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# ICDD ANNUAL REPORT





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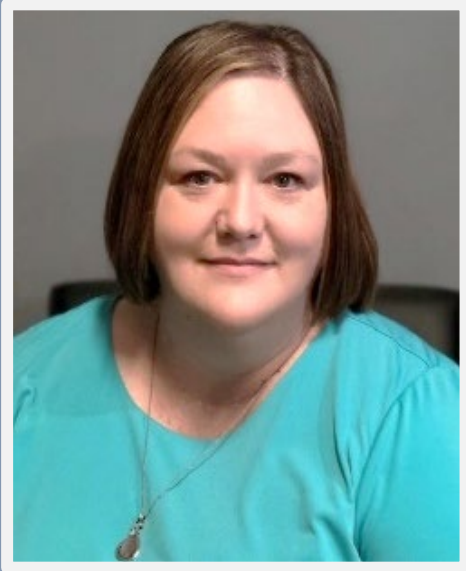
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Foreword by

# Stephanie Brown

ICDD Chairperson



January 1, 2023

The Honorable J.B. Pritzker  
Governor, State of Illinois  
401 S. Spring St.  
Springfield, IL 62704

Dear Governor Pritzker:

Please find attached the 2022 Annual Report from the Illinois Council on Developmental Disabilities (ICDD or the Council). This report details the Council's mission, membership, goals, impact, and budget. Our federal charge is to help lead change in Illinois so all people with developmental disabilities (DD) exercise their right to equal opportunity and freedom. Our underlying premise is that people with DD have the same rights and opportunities as all other Illinois citizens. We are an advisor and we work across a person's life span. We are involved in policy development with the various state agencies to reflect best practices in the field of developmental disabilities and shape the future system of services. We fund investments and demonstrations of new and innovative approaches to leverage systems change in Illinois to benefit people with developmental disabilities and their families.

As a mother of a pre-teen son living with Autism, my vision for Illinois is to focus on **education** and **advocacy**. I want Mason to have a choice to live in a community that includes and welcomes him. I would like Illinois to make improvements to the system and become an example for the rest of the nation to follow when it comes to the way we break down barriers and make sure that Illinoisans with ALL abilities have the opportunity to live a life like any other!

The Council is here to help lead the way! Please enjoy reading our 2022 Annual Report. We look forward to all of our work in 2023.

Best Regards,

Stephanie Brown  
Board Chair, Illinois Council on Developmental Disabilities

A handwritten signature in white ink that reads "Stephanie Brown". The script is cursive and elegant.





**MABB Tribute** | In May of 2022, after a year of planning, purging, and packing, the Chicago office relocated from the James R. Thompson Center (JRTC), where it had been located since 1985, across the street to the Michael A. Bilandic Building (MABB). The MABB was built in 1920 and has 21 floors. It was formerly known as the State of Illinois Building and was the former seat of state government until 1985 when the JRTC opened. The building was later renamed after former Chicago Mayor and Chief Justice of the Illinois Supreme Court, Michael A. Bilandic. Although the JRTC was internally adorned with many fine works of art, the MABB has an external massive stainless-steel sculpture titled *Free Form* that was designed by Chicago Artist, Richard Hunt. The sculpture was installed on the exterior of the building on the façade in front of the 7<sup>th</sup> and 8<sup>th</sup> floors. Richard Hunt (b. 1935) had an interest in harmonizing the tension between the natural and industrial, the organic and the abstract, along with the traditional and the contemporary. ICDD Chicago staff are working remotely but can be found on the 10<sup>th</sup> floor of the MABB occasionally. Reach out to see if we are downtown if you are ever interested in coming to check out our new space.



# Illinois Council on Developmental Disabilities

## Who We Are & 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 on Community Living (ACL). Our mission is to help lead change in Illinois so all people with developmental disabilities exercise their right to equal opportunity and freedom 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 makes investments in people and organizations that serve people with disabilities throughout the State of Illinois. 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.

