



Federal Fiscal Year 2019 Council Impact Project Performance & Council Activity Progress Report





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Who We Are and What We Do

The Illinois Council on Developmental Disabilities (ICDD) was created under a federal mandate in 1974 as an amendment to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and is administered by the federal Administration of Developmental Disabilities. ICDD works to promote the independence, productivity, integration, and inclusion of those with disabilities into the community, ensuring that those individuals with developmental disabilities have the same opportunities as others in the community. Moreover, the purpose of ICDD is to ensure that people with developmental disabilities participate and be included in everyday life and be able to choose the services and supports that best fit their needs. To accomplish this, ICDD uses our funding to innovate and create systems change via grant projects throughout the State of IL as well as advising on policy, organizing for advocacy, and partnering side by side with our government colleagues to implement the Council's vision.

The Council is comprised of no less than 60% individuals with developmental disabilities and/or their family members. In addition, there are also several state agency representatives that serve on the Council.

Agencies Include:

- Department of Disability and Human Development, University of Illinois at Chicago
- Department on Aging
- Office of Management and Budget
- Department of Children & Family Services
- Illinois State Board of Education
- Department of Healthcare and Family Services
- Equip for Equality
- Department of Human Services, Division of Rehabilitation Services
- Department of Human Services, Division of Developmental Disabilities
- Department of Human Services, Bureau of Maternal and Infant Health

The Council follows the federal definition of developmental disability, which is:
A severe, chronic disability of an individual that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age twenty-two;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency; and
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of life long or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children means an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

5-Year State Plan

Our investments and initiatives are based on the five-year plan, established by the Council, to ensure that people with developmental disabilities and their families have a part in the design of and access to culturally competent services, supports and other assistance and opportunities that promote independence, productivity and integration and inclusion into the community. Below is the Council's current Five-Year State Plan.

Individual & Family Advocacy Goal: Individuals with intellectual and developmental disabilities and their families knowledgeable advocate and take part in decision that affect their lives, the lives of others, and/or systems.

Objectives:

- By September 30, 2021 the Illinois Council on Developmental Disabilities will strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities; will 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 will support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions.
- By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders increase their knowledge and opportunity to advocate for their priorities among accessible, quality, efficient, effective service systems.
- By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders will have access to coordinated, streamlined information about services, supports and other assistance.
- By September 30, 2021 through outreach and training, youth with intellectual and developmental disabilities of transition and young adult age (14-30) in southern Illinois will expand their life choices through personalized support systems.

Systems Change Goal: Support systems are optimized so that individuals with intellectual and developmental disabilities in Illinois live and thrive in the broader community.

Objectives:

- By September 30, 2021, the Illinois Council on Developmental Disabilities will assist/facilitate a minimum of 3 state systems to provide coordinated, individualized, flexible, and/or responsive services and supports for individuals with intellectual and developmental disabilities.
- By September 30, 2021, the Illinois Council on Developmental Disabilities will help 10 communities develop local resources and adapt to provide full access to municipal, civic, social, spiritual, and all other aspects of community life for individuals with intellectual and developmental disabilities.
- By September 30, 2021, the Illinois Council on Developmental Disabilities initiates and/or collaborates to impact a minimum of 3 identified issues for individuals with intellectual and developmental disabilities.
- By September 30, 2021, through collaboration, the Illinois Council on Developmental Disabilities; Equip for Equality; the Institute on Disability and Human Development (Illinois UCEDD), University of Illinois at Chicago; and the Alliance, will develop a structure/process to support leadership of The Alliance to achieve issues of importance to their members using the expertise of legal, research, training, and policy experts of the Developmental Disabilities Network.

The Council's Five-Year Plan reflects the dual visions for community inclusion and advocacy. The goal for individuals with DD and family members to knowledgeably advocate (Goal 1) has 4 objectives intended to strengthen their skills and voices in advocating for necessary and desired services in a state in a poor fiscal situation when the ability to tap all possible resources in the most efficient means is crucial. The goal for support systems being optimized (Goal 2) dovetails with Goal 1 and is the aim for advocacy. It also has 4 objectives. The Council intends to effect change in state systems and continues a desire to shape the culture of communities to be inclusive. The eight objectives and the strategies being used reflect a vision of the strong beliefs of the Council: self-advocates must be leaders in redesigning a system that supports them to lead the lives they want; the culture of communities needs to be one that embraces people with developmental disabilities in all places within their communities; employment is the key to people with intellectual and developmental disabilities having options and taking advantage of opportunities in their communities; and Illinois needs to be strategic in the way that resources are used in order for people with intellectual and developmental disabilities to lead full lives in their communities. Rebalancing the system to use resources effectively and efficiently is key to providing supports in the community, yet systemic changes needed remain slow to be implemented.

The focus of this plan is on systemic change in housing, employment and community supports in its broadest sense. The strategies that have been used most often and with success include coordination/collaboration with state agencies and stakeholders; coalition development; and strategic outreach/technical assistance.

DD Council Areas of Emphasis:

The State Plan outlines the Council's priorities and objectives in ten areas of emphasis:

1. Education and Early Intervention
2. Employment
3. Child Care
4. Formal/Informal Community Supports
5. Health
6. Housing
7. Quality Assurance
8. Recreation
9. Transportation
10. Advocacy

Quick Data:

- Total **number of active investments** in FFY2019 was **30**
- Total **number of statewide investments** in FFY2019 was **15**
- Total **number of investments in targeted areas** in FFY2019 was **15**



2019 State Plan Investment Chart

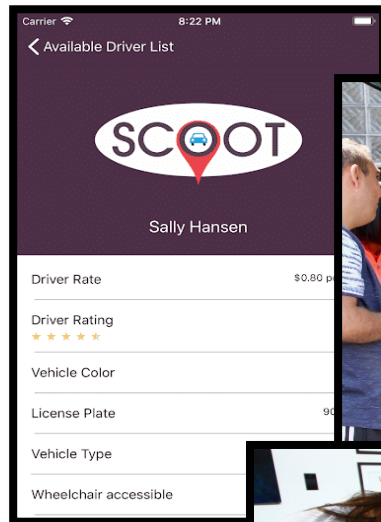
GOAL 1: INDIVIDUAL & FAMILY ADVOCACY	
Individuals with intellectual and developmental disabilities and their families knowledgeably advocate and take part in decisions that affect their lives, the lives of others, and/or systems.	
OBJECTIVES	INVESTMENTS
<p>OBJECTIVE 1.1: By September 30, 2021 the Illinois Council on Developmental Disabilities will strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities; will 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 will support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions.</p>	<p>1. IL Self-Advocacy Alliance Grantee: <i>IL Alliance</i> Start Date: <i>4/13/18</i> End Date: <i>4/12/21</i> Impact Area: <i>Statewide</i> Funding Amount: <i>\$400,923</i></p>
	<p>2. Speak Up & Speak Out (SUSO) Grantee: <i>Arc of Illinois</i> Start Date: <i>1/1/17</i> End Date: <i>12/31/21</i> Impact Area: <i>Statewide</i> Funding Amount: <i>\$800,000</i></p>
<p>OBJECTIVE 1.2: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders increase their knowledge and opportunity to advocate for their priorities among accessible, quality, efficient, effective service systems.</p>	<p>3. Consumer Stipend Program Grantee: <i>Arc of Illinois</i> Start Date: <i>1/1/16</i> End Date: <i>6/30/20</i> Impact Area: <i>Statewide</i> Funding Amount: <i>\$342,180</i></p>
	<p>4. Partners in Policymaking (PIP) Grantee: <i>HIGH Impact Mission-Based Consulting and Training</i> Start Date: <i>12/15/17</i> End Date: <i>12/31/20</i> Impact Area: <i>Statewide</i> Funding Amount: <i>\$622,911</i></p>
	<p>5. HCBS Rules Education Grantee: <i>Council on Quality and Leadership</i> Start Date: <i>8/1/2016</i> End Date: <i>12/31/2018</i> Impact Area: <i>Statewide</i> Funding Amount: <i>\$224,827</i></p>
<p>OBJECTIVE 1.3: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders will have access to coordinated, streamlined information about services, supports and other assistance.</p>	<p>6. Sibling Support Project Grantee: <i>Sibling Leadership Network</i> Start Date: <i>12/1/2109</i> End Date: <i>9/30/20</i> Impact Area: <i>Statewide</i> Funding Amount: <i>\$74,511</i></p>

<p>1.3 Continued</p> <p>OBJECTIVE 1.3: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders will have access to coordinated, streamlined information about services, supports and other assistance.</p>	<p>7. Medical Advocacy Grantee: EPIC Start Date: 6/1/19 End Date: 5/31/21 Impact Area: Peoria area (5 counties) Funding Amount: \$48,442</p> <p>8. Financial Wellness Grantee: National Disability Institute Start Date: 3/1/19 End Date: 2/28/22 Impact Area: Statewide Funding Amount: \$500,000</p> <p>9. Medical Advocacy Grantee: Univ. of IL. at Chicago Start Date: 6/1/19 End Date: 5/31/21 Impact Area: Chicagoland & Springfield Funding Amount: \$130,097</p> <p>10. Medical Advocacy Grantee: Ray Graham Start Date: 6/1/19 End Date: 5/31/21 Impact Area: DuPage County Funding Amount: \$105,522</p>
<p>OBJECTIVE 1.4: By September 30, 2021 through outreach and training, youth with intellectual and developmental disabilities of transition and young adult age (14-30) in southern Illinois will expand their life choices through personalized support systems.</p>	<p>11. Southern IL Transition Project Grantee: Human Support Services (HSS) Start Date: 10/15/18 End Date: 10/15/21 Impact Area: Southern Illinois Funding Amount: \$466,348.70</p> <p>12. Southern IL Transition Project Grantee: Lewis & Clark Community College Start Date: 10/15/18 End Date: 10/15/21 Impact Area: Edwardsville Funding Amount: \$272,859</p> <p>13. Southern IL Transition Project Grantee: CTF IL Start Date: 10/15/18 End Date: 10/15/21 Impact Area: Southern Illinois Funding Amount: \$108,726</p> <p>14. Southern IL Transition Project Grantee: Coleman Tri-County Services Start Date: 10/15/18 End Date: 10/15/21 Impact Area: Southern Illinois</p>

		Funding Amount: \$240,000
GOAL 2: SYSTEMS CHANGE		
Support systems are optimized so that individuals with intellectual and developmental disabilities in Illinois live and thrive in the broader community.		
OBJECTIVES	INVESTMENTS	
<p>OBJECTIVE 2.1: By September 30, 2021 the Illinois Council on Developmental Disabilities will strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities; will 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 will support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions.</p>	<p>15. Life Choices Grantee: National Association of State Directors of Developmental Disabilities Services (VA) Start Date: 8/17/15 End Date: 12/31/19 Impact Area: Statewide Funding Amount: \$608,222.39</p>	
	<p>16. Going Home Coalition (GHC) Grantee: ARC of IL Start Date: 3/1/19 End Date: 2/28/22 Impact Area: Statewide Funding Amount: \$390,000</p>	
	<p>17. Child Care Training Grantee: School Association for Special Education (SASED) Start Date: 2/1/15 End Date: 3/31/20 Impact Area: Statewide Funding Amount: \$158,475</p>	
	<p>18. ICDD Historical Database and Review Grantee: University of IL. at Chicago (UIC) Start Date: 12/1/17 End Date: 3/1/20 Impact Area: Statewide Funding Amount: \$150,000</p>	
	<p>19. Supportive Housing Grantee: Corporation for Supportive Housing Start Date: 12/1/13 End Date: 7/31/19 Impact Area: Statewide Funding Amount: \$946,992</p>	
<p>OBJECTIVE 2.2: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders increase their knowledge and opportunity to advocate for their priorities among accessible, quality, efficient, effective service systems.</p>	<p>20. Community Play Project Grantee: KCCDD Start Date: 4/1/17 End Date: 11/30/19 Impact Area: Galesburg Funding Amount: \$32,628</p>	

