

ICDD FFY 2023 Annual Report

Illinois Council on Developmental Disabilities

FFY 2023
Annual Report





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As we reflect on the past year, it is with great pride that I share with you the remarkable achievements of the Illinois Council on Developmental Disabilities. Our commitment to advocacy, empowerment, and inclusive policy has yielded significant outcomes that have positively impacted the lives of individuals with developmental disabilities across our state.

One accomplishment this year has been the success of our investment in The Illinois Self-Advocacy Alliance activities. Eighty percent of individuals surveyed reported that they have transitioned into active advocacy roles, demonstrating a powerful shift towards self-empowerment and community engagement. We also celebrate the graduation of 22 individuals from the Illinois Partners in Policymaking Course, equipping them with invaluable skills to influence policy and drive meaningful change.

Additionally, six ICDD Members were appointed to prestigious boards and commissions. These appointments reflect our commitment to diverse representation and impactful leadership. In collaboration with the Illinois Division of Developmental Disabilities,



Council Chair Stephanie Brown

we launched a groundbreaking Supportive Housing pilot program. This initiative, facilitated by Housing Navigators, has already begun assisting individuals in transitioning from home or residential facilities to supportive housing, fostering independence and community integration. Looking ahead to the upcoming Illinois Legislative Session, we are proud to have spearheaded the "Dignity in Pay" Coalition, which seeks to eliminate subminimum wages in Illinois, promoting fair compensation and dignified employment opportunities.

These accomplishments underscore our unwavering dedication to advancing equity, inclusion, and opportunities for all individuals with developmental disabilities in Illinois. As we continue to forge ahead, we remain committed to our mission of empowering individuals, driving systemic change, and ensuring that every voice is heard and valued.

Thank you for your continued support and partnership in this journey towards a more inclusive and just society.

Warm regards,

Stephanie Brown

Stephanie Blown

Chair, Illinois Council on Developmental Disabilities

WHO WE ARE & WHAT WE DO



Above: Illinois Council Members and Staff

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 (DD) exercise their right to equal opportunity and freedom. ICDD works to promote the independence, productivity, integration, and inclusion of those with DD into the community, ensuring that those individuals with DD have the same opportunities as others in the community. Moreover, the purpose of ICDD is to ensure that people with DD 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 DD throughout the State of Illinois.



ICDD follows the federal definition of DD, 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.

MEET THE COUNCIL

Council Members

Council Membership consists of 60% people with DD and family members. Members:

Stephanie Brown (Jackson), Tyson Bedford, (Henry), Diana Braun (Sangamon), Lisa Cesal (DuPage), Diane Compton, (DuPage), Adam Cooper (Madison), Natasha Croff (Cook), Ana Cruz (Madison), Curtis Harris (Cook), Nathan Joerndt (Livingston), Carl Nave (Macon), Teresa Parks (Woodford), Zoubida Pasha (Cook), Robert (Bob) Peterson (Rock Island), Consuelo Puente (DuPage), Jeff Stauter (Lee), Julie Stover (Lawrence), Julie Tracy (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

Staff Members

Kimberly Mercer-Schleider, Director Kimberly.Mercer-Schleider@illinois.gov

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The ICDD Staff hosted a group from South Korea, which visited the Chicago Office of ICDD.



EVERY FIVE YEARS, THE DD COUNCIL DEVELOPS A STATE PLAN WITH GOALS AND OBJECTIVES TO ADDRESS NEW WAYS OF IMPROVING THE LIVES OF ILLINOISANS WITH DEVELOPMENTAL DISABILITIES. SELF-ADVOCATES, FAMILIES, STATE AGENCIES, PROVIDERS, EDUCATORS, AND OTHER STAKEHOLDERS PROVIDE INPUT INTO THE DEVELOPMENT OF THE STATE PLAN.

GOAL 1: By September 30, 2026, a minimum of 1000 Individuals with DD and their families knowledgeably advocate and take part in decisions that affect their lives, the lives of others, and/or systems.

Objective 1: By September 30, 2026, ICDD will strengthen a program for the direct funding of a State self-advocacy organization led by individuals with DD; will support opportunities for individuals with DD who are considered leaders to provide leadership training to individuals with DD who may become leaders; and will support and expand participation of individuals with DD in cross-disability and culturally diverse leadership coalitions.

Objective 2: By September 30, 2026, individuals with DD, 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.

Objective 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 three (3) aspects of the service delivery system.

FIVE YEAR STATE PLAN - GOAL 2

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 three (3) identified issues impacted and support provided to racial or language minority communities in at least three (3) disparate geographic locations.