# Illinois Council on Developmental Disabilities

## Meet the Council

### Council Members

Membership consists of **60%** people with DD and family members. 2022 Members: Curtis Harris (Cook), Nathan Joerndt (Livingston), Ana Cruz (Madison), John Porter Jr (Sangamon), Tavarus Wesley (Cook), Stephanie Brown (Jackson), Teresa Parks (Woodford), Lisa Cesal (DuPage), Bill Bogdan (Will), Diana Braun (Sangamon), Adam Cooper (Madison), Zoubida Pasha (Cook), JJ Hanley (Cook), Jose Ovalle (Cook), Barbara Pritchard (Champaign), Jeff Stauter (Lee), Julie Stover (Lawrence), Tyson Bedford (Henry), Diane Compton (DuPage), Natasha Croft (Cook), Carl Nave (Macon), Robert (Bob) Peterson (DuPage), Consuelo Puente (DuPage), Julie Tracy (Cook), Suzanne Aaron (Cook).



### State Agency Representatives

1. Department of Disability and Human Development, University of Illinois at Chicago
2. Department on Aging
3. Office of Management and Budget
4. Department of Children & Family Services
5. Illinois State Board of Education
6. Department of Healthcare and Family Services
7. Equip for Equality
8. Department of Human Services, Division of Rehabilitation Services
9. Department of Human Services, Division of Developmental Disabilities
10. Department of Human Services, Bureau of Maternal and Infant Health

### Interested in applying to the Council?

These are Governor appointed positions with a two (2)-part application process:

Step 1 --- [Apply Here](#)

Step 2 --- [Apply Here](#)



### Join the ICDD Listserv

Join the ICDD listserv by emailing [ICDDInfo@illinois.gov](mailto:ICDDInfo@illinois.gov)





## Five-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.

**Individual & Family Advocacy Goal 1: By September 30, 2026, a minimum of 1000 Individuals with developmental disabilities and their families knowledgeably advocate and take part in decisions that affect their lives, the lives of others, and/or systems. Objectives:**

1. By September 30, 2026, ICDD 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.
2. By September 30, 2026, individuals with developmental disabilities, their families, and other stakeholders will increase their knowledge and access to coordinated, streamlined information about services and supports, and will increase opportunities to advocate for their priorities among accessible and effective service systems.
3. By September 30, 2026, in collaboration with community partners, ICDD will reduce service access barriers and decrease the disparity in available information for linguistically diverse communities (inclusive of but, not limited to: Spanish & Polish) and increase the cultural competency of the DD service delivery system by providing information in languages other than English to increase inclusion of linguistically diverse individuals with DD and their families in at least 3 aspects of the service delivery system.

**Systems Change Goal 2: By September 30, 2026, support systems will be optimized to increase stakeholder capacity, improve employment systems, community housing options, and post-secondary outcomes for youth in transition (ages 14 - 26). There will be 3 identified issues impacted and support provided to racial or language minority communities in at least 3 disparate geographic locations. Objectives:**

1. By September 30, 2026, ICDD will promote participation of people with developmental disabilities in Employment First activities, increase stakeholder capacity, and advocate for legislative and policy changes to increase competitive integrated employment.
2. By September 30, 2026, through interagency collaboration, a minimum of one (1) systemic change will be achieved in the area of housing / community living resulting in increased access for people with developmental disabilities to housing of their choice.
3. By September 30, 2026, ICDD will address any unanticipated emerging needs (e.g., natural disasters, pandemics, etc.) for individuals with developmental disabilities and families.
4. By September 30, 2026, ICDD will assist/facilitate three (3) or more individualized, flexible, and/or responsive services and supports for individuals with developmental disabilities.
5. By September 30, 2026, ICDD collaborates with other state agencies, advocacy groups, and/ or researchers to improve state systems for individuals with developmental disabilities.
6. By September 30, 2026, ICDD, Equip for Equality (EFE) and the Institute on Disability and Human Development (IDHD) at the University of Illinois Chicago will facilitate at least one policy and/or programmatic initiative to increase successful post-secondary outcomes for transition age youth (ages 14-26) in the area of employment, post-secondary education, and/or post-secondary training, and independent living.
7. By September 30, 2026, ICDD will support at least three (3) regionally significant racial or language minority communities in at least three (3) disparate geographic locations in Illinois to enable people with developmental disabilities to access a life like any other by increasing their inclusion in educational systems and related social settings.



# 2022 Investments

The Council makes investments (i.e., grants or projects) to a wide variety of organizations and individuals to help improve the lives of people with disabilities and entire communities. Calls for Investments are made throughout the year. The Illinois Council on Developmental Disabilities does not accept unsolicited proposals. All funded activities are chosen by our Council to meet the goals and objectives of our 5-Year State Plan.