<p>2.2 Continued</p> <p>OBJECTIVE 2.2: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders increase their knowledge and opportunity to advocate for their priorities among accessible, quality, efficient, effective service systems.</p>	<p>21. Change Champions Grantee: Center for Independent Futures (CIF) Start Date: 4/1/17 End Date: 3/31/19 Impact Area: Chicago suburbs Funding Amount: \$200,000</p> <p>22. IN Project Grantee: Community Choices Start Date: 4/1/17 End Date: 3/31/19 Impact Area: Champaign, Urbana Funding Amount: \$97,000</p> <p>23. CARES 377 Boards Grantee: AID Start Date: 6/1/19 End Date: 12/31/21 Impact Area: Statewide Funding Amount: \$66,500</p>
<p>OBJECTIVE 2.3: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders will have access to coordinated, streamlined information about services, supports and other assistance.</p>	<p>24. Hubs Grantee: Envision Unlimited Start Date: 9/15/17 End Date: 9/30/20 Impact Area: Chicago Funding Amount: \$149,816</p> <p>25. Supported Employment Action Team (SEAT) Grantee: Arc of Illinois Start Date: 9/15/17 End Date: 11/15/19 Impact Area: Statewide Funding Amount: \$193,000</p> <p>26. New Approaches to Breaking Down Barriers (Early Learning) Grantee: Illinois State University Start Date: 9/15/17 End Date: 9/30/20 Impact Area: Statewide Funding Amount: \$97,359</p> <p>27. New Approaches to Breaking Down Barriers (Transition) Grantee: Urban Autism Solutions Start Date: 9/15/17 End Date: 9/30/20 Impact Area: Chicago Funding Amount: \$75,136</p>

<p>2.3 Continued</p> <p>OBJECTIVE 2.3: By September 30, 2021 individuals with developmental disabilities, their families, and other stakeholders will have access to coordinated, streamlined information about services, supports and other assistance.</p>	<p>28. Purposefully Living (Transition) Grantee: <i>Roxana Community Schools</i> Start Date: <i>9/15/17</i> End Date: <i>6/30/19</i> Impact Area: <i>Roxana</i> Funding Amount: <i>\$58,264</i></p>
	<p>29. New Approaches to Transportation Barriers Grantee: <i>New Star</i> Start Date: <i>9/15/17</i> End Date: <i>9/30/19</i> Impact Area: <i>Chicago south suburbs</i> Funding Amount: <i>\$80,000</i></p>
	<p>30. Child Care Training Grantee: <i>Good Shepherd</i> Start Date: <i>4/1/18</i> End Date: <i>8/31/20</i> Impact Area: <i>Chicago south suburbs, Champaign</i> Funding Amount: <i>\$183,665</i></p>
<p>OBJECTIVE 2.4: By September 30, 2021 through outreach and training, youth with intellectual and developmental disabilities of transition and young adult age (14-30) in southern Illinois will expand their life choices through personalized support systems.</p>	<p>No funded project</p>



2019 Illinois Comprehensive Review and Analysis

This section provides information on the adequacy of health care and other services, supports and assistance that individuals with developmental disabilities in Illinois Intermediate Care Facilities (ICF) during FFY19.

According to the Ligas data report drafted in August 2019, there are approximately 15,216 people with developmental disabilities living at home, and 4,800 people residing in an ICFDD. There are 1673 people living in SODCs as July 2019. Illinois still has 7 SODCs with no sign of a decrease in the number of people moving in to that type of setting. In 2019, The process by which to measure the State of Illinois' compliance with the Ligas Consent Decree has been a topic of discussion between the Ligas parties and Court Monitor. The Parties and Monitor have come to an agreement on the review process, surveyor credentials, and compliance evaluation instruments.

From the Ligas Implementation Plan, 5/3/19. Effective August 2017, PUNS categories were revised to “Seeking Services” (for those who want supports now) and “Planning for Services (for those who do not currently want or need supports but may in the future). Future PUNS selections will be based on the length of time an individual has spent in the Seeking Services category since the age of 18. From the Independent Service Coordination Manual, posted July 2019. “PUNS selections for Waiver services will occur as funding is available. Selections will be based on a person's cumulative length of time in the Seeking Services Category after age 18. Selections will not be made from the Planning for Services category. If the individual enrolled in PUNS before turning age 18, the length of time begins calculating on the individual's 18th birthday provided that they are in the Seeking service category. In order to move from one category to the other, individuals and/or guardian must notify their ISC. Movement from one category to the other is not automatic. The reasonable pace that is required for PUNS selections are predicted to be met due to the changes in selection criteria.

The state was to provide a written update in September 2018. In 2018, the Judge found the State's Plan inadequate and ordered the State to review its rates structure. In 2019, DDD secured a contract with Navigant and has begun the process of a formal rate review. Anticipated results to be publicized in summer 2020.

Effective September 23, 2019, Allison Stark began her tenure as the Department of Human Services as Director of Developmental Disabilities and has taken up working with a rates review as a necessary thing to be able to comply with the court. Public Act 101-0010 authorized a 3.5% rate increase for ID/DD and MC/DD facilities for services delivered on or after August 1, 2019. This applies to all services under the HCBS waiver.

This section focuses on adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities served through home and community-based waivers during FFY19.

The Division issued an RFP for Independent Service Coordination services and all current providers needed to reapply. When the awards were made, some providers were given new contracts and some borders shifted which elicited a storm of protests and lawsuits. As a result of the RFP, 7 out of 18 ISCs remain in business and provide the conflict free case management and PUNS intake services. The Council was asked to organize a public comment period on the ISC transition in support of the Division's efforts to determine the impact of these changes on ISC customers. The public response was low but did reflect that many ISC staff, families, and people with DD were either confused and concerned with the changes or not impacted at all. The Division moved forward with their new ISC contracts.

There were 1249 individuals selected from the PUNS list in August 2019. This PUNS selection includes 1074 adults from the Seeking Services category who have been on PUNS for 6 years or more. It also includes 175 individuals who were in the Emergency category (which has now been combined with Seeking Services) and/or those who are 60 years old or older. As of October 2019, 19,487 people are on the PUNS list awaiting services. Illinois does not have an approved HCBS waiver community-based services transition plan as of November 2019.

Evaluation Results:

The Council primarily evaluates on two levels, the big picture state service system functioning, and the impact made by our investments. The movement on larger issues is a very qualitative process and relies on staff and Council member and partner advocacy groups feeding us constant information about happenings in the state and legislature. We have found in approaching systems change, visible movement can be very hard to discern. This FFY19 was another year of flux with a new administration as of January 2019. The slow pace of systems change within the Division of Developmental Disabilities picked up some with a temporary Director who pushed for rate and service definition change that has been discussed for years and will hopefully continue with the new appointed Director. Work on the new waiver includes new language. There has not been progress in state institution closure during this year and the census is up a bit. With the leadership changes in the Division, some progress was made to improve internal systems. However, the process remained slow moving in the implementation of rule changes, procedures, policy, etc. designed to better support community-based services. Through workgroups, the Division is beginning to make significant changes in the service coordination and person-centered planning process to support of individualized services shifting to community settings.



Goal 1: Individual & Family Advocacy 2019 Project Progress Reports

1. Speak Up and Speak Out (SUSO) 2019 Progress Report



The Arc of Illinois with support from the IL Self-Advocacy Alliance continued in their efforts to empower self-advocates from all over the state through the annual Speak Up and Speak Out (SUSO) Summit in October 2018. SUSO provides opportunity for self-advocates to come together from throughout the state and share activities and training designed to help each achieve the highest level of independence, inclusion and self-direction in their life as possible and to advocate for themselves and others on important issues to self-advocates. SUSO has evolved into a unique spirit of self-determination and advocacy. The program and keynote

presentations are often developed and led by individuals with DD and the Costume Dance that takes place on the second evening is a vision to behold. This year, there were 528 self-advocates, family members and personal support workers present, making the 12th year of SUSO the highest year of participation so far. The event kicked off with a tour to the capitol for attendees who wanted to learn about where legislators' Springfield offices are located.

At SUSO, self-advocates learn to speak up about what is important to them and how to work with community agencies, state agency decision makers, and state and federal policy makers to influence systems change.

Training sessions include, but are not limited to:

- Guardianship & You
- Playing the Rights Card: HCBS Settings Rule
- Expect the Best: How to Get the Most Out of Your Support Staff
- Self-Advocates and Sexuality: We Have Rights
- Speak Up for Supportive Housing



Self-advocates have an opportunity in this type of setting to feel comfortable enough to speak about what they feel which helps the staff and families understand better and also helps each self-advocate learn more about what they themselves want. Representatives from the IL Department of Human Services Division of Developmental Disabilities and the Division of Rehabilitation Services attended and spoke about their mission to serve people with DD. Self-advocates were able to ask questions and provide recommendations on service delivery for both agencies. Self-advocates were also able to voice what changes they want and need to the many policies both agencies have established.

This year, close to 15 community agencies attended as vendors and provided resources and information to those who were interested in learning more about services. Individuals with DD who are self-employed are also welcome to host vendor tables and sell their products. SUSO was run by and for self-advocates which was really pushed by Council leadership and The IL Self-Advocacy Alliance. The Summit has developed into a unique uplifting event that truly inspires and transforms people's expectations of themselves and the people who support them.

2. IL Self-Advocacy Alliance 2019 Progress Report



In order to function successfully as a statewide advocacy organization, self-advocates continued to work together to support the mission and vision of The Self Advocacy Alliance and each other. The Alliance continued their focus on training and empowering individuals with DD to become self-advocates and take on leadership roles whenever possible. New self-advocates, agencies, organizations and other stakeholders were engaged resulting in The Alliance establishing themselves as a more powerful, unified voice in Illinois.

The Alliance set out to increase membership for the Ambassador program from 25 to 40 self-advocates, with a focus on developing member groups in southern Illinois and organizing at least three groups in northern Illinois who are not involved in an agency group. Their reach allowed them to even establish groups in each of the State Operated Developmental Centers. The Ambassador program allowed for varying membership levels based on involvement allowing flexibility in leadership training levels and exposure for self-advocates. To promote active engagement and participation, the Board of Directors restructured procedures and elected new leaders, increased members, and hosted finance and bylaws subcommittee meetings.

Currently there are 32 Alliance member groups (10 more than in FFY 2018). Members are focused on outreach and growth. They are developing groups in underserved areas of the state and for underserved communities, in addition to working to increase diversity in groups: minority communities, cross-disability, transition aged. The Regional Self Advocacy Specialists & Project Specialists were hired to give intentional and individualized support to established and prospective self-advocacy member groups and local self-advocates. One new member group is Chicagoland Disabled People of Color Coalition (CDPCC); we hope to learn with and from CDPCC about any differences in providing self-advocacy skill development and support for those who identify as being a color other than white.

In the early months of 2019, the Alliance partnered with The Arc of Illinois, with support from Don Moss and Associates (a disability-focused trade association) and the ISC (Independent Service Coordination) agencies represented, to bring regional trainings to Murphysboro, Galesburg, Springfield, Joliet, and Arlington Heights. The regional trainings engaged self-advocates, parents/family members, and professionals in learning about self-advocacy, the disability service system in Illinois, and legislative advocacy. More than 200 people participated in the trainings. The Alliance successfully trained 338 self-advocates in leadership, self-advocacy, and self-determination. A total of 8 webinars were recorded focusing on different topics, from speaking up for supportive housing to Illinois ABLE. The Alliance updated their website and monthly newsletter and continue providing resources and information distributed across the state.

The Alliance continues to provide regular learning and advocacy opportunities and information through the use of daily emails and Facebook postings as well as monthly Alliance newsletters.

The Alliance has some national connections. The Alliance's application to be a member of SABE (Self-Advocates Becoming Empowered) was accepted.

12 webinars were recorded during FFY19. During the live webinars, the Alliance had 116 individual end users as noted by email registration and participation. There were 176 views of the recordings in the video library.

The Alliance continues to be an active and integral part of the annual Speak Up and Speak Summit from participating on the planning committee to co-presenting with self-advocates on several breakout sessions as well as facilitating the open mic speak out session.

The Alliance started its Self-Advocacy Certification Program this quarter with two agencies/organizations who have Member Groups. The Self-Advocacy Certification Program is a year-long process to support the development of and immersion into a culture of self-advocacy at their agency/organization. The Alliance partnered with the agencies to provide training for self-advocates and agency/organization staff; resources for implementing environmental changes as identified in the Action Plan; ongoing consultation related to creating a culture of self-advocacy as identified in the Action Plan.

3. Consumer Stipend 2019 Progress Report

Through the Consumer Stipend program offered by the Arc of Illinois, customers with developmental disabilities and their family members were permitted to attend a conference that they otherwise could not attend without the financial assistance of the program. In 2019, there were 226 applications for stipends and 222 were awarded. 222 people with DD or family members were trained on topics of personal interest. 37 of 89 who responded to the survey indicated they were better able to say what they needed.

