Illinois Council on Developmental Disabilities

YOUR VISION OUR FUTURE

2021 ANNUAL REPORT

Illinois Council on Developmental Disabilities Value People | Invest in Success

WORD FROM THE DIRECTOR

Kimberly Mercer-Schleider
Pronouns: she, her, hers
Director

Description: Cis-gender White woman with a tan jacket and white shirt, with dark brown hair, brown eyes, and a beautiful smile.

We started 2021 by creating ICDD's next five-year plan. Starting this year at day one from a place of vision and planning really set the tone for the entire rest of the year. Visioning, planning, listening, learning, creating, analyzing and improving were constant themes as we approached our work. We listened to so many voices across the State to create a plan that matches the diversity Illinois offers. We are so proud of every project featured in this annual report as well as those we proudly list on the ICDD website. While our projects are working in every corner of our State, our staff works behind the scenes to educate and advocate for the systems changes needed to make to make our State truly a place where people with developmental disabilities can have equal opportunities and freedom. Stay tuned, everyone! We have plans and look forward to partnering every step of the way. YOUR vision! OUR future! Thanks for leading the way.

ILLINOIS...
WE HAVE PLANS
FOR YOU!

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“Other Duties as Assigned”: In 2021 We Purged & Packed

In 2021, we purged and packed 37 years of reports, meeting minutes, project products, personnel records, supplies, toner cartridges….you name it, ICDD staff has sorted, moved and packed it! The James R. Thompson Center opened in 1985 and is scheduled to be sold and emptied of State agencies in 2022. ICDD staff has been engaging in “other duties as assigned” and purged and packed JRTC office space. Many dumpsters were filled with dusty files no longer needed while others were scanned or boxed. Like most businesses, ICDD will be moving to a smaller space and continuing to shift to electronic records storage. As of May 2022, ICDD’s new Chicago location will be the 10th floor of the Bilandic Building, 160 N. LaSalle. Special shout out to the Program Team for taking on the majority of this work. ICDD staff are excited to bring their vibrant energy to the new office space.

Individual & Family Advocacy (Goal 1): 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:**

1.1. 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.

1.2. 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.

1.3. By September 30, 2026, ICDD, in collaboration with community partners, ICDD will reduce service access barriers and decrease the disparity in available information for non-English speaking communities, and increase the cultural competency of the DD service delivery system by providing information in languages other than English to increase inclusion of non-English speaking individuals with DD and their families in at least 3 aspects of the service delivery system.

Systems Change (Goal 2): Support systems are optimized so that individuals with developmental disabilities in Illinois live and thrive in the broader community. **Objectives:**

2.1. 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.

2.2. 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.

2.3. By September 30, 2026, ICDD will initiate and/or collaborate to impact a minimum of three (3) identified issues for individuals with developmental disabilities.

2.4. 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.

2.5. 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.

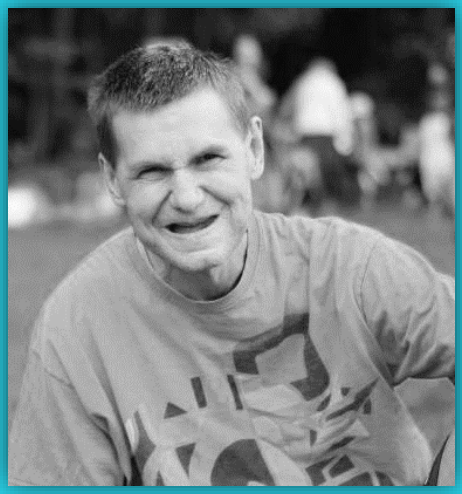
State Plan Activities

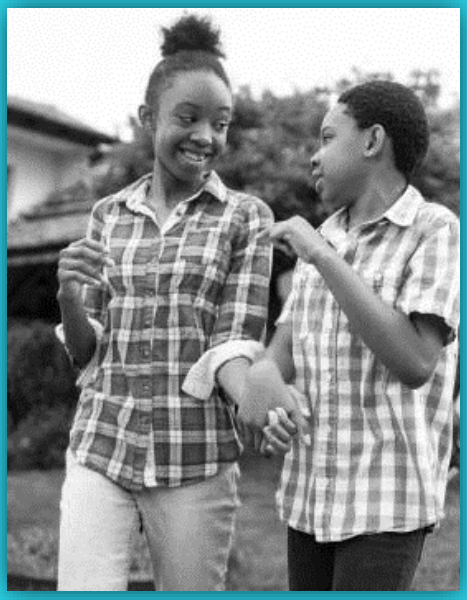
Investments

ICDD is a **100%** federally funded state agency in Illinois. The vast majority of funds are used to support people and organizations in the State for activities. 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.

Systems Change

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. 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.





