important is that the program is not prescriptive in the type of mentor they offer the young person. By allowing these mentees to say, "This is what I want to achieve and here is who I want to help me get there," programs are giving a gift that goes well beyond the support the mentor actually provides.

Programs can also ask mentors to explicitly engage mentees in activities that help them envision potential directions for their lives and allow for focused goal setting and asset mapping. This type of activity can greatly improve mentee feelings of self-competence, agency, pride, and life satisfaction, even if they don't reach their ultimate goals. A self-determination approach emphasizes the quality of the journey, not just the destination.

4. TEACHING AND PRACTICING ADVOCACY, BOTH FOR SELF AND OTHERS, CAN ALSO EMPOWER YOUTH WITH DISABILITIES.

Another skill mentors can teach that pairs well with a self-determination approach is the concept of self-advocacy. This empowers youth to stand up for themselves more effectively when interacting with institutions, such as schools or workplaces, and in their personal relationships, including with parents and other adults. Teaching youth to identify and respond to situations where their rights are discounted or when their decisions are negated will help

them not only fight back against discrimination but also access the proper supports and resources to pursue their goals.

Practicing **self-advocacy skills** with a mentor can help **prepare youth with disabilities** for situations where they need to push back against authority or protect their rights. It can also build **self-confidence** and feelings of **self-worth**.

This self-advocacy may be especially important for older youth who are on the cusp of aging out of services or special protections under the law. Youth with disabilities under the age of 18 are *entitled* to certain services, accommodations, and protections under the law, but upon entering adulthood are only *eligible* for services and protections and often have to request or even fight for them in the systems and institutions they will interact with in their young adulthood. Practicing these skills with a mentor can help prepare youth for situations where they need to push back against authority or protect their rights. It can also build self-confidence and feelings of self-worth.

While a self-advocacy approach can be instrumental in building a sense of self and in achieving personal goals, mentoring programs may also want to encourage youth with disabilities to go beyond their own journey and engage in civic activities, advocacy, and activism that improves the well-being of all people with disabilities or other underserved groups. One of the most popular ideas in recent years in the youth mentoring field is that of "critical" mentoring, which builds on the concepts of critical race theory, pedagogy of place, and other critical perspectives to focus the impact of mentoring beyond the individual to larger communities and groups of people. Most notably, this work has been championed by academics like Torie Weiston-Serdan, whose seminal work *Critical Mentoring: A Practical Guide* argues that mentoring programs have an obligation to not only help youth cope with the negative impact of living in "toxic" environments (both literally and metaphorically), but to also help youth do transformative work at the community level in an effort to, as she phrases it, "clean the air and purify the water."

This approach may have particular appeal to youth with disabilities who, as noted above, have often experienced frustrations with institutions, agencies, service providers, and a society that generally is not inclusive and can neglect, if not outright ignore, their needs. They may find tremendous purpose and passion in advocacy or activism that helps address causes of systemic discrimination or disenfranchisement. They may also have passions that are totally unrelated to disability, but from which they have been excluded from having and acting on their voice. Mentors can be especially supportive in helping young people understand the root causes of systemic discrimination and underrepresentation and, in turn, develop strategies to combat these things in the real world. Youth may also find supportive peer relationships and a broader community by engaging in activism and other forms of civic engagement. So, while much of the mentoring journey should be focused on personal development and growth, programs are encouraged to remember that many youth often relish the opportunity to channel their passions to change the often dismissive world they were born into.

5. E-MENTORING PLATFORMS OFFER AN OPPORTUNITY TO BUILD CLOSER RELATIONSHIPS, AS WELL AS EXPAND CIRCLES OF SUPPORT FOR YOUTH WITH DISABILITIES.

Of note in this review are the numerous examples of online mentoring programs and the use of technology to supplement and support mentoring relationships that also meet face-to-face. Online communication platforms can help youth with disabilities overcome many barriers to accessing the help of a mentor, particularly those that involve limited physical mobility. The ability to communicate with a mentor without leaving home can give these youth another pathway to getting the support they need, particularly in instances where there are transportation barriers, such as a lack of accessible public transit, instances of inclement weather that disproportionately impact those with disabilities, or for isolated rural youth who can find it especially challenging to meet face-to-face.

Increasingly, all youth, but especially youth with disabilities, are comfortable using digital platforms as the *primary* way of communicating. While this can be unfamiliar territory for older mentors, many youth today may prefer text-based communication to in-person meetings or even talking on the phone. Text-based communication can be helpful for youth who have trouble communicating orally because of a disability or who face anxiety bringing up certain subjects in person. In fact, many youth may prefer to discuss difficult or painful experiences and fears within the relatively safe space of a "chat," where the distance between the participants can somewhat mask feelings of pain and frustration and where they have more control over the flow and depth of the conversation. Mentors working with youth with disabilities are encouraged to accept these communication alternatives and recognize that online platforms can actually enhance the relationship and the mentor-mentee bond rather than subvert it.

Online chat groups and message boards can expose youth with disabilities to a chorus of supportive voices and other perspectives, which can be especially helpful in **career exploration** or **transition-focused programs**.

Online platforms also offer another advantage for youth with disabilities: access to a wider pool of mentors. Online chat groups and message boards can expose youth with disabilities to a chorus of supportive voices and other perspectives, which can be especially helpful in career exploration or transition-focused programs. This wider pool of mentors can help offset the impact of a mentor-mentee pair that is not "meshing" as intended, while also providing access to more social capital and networking opportunities that can help with career transitions or academic pursuits.

Of course, one key to providing meaningful online mentoring opportunities to youth with disabilities is doing so on platforms that are designed with their needs and limitations in mind. Programs offering some form of e-mentoring should work with a competent designer

who understands online disability issues and can ensure that the platform or technology will be accessible and easy to use for a variety of potential disabilities. This is yet another area where the principles of UDL can play a role in ensuring that technology platforms work not only for youth with disabilities but for *all* users. Common elements of accessible design include making text high-contrast with the background for low-vision or colorblind users and providing alternative text and transcripts for page elements such as images and any audio or video files. Once again, qualified designers can help ensure that all elements of online platforms will work with screen readers and other assistive technology, meeting the needs of all users.

One good example of a well-designed platform that is not only functional for youth with disabilities, but also hits on some of the additional benefits of e-mentoring noted here, is the Campus Career Connect platform ([c3.pyd.org](c3.pyd.org)) developed by Partners for Youth with Disabilities. Campus Career Connect (C3) was created to aid transitioning young adults with disabilities from school to work and connect them to mentors within their desired career field. By promoting job readiness, inclusion, and advocacy training and advice, C3 mentors help make the transition from school to employment positive and socially impactful. Mentoring on C3 can be found through the platform's use of online events, local job listings, networking, résumé building, soft- and hard-skill coaching, and an interactive forum space for questions and advice. C3 was designed by Thunder Media and was created to be fully accessible and meet the standards set by the Web Content Accessibility Guidelines (WCAG).

6. **ENSURE THAT MENTORS FOR YOUTH WITH DISABILITIES ARE WILLING TO COMMIT TO MAKING THE RELATIONSHIP SAFE AND POSITIVE.**

It goes without saying that all young people in mentoring programs deserve a relationship that is safe, supportive, and aligned with their needs and dreams. But youth with disabilities may be especially sensitive to experiences that fall short of this type of responsiveness. They may have a long history with "helping" services that are anything but helpful, and may be especially sensitive to feelings of rejection, bullying, and isolation from their peers. This means that mentors who are paired with youth with disabilities must possess some special characteristics that reduce potential harm and allow them to effectively serve youth with disabilities:

- They must commit to sticking with the match through all the ups and downs they may experience. All mentors commit to this at some level, but youth with disabilities might especially need someone to be a stable, constant, unwavering presence in their lives. This makes mentors who are likely to be mobile in their lives, or who seem unsure about taking on the challenge, a poor fit for mentoring a young person with a disability. These mentors also must be patient, especially with the possible extended transition to adulthood noted earlier. Programs must emphasize the nonnegotiable nature of meeting frequency and longevity of these relationships to prospective mentors.

- They must commit to learning about their mentee's disability and the impact that disability has on their life and their pursuit of goals. This includes becoming aware of

how to talk about the disability, either with the youth directly or with others, in ways that do not add to the stigma that these youth may already be experiencing. Mentors can follow the youth's lead in how they talk about and respond to disability within the relationship—an approach that can empower youth and allow them to determine what the relationship looks like. Programs can support mentors in this endeavor by providing trainings and learning materials related to disability etiquette and inclusive communication.

- They must have the capacity to express empathy, understanding, and compassion, while also challenging their mentee to grow and expand their horizons. This is a delicate balancing act, but mentors can be instrumental in encouraging mentees with disabilities to try something new or to take a risk—something other adults in their life may have discouraged. Mentors also have to be able to express empathy and understanding for those times when the youth may face barriers related to their disability. And most critically for mentors who themselves have a disability: they must be willing to talk about their own journey. While the research noted in this review is unclear on whether youth benefit more from having a mentor with a shared disability, there were qualitative examples in the literature (most notably Powers and colleagues[36, 51] where having a mentor who was willing to share their personal journey of overcoming adversity related to their disability was absolutely critical in helping the young person feel hopeful and inspired for the hard work that may lay ahead for them.

RECOMMENDED RESOURCES ON THE NMRC WEBSITE

- Best Practices for Mentoring Youth with Disabilities
- Starting a Mentoring Club in your High School for Students with Disabilities
- Supporting Students on the Autism Spectrum: Student Mentor Guidelines

OTHER RELEVANT ONLINE RESOURCES FOR SUPPORTING YOUTH WITH DISABILITIES

- Kids as Self Advocates
- National Consortium on Leadership and Disability for Youth
- National Gateway to Self-Determination
- National Youth Leadership Network
- Self-Advocates Becoming Empowered

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ATTACHMENT I

Introduction

On December 2, 2019, the Task Force on Advocacy invited the County Boards of Developmental Disabilities to participate in a survey. The purpose of the survey was to gather information about how local appointments are made to a county board of developmental disabilities.

The Task Force would like to thank the Ohio Association of County Boards of Developmental Disabilities for their assistance with the survey by sending out follow-up notices to the county boards on December 20, 2019 and January 6, 2020.

The survey was officially closed on January 10, 2020.

General Results

There were 16 questions to the survey. Almost 66% of the survey questions were answered by all of the respondents. There was a total of 59 responses to the survey, however, nine were duplicate entries. After accounting for the duplications, a total of 50 responses were received covering 58 counties, a response rate of sixty-six percent. Below are some of the general results:

- 58% of the county boards responding to the survey have a formal process or procedure for appointing a candidate to the county board. However, only 36% include how a person eligible to receive services or receiving services can apply to be a member.
- While almost 80% of the county boards publicize when a position becomes available on a county board, only 26% include a notification to a person eligible to receive services or who is receiving services.
- Of the 78% of county boards who provide input to the appointing authorities on a potential candidate, only 21% include input from individuals who are eligible to receive services or are receiving services.
- Only 16% of the county boards have a process or procedure for recruiting or finding an individual who is eligible to receive services or receiving services to serve as a member of the county board; 60% of the county boards do not have a process or procedure in place.
- 66% of the county boards responded there are no barriers for an individual with a developmental disability to become a member of the county board.

- Only eight county boards (or 16% of those responding) have had a person with a developmental disability on the board. 80% of the counties at no time have had a person with a developmental disability on the board.
- Six county boards provided support or a public accommodation to the individual to assist him/her in fulfilling their duties on the county board.
- 47% of the seven-member county board are immediate family members.
- 98% of the county boards are willing to be contacted about the survey.

Recommendations from the Task Force about the Survey

The Task Force believes the information from the survey should be used to identify additional steps to enhance the participation of individuals with developmental disabilities within the county board structure. Such steps should include further follow-up with the counties boards about certain aspects of the survey and developing an outreach campaign targeted at educating county commissioners, probate judges, and superintendents about the importance and value of appointing individuals with developmental disabilities to the county boards. Moreover, it may be necessary to make a concerted effort to recruit, educate and support, as needed, any individual with a developmental disability who might be interested in serving on a county board.

The Task Force recommends the Public Policy Committee of the Ohio Developmental Disabilities Council review and study the survey responses and work with the Task Force, the DD network and the Association of County Boards of DD 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.

A copy of the survey responses with written comments and a state map indicating which counties responded to the survey are attached.

County Board of DD Survey

Q1
Contact Info

Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Responses Name	100.00%	50
Responses County	100.00%	50
Responses Address	0.00%	0
Responses Address 2	0.00%	0
Responses City/Town	0.00%	0
Responses State/Province	0.00%	0
Responses ZIP/Postal Code	0.00%	0
Responses Country	0.00%	0
Responses Email Address	100.00%	50
Responses Phone Number	100.00%	50

Q2
Do you represent more than one County Board? If yes, please list all counties.