4. IL Partner in Policymaking (PIP) 2019 Progress Report



The reinvigorated IL PIP project continued in its second year and Class 2 commenced on November 2, 2018 and concluded on June 22, 2019, hosting 8 intense leadership sessions for 22 participants. After thoughtful review of the applications that were submitted, acceptance letters were offered to 20 parents of children with developmental disabilities and 6 self-advocates. The 26 individuals selected represented broad statewide geographic diversity from the Missouri to the Wisconsin

borders as well as significant ethnic/racial diversity. Class 2 was even more geographically diverse than class 1 as they hailed from 16 counties across the state (Coles, Cook, DuPage, Henry, Jackson, Jefferson, Livingston, Madison, McHenry, McLean, Montgomery, Morgan, Pike, Will, Winnebago, & Woodford). The group also represents a diverse group of disability "labels", including some of the parents. Among the disability labels are: autism and autism spectrum disorder; intellectual disability; seizure disorder; cerebral palsy; sensory-integration disorder; ADHD, complex type; Tourette Syndrome; Down Syndrome; global hypotonia; Trisomy 15; scoliosis; neurogenetic syndrome; mood disorder; microduplication syndrome; feeding disorder; and, auditory processing disorder. As was expected, there was some attrition and four participants did not complete the program for varying personal reasons.

High Impact Mission Based Consulting and core faculty included a host of new advances (after adjusting to feedback provided by class 1 participants), including regular homework, individual 7-month advocacy projects for all participants, and expert faculty who also learned from the participants themselves. Cohort 2 engaged geographically and ethnically diverse groups of parents and self-advocates who met in Bloomington/Normal Illinois for eight intensive 2 day-long trainings led by national experts. Participants experienced the training sessions as transformational (e.g., "This presentation has completely changed how I view employment for people with disabilities") and empowering (e.g., "Becoming part of this community [PIP] really changed my life in terms of who I am and who my people are and what is possible. I learned I could get help with home services

to figure out tools to help me [through PIP], PIP gives me acceptance and empowerment, asking what I need to do this.”). The participants gained knowledge, insights, skills and motivation to better advocate for themselves, their families and people with disabilities across Illinois.

On average, each class member spent close to 8-10 hours per month between classes on their homework as well as researching and developing their advocacy project required for graduation. These hours are in addition to Partners weekends of two full days of information on policies and "best practice" and skill development in a safe and community environment. The two days are long and intense, beginning on day one at noon and concluding at 9:00 pm and beginning on day two at 8:30 am and concluding at 3:30 pm. All Partners participants are required to identify a project that focuses on impacting policy and systems. More detail on projects is provided in the outcome section for this goal.

IL PIP 3rd Party Evaluation:

A 6-month post-graduation and long-term follow-up evaluation is administered to all graduates annually to measure their leadership activities. It is critical that this project evaluate the effectiveness of all aspects of the training to



ensure that the investment by the Council is achieving the anticipated outcomes. The project implements a series of formative evaluation mechanisms to evaluate this training and report results to the Council. The IL PIP program is fortunate enough to have this formal program evaluation conducted by National Lewis University. Judah Viola, Ph.D. Dean of the College of Professional Studies at National Lewis University, is the lead evaluator. Dr. Viola is nationally recognized for his program evaluation expertise and has significant experience in conducting evaluations on services provided to individuals with developmental disabilities. The program evaluation is a unique opportunity to tell the story of a government funded initiative designed to build community capacity and speak truth to power using multiple methods including participant observation, pre-post, and use of social media. The evaluation sheds light on the stimulating empowerment process through training for greater advocacy and activism and there is much evidence to support the successes of the program.

As stated, the National Lewis team conducted 6-month follow-up interviews for class 1 (during the FFY19). The interviews reflected much on how the support, learning, and new insights from the graduates continues even after the 8 weekends of training. The data also came through social media platforms such as the class 2 Facebook group, and through the policy and advocacy events that graduates attended together. The interviews were rich depicting many meaningful impacts for participants. Throughout every outlet, the participants raved about their PIP experiences. On the satisfaction surveys, the participants reported exceedingly high scores for virtually all presenters. They were thrilled with the new information, new skills, and motivation, enthusiasm and connections they felt with the other members of their cohort. Many participants wrote emails of thanks to Allan Bergman and Core Faculty and made many Facebook posts praising PIP and their experiences.

Graduation Day interviews were hosted by National Lewis immediately after the completion of the class 2 graduation. Additionally, brief interviews were conducted with 5 Partners graduates (both self-advocates and parents) from class 1 as part of their 6-months post-graduation evaluation process. The class 1 interviews were video-recorded, and the class 2 interviews were audio-recorded. These interviews were helpful in grasping, while it was fresh in their minds, the value the participants held in the program. They were able to share their motivations for enrolling and the ways in which their thinking and confidence had changed, and their expectations for future advocacy and engagement. All interviewees expressed the value they saw in the

supportive community, the relationships they built across participants, their experiences thus far, as well as their intention to stay connected.

5. Financial Wellness for People with Developmental Disabilities 2019 Progress Report



In January 2019, the Council voted to fund a Direct Investment with the National Disability Institute (NDI) after learning about the impact this organization had while working with other DD Councils across the nation. The purpose of this initiative is to train agencies and/or qualified individuals to conduct financial wellness training to help support financial understanding and empowerment. The purpose is to also create a streamlined communication that will impact economic standards and financial systems for individuals with developmental disabilities. The Council desired to bring resources to Illinois that have been shown effective in assisting people with developmental disabilities and their families to make the best use of their financial resources.

NDI is a national non-profit organization with a mission to drive social impact to build a better economic future for people with disabilities and their families. NDI is the first national organization committed exclusively to championing economic empowerment, financial education, asset development and financial stability for all persons with disabilities. NDI effects change through public education, policy development, training, technical assistance and research.

NDI is bringing rich resources to Illinois that have been shown to be effective in addressing the unique needs of the developmental disability community in achieving financial wellness. By the end of this project, NDI will increase financial wellness capacity, measured by a minimum of 2,000 people with developmental disabilities who will receive financial wellness training through financial education provided by a minimum of 90 Master Trainers statewide. Under this project, NDI will update the “Upward to Financial Stability Train the Trainer Curriculum” (that was previously developed for the North Carolina DD Council in 2014) to be specific for Illinois and retitled the curriculum to “Financial Wellness for Persons with Disabilities Trainer Curriculum.” NDI will create a total of 11 modules:

- Module 1: Money
- Module 2: Financial Capability and Access to Financial Services
- Module 3: Earned Income Tax Credit
- Module 4: Credit Matters
- Module 5: Continuum of Housing
- Module 6: Social Security Work Incentives
- Module 7: Medicaid, and Home- and Community-Based Services Waiver
- Module 8: Self-Employment and Public Benefit Work Supports
- Module 9: Protecting Your Identity
- Module 10: Getting ABLE-Ready
- Module 11: Guardianship Rights



In FFY19, NDI:

- Established an advisory committee that includes representatives from both the disability community (including self-advocates, family members, Council staff and members, and Partners in Policymaking members) and the financial services community to provide technical assistance, guidance, and direction on the proposed opportunities. The advisory committee provides input, reviews the training plan for Year 1, 2, and 3, helps to establish the Trainer Support Network, and provides guidance on the data to be collected. The advisory committee meets quarterly for one hour via conference call and in FFY2019 two meetings took place.
- Hosted the first webinar (as part of the 3-part webinar series) titled Financial Inclusion 101. 114 people across the state registered and 34 participated: 3 self-advocates, 17 family members, 13 service providers, and 9 were identified as “other”. Pre and post surveys are completed by participants to measure capacity building after webinars. It was reported that 64% of the participants increased knowledge on what financial capability is. 71% increased knowledge on how to set and achieve your financial goals. 50% increased knowledge on identifying indicators of financial capability. Overall, 79% increase in knowledge as it relates to the three areas mentioned.
- Developed a blog/article about the initiative, webinar 1 key takeaways, and opportunities to participate in future grant activities.
- Secured the location for the first three-day training in February 2020. The training will take place at the Council’s Springfield office.

6. EPIC (Medical Advocacy) 2019 Progress Report

EPIC began a project in central Illinois to provide training to individuals with disabilities and healthcare providers. The project is just beginning, so development of curricula is in progress and they are reaching out to potential partners. St. Francis Hospitals and Clinics and UnityPoint Health Methodist are identifying training opportunities with medical staff, and medical and nursing students. The University of Illinois School of Medicine will incorporate sensitivity training as well as topic specific training for medical and nursing students. A health screening and advocacy training is nearly complete, and the project is aiming for January to begin presenting to high school students with DD and adults with DD.

7. Ray Graham (Medical Advocacy) 2019 Progress Report

Ray Graham is developing a health resume tool to facilitate people being better to self-advocate for healthcare personalized to them. Individuals will be trained in its use as well as healthcare providers who will access it through the person’s electronic medical record. In its first quarter, the project gathered a steering committee to advise the development of the health resume. Protocols were developed for interviews and focus groups to gather input and assure the product will meet a wide range of needs. They are in discussion with the 4 local hospitals where most people in DuPage County get their healthcare with a goal of linking the health resume to electronic records and training healthcare staff in how to best use the healthcare resume to inform their care of patients with DD. A January 2020 roll out is anticipated for the tool though the project is focused on DuPage County, the plan is to make the healthcare resume tool available statewide to anyone interested in its use.



8. UIC (Medical Advocacy) 2019 Progress Report

The University of Illinois at Chicago (UIC) will provide pre-service training to medical and health professionals. The training will be embedded in their curricula, and the project will also create a network of university programs and a depository of instructional resources to promote sustainability and the potential for expanded use of curricula. Medical programs in partnership are: UIC College of Medicine, University of Chicago Pritzker School of Medicine, Northwestern University Feinberg School of Medicine, the Southern Illinois University School of Medicine at Springfield, and the LEND program at UIC. In the first quarter, plans were begun or in progress at each of the sites. The first two rounds of training were held at UIC including 12 medical students. The first training was held with 25 LEND students (from a range of healthcare professions).

9. CTF IL (Southern Illinois Transition Project) 2019 Progress Report

The CTF SITP project has focused on building collaboration with community partners in order to have a better understanding of available services for transition-aged youth. Through these collaborations, the project is identifying both opportunities and potential barriers for grant participants. One of the first activities CTF accomplished was securing partnerships with Family Matters, Division of Rehabilitation Services, Illinois Association of Microboards and Cooperatives, EIASE (Special Ed Coop), Prairieland Service Coordination, ARC of Illinois, Illinois Self-Advocacy Alliance, EIU Special Education, and others. CTF works with their partners to provide the most natural environment to people supported by the project in targeted activities. The CTF SITP service delivery area is across the following counties: Clark, Clay, Coles, Cumberland, Douglas, Edgar, Effingham, Jasper, Moultrie, Richland, and Shelby.



Navigating the system of services continues to be complicated. Although there are a number of support agencies throughout the community, the project has identified gaps in current services for employment and transportation. Some barriers include:

- Employment supports including the STEP Program, Fast Track and DRS programs have not focused on youth that may need supportive employment and job coaching that extends past the allotted time frames of the programs.
- A second barrier for employment is employer education and exposure.
- Public transportation is limited within the grant area. Challenges with limited door to door service, accessibility, limited routes and hours of availability have all been concerns.

In the grants first year, 45 youth took part in person-centered plans and individual outcomes have been identified and are being pursued. An additional 10 transition-aged youth have been identified to take part in person-centered plans in Spring 2020. Students attending the LIFE Academy in Mattoon participated in a self-advocacy training series and completed the AIR Self-Determination Scale to determine a baseline of their self-determination skills. The AIR will be given again at the end of the sessions, approximately seven months from initial date taken, to assess the effectiveness of the self-advocacy training they receive. One-on-one follow-up was also completed with attendees of trainings. PATH plans will be conducted with each individual served under the CTF SITP grant in the Spring of 2020. Assistance and guidance is being offered to facilitators to identify possible PATH participants.

10. Coleman Tri-County (CTS) (Southern Illinois Transition Project) 2019 Progress Report

CTS Creative Transitions provides a whole life, person centered approach for transition age youth by providing training, advocacy, and opportunities to allow for increased life choices. Transition aged youth with DD and their families are learning skills to teach them to communicate their wishes, self-advocate for supports that assist in the accomplishment of individual outcomes and utilize existing resources within systems of the local school, post-secondary educational entities, Department of Rehabilitation, and Division of Developmental Disabilities. Service delivery area will be across the following counties: Wabash, Edwards, Gallatin, Hamilton, Saline, Wayne, White, Pope and Hardin.