Investment Name	State Plan Alignment	Area of Emphasis
(1) *IL Self-Advocacy Alliance	Goal 1 / Objective 1	Advocacy
(2) Speak Up & Speak Out	Goal 1 / Objective 1	Advocacy
(3) Consumer Stipend	Goal 1 / Objective 2	Training
(4) *Financial Wellness for Persons w/ Disabilities	Goal 1 / Objective 2	Advocacy
(5) Better Communication Better Health Care	Goal 1 / Objective 2	Health
(6) Medical Advocacy	Goal 1 / Objective 2	Health
(7) CTS Creative Transitions	Goal 1 / Objective 2	Employment
(8) Transition Oversight	Goal 1 / Objective 2	Education
(9) ISC System Redesign	Goal 2 / Objective 4	Formal / Informal Community Supports
(10) The Going Home Coalition	Goal 2 / Objective 4	Advocacy
(11) Inclusion Everywhere	Goal 2 / Objective 4	Early Intervention
(12) *Project Initiate	Goal 2 / Objective 4	Early Intervention
(13) Competitive Pay and Meaningful Days	Goal 2 / Objective 1	Employment
(14) Disability Hiring Models	Goal 2 / Objective 1	Employment
(15) *Supportive Housing Technical Assistance	Goal 2 / Objective 2	Housing
(16) Policy Project	Goal 1 / Objective 2	Advocacy
(17) *Customized Employment Training Series	Goal 2 / Objective 1	Employment
(18) *HCBS Technical Assistance Pilot Project	Goal 2 / Objective 4	Formal/Informal Community Supports
(19) Leadership Institute Project	Goal 1 / Objective 2	Formal/Informal Community Supports
(20) SCOOT App	Goal 2 / Objective 4	Transportation

**\*Please note: On pages 7 – 13, 2022 outputs (i.e., activities), outcomes (i.e., results), and stories are shared for all of the investments highlighted above in blue.**



# Financial Wellness



**2022 OUTPUTS** | The [National Disability Institute](#) (NDI) influences thinking and behavior through pioneering research, advocacy, policy development, training and technical assistance. They collaborate with hundreds of organizations throughout the country—from financial institutions and employers to government and community agencies—to empower people with disabilities and their families to build a better

financial future. NDI received funding from the Council to provide rich Financial Wellness training and resources in Illinois. The purpose of their initiative is to train agencies and/or qualified individuals to conduct financial wellness training to help support financial understanding and empowerment and to 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, their families, and support networks to make the best use of their financial resources. In 2022, NDI continued to offer all virtual training, events, and monthly trainer support network support meetings. During 2022, the Financial Wellness initiative developed new materials based on needs expressed by the trainers, provided training and technical assistance to trainers through the Trainer Support Network, and developed videos to provide real life stories of individuals working towards and achieving financial wellness. New materials created included decision and comparison guides on types of transactional accounts, and all resources created were sent out to a vast audience not only in Illinois, but nationwide. NDI created streamlined communication.

**2022 OUTCOMES** | In 2022, 88 trainers remain engaged in providing financial wellness training and education. Over 1,000 people have accessed blogs or webinar recordings during 2022 with the most popular webinar recording being on housing. Financial wellness trainers throughout the state of Illinois trained 10,367 people on financial wellness and provided resources, and of those 5,855 were people with a developmental disability and 4,512 were family members.



**IMPACT STORY** | NDI offered online Financial Wellness training opportunities for self-advocates to avoid social isolation during the Pandemic. An individual that took the training reported that before the training he had a bank account but did not understand how to use it or review statements to understand his spending or that he could have a separate savings account. After taking the training and reviewing his expenses, he realized he was spending \$400 a month of his SSI income on cable TV and internet. As a result of this training, he became empowered to look for other services and providers and switched to an internet plan and streaming services that add up to \$100 a month. He now looks at his bank statement every month and realizes the importance of saving. He learned the importance of putting bill due dates on a calendar or paying them right away. He reported, *“Now, I’m making money and not spending it right away. It feels secure. It feels safe to the point that it is there if I want it. If I need to use it, it’s there, but why spend money right away when it can just sit there and earn interest?”* Another result of the training is that he has learned to carry a debit card rather than cash. He realized it was too easy for people to take advantage of him when he had cash. He is better able to track his spending with the debit card. He reported, *“After taking the training, I feel like I have more control of my money, on how I spend my money. I know where my money is going versus before.”*