Objective 1: By September 30, 2026, ICDD will promote participation of people with DD in Employment First activities, increase stakeholder capacity, and advocate for legislative and policy changes to increase competitive integrated employment.

Objective 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 DD to housing of their choice.

Objective 3: By September 30, 2026, ICDD will address any unanticipated emerging needs (e.g., natural disasters, pandemics, etc.) for individuals with DD and families.

Objective 4: By September 30, 2026, ICDD will assist/facilitate three (3) or more individualized, flexible, and/or responsive services and supports for individuals with DD.

Objective 5: By September 30, 2026, ICDD collaborates with other state agencies, advocacy groups, and/ or researchers to improve state systems for individuals with DD.

Objective 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 (1) 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.

Objective 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 DD to access a life like any other by increasing their inclusion in educational systems and related social settings.

2023 Investments: ICDD makes investments (i.e., grants or projects) to a wide variety of organizations and individuals to help improve the lives of people with DD 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 ICDD to meet the goals and objectives of our 5-Year State Plan.

Investments (By Short Name)	State Plan Allignment
(1) The IL Self-Advocacy Alliance	Goal 1 / Objective 1
(2) Speak Up & Speak Out Summit	Goal 1 / Objective 1
(3) Financial Wellness	Goal 1 / Objective 2
(4) Economic Justice Initiative	Goal 1 / Objective 2
(5) NLC Virtual Leadership Institute	Goal 1 / Objective 2
(6) Policy Project	Goal 1 / Objective 2
(7) Better Communication Better Health Care	Goal 1 / Objective 2
(8) Consumer Stipend Project	Goal 1 / Objective 2
(9) Partners in Policymaking	Goal 1 / Objective 2
(10) Customized Employment Technical Assistance	Goal 2 / Objective 1
(11) Supportive Housing Pilot Project	Goal 2 / Objective 2
(12) Supportive Housing Transition Assistance Fund	Goal 2 / Objective 2
(13) Increasing the IL Supportive Housing Pipeline	Goal 2 / Objective 2
(14) Supportive Housing Evaluation Project	Goal 2 / Objective 2
(15) SCOOT Application	Goal 2 / Objective 4
(16) Life Choices Technical Assistance	Goal 2 / Objective 4
(17) Project Initiate	Goal 2 / Objective 4



THE ILLINOIS SELF-ADVOCACY ALLIANCE Project Spotlight

A statewide advocacy organization, The Alliance empowers self-advocates to speak up and speak out about their wants and needs, and to participate in advocacy at the personal, community, and statewide levels. In 2023, The Alliance focused on training and equipping individuals with DD to become self-advocates and take on leadership roles. 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. In 2023, a total of 449 people with DD participated in The Alliance activities. Eighty percent of people surveyed reported back that they are now participating in advocacy activities. In 2023, 328 people participated in The Alliance Trainings on the rights of Self-Advocates, Voting, and the Home and Community Based Services Settings Rule. The Alliance collaborated with the Illinois Department of Human Services' Division of Developmental Disabilities and the University of Illinois at Chicago's Department on Disability and Human Developmental to create an inclusive language version of the document "Rights of Individuals Receiving Medicaid Home and Community-Based Services Developmental Disability Waivers."



ILLINOIS PARTNERS IN POLICYMAKING Project Spotlight

Illinois Partners in Policymaking is a leadership program that trains individuals with DD, family members of people with DD, and professionals to participate in activities that will impact systemic change, pursue leadership positions in the community, and advocate on policy issues that will increase opportunities and inclusion for people with DD.

In 2023, 22 people with disabilities and family members, including siblings, successfully completed the class. Over the course of four in-person sessions and three remote sessions for the class, information and training were provided on a wide range of topics by a diverse group of experts. The experts included Partners in Policymaking Graduates and the trainers also included the National Disability Institute, another ICDD Investment, which delivered a Financial Wellness Training.

As part of the graduation requirement, each participant is required to design and implement a class project. Class members present on their projects as part of graduation day festivities. Class members are expected to use their skills to continue project implementation beyond graduation day. A few examples of projects include: The Development of Artificial Intelligence in the discovery process for Customized Employment; presentations to raise awareness on the issue of seclusion and restraints in schools; and the development of resources to support people with sensory disabilities at the Dentist's office and the Doctor's office.

Congratulations to the Partners in Policymaking Class Four Graduates.