In FFY19, CTS SITP achieved the following:

- Outreach efforts succeeded, and partnerships were formed with the Wabash Ohio Valley Special Education District and Southern Illinois Coordination (which is an Independent Service Coordination agency). They met individually with youth and their families to introduce the CTS Creative Transition Program using materials developed by CTS that explained the services and benefits of participation to individuals and their families. When an agreement to participate in the program is reached, a formal referral form is sent to CTS to implement services. 14 individuals were recruited in year one and 18-19 individuals will be recruited in the 2nd and 3rd years for a total of 50 transition aged youth served by the end of the project.
- Once a referral was received by CTS for the program, the admission and assessment process began. A person centered and strength-based approach of gathering information and learning about the individual (including review of school records, observations, and interviews with the individual served, families, and all members of the team, including teachers, job coaches, personal aides and transition coordinators) has been utilized to develop a Personal Plan of Services. The Personal Plan of Services outlines short- and long-term outcomes, and is developed within 30 days of admission, and is reviewed every six months. A Discovery process (customized employment process) that is comprehensive and tailored to individual needs was also provided. Through this process a finished product was developed that identifies strengths, preferences, needs, supports, barriers, risk factors/safety, relationships/social skills, financial literacy, transportation, current and secondary training/education, career and income, soft skills, health and well-being, communication, assistive technology, and choice/decision making. Outcomes were then developed to address all areas to assist the individual and their family to learn skills and address barriers/challenges to future options for training and/or employment including understanding of the vocational and educational systems available in Illinois for assistance.
- CTS staff are working with each student and family to discover the resources available with DRS and the DHS-DD system. 6 students have open cases with DRS, four do not and two are pending/in the process of being opened. The Employment Specialist has worked with eight school systems to date, educating them on DRS and DHS-DD systems.
- The CTS Employment Specialist has worked with eight school systems so far, educating them on effective Job Coaching. The Employment Specialist also conducted monthly individual meetings using Whose Future Is It Anyway and Self-Advocacy practice.
- Group trainings were provided on the following:
 - Navigating the public transportation system in Southern Illinois presented by RIDES Mass Transit
 - Person Centered Planning and Self-Advocacy presented by Southern Illinois Case Coordination Services
 - IL ABLE and financial wellness

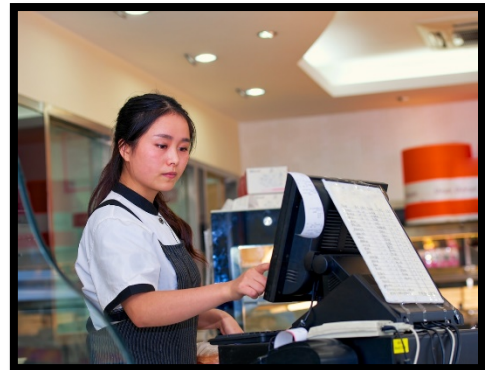
- Introduction to The Arc, the Illinois Life Span Program and website
- Family Support Network of Illinois
- The Arc of Illinois Family to Family Health Information Center, presented by The ARC
- Financial Literacy information presented by Employment Specialist.

In year one, school staff and personnel were welcoming and enthusiastic about the CTS transition program, trainings and information.

11. Lewis & Clark Community College (LCC or L&C) (Southern Illinois Transition Project) 2019 Progress Report

For those students with disabilities who have had few inclusive experiences in high school or who choose not to seek a college credential, the College for Life program at L&C not only provides courses that continue the educational experience, but it also provides inclusive social growth opportunities on a college campus. Through that grant, the L&C team developed transition programming for high school seniors and were able to strengthen linkages with local high schools, including the continuation of a transition project with Roxana High School. In October 2018, the Council voted to fund L&C with aspirations for the College for life project expanding to Edwardsville so that their reach and impact can expand. The L&C SITP service delivery area is across the following counties: Madison, Jersey, Macoupin, Greene, Calhoun.

The L&C SITP team is working to reach their desired outcomes with students in their program through three activities: person-centered planning to advise persons with developmental disabilities on educational and career choices, replication of the College for Life Program at a new site and developing and implementing training in best practices in transition and family financial literacy. The first many months were spent preparing the classroom space and curriculum, in addition to establishing internal quality assurance methods and identifying transition



best practices and tools, as was supported by Sue Walter (SITP Coach). After a site visit from Council staff, it was determined that the project needed course corrections to ensure the College for life was really included on the campus and designed to provide students with integrated experiences in natural settings.

12. Human Support Services (HSS) (Southern Illinois Transition Project) 2019 Progress Report

At the onset of the project, the HSS SITP team focused on building relationships with the schools in the county, striving to understand their individual procedures and practices related to employment and post-secondary education preparation and exploration. HSS was able to identify the unique barriers that each school and community has when attempting to implement their practice with individuals and families. Prior to working with transition aged youth, the HSS team consulted with Sue Walter (SITP Coach) on best practice approaches and tools. It was established early on that the ChoiceMaker self-determination curriculum and the AIR Self-Determination Scale would be used with transition aged youth. In year one, HSS SITP provided person-centered planning, self-determination trainings, and employment services to 24 students and 30 family members. 14 students obtained competitive integrated employment. HSS was also able to secure a location for SITP grant activities thanks to a community partner who offered space rent-free for one year. The office space is utilized for training youth, their parents and families and for meeting space for youth and their families to meet with the Case Coordinator or job coach/education mentor.

Goal 1: Individual & Family Advocacy Impact Stories

1. Speak Up & Speak Out (SUSO) 2019 Impact Stories

Participants who completed the survey shared stories/comments about how participating in SUSO activities in FFY19 helped them to speak up and speak out. Below are some examples of the comments received:

- Met friends that encourage me to move out on my own.
- I get to tell the staff what I want to work on and what I want to do.
- I stopped working on some personal goals (in my personal plan) that I didn't like.
- As an employee, it's an eye opener to see so many individuals not allowing their disability to define them. I am proud to be a part of an organization raising awareness.
- I can say "no" if I want.
- Learn to speak up and speak out.
- It's time for me to do more for myself because I can.
- Being around other people helps me to not be afraid.
- I am the boss of me!
- People told me I could, and I moved out into my own place. They just help me a little.
- It helps me better understand how I can help my clients advance and grow.
- It has helped me be able to speak up about where I want to live. I have recently moved into my own house. Being a part of Speak Up and Speak Out has opened many doors for me to get more involved.
- I spoke out about my position at Walmart being eliminated. I reached out to social media, news stations and newspapers. I received a lot of support. I was eventually offered a new position at Walmart.
- I have exercised more and have tried to eat healthier.
- It helped me because it gave me the courage to use my voice. It helped me grow and become more confident to speak up and speak out.
- I loved going to SUSO. I talked about it a lot in class and to all my friends. Over the past year I spoke up and got a tattoo.
- I love where I live. I had an excellent time at SUSO. I speak up at my meetings and at my discovery meetings.
- I had a wonderful time and learned so much. The classes really helped give me new ideas to use in my classroom.
- SUSO has helped me make decisions in my life. I have a bike. I would like to learn more about bike safety.
- Began acting with Community Play Project & writing for CAB newsletter.
- Our board members decided to become members of the Alliance and we are so glad we did. We now have what seems like endless resources and the wonderful support of our mentor, Tracy.
- I've been participating more at church & in my community.
- Gave me more confidence to speak up for what I think is right.
- Have joined more groups. Leader among my friends and in some small groups.
- Spoke up about wanting to move out of where I was living. I've been in my new apartment for almost a year, and I love it!

2. IL Self-Advocacy Alliance 2019 Impact Stories



James is a highly accomplished advocate; having completed The Illinois Self Advocacy Alliance Ambassador Leadership Program, serving as the Vice Chair of The Alliance Board of Directors and teaching hundreds of people with disabilities and their staff about the importance of self-advocacy at agencies and conferences all over Illinois. In addition, James had the honor of presenting at the 2018 National Self Advocates Becoming Empowered conference in Birmingham, Alabama and was also the keynote speaker at the 2018 annual Speak Up Speak Out Summit in Springfield, IL. In May 2019, James gave a presentation to students with disabilities at his former high school. Students were actively engaged in the presentation and learned the importance of speaking up and speaking out to achieve their goals, hopes and dreams. After presenting, James shared a dream of presenting at a disability service agency from which he received services in the past. Alliance staff are working with him in making that dream a reality.

Below are some comments from self-advocates who participated in Alliance project activities:

- I was able to speak up. I was able to function. I was able to communicate really well. I was able to stress my opinion. I was able to take requests when speaking up about things I want to do. I had the opportunity to talk to different people. Not getting angry and having a good time and feeling confident.
- It helped me to speak up for myself and not be afraid to talk.
- It helped me learn how to be a better self-advocate.
- Going to class and learning about respect and how to be respectful to other people. I learned how to take a friend with you if you get nervous. I learned how to be accountable.
- I let staff know what I need and want.
- I really enjoyed the Ambassador program.
- I enjoy learning better ways to advocate and leadership classes.
- I spoke up about how support staff should be paid more money.
- I participated in webinars and meeting and now I know there are services.
- To talk about my rights, and to be able to get my voice heard.
- I let people know when I want to work and when I don't!
- I did a presentation for the United Way.
- It gave me confidence to do a presentation at SUSO.
- Alliance meeting help me speak up and speak out by educating me about my rights.
- I used to keep everything to myself and now I do not.
- Going to The Alliance activities has helped you advocate for people, listen to others concern, and surround herself with positive people to grow as a better woman, as a person
- I enjoy learning better ways to advocate in class going out and being a great leadership.
- Helps me voice my opinion much better.
- I can express my needs and wants easier.
- I was able to attend the speak up and speak out 2019 summit by speaking up for myself.
- It's helped me by meeting new people and has helped me with finding a new career path.
- I went to the state capitol for the welcome home rally. I was able to voice my opinion.
- When I was on the Alliance board it really helped me understand how to speak up and speak out for myself that others who can't do it for themselves.
- I watch webinars, and I attend peer presentations on speaking up and speaking out.

1. IL Partners in Policymaking (PIP) 2019 Impact Stories



Mary, a PIP graduate from class 2 was named the chairperson of the Transition Parent Advisory Sub Committee. Two other PIP parent graduates are members of that advisory committee as well and assist Mary and the district in identifying ways to increase successful post-secondary outcomes for youth in transition.

Another parent described the personal impact of renewed hope in learning about more progressive policies in other states:

“Before I resisted empathy, I can make a difference, be more involved, loved the activity from Amber from Access Living. Doing tiny things that can help, a renewed sense of hope in supports available and what is possible—even if it is not currently in Illinois.”

Here is one narrative that captures the learning and insight gained through PIP which led to advocacy, hope and a sense of efficacy for the participant, including radiating effects across their school district, benefiting students with disabilities and their families:

“It has reinforced a mental shift that I have been going through.... In regard to inclusion- In previous years, I would have been the parent that didn’t see the point of inclusion, because my son has significant DD.... Because of PIP, my reaction is now cautious excitement... I took the lead with other parents that are nervous about it, I invited other parents to meet the district reps to support the teachers and our kids. My proactive engagement led them to invite me in their interview group for superintendent candidates. I was the parent who could ask the question about inclusion. The superintendent came to know this needs to be on their radar. There has been a relationship established... I am considered their mentor. Making sure the move towards inclusion has parental support. It will benefit the community and kids. This is one very tangible way I am a voice for inclusion in our district because of PIP.”

Sense of community and social capital go hand-in-hand. They are the active ingredients of positive outcomes. While sense of community represents a sense of connectedness and interdependence to one’s community, social capital is about the value of assets in having community connections. While parents certainly felt a strong sense of community with their PIP cohort, they expressed a stronger sense of community throughout the disability community. This following quote shows how sense of community is transparent in their broader home community outside of PIP program:

“Since starting my group, others in the community have taken notice. For me as a parent of a child with DD once the program was done, I started an advocacy group in my rural community, for parents like myself. I get phone calls and opens up a window for conversation in my community that didn’t exist before.”