Answered: 48
Skipped: 2

No
1/8/2020 1:38 PM

NA
1/7/2020 5:12 PM

no
1/7/2020 7:22 AM

No

1/6/2020 4:14 PM
no
1/6/2020 9:01 AM
Van Wert and Paulding
1/6/2020 8:55 AM
no
1/6/2020 8:53 AM
N/A
1/6/2020 8:52 AM
No
1/6/2020 8:51 AM
No.
1/6/2020 8:45 AM
Champaign and Shelby
1/6/2020 8:35 AM
no
1/6/2020 8:33 AM
No
12/27/2019 9:50 AM
No
12/23/2019 9:30 AM
no
12/20/2019 3:14 PM
No
12/20/2019 2:26 PM
No
12/20/2019 12:38 PM
No.
12/20/2019 11:40 AM
NO
12/20/2019 11:11 AM
No
12/20/2019 10:19 AM
Yes Guernsey and Muskingum
12/20/2019 10:14 AM
no
12/20/2019 10:04 AM
No
12/20/2019 9:56 AM
no
12/20/2019 8:09 AM
Belmont/Harrison/ Noble
12/20/2019 8:06 AM
No
12/10/2019 12:21 PM
no
12/10/2019 9:42 AM
No
12/6/2019 11:14 AM
No
12/6/2019 10:42 AM
No
12/4/2019 11:34 AM
No

12/3/2019 8:18 AM
no
12/3/2019 7:28 AM
No
12/2/2019 5:08 PM
no
12/2/2019 4:00 PM
Union, Hardin
12/2/2019 2:08 PM
No.
12/2/2019 2:03 PM
Fairfield Vinton
12/2/2019 1:54 PM
No
12/2/2019 1:47 PM
No
12/2/2019 1:35 PM
No
12/2/2019 11:43 AM
no
12/2/2019 11:43 AM
no
12/2/2019 11:32 AM
No
12/2/2019 11:12 AM
No
12/2/2019 11:10 AM
Knox and Coshocton
12/2/2019 11:10 AM
No
12/2/2019 11:08 AM
no
12/2/2019 10:38 AM
no
12/2/2019 10:36 AM

Q3
Does the county have a formal process or procedure for appointing a candidate to the county board?
Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	58.00%	29
No	24.00%	12

Responses		18.00%
Other (please specify)		9

Follow ORC/OAC requirements
1/6/2020 4:14 PM
Nothing in addition to the Ohio Revised Code requirements.
1/6/2020 8:51 AM
The appointing authority advertises a vacancy, and the DD Board post on Facebook and provides information to SSA's
12/20/2019 2:26 PM
the commissioners and Probate judge appoints board members. there is no formal process
12/20/2019 10:04 AM
Varies based on appointing authority but does follow a process
12/10/2019 12:21 PM
We contact appointing authority and they adevrtise and appoint
12/3/2019 7:28 AM
Fairfield does; Vinton does not.
12/2/2019 1:54 PM
We have a practice that followed ORC at one point. If ORC has changed recently, we have not changed it in a number of years.
12/2/2019 11:43 AM
Board of County Commissioners and Probate Judge use similar practices regarding their appointments, which may or may not include the Board's input.
12/2/2019 11:12 AM

TOTAL	50

Q4

If so, does it include how a person eligible to receive, or are receiving services from the board can apply to be a member of the county board?

Answered: 47
Skipped: 3

ANSWER CHOICES	RESPONSES	
Yes		36.17%
		17
No		23.40%
		11
Responses		40.43%
Other (please specify)		19

We previously had a person who received services on our board
1/9/2020 9:16 AM
we do not have any instruction specifically for a person receiving services/eligible. it is the same for anyone else.
1/6/2020 8:53 AM

We do not have a formal process
1/6/2020 8:52 AM
N/A (see response to item #3 above)
1/6/2020 8:51 AM
They would follow the same process as is outlined for any potential candidate.
1/6/2020 8:45 AM
Typically, we don't have potential board members apply. They express interest or are approached.
1/6/2020 8:35 AM
The process to appoint a board member involves the appointing authority publishing the need in the local newspaper(s). This is not specifically targeted to people eligible for Board services.
12/23/2019 11:42 AM
The COunty Commissioners/Probate run an ad in the paper. This would could be challenging if persons served do not receive the paper.
12/23/2019 9:30 AM
the posting is generic but SSA's are aware of the process
12/20/2019 2:26 PM
We have not had a board vacancy since the rule changed permitting people we serve to apply. We have board vacancies coming up for 2021 so will be including in the process a way for people we serve to apply.
12/20/2019 12:38 PM
there is no formal process
12/20/2019 10:04 AM
It includes how anyone eligible can apply
12/10/2019 12:21 PM
N/A
12/6/2019 11:14 AM
It is open to all residents of Athens County who meet the qualifications for the available slot
12/3/2019 7:28 AM
it does not specify whether or not the person has a disability. Anyone interested submits a letter to the appoint authority,
12/2/2019 2:08 PM
Fairfield includes this along with immediate family members.
12/2/2019 1:54 PM
No special process for a person with disability, but we have had people with disability apply using the general process.
12/2/2019 1:47 PM
Anyone can apply for an open position. We reserve three positions for local community representatives who have no immediate family members receiving services - ethics committee. We reserve one position to represent the Amish community - usually a parent or sibling.
12/2/2019 11:43 AM
we provide the commission and probate judge the rules
12/2/2019 10:38 AM

TOTAL   47

Q5
Are openings or vacancies on the county board publicized when a position becomes available?

Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	80.00%	40
No	12.00%	6
Responses Other (please specify)	8.00%	4

Vacancies occurring midterm are required to be publicized
12/20/2019 10:14 AM

Yes in Fairfield; not necessarily in Vinton.
12/2/2019 1:54 PM

Typically, yes, but seems to vary from appointment to appointment if the Commissioners or the Probate Court has a candidate in mind.
12/2/2019 11:12 AM

Depends if the commissioners or probate judge advertise them. We make sure staff are aware and to contact individuals who might have an interest in being on the board. Either a community member including people that may have a disability
12/2/2019 11:10 AM

TOTAL	50

Q6
Are individuals eligible to receive, or are receiving services, notified about their ability to become members of the board?

Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	26.00%	13
No	26.00%	13
Responses Other (please specify)	48.00%	24

Have not in the past; plan to in the future when an opening occurs

1/6/2020 4:14 PM
Board Vacancies are publicly posted in the local paper and anyone interested may apply.
1/6/2020 9:01 AM
Anyone can apply through the County website
1/6/2020 8:52 AM
Not in addition to ORC notification requirements.
1/6/2020 8:51 AM
We do a public notification. It is not targeted to any one specific population.
1/6/2020 8:45 AM
Not explicitly,
1/6/2020 8:35 AM
That is left to the appointing authority after discussion with DD Superintendent.
12/23/2019 11:42 AM
Not in a consistent manner
12/20/2019 2:26 PM
Please see my response to #4.
12/20/2019 12:38 PM
In the past, we were not able to identify a person who would be a good candidate.
12/20/2019 11:40 AM
We have not sent a specific notice on this.
12/20/2019 11:11 AM
We publicize
12/20/2019 10:14 AM
not everyone eligible for servcies are notified about a board opening. If it is believed that an individual would be a good fit they are talked to individually.
12/20/2019 10:04 AM
They have not been to this point in time; we typically keep board members for 2 terms and so turn over is not as often.
12/20/2019 9:56 AM
have not done so in the past
12/20/2019 8:06 AM
Through general information yes but probably not emphasized
12/10/2019 12:21 PM
public notice hasn't been issued in the past - probably a process that has been overlooked and needs to be revamped
12/10/2019 9:42 AM
The notification is in local newspaper
12/6/2019 10:42 AM
Not through any mechanism other than the public posting
12/2/2019 5:08 PM
yes if they read the newspaper or our newsletter
12/2/2019 4:00 PM
we advertise in the paper
12/2/2019 11:32 AM
Only through Project STIR and People First trainings and meetings
12/2/2019 11:12 AM

Not in a different capacity as the general public is aware. We use person centered planning to identify where interests are. That also includes citizenship and community opportunities to serve on boards or volunteer.
12/2/2019 11:10 AM

no, but the general public is not notified either
12/2/2019 10:38 AM

TOTAL	50

Q7
Do you or the county board provide input to the appointing authorities on a perspective candidate(s) to the county board?

Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	78.00%	39
No	4.00%	2
Responses Other (please specify)	18.00%	9

Yes, if requested.
1/6/2020 8:51 AM

If requested by the appointing authority.
1/6/2020 8:33 AM

The appointing authorities feels that it is there opportunity to select the canidate for the vacancy. They have not to date considered recommendations. They are informed of the options to include canidates served by the board.
12/6/2019 10:42 AM

Yes in Fairfield; at times in Vinton.
12/2/2019 1:54 PM

If requested by the appointing authority. Informaition on all candidates is provided to the appointing authority.
12/2/2019 1:47 PM

Yes, with the Commissioners and No for the Probate Court
12/2/2019 11:12 AM

We inform of vacancy, and if we know of a good candidate, it is not uncommon we would send along a letter of recommendation. Ultimately it is the Commissioners and Judge that makes this decision to appoint.
12/2/2019 11:10 AM

only if asked
12/2/2019 10:38 AM

When asked.

TOTAL   50

Q8
If the county board has input, does it include input from individuals that are receiving services?

Answered: 48
Skipped: 2

ANSWER CHOICES	RESPONSES	
Yes	20.83%	10
No	45.83%	22
Responses Other (please specify)	33.33%	16

Has not in the past.
1/6/2020 4:14 PM

We have not received any input to date
1/6/2020 9:01 AM

It would, if requested.
1/6/2020 8:51 AM

If requested by the appointing authority
1/6/2020 8:33 AM

If applicable
12/20/2019 3:14 PM

all applications received by the Board are transmitted to the appointing authority
12/20/2019 2:26 PM

Our Board's nominating committee consists of board members including a parent/family member rep. This committee has interviewed and made the recommendation to the appointing authority in the past. In our upcoming search for board members, we will include representatives from people we serve in making the recommendation to appointing authorities.
12/20/2019 12:38 PM

We share information/input with appointing authorities in meetings.
12/20/2019 11:11 AM

Not specificially
12/20/2019 10:14 AM

individuals have not been asked who they beleive should be on the board. If a circumstance would arise where it would be beneficial it would be completed.
12/20/2019 10:04 AM

It has not in the past.
12/20/2019 9:56 AM

Depends on the situation, number of people interested, etc
12/10/2019 12:21 PM

no formal input has been sought from any stakeholder groups in the past
12/10/2019 9:42 AM

As no member of our board is a client, there would be no formal input on the selection, but anyone can give input.
12/2/2019 11:43 AM

There is not a formal process to do this.
12/2/2019 11:12 AM

Typical input comes from the current Board and Board President. They ask for input from the Superintendent. The Superintendent handles communications to and from the local appointing authorities.
12/2/2019 11:10 AM

TOTAL	48

Q9
Does your county board have a process or procedure for recruiting or finding a person eligible to receive, or are receiving services from the county board to serve as a member of the county board?

Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES
Yes	16.00% 8
No	60.00% 30
Responses Other (please specify)	24.00% 12

Not a formal one, many times people are recommended through our self advocacy program
1/9/2020 9:16 AM

We have no formal process
1/6/2020 8:52 AM

Nothing in addition to the ORC requirements.
1/6/2020 8:51 AM

Not a formal process but when there is a vacancy some board members and staff share that with prospective candidates
12/20/2019 2:26 PM

See response to #4
12/20/2019 12:38 PM

no formal process. when a board opening occurs we seek people who fit the requirement and who is believed to be a valuable contributor.
12/20/2019 10:04 AM

We are currently looking at this; as a small county we know most of our adults very well.
12/20/2019 9:56 AM

General recruiting process for any eligible parties
12/10/2019 12:21 PM
We are developing one now for future use including persone we serve
12/3/2019 7:28 AM
We do not have a formal process, but we reach to those having expressed interest in participating on committees or other opportunities
12/2/2019 2:08 PM
We do not have a formal recruitment process. Open board positions are announced in the paper to the general public. The Board or Board President may provide suggested candidates and endorse a specific person.
12/2/2019 11:10 AM
we have an informal procedure/process
12/2/2019 11:10 AM

TOTAL	50

Q10
Are there barriers that prevent the county board from having individuals that are eligible for services or are receiving services apply to be a member on the county board?
Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	10.00%	5
No	66.00%	33
Responses Other (please specify)	24.00%	12

Appointment to the Board is based on the intent of the appointing authority. But, there are no barriers that I am aware of.
1/6/2020 9:01 AM
I have not had conversations with the appointing authorities about this topic.
1/6/2020 8:53 AM
I am not sure becasue we have not had a person who is elegible or receiving services apply
12/23/2019 9:30 AM
High functioning individuals are limited...
12/20/2019 3:14 PM
We will find out if barriers exist when we initiate our search next year.
12/20/2019 12:38 PM
not necessarily barriers as much as finding the right individual with the skills necessary and expected for the right board vacancy
12/10/2019 9:42 AM
None that couldn't be overcome
12/3/2019 7:28 AM

No legal barriers exist. Procedurally, there is no more recruitment of individuals eligible for services than there is anyone else.
12/2/2019 1:54 PM

A client would have to take one of the three positions reserved for family members.
12/2/2019 11:43 AM

We are investigating if the appointing authorities are open to the idea of having a eligible person on the board. We have a eligible person attending the metings to decide if they are interested.
12/2/2019 11:43 AM

I don't think so, but it would be helpful to have legislation designate at least one position so that our Appointing Authorities have something official to assist. Something similar to requiring positions to be family members.
12/2/2019 11:10 AM

depends - sometimes transportation, time, individuals job, interest,
12/2/2019 10:38 AM

TOTAL	50

Q11
If so, briefly explain.
Answered: 21
Skipped: 29

None known
1/6/2020 4:14 PM

We have had a person who receives services previously on our board.
1/6/2020 8:52 AM

N/A
1/6/2020 8:51 AM

I do not believe there are any specific barriers. This is something that I would like to pursue in the future as I believe it would be highly advantageous for our community.
1/6/2020 8:45 AM

Transportation would be one barrier in our community, but could likely be overcome.
1/6/2020 8:35 AM

Barriers unknown at this time. Knowing the county, we would need to educate those who appoint board members.
12/23/2019 9:30 AM

High functioning individuals are limited
12/20/2019 3:14 PM

N/A
12/20/2019 2:26 PM

na
12/20/2019 10:14 AM

Transportation to and from board meetings and required travel. The ability to review, understand, communicate, and actively represent the County as a member of the board.
12/20/2019 10:04 AM

Finding a board member with the right skill sets and available time to serve is challenging, especially when the ORC prescribes how/who fills certain seats. Local politics and dynamics add another layer of

complexity to develop a well-rounded and balanced board. I'm a believer in having individuals serve on the board, but it takes time to help identify and develop potential individuals to serve when those vacancies come available. Sometimes it can take years to have a vacancy and other times there is an unexpected opening that has to be filled very quickly.
12/10/2019 9:42 AM

n/a
12/6/2019 10:42 AM

We have issues finding someone who wants to be on the Board. We have some that may be good but have guardians. We also have some that have issues handling money.
12/4/2019 11:34 AM

NA
12/3/2019 8:18 AM

none
12/2/2019 5:08 PM

N/A
12/2/2019 1:35 PM

See above
12/2/2019 11:43 AM

We are investigating if the appointing authorities are open to the idea of having a eligible person on the board. We have a eligible person attending the meetings to decide if they are interested.
12/2/2019 11:43 AM

Has to be people that can make meetings, have some understanding of issues and can represent individuals as a whole. I have had a few different people on the board and some have worked out and a few have not.
12/2/2019 11:10 AM

We do not currently have a process in place. Putting a process together would be a temporary barrier.
12/2/2019 11:08 AM

see above
12/2/2019 10:38 AM

Q12
Has your county board ever had a person eligible to receive, or are receiving services on your county board?
Answered: 50
Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	16.00%	8
No	80.00%	40
Responses Other (please specify)	4.00%	2

Yes in Fairfield; no in Vinton.
12/2/2019 1:54 PM
no, but we are going to discuss with county commission next week because we have a vacancy
12/2/2019 10:38 AM

TOTAL	50

Q13

If so, did the county board provide any support or public accommodation to the individual to assist him/her in fulfilling their duties on the county board?