# Customized Employment (CE)



**2022 OUTPUTS |** Throughout 2022, Marc Gold & Associates (MG&A) continued to provide the Customized Employment Training Series that was started in 2021 to support the development of Customized Employment (CE) and Systematic Instruction (SI), to build service capacity, and to provide information and resources to stakeholders that included agency provider staff, state agency staff, self-advocates and their families. Employment First policies and the Workforce Innovation and Opportunity Act of 2014 (WIOA) established the expectation that all people can work and that everyone can contribute in their community. The project offered 5 rounds of gateway trainings that included the topics of Discovery, Customized Job Development, and Systematic Instruction, which is an ACRE (Association of Community

Community Rehabilitation Educators) endorsed training curriculum in employment services with an emphasis in customized employment, with 153 participants and of those there were a total of 84 participants who successfully completed both the Discovery and Customized Job Development gateway training and received a National Certificate of Achievement certifying their completion of the 40 hours of training. For those who completed the gateway training a series of 6 Community of Practice webinars were offered. The community of practice webinars covered developing power packed visual resumes, engaging employers, utilizing customized employment services and who can benefit, The intersection of Discovery, Customized Job Development and systematic instruction, engaging families in the CE process, addressing challenges with CE, conducting the CE plan for employment, and CE for families. This project also offered a series of 5 webinars for 141 state agency staff from the Division of Developmental Disabilities and the Division of Rehabilitation Services which covered the documents of discovery, the documents of customized job development, engaging families, and how to use the benchmarks of quality checklist.

**2022 OUTCOMES |** During 2022, 84 employment professionals, including 2 ICDD staff, successfully completed both the Discovery and Customized Job Development gateway training and received a National Certificate of Achievement certifying their completion of the 40 hours of training. A total of 145 ACRE certificates have been issued as a result of this project. This training has allowed those who have completed the training to be able to better support people with developmental disabilities and peers in implementing customized employment throughout the state while working to obtain community integrated employment.



**IMPACT STORY |** An Illinois mother was interested in CE because she knew there had to be opportunities for her son that others had overlooked. When she went through Discovery, immediately she recognized the potential of CE to successfully support her son to successfully move in community-integrated employment. She connected with a provider who was also taking the Discovery training and initiated services for her son. The provider is talking about how they can expand their reach once the person taking Discovery is ready to take on more clients.



# Supportive Housing



**2022 OUTPUTS |** The Supportive Housing (SH) Navigator Technical Assistance (TA) Project began in December 2021. The focus of outputs in 2022 were in developing the program framework/functionality (baseline program definitions, job descriptions, and roles and responsibilities) and moving to support implementation that commenced in July 2022. The core audience of the technical assistance project are seven (7) Independent Service Coordination (ISC) agencies and their executive leadership and program staff. The broader stakeholder groups such as potential service recipients, service providers, and policy makers are engaged through the 7 ISC's, the Council, and the state Division of Developmental Disabilities

staff. The Supportive Housing Navigator Technical Assistance Program created a meeting and engagement structure that included engagements attended by all 7 ISC's. The monthly program development meetings occurred between March and June to establish the program framework, implementations and key decisions.

As part of its overall support for this supportive housing initiative, ICDD awarded funds to our sister agency, IDHD at UIC to conduct an independent evaluation of the supportive housing pilot to begin in 2023. The intent is to document the required costs as well as analyze the operation and success rate to have data to take to policymakers so that supportive housing can be made a permanent option statewide with the necessary budget allocated. In 2022, seven (7) Independent Service Coordination (ISC) agencies were awarded start-up funds in an amount up to 5k each to ensure newly established Housing Navigators have what is needed to begin working with people with DD who are seeking transition assistance into community living of their choice (i.e., renting an apartment or home). With these funds, ISCs were able to purchase essential items for participants.

**2022 OUTCOMES |** The focus on the Supportive Housing Navigation Technical Assistance Program was on design, training, and supporting early implementation to document the needed changes to policy, procedure, and best practices. The Housing Navigator staff were hired between July and August 2022, and received onboarding training in August 2022. Direct client support and the implementation of several best practices (Housing Transition Fund, Housing Navigation Supports, Housing Assessment/Statewide Referral Network) did not begin true implementation until the end of the 2022 reporting period. Outcome data is expected in 2023.