Six months after completing PIP, every single interviewee spoke of the value and importance of the PIP program building friendships, a greater sense of community for them and social capital they gained. Allan, who ran the program, has an incredibly wide network of contacts in this area throughout the country, and often connected participants to the top experts in the field. This has been useful in building their confidence, helping them access resources and their continued advocacy efforts. Below are a few representative quotes that illustrate this impact of PIP:

- *“The very first thing is it [PIP] gave me a support group. I wanted to learn this as a parent and professional, I used to feel alone and misunderstood. Now I know I have peeps that are always with me.”*
- *“Becoming part of this community [PIP] really changed my life in terms of who I am and who my people are and what is possible. I learned I could get help with home services to figure out tools to help me [through PIP], PIP gives me acceptance and empowerment, asking what I need to do this.”*
- *“Friendships were made with Allan (High Impact CEO), the people in class, and they are resources if I need something. I also got more connections with people in the disability field.”*
- *“The biggest change is the friendship and support network, also the lens how I see things, how things can look like for my daughter.”*
- *“Huge friendship with PIP grads, we go to trainings together even out of state.”*

2. UIC (Medical Advocacy) 2019 Impact Story

The UIC project has 3 session trainings with UIC family medicine students as an internship elective. The current 5 students met with 12 individuals who are served by a near-west Chicagoland provider (medical students and individuals are ethnically diverse) to engage in conversation. Through their contact, the students chose to provide a healthy eating project addressing concerns about the upcoming Thanksgiving and Christmas festivities. During a planning class, they presented research they had done on the topic, decided to offer a smoothie bar, and planned a short training and the smoothie sampling event. They felt this was a fun way to highlight that eating fruits and vegetables can be tasty and enjoyable. The students were very insightful in their comments and reflections about what was of importance to these individuals. One student commented that their over reliance on cheap, fast, not very healthy foods was just like them as students, so they could readily relate. The last session would be back at the provider location for the smoothie event. The faculty noted that this interactive format has proved to highly engage the medical students who are very invested in the project they plan.



Goal 2: Systems Change 2019 Progress Report

1. Going Home Coalition (GHC) 2019 Program Report



The GHC is an advocacy campaign dedicated to full inclusion and equality for people with developmental disabilities. In 2013, ICDD invested in the creation and support of the GHC with the focus on outreach through media and organizing to gain momentum to close state operated developmental centers. Under the Quinn Administration, Howe and Jacksonville State Operated Developmental Centers (SODC) were closed, and there was a significant struggle around Mabley and the Murray Center. The GHC was able to collect and share stories of people moving from institution to community through material, video and the press.

Illinois remains one of the states with the most SODCs. In January 2019, the Council voted to fund the Arc of Illinois again to reinvigorate the Going Home Coalition after extensive strategic planning sessions that took place in 2018 with many community partners and self-advocates. Out of that discussion, the group agreed to expand the focus of the coalition to include the following priorities:

- Identify a policy agenda for the GHC each year.
- Hold one rally each year for the 3 years with a focus on systems change.
- Hold 5-10 legislator coffees each year around the state to develop relationships.
- Create advocacy and engagement trainings and a toolkit for families, hold 2-5 trainings per year.
- Create an administration strategy and identify 1-5 issues that can be changed administratively to impact people in SODCs and those on PUNS list (state run waiting list for funding/services).
- Build relationships with new administration officials in Healthcare and Family Services, Department of Human Services and Department of Public Health.
- Pursue evaluation and report on the cost of the array of care from community living to institutions to better understand the costs and any changes over the past three years.
- Engage a consultant to report at least twice on the numbers of people in institutions, the costs of institutions vs community and other key data points that can be used for media and policy advocacy.
- Create material, website and other communication tools to outreach to policy makers, media and others
- Hold media training / rapid response training for coalition members.
- Plan 3-5 regional meetings with members each year to engage them in issues.





The Going Home Coalition's revised goal is truly person-centered and responsive to programs and systems that ensure people with disabilities have lives that are full and lived in the broader community. Community living is at the core of the coalition both from the perspective of advocating for people to have the opportunity to move people out into the community as well as the idea of more people accessing services in the community. One of the largest advocacy events for this project is the annual Going Home Rally that provides self-advocates the opportunity to reinforce and educate legislators in Springfield. In May 2019, 250

people with disabilities, families and organizations attended the rally in Springfield. More than half of the participants were people with disabilities with the remaining participants consisting of staff, families and allies. Attendees were given folders including fact sheets titled Inclusion First. In addition to seeing Secretary Grace Hou and Ryan Croke, DHS Chief of Staff, at the Capitol that day, the advocates dropped off postcards to the Governor and Lt Governor to share the Going Home vision for Inclusion First. GHC staff continue outreach to key stakeholders previously involved in the coalition and laying out a plan to reach out to the organizational members who brought groups of self-advocates to the GHC rally in May 2020.

The GHC Steering Committee began working in sub-committees of three key areas: Public Policy, Data, and Messaging. These reflect a number of the areas identified during the three-day strategic planning meeting in 2018. The Messaging Working Group has been tasked with coming up with a clear, concise message to share with the public about what the Going Home Coalition represents. The Public Policy Working Group is responsible for developing public policy proposals to bring forward to the new administration. The short-term Data Working Group has been tasked with gathering and sharing data about state-operated developmental centers (SODCs), as well as determine what data is needed to proceed with decision-making. A membership working group will develop out of the messaging work group once the message has been agreed upon/looked at by the whole team.

Over the next two years, GHC staff and leaders will meet with administration officials to begin discussions about partnership on the four key areas: ending the PUNS waiting list, expanding community capacity to support all people regardless of needs in the community, and ensuring people in State Operated Developmental Centers understand and can access community supports and rebalancing away from institutional funding to community.

2. SASSED 2019 Progress Report



Stemming from work under the previous plan to implement an Award of Excellence in Inclusion as part of the state's quality program, SASSED coordinated a Summit to seek Illinois commitment to inclusion as given in the Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs. The Feb. 2017 Summit provided knowledge of the current state of inclusion in early learning and of best practice. In June 2018 a Summit Reconvene was held to review progress in areas identified at the Summit and plan continuing next steps. To move forward the work taken up by existing committees, the Inclusion Subcommittee invited the Early Childhood Least Restrictive Environment Stakeholders (EC LRE) to join

a meeting discussing outcomes of surveys about inclusion. The two committees then held a joint meeting with 40 attendees in March 2019 to share their individual work and jointly plan future work. The project followed up with a meeting of leaders from the two groups to set new goals related to inclusion of young children. The

Inclusion Subcommittee will continue work on the Community based organization (CBO) and school districts (LEA) collaboration efforts at a systems level and the EC LRE Stakeholders will work on the implementation models that will support CBO and LEA once they start collaborating. Public awareness and involvement of families was a major theme, so the EC LRE created a workgroup specifically for that purpose. Workforce continues to be a major theme and ICDD's project with ISU under 2.3 is working in that area. The EC LRE will keep a workgroup on professional development. The inclusion subcommittee is looking at policy issues that support the collaboration of CBOs and LEAs including finance models. Current work under this project is to look at models of successful implementation in community-based child care with support from school districts and documenting those successful strategies for replication.

The Inclusion Subcommittee of the Early Learning Council surveyed school districts and providers about barriers to inclusion and surveyed new graduates of Early Childhood programs to find out what they learned about inclusion and if their first employment experience matched what they expected from their EC education. The results are informing strategy choice. An example is a webinar Tools to Support Inclusion that was developed in response to educators noting the need for better tools and not knowing resources that are available to them. This group is updated regularly on the work of the Council's project with Good Shepherd under 2.3 with an eye to sustaining and expanding the training designed to meet the need to avoid expulsion of young children. The Early Intervention Advisory Council has a workgroup around serving young children with lead exposure. ICDD was able to partner to begin EI services for these children and pilot the service guidelines.

31. Life Choices (NASDDDS) 2019 Progress Report



Under the Life Choices project, NASDDDS facilitated a work group session with DHS/DDD employees in November 2017 that highlighted key priority areas for system reform and set the work plan target areas for the year. Person centered planning and supporting the State on improving the process set forth in the transition to conflict free case management. This includes creation of an Independent Service Coordination (ISC) manual that would detail policies/procedure of all ISC responsibilities. The review of this content is still underway. One of the values that DDD

promotes is independence – least restrictive setting. Each Life Choices workgroup has been asked to keep the values at the forefront of their discussions. Illinois's history of risk aversion has resulted in provider's reluctance to agree to serve people in intermittent or occasional support models.

Many people receive 24-hour CILA simply because agencies such as Office of Inspector General (OIG) hold providers responsible for all risks, regardless of frequency of contact/amount of service delivered. Anything that happens to the person, regardless of whether provider was scheduled to be present or not, the provider is held accountable by OIG. The mindset is similar to the belief that CILA is a medical model, and nurses must be available for every need. The ongoing concern is that if Illinois stands any chance of not over-serving people, this needs to be addressed. As far as DDD knows, this is an interpretation and practice issue; there is no specific place in statute or regulation that says providers are responsible for the full scope of a person's life, even if the services are only occasional. NASDDDS continues to provide counsel to DDD on this topic. NASDDDS has started the discussion of designing a regulatory review process at a high level: identifying the preparation tasks, relevant materials gathering, statute review, etc. The role of the DD Regulatory Review Committee is a challenge. The statute does not give them the authority they seem to have taken, and it needs to be a more useful process than reviewing every line of regulation and seeking agreement.

32. Corporation for Supportive Housing (CSH) 2019 Progress Report



The State of Illinois is one of the most institutionalized states in the United States and is ranked 44th in the country for community inclusion (United Cerebral Palsy Association, 2019). In this environment, there is a growing appetite for alternative housing options among people living with DD and their families. The CSH project sought to engage providers, community members, policymakers, and other stakeholders,

while further embedding supportive housing as an option within the DD community. In pursuit of this goal, CSH:

- 1) furthered an understanding of the overall potential of supportive housing as an option for people with IDD;
- 2) worked with system leaders to coordinate better access to supportive housing resources;
- 3) created tools designed to help self-advocates prepare to live in their own home; and
- 4) provided technical assistance to supportive housing project teams committed to developing and operating supportive housing for people with IDD.

The project activities in 2019 were focused on creating additional digital content, finalizing the product catalogue of digital resources and information, continuing the supportive housing coffee talk calls, and organizing a Peer Exchange trip to Missouri. Workshops and trainings resulted in 259 engaged.

CSH organized a peer learning exchange between Illinois DD staff and Missouri DD staff which produced key recommendations for ongoing systems change efforts. 27 people from Illinois attended the Peer to Peer, including State officials, providers, educators, an ISC membership organization, advocates, parents of individuals living with DD, and self-advocates. All were there to learn about how the State of Missouri “Helps People to Choose Housing like Any Other.” Attending from Missouri were 16 individuals including State officials, Council staff, advocates, providers and more. This group included their Division of Developmental Disabilities Director and their Director of the Missouri Council on Developmental Disabilities along with representation from their regional structure of support services. Missouri officials talked about their journey from a more institutional approach of housing to a still rapidly evolving person-centered approach of housing selection created around the individualized requests and desires of the person requesting support services. The goal of the peer exchange was to learn how Missouri continues to transition to a more individualized housing choice focused system instead of a system based on delivering group services in smaller and larger facilities. The event, combined with learnings from this grant over the past several years, contributed to a comprehensive report which:

- 1) highlights the need for greater alignment between the I/DD service systems’ priorities and the priorities of the mainstream housing and community development sector in Illinois; and
- 2) sets forth a roadmap to meet the housing and service needs of this population.

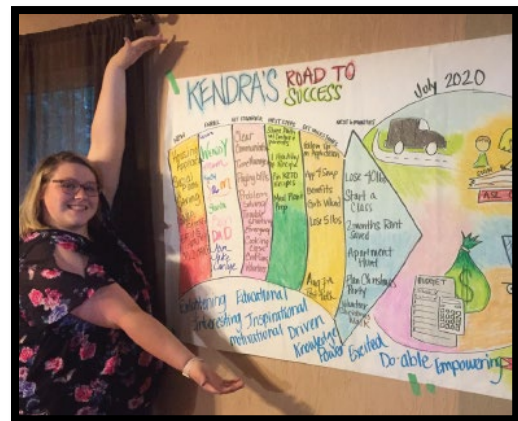
At the conclusion of the project, CSH created a product catalog which details all the materials needed to create the option of supportive housing for people with DD in the future. This includes basic educational materials in English, Spanish, and Polish. CSH created as many videos as possible with captions in both English and Spanish to make the materials more accessible to individuals who are hearing-impaired or have English as a second language.