Answered: 30
Skipped: 20

ANSWER CHOICES	RESPONSES	
Yes	20.00%	6
No	33.33%	10
Responses Other (please specify)	46.67%	14

NA
1/7/2020 5:12 PM

n/a
1/7/2020 7:22 AM

N/A
1/6/2020 9:01 AM

N/A
1/6/2020 8:51 AM

N/A
1/6/2020 8:45 AM

NA
12/27/2019 9:50 AM

na
12/20/2019 3:14 PM

N/A
12/20/2019 2:26 PM

na
12/20/2019 10:14 AM

The same support that is offered to all board members. Offer any additional meetings or explinations, offer car pooling when travel is required, etc.
12/20/2019 10:04 AM

n/a
12/6/2019 10:42 AM

N/A
12/2/2019 5:08 PM

NA
12/2/2019 4:00 PM
we would probably have to provide transportation and training and update service plan to incorporate info
12/2/2019 10:38 AM

TOTAL	30

Q14
How many immediate family members are currently appointed to the county board?
Answered: 50
Skipped: 0

3
1/9/2020 9:16 AM
3
1/8/2020 1:38 PM
3
1/7/2020 5:12 PM
3
1/7/2020 7:22 AM
4
1/6/2020 4:14 PM
5
1/6/2020 9:01 AM
3 in Van Wert; 4 in Paulding
1/6/2020 8:55 AM
5
1/6/2020 8:53 AM
6
1/6/2020 8:52 AM
3
1/6/2020 8:51 AM
Three immediate family members.
1/6/2020 8:45 AM
3
1/6/2020 8:35 AM
3
1/6/2020 8:33 AM
3
12/27/2019 9:50 AM
Three
12/23/2019 11:42 AM
3
12/23/2019 9:30 AM
3

12/20/2019 3:14 PM
6
12/20/2019 2:26 PM
Four.
12/20/2019 12:38 PM
3
12/20/2019 11:40 AM
5
12/20/2019 11:11 AM
Three
12/20/2019 10:19 AM
3 in each county
12/20/2019 10:14 AM
2
12/20/2019 10:04 AM
3
12/20/2019 9:56 AM
3
12/20/2019 8:09 AM
three per board
12/20/2019 8:06 AM
3
12/10/2019 12:21 PM
3
12/10/2019 9:42 AM
5
12/6/2019 11:14 AM
3
12/6/2019 10:42 AM
2
12/4/2019 11:34 AM
4
12/3/2019 8:18 AM
3
12/3/2019 7:28 AM
4
12/2/2019 5:08 PM
3
12/2/2019 4:00 PM
3
12/2/2019 2:08 PM
3
12/2/2019 2:03 PM
Three in Fairfield plus an individual eligible for services; three in Vinton.
12/2/2019 1:54 PM

4
12/2/2019 1:47 PM
3
12/2/2019 1:35 PM
There are 4 family members - 1 brother, 1 mother, 1 father, and the Amish representative has two children receiving support
12/2/2019 11:43 AM
4
12/2/2019 11:43 AM
3
12/2/2019 11:32 AM
6
12/2/2019 11:12 AM
3
12/2/2019 11:10 AM
3
12/2/2019 11:10 AM
5
12/2/2019 11:08 AM
4
12/2/2019 10:38 AM
4
12/2/2019 10:36 AM

Q15

Do you have any additional comments?

Answered: 27
Skipped: 23

No
1/7/2020 7:22 AM
I would recommend, proactively, that the ORC be amended to clearly specify that an adult eligible to receive county board services is an eligible candidate to be appointed to county board membership.
1/6/2020 8:51 AM
I would love to learn more from counties that have successfully implemented this. I would like to pursue this option when the next vacancy comes along.
1/6/2020 8:45 AM
no
12/27/2019 9:50 AM
not at this time
12/23/2019 9:30 AM
no
12/20/2019 3:14 PM
No
12/20/2019 2:26 PM

As a small county, we likewise have a small pool of adults to consider for a board appointment. We plan to actively seek someone who is a great advocate for future board member openings.
12/20/2019 11:40 AM

no
12/20/2019 10:14 AM

I have an individual on my board and it is working very well. However, this must be completed in a person centered manner. The individual must meet the requirements and must be able to contribute as we would expect all board members to.
12/20/2019 10:04 AM

No.
12/20/2019 9:56 AM

i am very open to the idea and will consider moving forward
12/20/2019 8:06 AM

We are taking a fresh look at our process and plan to include ideas to recruit someone who receives our services.
12/10/2019 12:21 PM

n/a
12/6/2019 10:42 AM

I am currently in the process of trying to appoint a person with disabilities to our Board. I am waiting on her response.
12/4/2019 11:34 AM

We have had an individual who receives services on our board for several years now and it has been very successful and beneficial.
12/3/2019 8:18 AM

No
12/2/2019 5:08 PM

no
12/2/2019 4:00 PM

We have worked with several people receiving supports from our boards about participating as board members. In at least two cases the person declined because board participation interfered with other activities. The same reasons we here from many people in our community.
12/2/2019 2:08 PM

No
12/2/2019 1:35 PM

If a client is appointed to the board, there are going to be many more conflicts of interest. We do contracts with most providers in our county. If a board member doesn't recuse themselves on these contracts, it will lead to claims of favoritism.
12/2/2019 11:43 AM

There may be an issue with board members sitting on the ethics committee if there are too many members with family.
12/2/2019 11:43 AM

no
12/2/2019 11:32 AM

No.
12/2/2019 11:12 AM

Again, passing legislation to require a person served to have a position on the Board would make this process easier at the local level and remove any unwanted politics surrounding the County Board making this request.
12/2/2019 11:10 AM
Happy to talk about this as we were the first 2 counties to put anyone with a disability on the board. There are some road blocks I had to work through, but have been successful.
12/2/2019 11:10 AM
no
12/2/2019 10:38 AM

Q16
May we follow up with you about this survey?
Answered: 48
Skipped: 2

ANSWER CHOICES	RESPONSES	
Yes	97.92%	47
No	2.08%	1
Responses Other (please specify)	0.00%	0
TOTAL		48
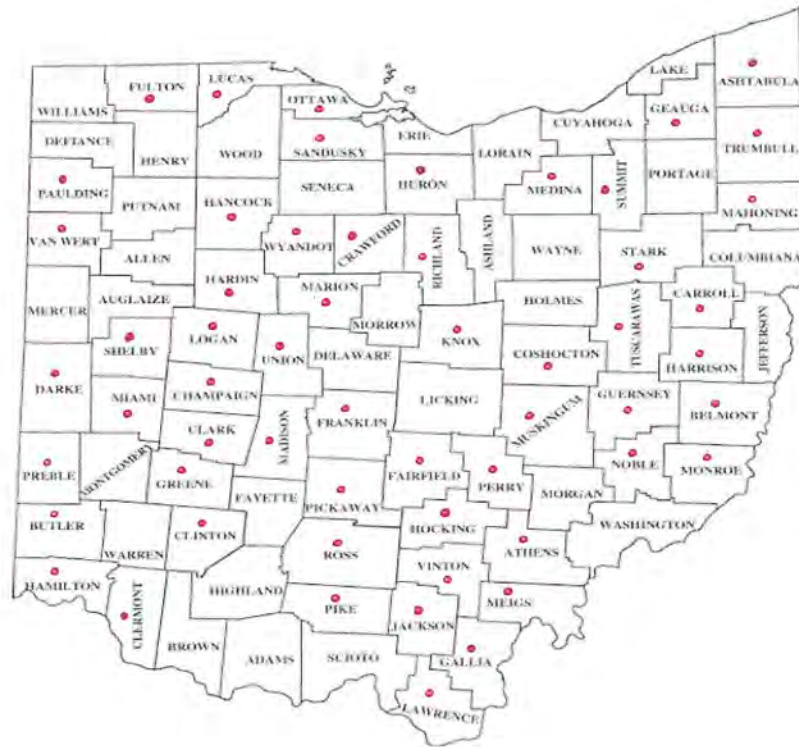
ATTACHMENT J

As Introduced

133th General Assembly
Regular Session
2019-2020

X. B. No. XXX

Sponsor XXX

A BILL

To amend section 5126.022 of the Revised Code to require the appointment of four individuals eligible to receive developmental disabilities services or who identify as a person with a developmental disability to the board membership of a county board of developmental disabilities.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF OHIO:

Section 1. That section 5126.022 of the Revised Code be amended to read as follows:

Sec. 5126.022. When making appointments to a county board of developmental disabilities, an appointing authority shall do all of the following:

(A) Appoint only individuals who are residents of the county the appointing authority serves, citizens of the United States, and interested and knowledgeable in the field of intellectual disabilities and other allied fields;

(B) If the appointing authority is a board of county commissioners, appoint at least ~~two~~ three individuals who are eligible for services provided by the county board, or who identify as a person with a developmental disability, and at least one ~~or are~~ immediate family member ~~members~~ of such individuals. ~~The board of county commissioners shall, whenever possible, ensure that one of those two members is an individual eligible for adult services or an immediate family member of an individual eligible for adult services and the other is an immediate family member of an individual eligible for early intervention services or services for preschool or school-age children;~~

(C) If the appointing authority is a senior probate judge, appoint at least one individual who is eligible for services provided by the county board or who identify as a person with a developmental disability. ~~an immediate family member of an individual eligible for residential services or supported living;~~

(D) Appoint, to the maximum extent possible, individuals who are interested and knowledgeable in the field of intellectual disabilities and other allied fields or have professional training and experience in business management, finance, law, health care practice, personnel administration, or government service;

(E) Provide for the county board's membership to reflect, as nearly as possible, the composition of the county that the county board serves.

Section 2. That existing sections 5126.022 of the Revised Code is hereby repealed.

Section 3. Section 5126.022 of the revised code will go into effect one year after the effective date of this bill.

ATTACHMENT K

2019 MOVE Summit Applications

Apply Today!

Welcome to I'm Determined!

The I'm Determined project, a state-directed project funded by the Virginia Department of Education, focuses on providing direct instruction, models, and opportunities to practice skills associated with self-determined behavior. This project facilitates youth, especially those with disabilities to undertake a measure of control in their lives, helping to set and steer the course rather than remaining the silent passenger.

Find us on Facebook

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Featured Video

07:38

2018 Youth & Parent Summit Closing
Program_OC

11:22

2017 Youth & Parent Summit Closing
Program_OC

Parent Summit Promo_OC

Browse All Videos

Explore our summits

With sponsorship from the Virginia Department of Education, we offer two annual summits for students with disabilities living in Virginia. Our Youth and Parent Summit is held in June at James Madison University. Participants work in groups, facilitated by I'm Determined Youth Leaders, to discover how the core components of self-determination can be applied to their lives.

MOVE is held in July at Virginia State University and utilizes state leadership and mentors to allow rising 9th-11th grade African-American males with disabilities to engage in activity-based learning. For more information on our summits, click the buttons below.

Youth & Parent
Summit

MOVE Summit

I'm Determined is Awesome!

_____

190+ Videos

200+ Documents

Membership

About

The I'm Determined project, a state directed project funded by the Virginia Department of Education, focuses on providing direct instruction, models, and opportunities to practice skills associated with self-determined behavior. This project facilitates youth, especially those with disabilities to undertake a measure of control in their lives, helping to set and steer the course rather than remaining the silent passenger.

Useful Links

Educators
Parents
Youth
Resources
Contact
Quick Links

Website

If you have questions or concerns about our website, please let us know! Send all feedback to: info@imdetermined.org

ATTACHMENT L

Ohio | Opportunities for Ohioans with Disabilities

Contracted Pre-Employment Transition Services and Transition Services

This document helps distinguish between Pre-Employment Transition Services (Pre-ETS) and Vocational Rehabilitation (VR) Fee Schedule services. Contracted Pre-ETS are typically brief, up to 8 hours, with introductory topics for students with disabilities age 14 through 21. Pre-ETS can precede or supplement traditional VR transition services. Pre-ETS can be provided individually, in a group, and to both potentially eligible students and students with open VR cases. Transition services provided under VR Fee Schedule are more in-depth, individualized, and can only be provided to eligible students who have an open VR case.

"MY STUDENT IS JUST STARTING TO THINK ABOUT WORK AND WHAT JOBS ARE OPTIONS FOR THEM."

Pre-ETS: Job Exploration Counseling is an introduction into the world of work. Activities include discussing career options, learning in-demand jobs, completing interest inventories to identify career pathways, establishing a Backpack on OhioMeansJobs.com, researching local labor market information, exploring the Job Seekers Guide on OhioEmploymentFirst.org, and exploration of occupational and resume videos.

Students with disabilities who may benefit from Pre-ETS Job Exploration Counseling are:
- 14 years old and want to work after school but cannot articulate a career field of interest.
- 18 years old and want to know the types of in-demand jobs that match their interests.
- 20 years old and unsure if they want to work.

How is this different from the fee schedule service Summer Youth Career Exploration?
Summer Youth Career Exploration occurs over three weeks for 15 hours a week and is more in depth than Job Exploration Counseling.

Pre-ETS: Work-Based Learning provides information regarding work settings including duties, personnel, shifts, expectations, productivity, accommodations, compensation, and unwritten rules of work. Students will participate in work site tours, job shadowing, informational interviewing and/or field trip experiences. Students begin to identify their network.

"MY STUDENT IS READY TO GET FIRST-HAND KNOWLEDGE OF WORK."