MARC GOLD & ASSOCIATES Project Spotlight

Marc Gold & Associates (MG&A) completed work begun in 2021to increase the capacity in Illinois to provide Customized Employment methods to individuals who could benefit from this highly personalized process. In total, this project trained 92 Illinois professionals to provide Customized Employment. In 2023, MG&A also presented "Discovery as a School to Work Transition Strategy" and "Deepening Employer Negotiation Skills Using the Employer Needs and Benefits Analysis" to further enhance skills of employment providers. MG&A fostered connections among the employment providers with experience to those who were new to this services area, knowing that identifying resources and connections is a key element of success.

This project opened participants' minds so that they could see possibilities for the people with whom they were working. This possibility-focused mindset is at the heart of Customized Employment and translates into staff seeing people differently throughout all of the services that they are providing – whether for employment or otherwise. Training attendees frequently shared how the training was impacting their thinking in this very positive way. Another interesting collateral gain had to do with introducing this information to parents and families, many of whom left the training very excited about what might be possible and connecting to providers who were able to conduct Customized Employment services for their sons or daughters.



INFINITEACH Project Spotlight

As the Covid pandemic crossed the globe, people with disabilities were found more at risk for various reasons. The Centers for Disease Control (CDC) reached out to Developmental Disability Councils and Areas on Aging to target populations who were especially vulnerable.

ICDD invested in a project with Infiniteach to share educational information on vaccines early in the pandemic. Given the success of the first projects, the CDC offered additional funds to continue the effort to keep those with disabilities protected through the latest vaccines. Infiniteach stepped up again to expand educational offerings on the Vax for All website and to host vaccine clinics.

Seven vaccine clinics were held in partnership with Chicago Internal Medicine Practice and Research (CIMPAR), administering over 143 vaccinations. Each vaccine clinic was held in conjunction with an event or at a location where individuals from the DD community were convening, with the goal of increasing access and reducing vaccination anxiety. 1-2 Peer Coaches were at each clinic to support outreach and vaccination support to individuals.

The Vax for All website supports the work of the clinic with resources and tools. New to the website is an interactive, video and scenario-based online medical provider training, which presents research, strategies, and resources for how to support patients with DD, autism, and other disabilities. The training includes research, interviews with Autistic adults, scenarios, and interactive comprehension checks.



SUPPORTIVE HOUSING TRANSITION FUND

In July of 2022 ICDD and the IL Department of Human Services Division of Developmental Disabilities (DDD) partnered on a pilot program to bring housing navigation services to qualifying individuals with DD. In order to provide these services DDD supported Housing Navigator positions at each Independent Service Coordination Agency Statewide.ICDD is providing expert technical assistance to the Housing Navigators, providing a program evaluation of the project, and funding a Transition Assistance Fund to support folks who otherwise could not afford essentials to move and be successful in their new community-based housing. Each ISC received a \$10,000 initial payment from ICDD to start their transition fund. Each participant has access to up to \$2,000 in these funds to purchase items such as, but not limited to: apartment application fees; security deposits or move-in fees; utility connections or deposits; furniture; linens and bedding; dishes; other household essentials; and moving costs. The Housing Navigators use a Transition Needs Assessment tool with each participant to assess essential items to purchase for their new home.

In 2023, 34 people with DD were able to move into housing by utilizing the fund.



SUPPORTIVE HOUSING SUCCESS SPOTLIGHT: FINDING INDEPENDENCE AND MORE SPACE

A 28-year-old male with DD was living in a small house with his family, including his brother and sister. All of his belongings were in just one room of the house. The young man and the family were working with a navigator through the Supportive Housing Transition Fund. At first, little happened in the housing process. But after several months, when the navigator contacted the family, they moved quickly, touring the property, signing the housing lease, and receiving the apartment keys all on the same day. The unit is a great fit, within walking distance of the man's bank, restaurants and a grocery store. With a space to call his own, the young man can be independent, which means many things, including traveling around the neighborhood on his own, and watching television without worrying about what his brother and sister are watching. According to the young man's mother, the 28-year-old self-advocate is a man of few words, but when he walked into the apartment, his face beamed and he exclaimed, "Oh! I like this!" When asked if she worried if her son would be lonely, his mother said confidently, "No!"



SUPPORTIVE HOUSING SUCCESS SPOTLIGHT: BRINGING A FAMILY BACK TOGETHER

Living in a shelter, a young woman regained custody of three of her children and secured a new home with the support of her Housing Navigator and the Supportive Housing Transition Program. In their new apartment, the family eagerly searched for beds, frames, and linen, and utilized the Chicago Furniture Bank to secure new furnishings to help make their new space a home. Settling in, the family assembled the beds themselves, proactively learned about their responsibilities as tenants, including lease compliance, and obtained utility assistance and rental insurance. Soon after moving into the apartment, the mother had to figure out how to maintain the in-home support that her family provided before transitioning to the apartment. The children's grandmother now helps, spending weekdays with the family and taking the kids to school. The mother earned a driver's license, enrolled her children in an After School program, and plans to study to become a phlebotomist. Reflecting on the journey of trial and triumph, the mother and the family credit their successful transition to a "willingness to endure."