33. UIC Historical Review 2019 Progress Report

UIC has completed a historical database of all funded projects of ICDD since it began. They completed a presentation on large trends seen over time, such as projects becoming larger in cost and longer in duration as more projects targeted systems change. Quality Assurance is the largest life area category, and about 50% of that is advocacy focused. To better inform an analysis, UIC has begun interviewing UIC has completed a historical database of all funded projects of ICDD since it began. They completed a presentation on large trends seen over time, such as projects becoming larger in cost and longer in duration as more projects targeted systems change. Quality Assurance is the largest life area category, and about 50% of that is advocacy focused. To better inform an analysis, UIC has begun interviewing Council members and other knowledgeable stakeholders about their insights of what Council work has been most impactful and why. A deeper analysis will be presented to our Council members to guide discussion of what Council work would be the best use of our funds under the next 5-year State Plan.

34. Change Champions 2019 Progress Report

Center for Independent Futures made community connections in 4 communities. An additional 5 individuals with IDD were engaged in the matching process to pursue their interests. Community partner entities vary and include: synagogues and churches, Chamber of Commerce, YMCA, city Library, Rotary and Lions Clubs, Pentathletes Estados Unidos Guinones Chicago, Corazon de Valor y Forteleza and others. Many trainings, including self advocates as trainers, took place for employees at the YMCA, library, Chamber of Commerce, Lions Club, etc. 179 people were trained. A technique which was particularly successful was involving people with DD in staff or member “ability awareness” trainings. People with DD sharing their own stories and talents as part of organizational capacity building models inclusion and allowed people with DD the platform to share their experiences and expertise. Participants spoke at the Frankfort Lions’ Club and Lincolnway High School’s Transition Program. The Evanston Library conducted a staff survey on the status of inclusion. The project shared with the Evanston Rotary and Northwestern University students enrolled in “Community Integration of Labeled People”. In Little Village, participants presented to staff of a domestic violence organization where 2 of their people are volunteering and participated in a Conference for Women Leaders. In the north shore suburbs, the project advocated for inclusion at the Pritzker Disability Policy Roundtable. As the project ended, it wrote and posted a Change Champions Guide and a Webinar Series on Asset Mapping.



35. IAMC 2019 Progress Report

IAMC is replicating its community connection model in a rural city. At project start, the community had one adult provider offering traditional services, so they were reluctant to try anything new and risk not using their day program. This year 7 individuals became engaged (PATH created) as well as 70 family members and 40 community members were reached and educated. Presentations were held with Bridgewater, the local mental health provider, Kiwanis, the local school, the new director of the Chamber of Commerce, and First Lutheran Church. The school has invited the young man back to speak with its transition students again. He was a recent graduate of ICDD’s Partners in Policymaking class. The young man who spoke to Kiwanis about employment and his desire to start his own business, was surprised by a \$200 seed money donation by a Kiwanis member. The church wants to adopt circles of support and the Star Raft model from the project. The focus shifted to

sustainability. The baton was passed to the parent group. The decision was made to form a human service cooperative. It is incorporated, named Quality Lives, and has joined the Chamber of Commerce. It held an organizational PATH to set direction. Customized employment is an initial desire. A “Circle builders” group was developed for the PATH facilitators to learn more about person centered planning. Quality lives applied for and hosted the community's ice cream social, which provided an opportunity to share its work publicly and garnered the first \$1000 for the organization.

36. The IN Project 2019 Progress Report



Community Choices used a 3-pronged effort to carve a new niche in the community. The mentor program included adults with IDD as mentors in an existing program in Champaign’s schools. 7 mentors are available, but only 3 mentor-mentee pairs were meeting at project end due to school faculty changes, students moving, etc. Two engaged mentees in discussions of participating in their IEP meetings. The second strategy was to hold community conversations. An advisory board of 6 people with disabilities continues to lead discussion of what issues they wanted to engage in, and identified education, healthcare, housing, and transportation. Engagement with the healthcare community continued to grow as a result of the initial conversation. A Healthcare Professional's Guide to Working with

Patients with Developmental Disabilities was written and disseminated. Corporation for Supportive Housing, another of ICDD’s projects, was invited to meet and discuss potential supportive housing projects in the Champaign-Urbana area. The 3rd strategy was to support people with IDD to contribute to the media. Two women submitted articles to Smile Politely, a popular local online magazine this year and had articles with a disability angle published. As ICDD funding ended, a Guide to replicate the project was developed.

37. Community Play Project (CPP) 2019 Progress Report



KCDD is developing an all-inclusive theater, Community Play Project (CPP). Ten-week weekly classes are offered in the fall and spring sessions on theater skills. Last fall participants were interested in a musical, so learned choreography to a song from Joseph and the Amazing Technicolor Dreamcoat. They learned stage directions, proper warm-ups, too. Spring workshops honed skills as planning geared up for a full production. By summer, Shrek: The Musical was cast, and practices begun to rehearse lines and practice songs. This attracted a full production crew of director, directing intern, choreographer, costume designer, set designer, lighting designer, videographer and stage production manager, as well as actors and mentors. 8 new PWIDD and 40 new community members participated. The Galesburg Civic art Center hosted the group to work on creating costumes. A partnership with the Prairie Players was formed which brings resources and a means for sustainability of the Community Play Project. Shrek was presented to a sold-out house (about 100 capacity) three times in October 2019.

38. Proud & Included 2019 Progress Report

Neumann/ Envision engaged 14 additional people with DD who also identify as LGBTQ for a total of 128 participants. The project refocused in the summer of 2018 from recruiting new members and growing to a goal of embedding leaders in LGBTQ organizations to help the group sustain when ICDD funding ends. The project continued monthly meetings at The Center on Halsted, an organization for LGBTQ activities. Attendance was considerably lower with the shift away from an activity focus in the LGBTQ community. July 2019 provided the



opportunity to reconnect with participants who were invited to join Pride month events with groups Proud & Included had connected with. A contingent marched in the Pride Parade with the Center on Halsted. The Project Manager focused on skills of the 4 ambassadors to take on a leadership role since there will be no paid staff once Council funding ends. This proved a challenge. These included time management, meeting deadlines, and taking over a weekly contact with participants and leading the monthly meetings. For even those who had taken a lead as Ambassadors, there were instances when they were not able to fill a role or attend in part due to their inability to advocate for themselves at their home with staff; their fear of reprisal ran deep despite the rights and self advocacy training they had received through the project. Transportation continued to be a challenge for all who were not able to self travel. As the project sought to connect participants in the LGBTQ community, and additional 34 organizations were contacted, including some churches. A directory of groups and resources was compiled and distributed to participants and the provider organizations supporting them.

39. AID CARES 2019 Progress Report

The Association for Individual Development (AID) began CARES to bring knowledge to a community of how to form a 377 Board in a local area as a means to garner funds through taxes which can be used to bring new options to people with DD in that area. The project is still in the development and planning phase. A marketing entity was engaged to develop a strategy and campaign for local areas to use to get sufficient signatures on a petition to get the issue on the ballot, and then to educate their community ahead of the vote. Formerly, a county needed to pass a 377 Board, but now it can be done on a city, township or other basis, making it more flexible and feasible. An Advisory Committee formed and met to review project deliverables and plan with the consultant. The toolkit that will be the basis for coming statewide trainings is in development.

40. Good Shepherd 2019 Progress Report



Good Shepherd for Exceptional Children (GS) is providing training and technical support to child care centers to assist them in serving children with challenging behavioral issues. This is in response to a new law which disallows expulsion and requires working with the child and if necessary a planned transition. Good Shepherd is the Resource and Referral entity for the west and south suburbs of Chicago and was aware that it was nearly impossible to find a center to accept a difficult child. They partnered with the University of Illinois to also implement this model in the Champaign area. The project developed and is offering a training series for cohorts of child care workers. The Building Better

Behavior Training initially was held in person but has successfully transitioned to a web-based training via Zoom.

This has proved popular with the participants who appreciate the ability to log on from home or anywhere. During this FFY, the first six cohorts were trained, reaching 74 child care workers. The majority are in the Chicago suburbs with only one participant in the Champaign area despite efforts to recruit in that county as well. After completion of the 4 web trainings, a Behavior Analyst makes an on-site visit to each classroom to observe and lend technical assistance in applying what was learned to children in the class identified as having behavioral issues interfering with their inclusion and learning. The project has gotten 7 trainings approved by the Gateways educational system which is how child care professionals in Illinois get their continuing education credits. The project also provides “triage” technical assistance when a child is at risk for expulsion, with 4 new requests this FFY.

41. Legal Council 2019 Progress Report

Legal Council for Health Justice is partnering with the Early Intervention (EI) Program and others to change policy and service protocols for young children with high lead levels. The Dept of Public Health last FFY adopted a lowered blood lead level of 5 micrograms. The project provided input as DPH wrote its revised rules and procedures related to inspection of the home and nurse visiting. Education and advocacy got a bill adopted to change Early Intervention (EI) eligibility to automatic eligibility for children at a lead level of 5. Children were provided EI services in 3 regions to pilot the procedures and service guidelines. Trained therapists in an additional EI service area (increased from 2 to 3 this year) to pilot service and referrals began to be made. Pediatricians in those regions were educated on making referrals to EI. Local Department of Public Health Offices proved strong referral sources. By project end, 138 children had been referred with high lead levels and 38 were receiving EI services and 26 were enrolled in the pilot but not yet receiving service. Educational and marketing materials were developed for EI and other service providers, health care workers, families, including draft EI Service Guidelines and updated enrollment forms, videos, handouts, posters, etc. Presentations on this work were made to 1337 people locally and nationally and multiple articles/blogs were published in magazines and medical journals. A few of the events were: IL Developmental Therapists Assn., Southern Regional Lead and healthy Housing Conference, Rush University Medical Center Grand Rounds, 2018 Housing Matters Conference, American Academy of Pediatrics National Conference, National Collaborative for Education to Address Social Determinants of Health Conference, Association of State and Territorial Health Officials. Publications included: Pediatric Annals, Georgetown University Health Policy Institute, Huffington Post.

42. Envision (Hubs) 2019 Progress Report

Envision Unlimited is changing its service model from large workshops to community hubs, which will ultimately mean all 770 people will be served at hubs, 130 were in hubs at the project start. The project expanded by 120 when Envision merged with another provider. People served, family, and staff from that agency were all trained in the community philosophy and are now incorporated into Envision’s services and philosophy. During this FFY, Diversy (50 people), Sherman Park (15 people), Wendell Smith Park (20 people) opened as new hubs for a total of 9 hubs, with a 10th open 3 days a week, and 362 people attending a hub. The project notes that these statistics are continuously in flux as clients come and go. Several other sites for hubs have been identified and community partnerships are places where there is discussion of future hubs beyond just people being included in activities. Hopefully to open soon are hubs at 36 squared (a business incubator), Dorchester Art Housing Collective, Kimball Art Center, Kroc Center, Chase and Foster Parks, and a storefront location. The legacy Westtown Center has now downsized to become a hub with fewer than 50 people attending there. It has an arts focus and a community commercial kitchen opened this year to monetize the large building. Two of the existing hubs are considering changing location, and Envision notes this is not viewed as a problem but expected and healthy in that they expect hubs to change over time as needs and interests and partnerships change and evolve. All hub staff, participants, and families were previously trained in the new model and throughout the

year refresher training was held as new hubs opened and people transitioned to new places. All Envision participants have a person-centered plan in an online Quantum system accessed by staff and clients via tablets. Individuals are encouraged to track their own progress with whatever level of assistance needed being provided. There are now 95 (up from 75) people who have employment and 300 (up from 220) in regular volunteer positions, 70 (up from 51) of which are “work like” in expectations. Staff are trained in employment methods including the IPS (individual placement service) model to encourage more employment outcomes. Envision participants are involved in numerous community activities and events, a few examples: paid and unpaid work at multiple summer camps for children, presenting to Blue Cross Blue Shield employees, Veteran’s Day Weekend Hunger Heroes event, Chicago Reuse Zero Landfill event, Biking Buddies and Bike the Drive - with video club filming for a Chicago Design Museum exhibit, participating in an Art Institute focus group on accessibility, and much more. Envision clients advocate for themselves and others through participation in agency decision making mechanisms and staff interviews.



43. ISU 2019 Progress Report

Illinois State University (ISU) will improve the professional development of early learning professionals. An Advisory Team is assisting and reviewing work. 56 Gateways (early childhood professional development system) Early Childhood Competencies were coded and analyzed with inclusion standards and best practices. These were linked to existing best practice resources over this spring and those needing resources had them developed. As the resources were connected to the competencies, drafts were presented at the Gateways Higher Education forum and Illinois Association of Early Childhood Teacher Educators to tap experts at those events and to get feedback for improvement. A Landscape Study was completed and distributed. It identifies all Early Childhood education training programs in Illinois and charted detail on what degrees/credentials are offered (pathways to inclusive teaching) and what coursework is required related to inclusive education. The project convened a cross sector Inclusion meeting in August with representatives from 2- and 4-year higher education institutions, Head Start, The Governor’s Office of Early Childhood Development, Dept. of Human Services, State Bd. of Education, STARnet, Early Choices, Gateways, and the Ounce of Prevention. The purposes were to share the inclusion competencies and resources, educate attendees on the Landscape Study and its finding of a highly incoherent system, and to plot future work and next steps.