Students with disabilities who may benefit from Pre-ETS Work-Based Learning are:
- 15 years old and needs assistance to identify what a work site looks like in the community.
- 18 years old and needs assistance to identify entry level job tasks.
- 21 years old and wants to work however they do not understand what a job entails.

How is this different from the fee schedule service Summer Youth Work Experience?
Summer Youth Work Experience is a paid five week work experience with an educational component, and students must have an approved Individualized Plan for Employment (IPE) to participate. In Work-Based Learning, students are not performing work but rather job shadowing and touring businesses.

Pre-ETS: Workplace Readiness Training includes addressing professional skills such as teamwork, networking, safety, basic customer service, and personal skills such as enthusiasm, work ethic, responsibility, time management, self-representation online, and independent living skills such as budgeting, hygiene, and household management.

Students with disabilities who may benefit from Pre-ETS Workplace Readiness Training are:
- 14 years old and need tools to communicate with peers and supervisors on a job site.
- 15 years old and need assistance with time management related to employment.
- 21 years old and needs assistance with professionally representing themselves online.

How is this different from the fee schedule service Summer Youth Work Experience or Job Readiness Training?
Summer Youth Work Experience is a paid five week work experience with an educational component. Job Readiness Training is similar but can be long term (an entire school year). Students must have an approved IPE to participate. Workplace Readiness Training teaches many soft skills needed but not on the worksite.

Pre-ETS: Counseling on Post-Secondary Opportunities provides information on various degrees and industry recognized credentials (e.g. certifications, licenses) obtained through training programs, community colleges or universities. Students learn the application and admissions process, how to connect with disability services and/or other career services, work incentives, and resources such as Free Application for Federal Student Aid (FAFSA).

Students who may benefit from Pre-ETS Counseling on Post-Secondary Opportunities are:
- 14 years old and express interest in further training but need help researching options.
- 17 years old and interested in types of accommodations available at a culinary program.
- 21 years old and unsure of financial responsibilities involved with post-secondary training.

How is this different than Career Exploration?
Career Exploration is an individualized service to explore specific employment options and is not intended to research academic programs. Pre-ETS Counseling on Post-Secondary Opportunities explores post-secondary admissions processes and resources available at all of these different types of training programs.

Pre-ETS: Instruction in Self-Advocacy provides information regarding rights and responsibilities such as requesting accommodations at work, learning about services and supports available, and practicing self-advocacy skills. Activities develop leadership skills to support success in the workplace and exploring leadership or peer mentoring groups in the community.

Students who may benefit from Pre-ETS Instruction in Self-Advocacy are:
- 14 years old and interested in learning about their rights at the IEP meeting.
- 16 years and want to learn about self-advocacy and rights as a person with a disability.
- 21 years old and unsure if they want to disclose their disability at work.

ATTACHMENT M

A National Gateway to Self-Determination

10 Steps to Independence:
Promoting Self-Determination in the Home

Written by:

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2010

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University of Oregon
Center on Human Development (UCEDD)

The National Gateway to Self-Determination

The National Gateway to Self-Determination (SD) is a consortium of University Centers for Excellence in Developmental Disabilities (Missouri, Kansas, Oregon, New York, Illinois) in partnership with a National Self-Determination Alliance (including self-advocates, families, and numerous national partners). The overall goal of this project is "***to establish a sustainable, evidence-based training system that enhances self-determination training programs that lead to quality of life outcomes for individuals with developmental disabilities throughout the lifespan.***"

There are a number of important beliefs upon which this SD initiative is founded. They include:
- SD is best considered in the context of a ***social-ecological framework***
- Development of SD is a ***lifelong process***
- Scaling-up SD training activities must occur within an ***evidence-driven*** framework
- The development of SD is a means to obtaining an ***improved quality of life***
- People with developmental disabilities ***must be equal partners***

For more resources on self-determination, please visit the National Gateway to Self-Determination website: www.aucd.org/ngsd.

About the Authors

Michael L. Wehmeyer, Ph.D., is Professor of Special Education; Director, Kansas University Center on Developmental Disabilities; and Senior Scientist and Associate Director, Beach Center on Disability, all at the University of Kansas. Dr. Wehmeyer's research interests include self-determination, access to the general education curriculum for students with severe disabilities, and technology use by people with intellectual disability.

Sharon Davis, Ph.D., now retired, is the former Director of Research and Program Services at The Arc of the United States. She also worked with the Council for Exceptional Children's staff previous to working at The Arc of the United States.

Susan B. Palmer, Ph.D. is a Research Professor at the University of Kansas, affiliated with the Beach Center on Disability, the Kansas University Center on Developmental Disabilities, and the Department of Special Education. Dr. Palmer's research interests include self-determination and access to the general education curriculum for students of all ages and abilities.

10 Steps to Independence

It happens in almost every family: the final outcome of parenting. One day, your children leave. As they go, you hope that your son or daughter has the skills and the abilities to make it. The road leading to this moment is sometimes rocky. It may be marked by adolescent hijinks which look, from the parent's point of view, like rebellion or downright hardheadedness. However, those trying times are necessary steps toward independence. Adolescents, especially those who have a disability, need to learn to make choices and decisions.

The road leading to a successful transition from childhood to adulthood begins much earlier than the teenage years. It starts when children learn about themselves, their strengths and weaknesses and, in doing so, begin to value themselves. It ends when, as adults, these same children can take control over choices and decisions which impact their lives and take responsibility for their actions. This is called self-determination.

For children with intellectual and developmental disabilities, families and teachers may need to take extra responsibility to be sure that this process occurs. Children learn many of the attitudes and abilities leading to self-determination by watching their families. Children with disabilities must be taught these lessons. Here are 10 ways that families can play a critical role in teaching their son or daughter to be self-determined:

1. Walk the tightrope between protection and independence. Allow your son or daughter to explore his or her world. This may mean biting your lip and watching from the kitchen window when your child first meets the neighbor's kids, instead of running out to supervise. While there are obvious limits to this, all parents have to "let go" and this is never easy. **EXPLORATION**

2. Children need to learn that what they say or do is important and can have an influence on others. This involves allowing risk-taking and exploration. Encourage your child to ask questions and express opinions. Involvement in family discussions and decision-making sessions is one way of providing this opportunity to learn. **SELF-EXPRESSION**

3. Self-worth and self-confidence are critical factors in the development of self-determination. Model your own sense of positive self-esteem to your child. Tell your child that he is important by spending time with him. Again, involve him in family activities and in family decisions. **SELF-ESTEEM**

4. Don't run away from your child's questions about differences related to her disability. That doesn't mean, however, to focus on the negative side of the condition. Stress that everyone is individual, encourage your child's unique abilities while helping him or her accept unavoidable limitations. **EMPHASIZE ABILITIES**

5 Recognize the <u>process</u> of reaching goals, don't just emphasize outcomes. Children need to learn to work toward goals. For older children, encourage **GOAL PROCESS** skills like organization and goal-setting by modeling these behaviors. Make lists or hang a marker board in the laundry room which shows the daily schedule for each family member. Talk about the steps you are going to use to complete a task and involve them in tasks leading to family goals, such as planning for a vacation.

6 Schedule opportunities for interactions with children of different ages and backgrounds. This could be in day care centers, schools, churches and in the **INTERACTIONS** neighborhood. Start early in finding chances for your son or daughter to participate in activities that help all children realize that everyone is unique.

7 Set realistic but ambitious expectations. The adage that our goals should extend just beyond our reach is true here. Take an active role in your child's educational **GOALS** experience. Be familiar with his or her reading ability and identify books that provide enough challenge to move to the next reading level. Be sure you don't just force activities which lead to frustration, but don't assume that all of the progress should occur at school.

8 Allow your child to take responsibility for his own actions… successes and failures! Provide valid reasons for doing things, instead of simply saying, **RESPONSIBILITY** "Because I said so!" Providing explanations provides the opportunity for the child to make an activity his own.

9 Don't leave choice-making opportunities to chance. Take every opportunity to allow your child to make choices; what she wears, what is served for dinner, or **CHOICE** where the family goes for vacation. And, although this is not always practical or possible, make sure that these choice opportunities are meaningful. For example, for most children choosing between broccoli and cauliflower is not a choice! Also, when offering choices, make sure that the child's decision is honored.

10 Provide honest, positive feedback. Focus on the behavior or task that needs to be changed. Don't make your child feel like **CONSTRUCTIVE FEEDBACK** a failure. For example, if your son or daughter attempts to complete a school activity, say a math sheet, but is unable to do so, phrase the feedback so that he or she knows that the failure was specific to the worksheet and not to him or her. We all learn from our mistakes, but only if they are structured so that they do not lead us to believe that the problem is within us.

There is no more important environment in which the child with intellectual disabilities learns to become self-determined than the home. A child who learns from his or her parents that he or she has worth will become a self-determined adult. By being allowed the opportunities to make choices and decisions, to explore and take calculated risks and to learn from experiences of success and failure, your child will develop the abilities and attitudes necessary to reach his or her potential.

ATTACHMENT N

NATIONAL GATEWAY TO SELF-DETERMINATION

UCEDD
SELF-DETERMINATION SELF-ASSESSMENT

CHECKLIST

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National Training Initiative in Self-Determination

The authors would like to thank:

UCEDD Self-Determination Self-Assessment Checklist

Purpose of UCEDD Self-Determination Self-Assessment Checklist

The purpose of The **UCEDD Self-Determination Self-Assessment Checklist** is to provide the UCEDD with a straightforward tool and process to determine the **degree to which its policies, practices, and personnel, at a given point in time, are promoting self-determination for people with intellectual and developmental disabilities (I/DD) and their families**. The result will be a profile of the organization's performance that can be used to identify areas to strengthen, and to suggest resources and strategies for desired improvements.

Views of Self-Determination

The UCEDD Self-Determination Self-Assessment Checklist adopts a **social-ecological** approach to promoting self-determination advanced by several theorists (Wehmeyer, M.L., Abery, B., Mithaug, D.E., & Stancliffe, R.J., 2003; Abery, B., & Stancliffe, R.J., 1996) by which individual self-determination is impacted by a person's capacities, interests and motivations interacting with his or her physical, social, and cultural environment. Self-determination refers to *self-* (in contrast with *other-*) *caused action --* it refers to people acting volitionally, based on their own will. People who are self-determined cause things to happen in their lives; they are actors in their own lives, rather than being acted upon. People who are self-determined set and work toward goals, advocate for themselves, and seek to improve the quality of their lives.

The DD Act defines self-determination activities as occurring when an individual with developmental disabilities, with assistance: (a) has the ability and opportunity to make *choices and decisions*, (b) has the ability and opportunity to *exercise control over services*, supports, and other assistance, (c) has the authority to *control resources* and obtain needed services, (d) has the opportunity to *participate and contribute to their communities*, and (e) has the *support, including financial, to advocate*, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making. This definition suggests that both the *abilities* and *motivation* of the person, and the *opportunities* presented by the environment, contribute to the degree of self-determination that can be expressed.

While there are many definitions of culture, this Checklist views **culture** as the learned and shared knowledge that specific groups use to generate their behavior and interpret their experience of the world. It includes, but is not limited to, communications, languages, practices, beliefs, values, customs, courtesies, rituals, manners of interacting, roles, relationships, and expected behaviors of a racial, ethnic, religious, political, professional, or other social group (Gilbert, J., Goode, T.D., & Dunne, C., 2007 -- National Center for Cultural Competence). Culture is an integral and inseparable aspect of a person's social environment. *Thus, a person's culture influences the way in which self-determination is perceived, experienced, and expressed.* For example, cultures often define and value interdependence and independence differently. Many people

within these cultures believe that families should assume a significant role in making decisions that affect individual family members or actually make the decision on behalf of an individual family member. These cultural beliefs and practices will in part determine if and when an individual with I/DD leaves the family home, is able to marry, seeks and maintains employment, and makes health care decisions. Culture should be viewed both as a set of critical personal characteristics and important environmental influences in understanding what self-determination means to an individual, family, or group in any given context.

Guiding Principles of Organizational Self-Assessment

- **Self-assessment is undertaken to identify an organization's relative strengths and areas it wishes to enhance, in order to provide a structure for self-examination and constructive discussion.** These activities should focus on programmatic improvements and organizational changes that build on existing capacities to move the organization in desired directions.
- **Self-assessment is best conducted in a non-judgmental atmosphere**, with appropriate considerations for privacy, and respect for personal opinion. All those who take part in the self-assessment process should feel free to be honest in expressing their views, with no fear of repercussions or stigma.
- **All key participants in the organization must have a voice in the process.** This includes staff at all levels, including: faculty; support, service, and technical staff; students; service recipients; self-advocates; family members of people with developmental disabilities; and members of communities impacted by the activities of the organization.
- **The process of self-assessment should result in a profile of the organization** that can guide the development of a set of actions to increase its capability over time in specific areas. Activities may be directed towards identifying and addressing current limitations and/or enhancing existing strengths.
- **A plan should emerge that allows for the organization to take specific actions** that improve organizational performance in relation to its mission, increase service quality, achieve strategic objectives, develop inclusiveness and cultural and linguistic competence, and collectively enhance the satisfaction of people with I/DD and their families, students, faculty, and staff.

UCEDD Mission and Core Functions

The UCEDD Self-Determination Self-Assessment Checklist is organized into topic areas that correspond with the statutory mission and core functions of UCEDDs. Section 153 of PL 106-402 outlines the purpose and scope of UCEDD functions. UCEDDs engage in one or more core functions in order to implement their mission. These core functions include:

- Provision of **interdisciplinary pre-service preparation and continuing education** of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel;
- Provision of community services that provide **training** or **technical assistance** for individuals with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community;
- Provision of **services, supports,** and **assistance** for all groups noted above, through **demonstration** and **model development** activities;
- Conduct of **research**, including basic or applied research, **evaluation**, and the **analysis of public policy** in areas that affect people with developmental disabilities and their families; and
- **Dissemination of information** related to activities undertaken to address the purpose of the law, and to act as a national and international resource that includes specific substantive areas of expertise.

In addition to guiding the UCEDD in the assessment and ongoing monitoring of its core functions, the Self-Determination Self-Assessment Checklist provides an additional topic area that reviews other aspects of the organization that are often the subject of self-assessment, such as its **mission, organizational culture, governance,** and **human resource policies**.