POLICY WORK

The Illinois Council on Developmental Disabilities engages on policy issues that are related to ICDD's mission to "lead change in Illinois so all people with developmental disabilities exercise their right to equal opportunity and freedom." In some cases, ICDD serves in an advisory role. In other cases, we actively raise awareness and educate on critical issues. Below is a listing of a few policy issues on which we worked in 2023.

Money Follows the Person (MFP): MFP is a Federal Program sponsored by the Centers for Medicare and Medicaid Services. The program aims to increase capacity for housing and services in community settings. ICDD efforts seek to require Illinois to pursue Federal MFP Funding.

Choate Transformation: A transition initiative of the Illinois Department of Human Services designed to repurpose an existing state institution and give residents the opportunity to move into a setting of their choice.

1115 Demonstration Waiver: The 1115 Demonstration Waiver is designed to address health disparities by focusing on social determinants of health. IL Healthcare and Family Services (HFS) applied for this waiver to improve the lives of Medicaid recipients through a vast plan of program enhancements inclusive of innovations for people with DD in the areas of housing, employment, and community integration.

Access Rule: The Access Rule addresses critical dimensions of access across Medicaid and managed care delivery systems. The rule seeks to improve access to services and healthcare.



POLICY HIGHLIGHT DIGNITY IN PAY



A Rally for National Disability Employment Month

In 2023, ICDD committed to Illinois House Bill 793 - The Dignity in Pay Act. When passed, IL HB 793 would phase out subminimum wage for people with disabilities, ensuring that all people with disabilities who worked would be guaranteed a fair wage. In 2023, to prepare for the 2024 Legislative Session, ICDD joined a coalition of advocacy groups, providers, and state agencies committed to the elimination of subminimum wage. ICDD also began to build the Dignity in Pay Advocacy Team. The team includes family members, self-advocates and allies who would be ready to take action in 2024, educating and raising awareness around Dignity in Pay. ICDD also launched a public service announcement, which featured self-advocates speaking directly about the dignity of competitive employment, and the inequity of sub minimum wage.

ICDD AND SOCIAL MEDIA

In 2023, the ICDD rebooted its Facebook and Twitter (X) pages, and launched a YouTube Channel. Using these tools, ICDD highlights critical policy issues, amplifies the messages of coalition partners and subgrantees, and educates the community about ICDD's mission. ICDD invites you to check out all three pages and join the conversation.







Annual Report Expenditures ICDD's Financial Breakdown

FFY 2023

Goal 1: Individual & Family Advocacy Objectives:

- State Self Advocacy Organization
- Increased Knowledge & Self Advocacy
- Targeted Disparity = Linguistically

\$1,135,346.08

Goal 2: Systems Change Objectives:

- Competitive Integrated Employment
- Housing Systems Change
- Emerging Need
- Services & Supports
- State System Collaboration
- DD Network Collaboration
- Minority Communities

\$887,580.62

Administrative:

\$794,694.55

Grand Total:

\$2,817,621.25

Letter from the Director

Dear Reader,

Thank you for taking the time to read through some of the highlights of a really productive year for ICDD. 2023 brought about significant systems change progress and we are so grateful to have the opportunity to have played an essential role in these efforts. Our Governor appointed ICDD members continue to guide our staff work in the direction of efforts that will result in a more inclusive IL where people with DD can live a life just like any other. Our staff team gives their best day in and day out to move our mission forward. I am thankful each day that I have the opportunity to serve our members and work to make Illinois a better place.

2023 was a productive year for systems change. While there are many points of progress to mention, two in particular stand out as successes for collaboration and commitment to equity: Dignity in Pay and DD Housing Navigation. Dignity in Pay is poised to mandate the systems change needed to ensure that Illinoisans with DD have equal access to employment supports to achieve competitive integrated employment. DD Housing Navigation efforts continue to bolster our community system by diverting folks from homelessness, and creating housing options that maximize independence. We look forward to building on this momentum, and more, in 2024.



Director Mercer-Schleider interviewed in the hallways of the Illinois State capitol

Sincerely,

timberly Mercer-Schleider

Kimberly Mercer-Schleider

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ICDD members participating in a meeting



ICDD staff with Infiniteach



Staff and allies at the 2023 disability pride parade

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If you would like this report in an alternative format, please contact the ICDD Office.

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