44. New Star (SCOOT App) 2019 Progress Report

New Star is a provider agency that was funded by the Council to develop and implement an innovative transportation application. For individuals with DD, transportation is paramount in order to live, work, learn and thrive within their communities. Despite public transportation opportunities, however, significant barriers to safe, reliable and consistent 24-hour, door-to-door, accessible transportation still exist. In an effort to provide people with DD more transportation options, New Star worked closely with an App developer to create SCOOT. This required much more time than originally was set aside. There were many roadblocks when trying to get the application developed and then get it approved by the Google Play and Apple Store. During the time of creating the Application, the New Star team created policies and procedures to be followed concerning driver requirements to utilization of the Application and Content Management System. New Star also worked to develop a driver pool and identify consumers that would participate in the pilot project. New Star was able to identify 22 drivers that were ready to move forward with SCOOT and 8 riders that were interested in participating in the pilot program that will allow for feedback and revisions to the app if needed.

45. Roxana Community Schools (Transition) 2019 Progress Report

Café de Shell provides real life opportunity for 25-30 students with developmental disabilities to operate a fully functioning coffee shop on the Roxana Community School District campus. The café is open from 7:30 a.m. to 2:00 p.m. daily during school days. At the beginning of the project, the café had gross sales of \$400 per day by brewing fresh coffee, baking cookies, smoothies, popcorn, parfaits, and other grab and go food items. As the project ramped up, students with all levels of disabilities made the new food item of fresh wraps. Students ordered necessary fresh food items, assembled wraps using standard food safety sanitation practices which were taught to all students within a modified curriculum, packaged for sales, interacted with workers using high level of customer service skills, and provided exchange of payment. Students also managed delivery services of box lunches with many days providing almost 100 lunches.



Students enrolled in an Occupational Knowledge course and learned the key skills needed for successful employment with minimal to no support and food handling certification. Students interested in a first-time job experience, working in the food industry or business field enrolled in the off-campus STEP employment learning. Students increased a variety of job readiness skills as scored on a Transition Planning Committee approved rubric; punctuality: attendance, on-time and prepared to work, calling off, breaks; personal presentation (appearance, hygiene); communication; communication with supervisor(s), communication with co-workers, customer service skills, asking for help, following directions; work-place behavior (displays appropriate attitude, displays appropriate behavior, accepts criticism, recognizes boundaries); work skills: follows work place safety, accepts change (duties as assigned), completes duties, work independently, work unsupervised, good decision making, accountability/accepts responsibility, work speed, multi-task, multi-step, work quality, work endurance. By collecting and reviewing data on a quarterly basis, short term objectives were established for each student and through weekly collaboration of all staff including social worker, speech language pathologist, school psychologist, STEP coordinator, job coach, classroom teachers, ABA specialists, and special education director a coordinated effort to consistently teach skills will be accessible to the students.

Roxana Community School district has been able to maintain the opportunity for supported college transition by funding close to \$30,000 in tuition and supports for our students over the past three years. Students in their senior year were funded to take a class each semester at Lewis & Clark Community College (L&C), with a paid tutorial and mentoring services to support them in the transition process. Students had the opportunity to enroll, complete orientation, take placement testing, complete a supported college transition (SCT) course, and at least one college class of their choosing in the program. The profits from the café of approximately \$8000 per school year were used to fund scholarships at L&C, Southern Illinois University, and Southwestern Illinois College for individuals with developmental disabilities to enroll in classes during their last year of special education services within the district. Funds were used to remove all barriers including access and use of public transportation, purchasing books and supplementary educational supplies, tuition, tutoring, and job training at the post-secondary settings. Funds were also used to support access to College for Life at L&C and New Opportunities job training.

46. Supported Employment Action Team (SEAT) 2019 Project Report



In FFY2019, the Arc of IL worked hard to create systems change by educating individuals and families about the supported employment system, training about advocacy, and coordinating statewide efforts. The goal was to have an organized and empowered group of individuals and families who along with service providers were a voice for changes to the supported employment system so that it can work better for individuals with DD. Once the listening sessions were completed, the SEAT team collected the final surveys, holding a focus group and finally in September,

a Summit. Throughout it all, the SEAT project engaged more than 165 people through the 5 listening sessions in Hillside, Mascoutah, Bloomington, Dixon and by webinar, one focus group of consumers and a survey of 75 respondents. A focus group and a summit with more than 120 in three locations (Lisle, Springfield and Alton) allowed for further engagement. From the key findings and the summit, the advisory group established policy goals for the next year.

SEAT worked with four staff from the Div. of Rehab and the Div. of DDD to create a supported employment and self/systems advocacy training. Systems change occurred through this process because it was the first time DRS and DDD have put together a joint training, and it resulted in meetings between the two divisions on how to talk about the draft implementation plan for the Interagency Governmental Agreement between the two divisions. More than 90 people registered for the training and 60 people attended including 20 people with disabilities, 10 family members, and 30 professionals (service providers, transition specialists, and other advocates). Of the 60 about 35 indicated they had no knowledge of the supported employment system at the beginning of the training, 20 indicated they had some knowledge and 5 indicated they had a lot of knowledge of the system.

47. Urban Autism Solutions (UAS) Breaking Down Barriers (Transition) 2019 Progress Report

UAS is partnering with two schools in the Chicago Public Schools system to provide transition services, community work-based experiences, and job placement to young adults (ages 18-21) with DD. UAS has expanded their programming for students who experience extreme inaccessibility to high quality programs and resources needed to reach their post-secondary outcomes.

Through the implementation of assessments including the Autism Speaks Community Based Skills Assessment (CSA), Adolescent Young Adult Card Sort (AUA-ACS) and the IL DHS Discovery Tool, 30 young adults have completed assessments and 2-year Person Centered Plans and goals have been initiated for each of these young adults. UAS was able to secure a vibrant job coach who reviewed each student's plans to establish skill building and other areas of need. UAS staff collaborated with CPS staff, IEP teams, families, and the students to establish person centered plans that include employment goals, a goal to obtain/renew State ID (if applicable), and at least one goal for community engagement or independent living, depending on the young adult needs and interests. A visual "resume" was created with each student to accompany their person-centered plan. Students received travel training and Community Based Instruction to alleviate the transportation barriers and to build independence and self-esteem.



Goal 2: Systems Change 2019 Impact Stories

1. Center for Independent Futures (CIF) 2019 Impact Story

CIF found a best practice to be multi-lingual application of acronyms and mnemonics. They created LEARN acronym as a way to describe and remember the process of organizational change (Listen, Engage, Act, Review, New). They also created the “5 P’s” (People, Place, Partnerships, Public relation, Policies) as a mnemonic device to organize inclusion indicators. They did not consider how to translate these to Spanish. For example, “people” translates to “gente” and “place” becomes, “lugar”...neither of which start with a “P”! They learned with multiple languages, they needed to consider how acronyms would translate.

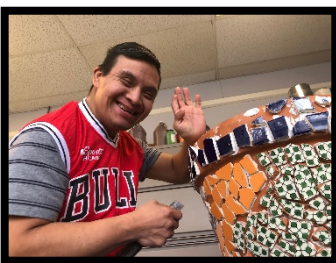
2. Community Play Project (CPP) 2019 Impact Story

KCDD notes growth in CPP participants. One individual who always watched from the sidelines now participates in 100% of the activities without any prompting and tries his hardest to engage in activities. Another is non-verbal but participates in every activity that he can. He has found new ways to communicate using different body language and gestures, and those who could not communicate clearly with him before now are able to find ways to communicate. Participants are advocating for themselves to get rides and attend classes. One community member got picked up one night and his dad asked him if he had many new friends. His son, the CPP participant, said that he had become great friends with Drew (one of the participants with DD).

3. Good Shepherd 2019 Impact Story

"Since initiating triage in August 2019, we've been able to work with staff to identify specific antecedents for challenging behaviors (noncompliance and emotional dysregulation). For example, as a team, we were able to quickly identify a primary trigger as "hair." A'Nyla gets her hair redone weekly by her mother who reports that "A'Nyla has to have long hair...or she doesn't think she's pretty." A'Nyla is highly distracted/preoccupied or "obsessed" throughout the day across settings with her hair (too tight, repeatedly going to the bathroom to check, hand-washing repetitively to look in the mirror). Behaviors increase significantly when hair is tight (scalp folds, white bumps), hair extensions below shoulders, in-face, and/or weighted w/ hair barrettes. Staff were unable to block, interrupt, or re-direct the aforementioned behaviors. Behaviors have impacted her availability for learning from day-to-day. When hair is too tight it also impacts her sleep. Parents have been receptive to feedback. A'Nyla's behaviors have vastly improved since initiating triage. She has required far less direct support averaging 2- hrs of staff coaching per week since we've been able to identify relevant triggers."

4. Envision (Hubs) 2019 Impact Story



Rodney has had long term participation issues and often slept during programming time. When disturbed, Rodney would respond aggressively. He paced much of the day and eloped on a nearly daily basis at his previous day program. Now Rodney cheerfully makes coffee for his program each morning, helps serve anyone needing assistance and washes the coffee mugs afterwards. When asked about Diversey Center, Rodney responded, *"This is not a sleeping program. I love it here and I want to do well."*

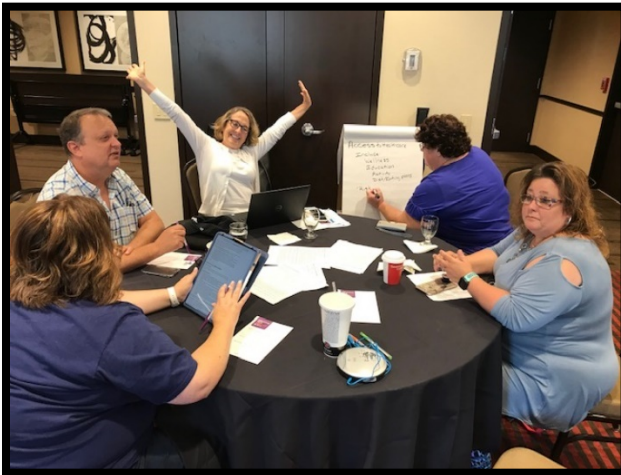
5. Roxana Community Schools (Transition) 2019 Impact Story

- Curtis is a young man w/ multiple disability including diminishing fine/gross motor movement, used the wrap operation assembly line to strengthen his non-compliant muscles.
- After receiving job training at the café, Tommy acquired the skill-set necessary for maintaining employment at McDonalds. Currently, Tommy is in training for his first management position under the Golden Arches.
- Neighboring school district, Edwardsville, will expand their Tiger Den café operations to the Lewis and Clark Edwardsville campus next at school year, influenced by Café de Shell's Roxana Wraps, where students with disabilities will learn the lunch/wrap operation in hopes of going public.



Replication:

The primary goal of Council-funded activities is to produce short and/or long-term system change. The Council encourages replication of Council funded activities and projects. For more information on project implementation, please visit the ICDD website for grantee contact information: ICDD.Illinois.gov.



Council & Staff Activity 2019 Progress Report



We help lead change in Illinois so all people with developmental disabilities exercise their right to equal opportunity and freedom.

ICDD is 100% federally funded yet is still in fact a state agency in Illinois. We are in existence because of federal law, what we call in short, the Developmental Disabilities Act (DD Act). Our federal funds come to the State from the US Department of Health and Human Services and must be used to meet the outcomes of our federally mandated and approved State Plan. The State Plan guides our activities and investments. By law, we cannot fund or supplant services and supports that are funded and/or provided by other agencies. The vast majority of our funds are used to support people and organizations in the State for activities that focus on systemic change activities, capacity building activities and advocacy services that benefit people with intellectual and developmental disabilities. Our underlying premise is that people with intellectual and developmental disabilities have the same rights and opportunities as all other Illinois citizens. We work across a person's life span. In order to meet our mandate, our work is accomplished through a variety of activities that include:

- We fund investments and demonstrations of new and innovative approaches to leverage systems change in Illinois to benefit people with intellectual and developmental disabilities and their families;
- We are involved in policy development with the various state agencies to reflect best practices in the field of intellectual and developmental disabilities and shape the future system of services; and
- We also collaborate with other agencies and organizations to implement change to help position the State to be a leader in the field of intellectual and developmental disabilities.