Self-Determination Self-Assessment Scoring Options

The UCEDD Self-Determination Self-Assessment Checklist is not intended to produce a *score*, per se, but rather a profile indicating areas of strength, opportunities for improvement, and information for constructive dialogue. However, the Self-Determination Self-Assessment Checklist offers an item-by-item scoring system that allows the UCEDD to develop a profile based on the quantitative score in each topic area, if the UCEDD so desires. Items are rated on a **four-point scale** that can be converted to numerical values of 1 through 4, with **4 always signifying greater support for self-determination**.

The scoring system allows the UCEDD to tally up its ratings, display them graphically by each core function, and track changes over time. *Numerical scoring and profiling based on summative scores are completely optional.* As already stated, the primary purpose of the Self-Determination Self-Assessment Checklist is to elevate the UCEDD's awareness of how its activities and policies promote self-determination, and foster productive discussion around this topic by the UCEDD community, its partners, constituents, and individuals it serves.

Discussion Questions for Self-Advocates and Family Members

UCEDDs have a strong commitment to engage a diversity of perspectives in the self-assessment process. This may include, but is not limited to self-advocates, CAC members, family members, and key constituency groups in the area served by the UCEDD. In order to enhance accessibility to the basic concepts explored by the Self-Determination Self-Assessment Checklist, and insure the active participation of all UCEDD team members, specific questions have been provided at the end of each topic area for self-advocates and family members to consider.

Notes and Resources

After each section, space is provided for UCEDD staff to record comments, key points, or other ideas raised by discussion of the issues in that section. Strengths and areas for growth may be noted here, as well as ideas for follow-up activities or next steps.

Especially important to note in this section are **resources**. One of the purposes of the UCEDD Self-Determination Self-Assessment Checklist is to assist UCEDDs and the UCEDD network to identify resources that can be useful in improving performance in desired areas related to supporting self-determination. As the UCEDD goes through the self-assessment process on an item-by-item basis, participants in the process should take time to reflect on whether their UCEDD has resources (e.g., policies, manuals, curricula, reports, media) that could be helpful to others in promoting self-determination.

The five UCEDDs collaborating on the **National Gateway to Self-Determination** initiative intend to establish an on-line library of these and other resources, located at the National Gateway to Self-Determination website (www.aucd.org/ngsd). The goal is to link the need areas identified by the Self-Determination Self-Assessment Checklist to appropriate resources and promising practices.

Appendices

Appendix A provides a space to record the names, titles, and roles of participants in the self-assessment process, as well as the current assessment date, for future reference.

Several items in the Self-Determination Self-Assessment Checklist ask about UCEDD **training, technical assistance,** and **information dissemination** activities conducted in the community. Many individuals and groups may be the focus of these activities. Extensive lists are provided for reference in **Appendix B** to assist the UCEDD in considering the wide range of potential audiences, groups, and organizations that might benefit from these UCEDD services.

Pre-Service Preparation and Continuing Education

Definitions for this Section

Interdisciplinary Pre-Service Preparation

An instructional program offered by the UCEDD that: (1) integrates knowledge and methods from two or more distinct disciplines; (2) integrates direct contributions to the field made by people with disabilities and family members; (3) examines and advances professional practice, scholarship and policy impacting the lives of people with developmental and other disabilities and their families; (4) is designed to advance an individual's academic or professional credentials; and (5) takes place in an academic setting or program. It may: (1) lead to the award of an initial academic degree, professional certificate, or advanced academic credential; and (2) contribute to a discipline-specific course of study offered by the UCEDD or by another academic department.

UCEDD Discipline Specific Training

An instructional program offered by the UCEDD that: (1) focuses on a particular professional discipline or distinct field of study; (2) integrates direct contributions to the field made by people with disabilities and family members; (3) examines and advances professional practice, scholarship, and policy that impacts the lives of people with developmental and other disabilities and their families; (4) is designed to advance an individual's academic or professional credentials; and (5) takes place in an academic setting or program.

UCEDD Continuing Education

Seminar(s) or courses of instruction offered by the UCEDD that: (1) serve to maintain professional credentials; (2) encourage professionals to expand their knowledge base and stay up-to-date on new developments; and (3) award certificates of completion or CEUs (or their equivalents).

1.1 To what extent are UCEDD faculty and staff **specifically trained in the concept of self-determination** for people with I/DD (i.e., it is part of their orientation and/or staff development training)?

1.2 To what extent does this training include information on **multicultural beliefs and practices related to self-determination**?

1.3 To what extent do students, faculty, and staff at the UCEDD understand how to **promote self-determination while taking into account cultural beliefs and practices**?

1.4 To what extent does your UCEDD include people with I/DD and family members as **lead instructors, co-instructors, and curriculum developers in pre-service preparation and continuing education programs**?

1.5 To what extent do your UCEDD's **pre-service preparation and continuing education curricula** and **field experiences** promote self-determination principles and practices?

Area 1 Total: _____

Notes and Resources for Area 1

Include comments, key points, or other ideas raised by discussion of the issues in this section. Note strengths and needs, as well as ideas for follow-up activities or next steps. Finally, identify resources that your UCEDD has that promote self-determination and may be useful to other UCEDDs or network members.

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Training and Technical Assistance

Definitions for this Section

Community Services – Training

Training provided by UCEDD faculty/staff to enhance knowledge of a variety of community members (individuals with developmental and other disabilities, their families, professionals, paraprofessionals, policy-makers, students or others in the community).

Community Services – Technical Assistance

Direct problem-solving services provided by UCEDD faculty/staff to assist individuals with developmental and other disabilities, families, programs, agencies, or other entities in improving their outcomes, services, management, and/or policies.

(**Note**: TA may be provided in person, by digital and electronic media such as websites and webinars, by telephone, video, e-mail, and by other means. The following are examples of technical assistance: needs assessment; program planning or development; curriculum or materials development; administrative or management consultation; legislative testimony; program evaluation and site reviews of external organizations; advisory group participation; policy development; coalition building; and consultation to service providers about people served.)

2.1   To what extent does your UCEDD conduct or support **community training and/ or technical assistance** that promote a **general understanding of the importance of self-determination** for people with I/DD?

2.2   To what extent does your UCEDD conduct **community training and/or technical assistance** that promote **self-determination as it relates to employment** for people with I/DD?

2.3   To what extent does your UCEDD conduct **community training and/or technical assistance** that promote **self-determination as it relates to community living** for people with I/DD?

2.4   To what extent does your UCEDD conduct **community training and/or technical assistance** that promote **self-determination as it relates to health** for people with I/DD?

2.5   To what extent does your UCEDD provide **training and/or technical assistance** designed to **increase the capability of people with I/DD to**:

   2.5.1   make choices, decisions and solve problems as independently as possible?

   2.5.2   live independently and become more self-sufficient?

   2.5.3   work, volunteer, and contribute to their communities?

   2.5.4   manage their own health and health care (e.g. make healthy choices, interact effectively with health care providers)?

2.5.5 form friendships, expand social networks, and use social skills? ☐

2.5.6 address bias, discrimination, and stigma they may encounter due to race, ethnicity, culture, disability, or language spoken? ☐

2.5.7 access mental health services and supports? ☐

2.6 To what extent does your UCEDD provide **training and/or technical assistance** designed to **increase the capacity of organizations/entities to**:

2.6.1 provide environmental supports, technologies, and opportunities for people with I/DD to exercise self-determination? ☐

2.6.2 support the formation and operation of local self-advocacy groups? ☐

2.6.3 influence public attitudes toward acceptance and inclusion of people with I/DD in all aspects of community life? ☐

2.6.4 identify and address cultural and linguistic preferences and needs among individuals with I/DD and families as they relate to self-determination? ☐

2.7 To what extent does your UCEDD include people with I/DD and family members as **lead instructors, co-instructors, and curriculum developers in providing community training and technical assistance?** ☐

Area 2 Total: _____
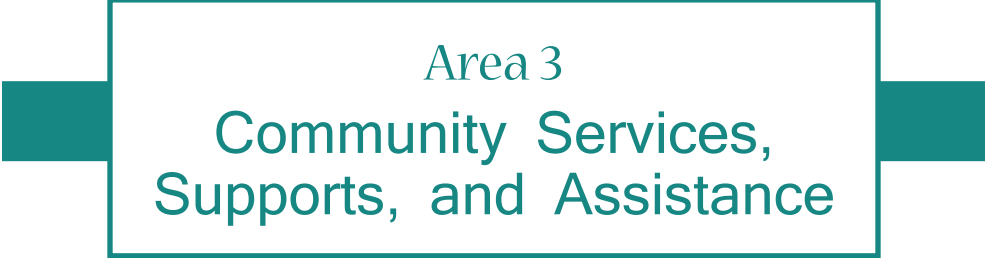
2a. What kind of activities does our UCEDD do to teach people with developmental disabilities about self-determination and self-advocacy?

2b. How does our UCEDD inform communities about self-determination, so that schools, businesses, and organizations will better support people with disabilities?

2c. How are self-advocates and families involved by our UCEDD in providing community training and technical assistance?

Notes and Resources for Area 2

Include comments, key points, or other ideas raised by discussion of the issues in this section. Note strengths and needs, as well as ideas for follow-up activities or next steps. Finally, identify resources that your UCEDD has that promote self-determination and may be useful to other UCEDDs or network members.

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Area 3
Community Services, Supports, and Assistance

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Definitions for this Section

Community Services – Model Services
Specialized services delivered with the intention to enhance the well being and status of the recipient and not for testing new practices, which may be integrated with training, research, and/or dissemination functions.

Community Services – Demonstration Services
Services that field test promising or exemplary practices, which may be integrated with training, research, and/or dissemination functions.

Scoring Instructions

For each item, use the following scale to select the response that best describes your UCEDD. Place a score of 0 to 4 in the appropriate box. You may sum the item scores in each topic area.

4	3	2	1	0 DN	0 NA
Very Much	Somewhat	Very Limited	Not At All	Do Not Know	Does Not Apply

3.1 To what extent does your UCEDD promote **model and demonstration services** that support **self-determination, independence, productivity, and the integration and inclusion** of people with I/DD in all facets of community life?

3.2 To what extent do the **model and demonstration services** provided by your UCEDD encourage opportunities for participant **choice, control, decision-making and self-management**?

3.3 To what extent are self-advocates and family members involved in the **planning, implementation, and evaluation of model and demonstration programs**?

3.4 To what extent do the **strategies and curricula used to promote self-determination, community inclusion, and leadership address cultural and linguistic differences** among people with I/DD?

3.5 To what extent does your UCEDD (either alone or in collaboration with other organizations) **address the culturally-defined roles families assume in self-determination?**

3.6 To what extent does your UCEDD engage in activities that promote **self-directed (or participant–directed) service models?** (Activities may include policy development, research, training, or community service.)

Area 3 Total: _____

Discussion Questions for Self-Advocates and Family Members

3a. How does our UCEDD support self-advocates to participate fully in their communities?

3b. How does our UCEDD teach families about self-determination, so they can help their family member with a disability become more independent?

3c. How does our UCEDD show that it values every family's culture, language, and traditions?

3d. How does our UCEDD encourage self-advocates and family members to become leaders and strong advocates for people with developmental disabilities?

Notes and Resources for Area 3

Include comments, key points, or other ideas raised by discussion of the issues in this section. Note strengths and needs, as well as ideas for follow-up activities or next steps. Finally, identify resources that your UCEDD has that promote self-determination and may be useful to other UCEDDs or network members.

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Research and Information Dissemination

Definitions for this Section

Research

Planned activities to create useable knowledge and information to guide organizational practices. Implementation of *basic* and *applied research*, *program evaluation*, and *analysis of public policy* on issues impacting individuals with developmental disabilities.

Basic Research

Research for the purpose of extending knowledge by adding to the existing body of knowledge in the discipline. Such research has a more general orientation.

Applied Research

Research for the purpose of solving an immediate, practical problem. Such research is oriented to a particular problem.

Field Test

A test to examine a promising or exemplary service, technique, or method using the conditions under which it is designed to operate (can be thought of as applied research).

Evaluation

A form of research to assess the merits of a product, program, or practice. The application of results is at a given site or sites and this is the primary focus of the evaluation. Evaluation results aid in decision-making in a specific situation.

Analysis of Public Policy

A process that usually begins with problem definition and results in an action plan and/or specific alternatives or strategies. It has a specific client and a single point of view, a shorter time horizon, and an openly political approach.

Information Development and Dissemination

Distribution of knowledge-based information through UCEDD-developed products and activities.

Participatory Action Research (PAR)

The Oregon Institute on Disability and Development (OIDD) developed a PAR Toolkit that includes educational modules on PAR and how to implement an inclusive approach to action research at the UCEDD organizational level. Action research involves utilizing a systematic cyclical method of planning, taking action, observing, evaluating (including self-evaluation) and critical reflection prior to planning the next cycle. The actions have a set goal of addressing an identified problem -- for example, increasing health literacy by using new strategies, or improving employment outcomes for students with a disability who are graduating.

PAR is research that involves all relevant parties in actively examining current action (which they experience as problematic) in order to change and improve it. PAR differs from most other approaches to research because it aims to improve a problem through the meaningful involvement of people affected by the problem. "PAR pays careful attention to power relationships, advocating for power to be deliberately shared between the researcher and the researched: blurring the line between them…." The researched "become partners in the entire research process, including selecting the research topic, data collection and analysis, and deciding what action should happen as a result of the research findings" (Baum F., MacDougall, C., & Smith, D., 2006 – *Epidemiology and Community Health*).

(**Note**: All types of research entail basically similar functions such as proposal development, report writing, experimental/quasi-experimental design initiatives, interviews, focus groups, surveys, data entry, data analysis, as well as other types of project-specific functions. Research and evaluation functions can also support measurement of progress in areas such as consumer satisfaction, collaboration, and improvement.)

Scoring Instructions

For each item, use the following scale to select the response that best describes your UCEDD. Place a score of 0 to 4 in the appropriate box. You may sum the item scores in each topic area.

4	3	2	1	0 DN	0 NA
Very Much	Somewhat	Very Limited	Not At All	Do Not Know	Does Not Apply

4.1 To what extent does **research conducted by your UCEDD** address the self-determination of people with I/DD?

4.2 To what extent does your UCEDD ensure the meaningful involvement of people with I/DD and their families as **active participants in all phases of the research process** (e.g., development, design, and implementation of research activities)?