**IMPACT STORY |** The Council will have impact stories to share in 2023.



# HCBS Compliance

**2022 OUTPUTS** | Illinois' quest towards compliance with the final Home and Community Based Settings (HCBS) Rule was still very much a relevant issue in 2022. Seeing a need for technical assistance for HCBS providers seeking to come into compliance lead to the HCBS TA project in partnership with Council on Quality Leadership (CQL). Initially, project staff met with 19 pilot sites to

evaluate their need for assistance and develop a plan to meet their needs. Each of the organizations received customized technical assistance and policy reviews to assist with their efforts. Project staff assisted organizations in the development and/or revision of 109 policies dealing with HCBS. Educational efforts were also conducted including a recorded webinar tailored to individuals receiving HCBS services (reaching 674 people), a recorded webinar tailored to direct support professionals supporting people receiving HCBS services (reaching 1,131 people), and a live webinar on guardianship and the rights of people receiving HCBS that reached the maximum 500 attendees. Other outputs of the project include documents developed by the state Division of Developmental Disabilities that were reviewed and edited by project staff including informational bulletins, an accessible version of the IL residency agreement for people receiving HCBS and assistance in the development of the Illinois HCBS Site Validation and Evidence Collection document.

**2022 OUTCOMES** | The technical assistance provided to the 19 organizations was a critical resource which enabled them to successfully develop and amend policies and practices that are impacted by the HCBS Settings rule. Without the guidance provided, many of the organizations would have continued to struggle to come into compliance. Educational efforts were sorely needed in the State, as only about half of organizational leadership reported being very familiar with the rule. Staff were even less familiar (respondents indicated almost 60% were NOT very familiar). Respondents indicated that the people they support, and family members were almost all NOT familiar with the rule (88%). The exposure to training and resources on the settings rule is essential in increasing awareness of the rights outlined in the rule. By making the materials available online on YouTube, people receiving services, direct support professionals, guardians, and providers will have a lasting resource they can turn to whenever they want a refresher on the rule and the mandates it contains.



**IMPACT STORY** | Provider staff that have received technical assistance on the HCBS Settings rule have enthusiastically embraced the knowledge and have expressed their appreciation for the support. They liked that they were able to share policies with us to be reviewed without fear of being judged – CQL was merely there to support them to come into true compliance with the rule. This strengths-based, partnership approach proved very beneficial when working with the providers.



# Early Intervention



**2022 OUTPUTS** | Project INITIATE is a research project at Neonatal Intensive Care Units (NICUs) at three large teaching hospitals. The project began at Northwestern's Lurie Hospital under a grant from the Patrick Magoon Foundation to provide home physical therapy to infants at discharge until they were served by Early Intervention. ICDD funding allows expanding the Lurie participant pool and expanding to 2 additional hospitals. Data is being gathered to determine if uninterrupted therapy

produces better outcomes for the infants. If so, the intent is to use the data to advocate for expansion of this project and legislative inclusion of support in the budget. The project data is being awaited by the Early Intervention Bureau, the Raising Illinois Project and other early childhood advocates having drawn considerable anticipation for the results and final report. Beginning the study was much slower than planned due to the hurdles of completing the internal research board (IRB) requirements. Lurie began in spring 2022, University of Illinois hospital enrolled their first infant right at the end of the FFY, and U. of Chicago Med. Center has not started. The INITIATE project has been very well received by the Lurie NICU staff and parents. A process flow was developed for the project, and it has worked well as a pathway. The INITIATE research team meets weekly and communicates regularly regarding the infants that meet study inclusion criteria, those enrolled in the study and the overall process. Ninety-five percent of the parents, who have infants that meet eligibility criteria and have been approached, have consented to be in the study. Lurie's two in-house therapists have met the competency requirements for the INITIATE therapist education. This training included the operations in the NICU, mental health stressors, precautions after surgery and opportunities for resources for the families. All members of the team have reviewed and have a better understanding of the Early Intervention automatic-qualifier criteria and location of the Illinois Child and Family Connection Sites. Connection calls between NICU therapists and in-home therapists have provided important continuity for the caregivers. A data entry system, Red Cap, was created and team members were trained to submit data. All NICUs have identified project staff and trained them in the procedures and their roles. Recruitment has occurred at a rate of 1-2 patients per week and Lurie also identified its cardiac ICU as an additional unit for potentially eligible patients. The project was approved by the Cardiovascular Research Review Committee and the IRB in September 2022. The first intervention infant was recruited from the CICU in October. At the end of FFY 2022, 19 infants were enrolled in the research project.