Council staff works hard to establish linkages with organizations, individuals and agencies to implement Council policies and represents the agency on internal and external work groups, committees and task forces. Staff conducts extensive research on State and Federal laws, policies, regulations and develops recommendations for the Council on issues that have an impact upon individuals with developmental disabilities. Staff also lead in the facilitation of the Council's Call for Investment process.

Staff Activity 2019 Progress Report

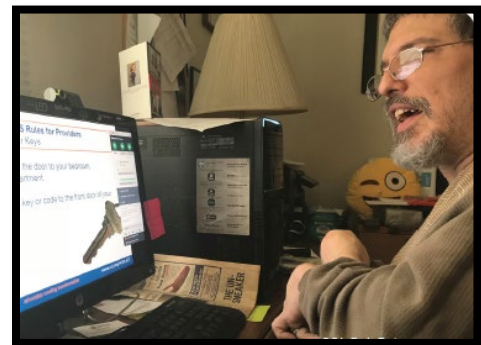


Staff at the Illinois Council on Developmental Disabilities is guided by the Council's 5-year state plan and is led by Director Kimberly Mercer-Schleider. The team is comprised of six employees who focus on fiscal operations, programs, and policy. Staff is divided between Springfield and Chicago with statewide responsibilities in implementing the Council's core values and goals. The Council is often looked at as a key collaborator, supportive neighbor, convener, and expert advisor to the state's many state and community agencies, families, and people with developmental disabilities. With over 30 projects in FFY2019, the program staff worked hard to provide quality grant monitoring and project evaluation to ensure real impact and systems change. Staff's skills, experience, and knowledge in this field allow them to contribute to the initiatives and mission of the organization.

The Director and program staff currently participate in over 10 taskforce/workgroups across the state. Below, is a description of progress and impact through staff activities in FFY2019:

ISC Transition Advisory Committee: The ICDD Director was asked by IL Secretary to Chair advisory group. Advisory group met to create a series of recommendations for DHS/DDD on how to better implement a process of contracting that could result in individuals and families having to receive independent service coordination services (ISC services) from a different provider. The advisory group detailed the perspective of self-advocates/families that consisted of Partners in Policymaking graduates and Council members. This effort resulted in a document of 15 recommendations which was presented to DHS leadership.

IL HCBS Settings Rule: Ongoing advocacy on this topic has resulted in a formal letter being delivered to DHS to detail stakeholder concerns from 9 different advocacy groups across IL. Results of these efforts led to ICDD Director in partnership with CQL Director to train IL DHS/HFS Staff on Settings Rules 101 to bring the new administration up to speed. 40 people trained. Subsequently, Kim was asked to train again, but this time specifically for Bureau of Accreditation Licensing Certification (BALC) and Bureau of Quality Management staff (roughly 40 at that time as well). Kim has also had the opportunity to advocate for IL on the national level through interactions with ACL and CMS on the topic. The level of awareness of settings rules and the importance of compliance has increased among DHS staff. Another direct result of the training was the awareness that DHS Medicaid waiver service rules had to be screened for settings rule compliance. The Council was able to leverage the co-current contract with NASDDDS to provide preliminary settings rule compliance review to guide the next phase of rule 115 edits. As of this moment we still do not have an initial plan approved with CMS but the need for stakeholder input has been shared through Council advocacy efforts.



Community advocacy agencies came together and sent a letter to the Division of Developmental Disabilities, HFS (Medicaid agency) and The Council sharing their concern about the need for greater transparency, consistency, clarity and urgency in Illinois in the effort to fully implement the federal Home and Community-based Services (HCBS) Settings Rule. The Council was asked to:

- Act as convener and facilitator for stakeholder meetings;
- Support DHS and HFS with training materials and on-site trainings through the HCBS ACT project completed in partnership with Council on Quality Leadership; and
- Continue to work with national and state experts to support Illinois in moving forward with fidelity and accountability for valued outcomes in implementation.
- Department of Human Services hiring committee for new DDD Director: Council Director participated in recruitment and hiring committee of new Division of DD Director who started in September of 2019.

Early Learning Subcommittee: Council participation keeps us abreast of State Board of Education rules and policy. This session, HB355 amended the school code to require 15 of 120 required hours of professional development be inclusion training for teachers to renew their license. The State Bd. of Education removed a proposal for licensed teachers to get an early childhood special education endorsement by padding a content test rather than completing the stricter training requirements currently in place. ICDD was able to speak on behalf of quality education for children with delays and IEPs in other policy meetings.

Early Intervention Advisory Council: The Early intervention Advisory Council is another place where ICDD is able to ensure information is shared and used. The Early Intervention Program is working toward automatic eligibility of young children at risk due to high lead levels under legislation passed in spring session. Legal Council (see 2.3) is piloting this now and EI will be ready to implement the new policy statewide on 7/1/20. Another impact is seen in growing coordination between EI service providers and Maternal, Infant, and Early Childhood Home Visitors. This has come about from recommendations at the Summit held by SASSED. They are sharing training now and looking at how to share referrals.

Employment First: implementation is slowed, and Employment & Economic Opportunity for Persons w/ Disabilities Taskforce activity was minimal this year with a change in administration. Many of the committee members left state employment and it took months to get the new co-chairs identified and agency representatives named by new agency Directors.

Chicago Mayoral Task Force on Employment and Economic Opportunity for People with Disabilities: was comprised of 26 members representing workforce agencies, disability leaders, job seekers, employers and representatives from local and state government agencies. Council staff were active members. The Task Force defined four areas of focus and specific recommendations aimed at improving the employment outcomes of people with disabilities. Four work groups were formed in which a report providing each group's recommendations was finalized and shared.

Interagency Committee for Employees with Disabilities (ICED) Taskforce: Council staff remained active members of ICED task force, which held regular meetings to plan activities that promote and expand access, opportunity, and independence within State employment.

SELN Membership: The Council funded membership to the State Employment Leadership Network (SELN) engagement and is partnering with the Div. of Rehab and Div. of DD. IL is currently in this nationwide learning cohort that includes many other states who have recently made significant policy shifts in their employment service provision.

DD Network Collaboration 2019 Progress Report



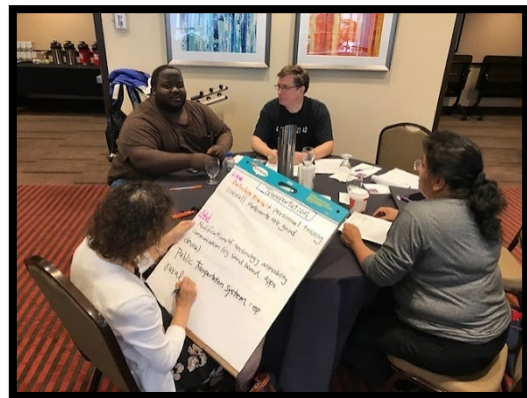
The Council, under previous plans, funded an entity to work with self-advocates in Illinois to determine their interests and desires in coming together for self-advocacy and advocacy on issues. At that time, there was not a strong state-wide organization. As a result of that work, The Self-Advocacy Alliance was formed, linking several regional and local groups into a network under “The Alliance”. The Alliance has continued to grow in numbers and in scope. It is led by self-advocates and has a growing number of people stepping into leadership roles. The sister agencies are all encouraged by the enthusiasm seen in The Alliance and readily agreed that bringing the resources of each agency

to the benefit of The Alliance was something all desire, and The Alliance leadership welcomes working with the sister agencies to increase the impact of its members.

As a result of Council facilitation, in March 2019, the Public Policy Director from the P&A spent two days with the Partners in Policymaking cohort during the legislative themed weekend which included members of the Illinois Self Advocacy Alliance in the cohort. She presented on current relevant legislation, as well as supporting participants through a Capitol tour, legislative advocacy preparation, and role play with participants and legislators in order to practice delivering succinct, impactful advocacy stories.

A UCEDD staff is provided to the Alliance to help the network develop and support member groups and help support ambassadors. This UCEDD staff member additionally took over supporting the Alliance Board of Directors, and does other tasks as needed. Another Council/UCEDD/Alliance collaboration has come in the form of collaborating on the UCEDD’s webinar series that shares the latest in cutting edge research, practice, and policy from experts on a range of topics related to disability. They have included the Council and the Alliance in the dissemination of the webinar series as well as collaborating with the Alliance on one webinar within the series.

Alliance leadership is much stronger as a result of all of these collaborations. There have been three Alliance members who have been appointed to the Council as members. Others have been active participants in policy tables within the Division of Developmental Disabilities and active with IL Partners in Policymaking.



Goals for Illinois at a Glance



Supported Living

Access and supports for supported living with individually controlled leases.



Self-Directed Supports

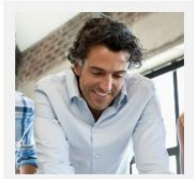
Service delivery for individuals with developmental disabilities who wish to exercise more choice, control and authority over their supports.



Reduction in PUNS

People are selected off PUNS at a reasonable pace.

Outreach to individuals and families to determine future desires for supports.



Active Self-Advocates

Self-Advocates are included, valued, and heard. Systems change efforts are implemented in partnership with self-advocates.



Rebalancing

Adequate funding is available to promote community living as an option and choice for where people with I/DD live in Illinois.



HCBS Rules

Public education on community living and benefits of inclusion.

Measures of Collaboration in Reaching Goals:

Nationally, IL suffers a reputation of being far behind other States when it comes to innovation of services, ranking 44th in the nation. Unsurprisingly, IL remains with only 6 other states not having an initial transition plan approved with CMS. In addition, with IL still out of compliance with the Ligas Consent Decree, there was a need to come together to recommit to the settings rule through stakeholder engagement, greater education and training, and transparency among state employees, community organizations, people receiving services and families. The UCEDD, P&A, and DD Council, along with Centers for Independent Living, ARC of IL, and IL Self Advocacy Alliance came together to raise this critical issue with a new Governor's administration to kickstart new leaders' learning curves.

The above-mentioned groups met regularly to strategize on approach which resulted in a multi-stakeholder letter that advocated for the following:

- Immediately planning a stakeholder meeting to discuss the transition plan and follow up with at least quarterly stakeholder meetings through 2022
 - Prior to this meeting, make current version of IL STP publicly available if edits have been made since first public posting of STP
 - Provide stakeholders with category 1 and 2 setting designations and talk stakeholders through validation process that has brought the work to where it is today
 - Share specific feedback from CMS received to date and State's efforts to implement feedback
- Providing vision of implementation of heightened scrutiny process in response to additional guidance provided by CMS
- Reviewing and updating the transition plan with stakeholder input with the goal of CMS approval by a date determined by CMS/DHS/HFS
- Creating and sharing with stakeholders Illinois' strategy to coordinate between HFS and DHS for consistent interpretation and implementation of the plan

- Inclusive of a rules/policy review to determine specific rules/policies that inhibit HCBS settings rule implementation and plans to amend these rules/policies
- Sharing your strategy for education of all key department staff including licensing and compliance staff about the HCBS settings rule
- Identify a point person within DHS to serve as support for providers working to come into compliance with HCBS settings rules

The expected outcome of the advocacy points above are twofold. Ultimately increased stakeholder engagement in the creation of a statewide transition plan and a much overdue initial plan approval that puts IL on the way to implementing the new rule requirements with fidelity. Ongoing advocacy on this topic has resulted in a formal letter being delivered to DHS to detail stakeholder concerns from 9 different advocacy groups across IL. Results of these efforts led to ICDD Director in partnership with CQL Director to train IL DHS/HFS Staff on Settings Rules 101 to bring the new administration up to speed. 40 people trained. Subsequently, DD Council Director was asked to train again, but this time specifically for Bureau of Accreditation Licensing Certification (BALC) and Bureau of Quality Management staff (roughly 40 at that time as well). DD Council Director has also had the opportunity to advocate for IL on the national level through interactions with ACL and CMS on the topic. The level of awareness of settings rules and the importance of compliance has increased among DHS staff. Another direct result of the training was the awareness that DHS Medicaid waiver service rules had to be screened for settings rule compliance. The Council was able to leverage the co-current contract with NASDDDS to provide preliminary settings rule compliance review to guide the next phase of rule 115 edits. As of this moment we still do not have an initial plan approved with CMS but the need for stakeholder input has been shared through Council advocacy efforts.

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