4.3 To what extent does your UCEDD include the diversity of people with I/DD and their families in the **development of products and resources that are disseminated**?

4.4 To what extent does your UCEDD **develop and disseminate information using principles of universal design** to ensure that resources are available in multiple accessible formats?

4.5 To what extent are **information dissemination activities** conducted by your UCEDD in a **culturally and linguistically competent manner**?

4.6 To what extent does your UCEDD **disseminate research findings, policy papers, or other materials that promote self-determination** for people with I/DD, to inform and influence constituency groups, stakeholders, and the general public?

Area 4 Total: _____

Discussion Questions for Self-Advocates and Family Members

4a. How are self-advocates and families involved in our UCEDD's research projects? Do they help to design and conduct research projects, collect information, and present the findings at conferences? Do they co-author publications?

4b. How does our UCEDD make sure that people with developmental disabilities can understand the materials it distributes, such as reports, brochures, newsletters, and DVDs?

4c. How does our UCEDD make sure people who have trouble seeing or hearing, or those with physical challenges, can read or listen to the information it distributes?

4d. How does our UCEDD make sure people with developmental disabilities and their families can understand and use its website?

Notes and Resources for Area 4

Include comments, key points, or other ideas raised by discussion of the issues in this section. Note strengths and needs, as well as ideas for follow-up activities or next steps. Finally, identify resources that your UCEDD has that promote self-determination and may be useful to other UCEDDs or network members.

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Area 5
Mission, Governance, and Organizational Culture

5.1 To what extent does your UCEDD's **mission statement** make reference to the promotion of self-determination as an organizational value, goal, or objective?

5.2 To what extent does your UCEDD make it a priority **to employ, and advance in employment, qualified individuals with developmental disabilities**?

5.3 To what extent do members of the CAC receive initial and ongoing **training in self-determination, self-advocacy, and leadership**?

5.4 To what extent does your UCEDD make **accommodations available for members of the CAC to enhance their participation** (e.g., accessible materials, technology, training, mentoring, etc.)?

5.5 To what extent does your UCEDD include self-advocates and family members as **full participants on UCEDD committees, task forces, and work groups**?

Area 5 Total: _____

Discussion Questions for Self-Advocates and Family Members

5a. How does our UCEDD show its commitment to self-advocacy and self-determination?

5b. How does our UCEDD assist and support CAC members who are self-advocates and family members to participate fully in CAC activities?

5c. How does our UCEDD make sure that people with developmental disabilities and family members have a chance to work for the UCEDD?

5d. How does our UCEDD assist and support staff with disabilities?

Notes and Resources for Area 5

Include comments, key points, or other ideas raised by discussion of the issues in this section. Note strengths and needs, as well as ideas for follow-up activities or next steps. Finally, identify resources that your UCEDD has that promote self-determination and may be useful to other UCEDDs or network members.

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Appendix A
Dates and Participants

Appendix A provides a space to record the names, titles, and roles of participants in the self-assessment process, as well as the current assessment date, for future reference.

Dates

Beginning Date of Self-Assessment: _____

Completion Date of Self-Assessment: _____

Participants

Name	Title	Role

Appendix B
Potential Audiences for Training, Technical Assistance, and Information Dissemination

Appendix B provides lists of potential audiences, groups, and organizations that might benefit from UCEDD services, training, technical assistance, and information dissemination.

UCEDD Faculty and Staff

- Administration, general operations
- Attorneys/legal staff
- Faculty/instructors
- Medical personnel (e.g., MDs, Dentists, RNs, LPNs)
- Public relations/fund raising staff
- Research faculty/staff
- Social workers/case managers/service coordinators
- Students/interns
- Therapists (e.g., OT, ST, PT)
- UCEDD project and/or grant staff
- Volunteers

Audiences for Community Training

- Adults with I/DD
- Aging agencies and organizations administrators/staff
- Corporations/businesses/other potential employers
- Children/adolescents with I/DD
- Community organizations/clubs/civic groups
- Cultural or ethnic organizations
- Developmental Disability Council Members
- Direct support staff
- Disabilities services provider agency administrators/staff
- Early Intervention, child care, Head Start program administrators/staff
- Employment/vocational rehabilitation agency administrators/staff
- Faith-based organizations/spiritual communities
- Family members of people with I/DD
- Family support and/or advocacy organizations
- General public
- Government officials/policy makers/legislators
- Hospital/health agency administrators/staff
- Medical personnel (e.g., MDs, Dentists, RNs, LPNs)
- Mental health/substance abuse agency administrators/staff
- Postsecondary education faculty/administrators
- Protection and Advocacy Agency staff
- State/local general education teachers/administrators
- State/local special education teachers/administrators
- Therapists (e.g., OT, ST, PT)
- Transportation agencies/providers/staff

Organizations for Training and Technical Assistance

- Aging agencies and organizations
- Community organizations/clubs/civic groups
- Corporations/businesses/other potential employers
- Cultural or ethnic organizations
- Developmental Disability Council
- Direct support staffing agencies
- Disabilities services providers
- Early Intervention, child care, Head Start programs
- Employment/vocational rehabilitation agencies
- Faith-based organizations/spiritual communities
- Family support and/or advocacy organizations
- Hospitals, clinics, and other health/medical organizations
- Governmental units
- Law enforcement/fire fighters/EMT
- Mental health/substance abuse agencies
- Postsecondary education programs/community colleges
- Protection and Advocacy Agency
- State/local general education programs
- State/local special education programs
- Transportation agencies

Groups for Information Dissemination

- Aging agencies and organizations
- Children, adolescents, and/or adults with I/DD
- Community organizations/clubs/civic groups
- Corporations/businesses/other potential employers
- Cultural or ethnic organizations
- Developmental Disability Council
- Direct support staffing agencies
- Disabilities services providers
- Early Intervention, child care, Head Start programs
- Employment/vocational rehabilitation agencies
- Faith-based organizations/spiritual communities
- Families of people with I/DD
- Governmental officials/policy makers/legislators
- Hospitals, clinics, and other health/medical organizations
- Law enforcement/fire fighters/EMT
- Mental health/substance abuse agencies
- Postsecondary education programs/community colleges
- Protection and Advocacy Agency
- State/local general education programs
- State/local special education programs
- Transportation agencies

ATTACHMENT O

ISSUE BRIEF
Self-Determination and Self-Advocacy by People with IDD

People with intellectual and developmental disabilities (IDD) have the capacity to make choices and express preferences, solve problems, engage in making decisions, set and attain goals, self-manage and self-regulate action, self-advocate, and acquire self-awareness and self-knowledge. Such actions, known as self-determination, emerge across the lifespan and the value of developing these skills is endorsed in public policies concerning education, health, employment, and community-living for people with IDD. However, research is necessary to assure that practices and interventions support optimal skill development and self-determination outcomes.

▶ Introduction

Over the past 25 years, changes in the field shaped by the self-advocacy movement and social-ecological models of disability have led to an explosion of research on self-determination. While the notion of the inherent capacity and fundamental right of all people—including people with intellectual and developmental disabilities (IDD)—to be self-determining is relatively new, the civil rights and self-advocacy movements have played a critical role in shifting power to people with disabilities and enabling person-centered, self-directed supports that promote self-determination (Wehmeyer, Bersani, & Gagne, 2000). Self-determination has been identified as a right of people with disabilities in federal policy, and research has documented that self-determination status predicts employment and community participation outcomes (Shogren & Shaw, in press; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997).

This brief describes the research goals identified by the invited participants of a strand charged with addressing self-determination and self-advocacy by people with IDD at the *National Goals* Conference in Washington, DC on August 6-7, 2015. The goals described here provide a vision for leaders in the self-advocacy movement, researchers, funding agencies, policy-makers, and practitioners for key considerations that must be emphasized to move the field forward and enable the conditions that support all people with IDD to lead self-determined lives.

▶ Need for Research

While self-determination is at the core of self-advocacy efforts by people with IDD and acknowledged as a goal by current disability policy and practices, research is needed to identify the most effective ways to develop and support self-determination within complex systems, identify practices that promote supports based on individual preferences, and to establish metrics to monitor and evaluate the success of related public policies.

▶ Support Need Research Goals

To assure that all people with IDD, including those with extensive support needs, will be self-determining, research is necessary to identify the most effective intervention strategies and to demonstrate that the practices can be successfully implemented in multiple settings. Inquiries to discover effective interventions employing universal design and addressing the needs of individuals with emerging communication skills will

enhance the capacity of service systems to support self-determination for all people with IDD.

▶ Technology Research Goals

To assure that individuals can advocate for themselves using

IMPACT

Tia Nelis, a leader in the self-advocacy movement and current president of Self-Advocates Becoming Empowered (SABE), describes the impact of self-determination and self-advocacy on the quality of life of people with IDD:

We (self-advocates) first need to learn how to advocate for ourselves. We have to be able to express what we need in our lives. If not, others will make decisions for us, and they won't be the decisions we want. As we grow and learn, we start also advocating for others and systems change and policy and legislation. This is the self-advocacy movement, and the most important thing is that it is controlled by the people.

It is also important for everyone to understand that self-determination doesn't mean that we will do everything on our own. We need support to help us live our lives. The key is that the support people understand that their role is to give us the resources and tools we need to make informed decisions, not take over.

For policy makers to support self-advocacy and self-determination, they need information to back up what we are saying. They want numbers and ways to prove that it is working. They want to know the difference that it is making. Research could give us this information if it is done in a way that involves people with disabilities from the very beginning. If we all work together, we will have good research, good policy, and good lives for people with disabilities.

existing and emerging technologies and in the online environment, research is needed to identify the most effective tools, strategies, and features, and to demonstrate that such strategies can be successfully utilized by people with IDD. Inquiries are needed in the following areas: to discover universal design features that are most important to promoting cognitive access and self-determination; the most effective strategies to teach and support technology use to enhance self-determination; and strategies that successfully involve self-advocates in the research and development process with technology companies.

▶ Training Research Goals

To assure that people who provide support across the lifespan (i.e., teachers, employers, direct support professionals, family

members) understand and enhance opportunities for self-determination of people with IDD, research is crucial to identify the most effective, culturally competent policies and practices and to demonstrate that those policies and practices can be successfully implemented in multiple settings. Inquiries to discover—across the life-span for people with IDD—the most effective strategies for training of support providers by self-advocates, policies and practices for promoting for self-determination in community environments, technologies for supporting self-determination, and strategies for scaling up self-determination interventions in all community environments, will inform policies and practices. In addition, research on the most effective strategies for supporting self-advocates to communicate their needs and wants is crucial to promoting self-determination.

▶ Solidarity Research Goal

Organizations led by self-advocates have begun to emerge; however, have been challenged in achieving financial independence, cultivating leadership, and developing infrastructure. Research to identify and evaluate best practices to advance the financial independence and capacity of self-advocates and self-advocate led organizations, with a focus on supporting self-advocacy organizations to build leadership, independent funding sources, and infrastructure would advance the principles of self-determination.

▶ Systems Change Research Goals

As states increasingly embrace the notion of self-determination in their IDD policies, research designed to identify effective systems of supports based on individual preferences and support needs is necessary to meet the mandates of policy. Inquiries are needed in these areas that can drive changes in future policy, research, and service delivery: to discover the impact of supported decision-making on the quality of decision-making outcomes; critical factors at all system levels that support or serve as barriers to developing self-directed supports; the impact of self-directed supports on the exercise of self-determination; and the most effective strategies to scale-up self-determination practices across organizational systems.

▶ Quality Research Goals

Research designed to elicit and evaluate self-determination strategies, metrics, and outcome data is essential to enable states and service providers to continually improve policies and practices and to facilitate the successful implementation of practices that support self-determination. Inquiries concerning people with IDD across the lifespan to discover validated assessments of self-determination, effective strategies to assess self-determination among people with extensive support needs, and critical environmental and contextual factors that impact

self-determination will drive changes in future policy, research and service delivery.

▶ Participatory Action Research Goals

To ensure that people with IDD are optimally prepared to participate in research about their lives, research is necessary to identify the most effective strategies to involve self-advocates in the research, planning, implementation, analysis, and dissemination phases of such research projects. Inquiries to discover methodologies that equalize the power dynamics in all phases of research, promote self-advocate involvement in the research review and application processes, and that could build a leadership pipeline of self-advocates with research literacy would enhance the validity of results of research on the lives of people with IDD.

▶ Conclusion

In order to continue to advance self-determination policies, practices, and outcomes in all settings, we must continue to refine and support effective practices to increase the expectations, assessment, participation, and achievement of people with IDD.

▶ References

Shogren, K. A., & Shaw, L. A. (in press). The role of autonomy, self-realization, and psychological empowerment in predicting outcomes for youth with disabilities *Remedial and Special Education*.

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▶ Acknowledgements

ATTACHMENT P

6%

Please help us! We want to hear from self-advocates from around the country about their self-advocacy groups. Self-advocates are people with disabilities who speak up for themselves. If you are a self-advocate AND a member of a self-advocacy group, please fill out this survey.

We know that some self-advocates don't belong to a group, but still have strong opinions. In this survey, we are trying to learn about what self-advocates think about their self-advocacy group. As a result, if you are not a member of a self-advocacy group you wouldn't be able to answer the questions.

We hope to use the information we get to help self-advocacy groups get bigger and stronger.

This survey takes about 20 minutes to complete.

If you complete this survey, you can win a $100 gift card! To enter the drawing for a chance to win, just give us your email address at the end of this survey. One name will be drawn when the survey closes on Wednesday, November 30, 2011. Don't wait. Take the survey today!

Your answers are confidential. We will not share your answers with family members, advisors, staff or others. We will use everyone's answers together to write a report about the self-advocacy movement nation wide. We will share the report with self-advocates and others.

If you need help filling out this survey, ask someone you trust for help. This person can be a family member, a staff person, or a friend. Your opinion is the one we want to hear.

REMEMBER: To complete the survey you MUST be a self-advocate AND a member of a self-advocacy group.

Have questions about the survey? Please contact Yoshi Kardell at 503-924-3783 ext. 18, or ykardell@hsri.org.
Our fax number is 503-924-3789.