**2022 OUTCOMES** | Project Initiate began with \$25,000 from the Patrick M. Magoon Institute for Healthy Communities. ICDD chose to join as a funder after the researchers attracted other money. Parents have been extremely positive about the in-home intervention sessions. Physical therapy has started on infants in the intervention group within several weeks after discharge. This NICU to home therapy model is very accelerated compared with a retrospective data analysis completed prior to starting the study. Evidence-based physical therapy consisting of strength based learning, motivational interviewing, routines based interventions, just right challenge, and active motor cognitive activities are included in the weekly therapy sessions.



An important aspect of this study is identifying if parental stress and quality of life (QOL) are impacted by a seamless transition to home-based physical therapy services immediately after hospital discharge. Though the project does not yet have the data to compare the parental stress at discharge and at the 3-month follow-up visit, they can look at the NICU discharge QOL data from a limited number of participants. Interestingly, there was not a clear trend at NICU discharge related to parental QOL. Some parents reported concerns in the domain of physical functioning, while others identified concerns related to the domain of worry, social functioning, or family relationships. This speaks to the heterogeneity of the population enrolled in the study. When the parents were asked if they were worried about their child's future, 44% (8/18) of parents replied "sometimes", 6% replied "often" (1/18) and 22% (4/18) replied "always." The project looks forward to analyzing the comparison data in the next several months.



# Early Intervention

- Continued -

**IMPACT STORY** | A mother of a baby who participated in the INITIATE project wrote:

I would love to share our story and experience with INITIATE PROJECT. My family and I are extremely grateful (and baby) for the help and care we have received. It was hard enough to understand and navigate our son's needs let alone help him in a way that was conducive to his growth. The wonderful nurses (navigator) and therapist have done the most amazing job by helping our baby. We owe his progress to them. Our baby was born in May 2022. He was diagnosed with Down syndrome. Because of his low tone and oxygen deficiency he had to stay in the NICU for about a month. When we found out about his diagnosis early on in the pregnancy, one of our biggest concerns was how are we

going to have our baby stay on track with kids his age? Having a baby with special needs, we were aware that he would require a lot of help. We spoke to doctors, nurses, and therapists in the NICU. We spoke to other parents and did our own research. We then understood what needed to be done. We were going to ask for help from anyone that would listen. We were told about Early Intervention Programs and the obstacles we might face. It was scary. About a week or so before our baby was discharged from NICU, we were told about "Initiate Project" which we were told was a program that was gathering information on kids with special needs and premies and the importance of these kids getting the help they need as soon as possible. We could not agree more. We understood that the sooner our baby would start receiving the help he needed, the sooner he would be as on track with his development as possible. We cannot describe how happy we were when we received the call from the project navigator. Now he is 4 months old and we have seen big improvement with his development, gross motor skill and cognition, and we hope it improves even more once early intervention services begin. We are extremely grateful for all the therapy he received from the kindest and caring Initiate physical therapist. She worked so hard to teach us the exercises that our baby would benefit from. I have learned that if babies receive early intervention services as soon as they are discharged from NICU, they can really benefit!

A second family of a child who experienced a NICU stay and completed the INITIATE program shared their reflections on this experience. This mother reports that she was somewhat familiar with the NICU, as her older child was born prematurely. She reports that she was appreciative of the therapy her child received in the NICU and had an excellent experience transitioning from the NICU therapies to home-based physical therapy. She appreciates the regular check-ins by the home therapist to make sure that her child is developing appropriately. She was taught activities to do with her infant in the NICU, and it was nice to be able to advance those exercises at home as her child progressed. She has worries, however, because the INITIATE program will be ending shortly for her child, and she has not yet had any contact with Early Intervention. Despite a referral being sent from the hospital to Early Intervention at NICU discharge, it has been over 4 months and she has not received a call from a service coordinator. Not only does her child not have ongoing therapies through EI, but she has not even had an intake meeting or evaluation.

This experience is impactful for our INITIATE team. Though EI reports on the time a family waits from intake call to evaluation, the system does not track the time from the actual EI referral to the intake meeting. This child has already waited one-third of a year to be introduced to their service coordinator, and this wait data does not appear to be used to impart policy decisions. We are hoping that with the results from the INITIATE project, experiences will be different for families whose babies are being born in the future.