Our mailing address is:

Attn: Yoshi Kardell
Human Services Research Institute (HSRI)
7690 SW Mohawk Street
Tualatin, OR 97062

Thank you for taking this survey!

This survey was developed by The Riot at the Human Services Research Institute
www.theriotrocks.org
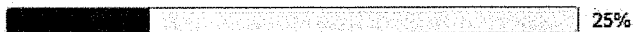
13%

1. Select the answer that best describes you

● Self-advocate or person with a developmental disability

○ Family member

○ Advisor to a self-advocacy group

○ Service provider

[Prev] [Next]

25%

2. I am a self-advocate and I am:

● Filling out this survey myself

○ Filling it out with help from someone

3. As a self-advocate, I am:

○ The President or leader of the group

● A member of a self-advocacy group

○ I'm not a part of a self-advocacy group

[Prev] [Next]

38%

Please answer the following questions about your group.

4. What state is your self-advocacy group located in?

State: — select state — ▼

5. What is the name of the self-advocacy group you are completing the survey for?

6. Is the group you listed in the item above a state organization or a local group? (Choose one)

◯ State organization

◯ Local group

7. Is your self-advocacy group a 501c3 nonprofit organization? (Choose one)

◯ Yes

◯ No

◯ I don't know

Prev   Next

44%

Please answer these questions about your group.

8. How long has your group existed? (Choose one)

○ Less than a year

○ 1 to 5 years

○ 6 to 10 years

○ 11 to 20 years

○ Over 20 years

○ I don't know

9. Tell us how many people are in your group. (Type in a number)

Total number of people in your group.

```

```

10. How old are the people in your group? (Choose one)

○ All of them are OVER 30 years old

○ Most of them are OVER 30 years old

○ They are a mix of over 30 and under 30 years old

○ Most of them are UNDER 30 years old

○ All of them are UNDER 30 years old

○ I don't know

11. Over the past few years, how much has the size of your group's membership grown? (Choose one)

○ A lot

○ A little

○ Not at all

○ It is getting smaller

○ I don't know

12. What types of disabilities do your members have? (Choose all the apply)

☐ Intellectual and developmental disabilities

☐ Physical Disabilities

☐ Autism

☐ Mental Health Challenges

Prev   Next

50%

Please answer these questions about your group.

13. Tell us about the purpose of your group. Your group can exist for a lot of reasons. Choose how important each purpose is to your group on a scale from 1-5 with 1 being NOT important at all and 5 being VERY important.

	Not important - 1	2	3	4	Very Important - 5
Make life better for people with disabilities	◯	◯	◯	◯	◯
Change the service system so we can get the services we need	◯	◯	◯	◯	◯
Provide trainings and education to self-advocates and others	◯	◯	◯	◯	◯
Have fun	◯	◯	◯	◯	◯
Help each other when we need help	◯	◯	◯	◯	◯
Help others in the community	◯	◯	◯	◯	◯
Attend events to advocate for our rights	◯	◯	◯	◯	◯

14. This item is about issues that are important to your group. Overall, how important are these issues to your group? Choose how important each issue is to your group on a scale from 1-5 with 1 being NOT important at all and 5 being VERY important.

	Not important - 1	2	3	4	Very important - 5
Being in charge of our own lives	◯	◯	◯	◯	◯
Having accessible transportation available when we need it	◯	◯	◯	◯	◯
Getting jobs we want	◯	◯	◯	◯	◯
Closing sheltered workshops	◯	◯	◯	◯	◯
Choosing where we live	◯	◯	◯	◯	◯
Closing institutions	◯	◯	◯	◯	◯
Taking care of our health	◯	◯	◯	◯	◯
Having friendships and romantic relationships	◯	◯	◯	◯	◯
Dealing with Guardianship issues	◯	◯	◯	◯	◯
Getting or keeping services	◯	◯	◯	◯	◯
Getting people off the waitlist for services	◯	◯	◯	◯	◯
Finding ways to help each other	◯	◯	◯	◯	◯
Working on ways to contribute to our community (volunteering, etc.)	◯	◯	◯	◯	◯

Prev   Next

56%

15. Overall, how helpful do you think the following state agencies and organizations are to your group? Choose how helpful each agency or organization is to your group.

	Very helpful	Somewhat helpful	Not helpful	I don't know
Council on Developmental Disabilities	○	○	○	○
State Developmental Disability Services agency	○	○	◉	○
University Center of Excellence on Developmental Disabilities (UCEDD)	○	○	○	○
Protection and Advocacy agency or Disability Rights organization	○	○	○	○
Other self-advocacy groups	○	○	○	○
Family advocacy groups	○	○	○	○
Service providers	○	○	○	○

16. Tell us how well people listen to your group. Below is a list of people who may or may not listen. Choose how well each person listens to your group.

	Listen well	Listen okay	Don't listen	I don't know
Your state legislators	○	○	○	○
Your state Governor	○	○	○	○
Service providers/provider agencies	○	○	○	○
Direct support staff	○	○	○	○
Family members	○	○	○	○

Prev   Next

63%

Please answer the following questions about your group.

17. Does your group have someone to help get things done? This person can be called an advisor, facilitator, staff, or another name. (Choose one)

○ We have one person to help

○ We have more than one person to help

○ We do not have anyone to help

○ I don't know

Prev   Next

69%

18. Does the person who helps your group get paid for the help he or she gives? (Choose one)

● Yes this person is paid

○ Yes, and more than one person is paid

○ No this person is not paid

○ I don't know

19. What kind of help does your group get from advisors, facilitators, paid staff, or other helpers? (Choose all that apply)

☑ Help to organize meetings, activities, and events

☑ Help to do our jobs

☑ Help to get information

☑ Shares ideas or information when we ask

☑ Supports our choices

☐ Other

(If you chose "other" please describe)

_____

20. Overall, how happy or satisfied are you with the help you get from advisors, facilitators, paid staff, or other helpers? (Choose one)

○ Very satisfied

● Satisfied most of the time

○ Satisfied sometimes

○ Not satisfied at all

21. Overall, who is in charge of your group? Who would you say is really leading and in charge of your group? (Choose one)

○ Self-advocates totally

● Mostly self-advocates

○ Pretty much an equal between self-advocates and helpers (like advisors, facilitators, or paid staff

○ Mostly helpers (like advisors, facilitators, or paid staff)

○ Totally helpers (like advisors, facilitators, or paid staff)

| Prev | Next |

75%

During spring 2011, the US Administration on Developmental Disabilities (ADD) hosted five Envisioning the Future Allies in Self-Advocacy Summits around the country. The summits were held in:
Atlanta, GA, March 10-11, 2011
Los Angeles, CA, March 24-25, 2011
kansas City, MO, April 11-12, 2011
Columbus, OH, April 28-29, 2011
Providence, RI, May 16-17, 2011

22. Which if any of these did you attend? (Choose one)

◯ I did not attend a Summit

◯ Atlanta, GA, March 10-11, 2011

◯ Los Angeles, CA, March 24-25, 2011

◯ Kansas City, MO, April 11-12, 2011

◯ Columbus, OH, April 28-29, 2011

◯ Providence, RI, May 16-17, 2011

[Prev] [Next]

81%

23. You were chosen to participate on your State Team because you represent a certain group of people or an organization. Choose the option below that best describes which group or organization YOU represent as a member of your State Team. (Choose one)

◉ Statewide self-advocacy organization

◯ Youth self-advocates

◯ Autistic self-advocates

◯ Developmental Disabilities Council

◯ Protection and Advocacy organization

◯ University Center for Excellence in Developmental Disabilities

◯ State developmental disabilities services agency

◯ Other (please specify)

[   ]

24. What has your State Team been doing since you all attended the Summit? (Choose one)

◯ We are planning to meet by phone or in person

◉ We are meeting by phone or in-person

◯ We have not been meeting at all

◯ Other (please specify)

[   ]

[Prev] [Next]

88%

25. What has your State Team worked on since the Summit? (Select all that apply)

☐ We are working on one or more of the goals we set DURING THE SUMMIT

☐ We are working on one or more NEW goals

☐ We are working on raising money to reach our goals

☐ We are getting more people involved in our work

☐ We are working on getting new members

☐ We are working on getting more support

☐ Other (please specify)

[   ]

[Prev] [Next]

Enter the drawing

94%

To enter the drawing for $100 gift card, type in your email address below. The winner of the $100 gift card will be notified by email on Friday, December 2,2011.

26. Type in your email address

[   ]

[Prev] [Next]

Thank you!

100%

Thank you for taking this survey! Please click on the "DONE" button to submit your survey. When you press "DONE" you will go directly to The Riot homepage. Check us out and have yourselves a regular Riot!

[Prev] [Done]

ATTACHMENT Q

IDENTIFICATION OF SELF-ADVOCACY PROGRAMS IN OHIO

BACKGROUND

The Task Force on Self-Advocacy has reviewed a listing of advocacy organizations in Ohio developed by the Ohio Self-Determination Association (OSDA). The Task Force feels the information contained in the document would be of benefit to people with disabilities, self-advocacy organizations, and state agencies, but only if the advocacy organizations can demonstrate that they are providing self-determined activities that increase the skills and knowledge of people with disabilities. Furthermore, the information must be kept up-to-date, readily accessible and expanded to include additional organizations. The Task Force believes this is a prudent first step to determine if there exists an actual "system of self-advocacy organizations" in Ohio in which to build upon.

RECOMMENDATION

The Task Force on Self-Advocacy recommends to the Ohio Developmental Disabilities Council that additional data be gathered through its grant process. The grant should identify all of the local, regional and statewide self-advocacy organizations in Ohio using as a starting point the listing developed by OSDA. The Task Force believes that additional data must be collected on the type of services provided, the regions covered by such organizations and the populations served by such organizations. Moreover, the initiative should seek to determine what type of leadership training opportunities are available through self-advocacy organizations.

KEY ACTIVITIES:

(I)   Identify and update the number of self-advocacy organizations/programs in Ohio;

(II)   Determine what services are provided by the self-advocacy organizations/programs;

(III)   Determine what regions and populations are served by the self-advocacy organizations/programs;

(IV)   Determine what type of leadership training opportunities are available through such organizations/programs;

(V)   Develop an electronic repository to house such information that includes a way to search the data; and

(VI)   Provide any further recommendations as determined by the grantee.

RESOURCES TO BE INVESTED:

Federal	$ xxxxx
Matching Funds:	$ xxxxx
	$ xxxxx

ATTACHMENT R

Self-Advocacy Services for People With Intellectual and Developmental Disabilities: A National Analysis

Carli Friedman

Abstract

Self-advocacy plays an important role in facilitating the empowerment of people with intellectual and developmental disabilities (IDD), and helps people with IDD develop the skills necessary for the participant direction of services. The purpose of this study was to examine Medicaid Home and Community Based Services (HCBS) 1915(c) waivers across the nation to determine how states were utilizing self-advocacy services for people with IDD. Findings revealed approximately half of waivers provided self-advocacy services; however, less than .01% of waiver spending was projected for stand-alone self-advocacy services. States need to expand the provision of self-advocacy services for people with IDD in order to strengthen their ability to direct their waiver services and exercise their rights.

Key Words: *self-advocacy; people with intellectual and developmental disabilities; Medicaid Home and Community Based Services (HCBS) 1915(c) waivers; long-term services and supports (LTSS)*

Self-advocacy is the civil rights movement of and by people with intellectual and developmental disabilities (IDD). Self-advocacy serves both as a source of empowerment for people with IDD and a method for grassroots organizing. One self-advocate describes identifying as a self-advocate to mean

> knowing your rights and responsibilities. Self-advocate means standing up for your own rights. Self-advocate means speak for yourself and make your own decisions, being more independent, standing on your own two feet and sticking up for your rights. (Shapiro, 1994, p. 209)

Priorities of the self-advocacy movement include: (a) closing institutions; (b) ending subminimum wage; (c) ending use of the word 'retarded;' and (d) directing their services (Caldwell, 2011; Shapiro, 1994). According to Shapiro (1994), self-advocates "are saying they are willing to take risks like anyone else to live like other adults around them. They want places to turn to for support, but they also want the feeling of respect and self-confidence that comes from taking chances" (p. 192).

Self-determination, a key aspect of self-advocacy, includes knowing one's rights and speaking out about what one wants (Nonnemacher & Bambara, 2011). Self-determination also includes being in charge of daily decisions in order to reach one's goals (Nonnemacher & Bambara, 2011). Because of this push for control by self-advocates, many IDD-related policies, such as long-term services and supports (LTSS), have become more person-centered (Heller, Arnold, McBride, & Factor, 2012). The Centers for Medicare and Medicaid services (CMS) has pushed states to expand the participant direction of their LTSS, which allows people with IDD and/or their families to direct their own services (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015; Medicaid Program, 2014). Because of its basis on principles of self-advocacy and self-determination, participant direction results in improved choice, control, satisfaction, quality of life, independence, and empowerment (Crisp, Doty, Smith & Flanagan, 2009; Heller et al., 2012; Swaine, Parish, Igdalsky, & Powell, 2016; Timberlake, Leutz, Warfield, & Chiri, 2014).

A recent analysis of the largest provider of LTSS for people with IDD, Medicaid Home and Community Based Services (HCBS) 1915(c) waivers (Braddock et al., 2015), found that although the majority of waivers allowed participant direction by

people with IDD, states' goals for the number of people with IDD who would utilize participant direction were extremely low (Friedman, in press-b). Friedman (in press-b) suggests this discrepancy may relate to states' low expectations of people with IDD. The low utilization of participant direction may also relate to a lack of training programs that educate people with IDD on the self-advocacy skills necessary to direct their own services. For this reason, and because of the important role self-advocacy plays in facilitating the empowerment of people with IDD, the purpose of this study was to examine the provision of self-advocacy services within Medicaid HCBS 1915(c) waivers for people with IDD across the nation. In doing so, we examined which states were providing self-advocacy services for people with IDD, and how self-advocacy services were utilized. Specifically, we analyzed the (a) projected unduplicated participants; (b) total projected spending; (c) spending per participant; and (d) annual service provision. We also examined waiver definitions of self-advocacy services in order to determine states' motivation to provide these services, and how states described the usefulness of self-advocacy.

Methods

Medicaid HCBS 1915(c) waivers were gathered from the CMS Medicaid.gov website over approximately 11 months (May 2015 to April 2016). Waivers that were not 1915(c), did not serve people with IDD (developmental disabilities (DD), intellectual disability (ID), autism (ASD), and/or mental retardation (MR)); and were pending or inactive, were excluded. (Despite being an outdated term, MR continues to be used by a number of HCBS waivers and therefore was a necessary search term; see Friedman, 2016). Finally, waivers were required to include 2015; most often this was the state fiscal year (FY) (July 1, 2014 to June 30, 2015); however, other states used the federal FY (October 1, 2014 to September 30, 2015) or the calendar year (January 1, 2015 to December 31, 2015). The term FY is used for consistency. Through this process we amassed 111 Medicaid HCBS 1915(c) waivers for people with IDD from 46 states and the District of Columbia.

CMS requires waivers to describe: (a) CMS assurances and requirements; (b) levels of care; (c) waiver administration and operation; (d) participant access and eligibility; (e) participant services,

including limitations and restrictions; (f) service planning and delivery; (g) participant direction of services; (h) participant rights; (i) participant safeguards; (j) quality improvement strategies; (k) financial accountability; and (l) cost-neutrality demonstrations (Disabled and Elderly Health Programs Group et al., 2015). We utilized this information to determine which waivers provided any type of self-advocacy by going through almost 3,000 services and noting provision of self-advocacy services. This included bulk services (e.g., employment, residential habilitation, etc.) that included self-advocacy within the service, as well as stand-alone services that exclusively provided self-advocacy. The definitions of these services were then qualitatively analyzed for major and minor themes.

We were able to differentiate utilization and expenditures for stand-alone self-advocacy services, but not for bulk services. Therefore, we further analyzed stand-alone self-advocacy services quantitatively to determine the projected number of: (a) unduplicated participants; (b) total projected spending; (c) average spending per participant; (d) reimbursement rates; and (e) annual service provision per participant.

Findings

Service Definitions

Fifty-two waivers (46.8%) from 24 states provided self-advocacy through 74 services in FY 2015. Of those 74 services, 11 (14.9%) were stand-alone self-advocacy services, while 63 (85.1%) provided self-advocacy embedded within another service. It was most common for self-advocacy to be embedded in day habilitation services, supports to live in one's own home (companion/homemaker/personal care/supported living services), and supported employment services, see Table 1.

Stand-alone services. Stand-alone self-advocacy services enhance a participant's ability to function in the community and were often described as a

> service provided to participants to promote self-advocacy through methods such as instructing, providing experiences, modeling and advising. This service includes assistance in interviewing potential providers, understanding complicated health and safety issues, and assistance with participation on private and

Table 1
Location of Self-Advocacy Within Embedded Services

Service Category	n	%
Day habilitation	17	27%
Supports to live in ones' own home (Companion, homemaker, personal assistant, supported living)	10	16%
Supported employment	9	14%
Individual goods and services	6	10%
Community transition supports	5	8%
Financial support services	5	8%
Prevocational	3	5%
Residential habilitation	3	5%
Care coordination	2	3%
Family services	2	3%
Health and professional services	1	2%

public boards, advisory groups and commissions. (Colorado Supported Living Services Waiver; CO293.R04.00)

Many of the stand-alone self-advocacy services also included peer support, which is

designed to provide training, instruction, and mentoring to individuals about self-advocacy, participant direction, civic participation, leadership, benefits, and participation in the community. Peer support is designed to promote and assist the waiver participant's ability to participate in self-advocacy through either a peer mentor or through an individual/agency peer support facilitator. Peer support may be provided in 1) small groups or 2) peer support may involve one individual who is either a peer or an individual peer support facilitator providing support to a waiver participant. The one to one peer support is instructional; it is not counseling. (Massachusetts Adult Supports Waiver; MA828.R01.00)

The majority of stand-alone self-advocacy services also allowed peer support to be provided over technology such as iPads, iPhones, and Skype.

Embedded services. States provided self-advocacy within embedded services for a number of reasons. Most commonly ($n = 55$, 87.3% of embedded services), the self-advocacy was provided for training and skill development. For example, Colorado Children's Habilitation Residential Pro-

gram (CO305.R04.00) waiver's 'Habilitation' service described its provision of self-advocacy services as:

Self-Advocacy Training and support includes assistance and teaching of appropriate and effective ways to make individual choices, accessing needed services, asking for help, recognizing abuse, neglect, mistreatment, and/or exploitation of self, responsibility for one's own actions, and participation in all meetings.

Many waivers ($n = 15$, 23.8% of embedded services) also embedded self-advocacy within their services in order to support participants as they exercise their rights. For example, Montana Home and Community-Based Waiver for Individuals with Developmental Disabilities' (MT20 8.R05.01) 'personal supports' service described its inclusion of self-advocacy as aimed at: "assisting the individual to develop self-advocacy skills, exercise rights as a citizen, and acquire skills needed to exercise control and responsibility over other support services."

Instead of promoting self-advocacy as a general life skill, a number of waivers ($n = 10$, 15.9% of embedded services) also included self-advocacy training specifically to help participants advocate for their waiver services. For example, Wyoming Comprehensive Waiver's (WY1061.R00.00) 'Independent Support Brokerage' service explained, "other functions include assisting the participant in: conducting self-advocacy and assisting with employee grievances and complaints." Similarly, six services (9.5% of embedded services) included self-advocacy specifically for employment advocacy. For example, Indiana Community Integration and Habilitation Waiver's (IN378.R03.01) 'Extended Service' service included: "job-specific or job-related self-advocacy skills training."

A number of embedded services ($n = 8$, 12.7% of embedded services) also described service provision aimed at providing opportunities for self-advocacy. For example, Tennessee Comprehensive Aggregate Cap Waiver's (TN357.R03.00) 'Support Coordination' service explains the support coordinator

will provide the individual with information about self-advocacy groups and self-determination opportunities and assist in securing needed transportation supports for these opportunities

when specified in the ISP or upon request of the individual.

Service Expenditures

In FY 2015, eight waivers provided 11 stand-alone self-advocacy services. These 11 services projected spending $1.57 million for approximately 2,000 unduplicated participants (see Table 2). However, both total projected spending and unduplicated participants ranged widely by service. While the average waiver provided stand-alone self-advocacy services for 324 participants, this ranged from 5 participants for Connecticut Employment and Day Supports waiver's (CT881.R00.02) 'Peer support per 15 minutes Agency' service to 1,090 services for Colorado Supported Living Services waiver's (CO293.R04.00) 'Mentorship' service. Moreover, total projected spending ranged from $7,011 for Connecticut Comprehensive Supports (CT437.R02.01) and Individual and Family Support Waivers' (CT426.R02.01) 'Peer support per 15 Minutes individual' services to $1.05 million for Colorado CO293.R04.03 waiver's 'Mentorship' service, with waivers projecting an average total spending of $261,213. Spending per capita on stand-alone self-advocacy services was relatively low across the states, averaging at $0.07 per capita. Colorado had the highest spending per capita for stand-alone self-advocacy services ($0.19), Wis-

consin the second highest ($0.05), and Connecticut and Massachusetts the lowest ($0.02).

Average yearly spending per participant on stand-alone self-advocacy services ranged from $293 for Massachusetts Intensive Supports Waiver's (MA827.R01.00) 'Peer Support – 15 minutes' service to $1,476 for Connecticut CT881.R00.02 waiver's 'Peer support per 15 minutes Agency' service. Waivers providing stand-alone self-advocacy services were projected at $862 per participant per year, on average. Figure 1 details average spending per participant further.

All stand-alone self-advocacy services were paid by a 15-minute reimbursement rate other than Wisconsin's Children's Long Term Support DD Waiver's (WI414.R02.01) 'Consumer Education and Training' service, which paid an hourly reimbursement rate of $64.00. The average reimbursement rate for 15-minute rate stand-alone services was $5.43 (which works out to $21.70 an hour). Six services (54.5%) had a 15-minute reimbursement rate between $3.50 and $4.00, two services (18.2%) between $7.00 and $7.50, one service (9.1%) between $7.50 and $8.00, and one service (9.1%) between $9.50 and $10.00.

The 15-minute rate services provided 162 15-minute units of stand-alone self-advocacy services per participant in a year on average (approximately 40 hours). One service (9.1%) provided 82 15-minute units (20.5 hours), one service (9.1%) 98

Table 2

Stand-Alone Self-Advocacy Services in HCBS Waivers for People With IDD (FY 2015)

| State	Waiver	Service	Unit	# Users	Total projected spending
Colorado	CO293.R04.00	Mentorship	15 Minutes	1,090	$1,048,972
Connecticut	CT437.R02.01	Peer Support per 15 Minutes Agency	Per 15 Minutes	20	$27,854
Connecticut	CT437.R02.01	Peer Support per 15 Minutes individual	Per 15 Minutes	10	$7,011
Connecticut	CT426.R02.01	Peer Support per 15 Minutes Agency	Per 15 Minutes	20	$27,854
Connecticut	CT426.R02.01	Peer Support per 15 Minutes individual	Per 15 Minutes	10	$7,011
Connecticut	CT881.R00.02	Peer Support - 15 minutes	Per 15 minutes	10	$7,429
Connecticut	CT881.R00.02	Peer Support per 15 Minutes Agency	Per 15 minutes	5	$7,382
Massachusetts	MA828.R01.00	Peer Support - 15 minutes	15 minutes	87	$45,967
Massachusetts	MA826.R01.00	Peer Support - 15 minutes	15 minutes	66	$34,872
Massachusetts	MA827.R01.00	Peer Support - 15 minutes	15 minutes	269	$78,747
Wisconsin	WI414.R02.01	Consumer Education and Training	Hours	357	$274,176
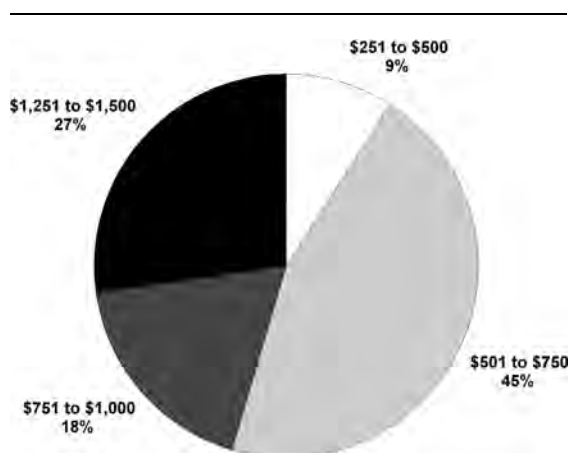
Figure 1. Average spending per participant for stand-alone self-advocacy services.

units (24.5 hours), 2 services (18.2%) 148 units (37 hours), and 6 services (54.5%) 190 units (47.5 hours). Wisconsin's stand-alone self-advocacy service provided on average 12 hours of services per participant per year.

Discussion

Approximately half of HCBS waivers for people with IDD provided some sort of self-advocacy service in FY 2015. As mentioned above, waivers provided self-advocacy services to help people with IDD function in the community by building and strengthening their decision-making and self-advocacy skills and allowing them to exercise the rights granted to them as citizens. States also recognized the ways self-advocacy promotes general life skills, including those that help them advocate for waiver services.

Self-advocacy was provided through both stand-alone services and embedded within another service, most commonly day habilitation. Projected spending for stand-alone services in FY 2015 was $1.57 million for approximately 2,000 participants. Although this may seem significant, it is less than .01% of the total HCBS IDD waiver spending projected for FY 2015 (Friedman, in press-a). Spending per capita was also quite low across the states providing stand-alone self-advocacy services.

On average, FY 2015 projected spending was approximately $900 per participant on stand-alone self-advocacy services, with the average participant projected to receive approximately 40 hours of stand-alone self-advocacy services a year. Although

spending and annual service provision for stand-alone self-advocacy services varied widely by state, utilization was fairly low across all states.

In the current system, "self-advocacy services remain 'a hodgepodge of local, regional, and national schemes, largely uncoordinated and unregulated, and often relying on untrained and unpaid volunteers'" (Atkinson (1999) as cited by Redley & Weinberg, 2007, p. 769). Most self-advocacy organizations currently operate via a patchwork of small funds and volunteers; services and supports are key (Caldwell, 2010). Lack of services and supports hinders opportunities to access the community and to participate in self-advocacy. A self-advocacy leader in Caldwell's (2010) study "used the phrase 'fallen leaders' to describe individuals who could have grown into leaders, but did not have necessary and adequate supports and services" (p. 1009). As the most prominent providers of LTSS, Medicaid HCBS waivers are the perfect vehicle to help promote self-advocacy by providing opportunities within waivers.

One limitation of our findings should be noted. Medicaid HCBS 1915(c) waivers are state projections provided to the federal government—not utilization. However, they are reasonably accurate proxies because of their basis on previous years' utilization. Moreover, previous analyses of HCBS waiver projections (Rizzolo, Friedman, Lulinski Norris, & Braddock, 2013) have revealed similar findings to utilization research by Braddock et al. (2015) and Irvin (2011).

In the 2014 1915(c) final settings rule, CMS noted,

> several commenters recommended that CMS include training as one aspect of employer-authority activities that self-directing beneficiaries may be allowed to exercise. A couple of commenters urged CMS to require states to offer training for individuals on selecting, hiring, supervising and firing service providers, in addition to service provider training. (Medicaid Program, 2014, n.p.)

CMS goes on to "agree with this recommendation" and suggests that states utilize training programs to meet this requirement (Medicaid Program, 2014, n.p.). CMS's recommendation reinforces the importance of self-advocacy service provision by states. This is especially pertinent as Swaine (2016) found many people employed under partic-

ipant direction felt they needed more job training from their employers with disabilities. Both the importance of self-advocacy, and our findings suggest states need to significantly increase states' provision of self-advocacy services, especially as they redesign their waiver program in response to the person-centered planning requirements of the Medicaid final settings rule (Medicaid Program, 2014). Self-advocacy is a vital tool that allows people with IDD to produce deeper senses of community, culture, identity formation, and disability pride. Service provision by the largest provider of LTSS for people with IDD should reflect the advances made by the movement by *actively* working to encourage it.

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