# Self-Advocacy

**2022 OUTPUTS** | The IL Self-Advocacy Alliance is a statewide advocacy organization where self-advocates continue to work together to support the mission and vision of the Illinois Self-Advocacy Alliance (The Alliance) and each other. They continued their focus on training and empowering individuals with DD to become self-advocates and take on

leadership roles whenever possible. The Alliance has been a fierce network of self-advocates who engage in local action to improve their lives, the lives of others, and to change local service systems. Information was shared with the Alliance community via monthly newsletters, email listserv, posts on social media, and the Alliance's website. In FFY 22 the Alliance worked to increase public outreach and marketing to become a more visible organization and to increase self-advocate membership statewide, and to mentor a self-advocate to take on a leadership role in the organization. In 2022, The Alliance achieved and exceeded some of the project goals as the grant came to an end in December 2021. The Alliance continues to provide community outreach and grew from 40 member groups to 42 in FFY 22, exceeding the project goal by 2 member groups. Member groups are a network of self-advocacy groups and self-advocates who continue to work locally and statewide to advocate on issues that include transition, community living, home and community based services, and employment. The Alliance continued to provide most grant activities in virtual format via Zoom as a result COVID, and slowly began to host in person events and travel for presentations again.

**2022 OUTCOMES** | The Alliance developed and mentored 52 people with DD; increased local community group membership to 42 active groups representing all regions of Illinois; increased involvement and active participation in systems change advocacy through partnerships and inclusion in coalitions with disability and non-disability entities; 725 people with developmental disabilities have participated in activities designed to increase their knowledge of how to take part in decisions that affect their lives, the lives of others, and/or systems; 85 family members have participated in activities designed to increase their knowledge of how to take part in decisions that affect their lives, the lives of others, and/or systems; 775 professionals educated through activities; 41 Member Group Chapters Participation in more than 18 committees statewide.



**IMPACT STORY** | A self-advocate and Alliance staff were walking through the updated Discovery Tool template that was shared by the Division of Developmental Disabilities (DDD). It was noted in the Discovery Tool under Autonomy and Independence, that the guidance speaks very briefly to supported decision-making in relation to wanting to learn skills and/or participate in the supported decision-making process. Since Supported Decision making is now recognized legally in Illinois as an alternative to guardianship, the self-advocate felt strongly that it should be given more prominence. The self-advocate emailed the acting Director of DDD to start a conversation about supported decision making around the language and options in the Discovery Tool for a possible future revision.



# Financials at a Glance

The Illinois Council on Developmental Disabilities (ICDD) is 100% federally funded through the Developmental Disabilities Assistance and Bill of Rights Act.

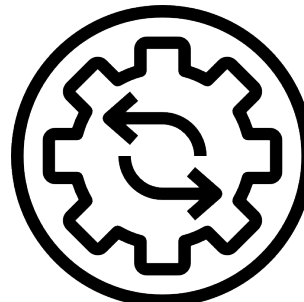
State councils on developmental disabilities receive federal funds through the U.S. Department of Health and Human Services, and are funded by the Administration on Intellectual and Developmental Disabilities.

Each year, the Illinois Council on Developmental Disabilities awards nearly 56% of funds received to investments around the state.

These investments align to the Council's 5-Year State Plan in the goal areas of Individual & Family Advocacy and Systems Change. Remaining funds cover Administrative Costs.



Individual &  
Family Advocacy  
=  
**\$1,117,702.91**



**+**  
Systems  
Change  
=  
**\$900,868.68**



**+**  
Administrative  
=  
**\$689,634.02**

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**Grand Total for Federal  
Fiscal Year 2022 =  
\$2,708,205.62**





# ICDD 2022 Annual Report Closing Statement



Thank you for taking the time to read about the important work we are doing to change lives for people with developmental disabilities in Illinois. I would like to share a big thanks to the ICDD staff team for their dedication and service to our Council. In addition, THANK YOU to our members who show up to advocate for a future they want and who roll up their sleeves with us to make it happen. We cannot do this work alone. In Illinois, we continue to face huge issues that present barriers to people living a life like any other. From housing, to language access, to employment, to provider shortages, we still have so much work to do to ensure people with developmental disabilities have access to equal opportunity and freedom. We look forward to 2023 and continuing progress.

Stay in touch with us to learn how you can help.

Sincerely,

Kimberly Mercer-Schleider  
Director

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### Helpful Links

[ICDD Website](#)  
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