2021 Council Investment Listing

The Council makes investments (grants) to a wide variety of organizations and individuals 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

Investments:

1. IL Self-Advocacy Alliance
2. Speak Up & Speak Out
3. Partners in Policymaking
4. Consumer Stipend
5. Financial Wellness in Illinois
6. Medical Advocacy (3 total)
7. Southern Illinois Transition Projects (3 total)
8. Going Home Coalition
9. Customized Employment Training Series
10. NASDDDs Technical Assistance
11. Inclusion Everywhere
12. AID CARES
13. Competitive Pay & Meaningful Days (2 total)
14. Sex Education Curriculum
15. Leadership Institute
16. Policy Project
17. Transition Oversight
18. Health for All: Public Health Campaign

Systems Change:
Workgroups & Taskforces

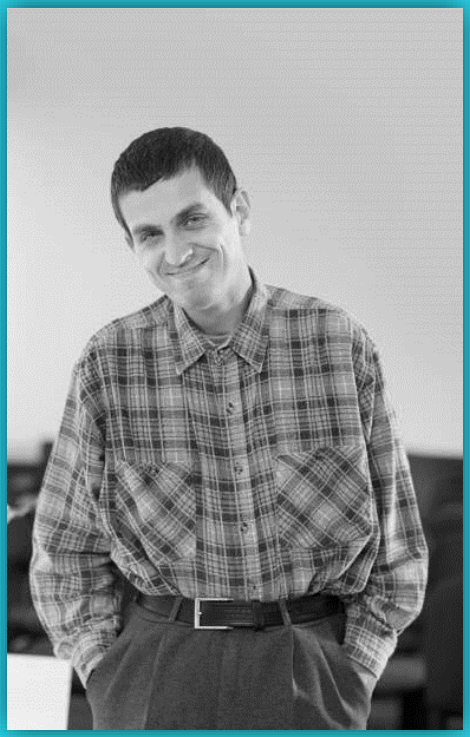
Council Staff participate on a variety of workgroups and taskforces to educate, advise, and create systems change in Illinois for people with DD and families.

2021 Workgroup & Taskforce Listing:

1. HB 3299 Sex Education Work Group
2. Statewide Independent Living Council
3. Employment and Economic Opportunity
4. MOPD Partners Meeting
5. MOPD Disability Advisory Committee
6. IL Interagency Council on Early Intervention
7. DRS Career Counseling
8. ACL RISE employment TA Project
9. IL Interagency Committee for Employees with Disabilities
10. Inclusion Sub-Committee of the Early Learning Council
11. State Employment Leadership Network
12. UIC-IDHD Consumer Advisory Committee

2021 Council Committees

1. Executive
2. Policy
3. Community Inclusion & Housing
4. Education & Employment
5. Health & Individual & Family Advocacy



Illinois Self-Advocacy Alliance

IL Self-Advocacy Alliance:

2021 Project Snapshot

www://

The IL Self-Advocacy Alliance (The Alliance) is a statewide network of self-advocates, advocacy groups and allies' who work together to empower people to speak up and speak out about their wants and needs and to participate in advocacy at the personal, community, and statewide levels through education, training, and mentoring. During 2021, The Alliance finalized their Ambassador Leadership training manuals. Members also hosted a series of presentations on topics that included pieces of the self-advocacy puzzle, healthy relationships, healthy living chats, human rights, and legislative advocacy, for self-advocates, family members, and disability providers for the Division of Developmental Disabilities.

Alliance members collaborated with the Division of Rehabilitation Services to provide input to update the Career Counseling presentation. This training is now in plain-language and self-advocates from The Alliance will co-present it annually to people who receive sub-minimum wage. In July, The Alliance hosted a virtual Empowerment Rally: Activating Advocacy for All. The Alliance continued to add new members to its email listserv and Facebook page.

Sex Education Curriculum:

2021 Project Snapshot

Public Act 101-0506, passed by the Illinois legislature in 2020, states “persons with intellectual/developmental disabilities receiving “habilitation” in state-operated facilities, Community Integrated Living Arrangements (CILAs), Intermediate Care Facilities for persons with intellectual/developmental disabilities (ICFDD), and day training programs” shall have access to sex education, resources, and treatment planning supports. To aid providers in meeting the new law, the Council collaborated with the Division of Developmental Disabilities (DDD) to bring in a consultant with expertise in sex education to create a Train the Trainer curriculum. The Train the Trainer curriculum will consist of 8 Modules: 1) Sex Education for Persons with Intellectual and Developmental Disabilities Public Act 101-0506; 2) Sexual Rights; 3) How to be a Sexual Educator Part 1; 4) How to be a Sexual Educator Part 2; 5) Trauma-Informed Sexuality Education; 6) Building your Sex Education Program; 7) Creating an Inclusive Sex Education Program; 8) Partnering with Parents, Families, and Guardians to Support Sex Education. The modules are posted to the IDHS website and available to all providers to use as a reviewed and approved curriculum meeting the law.

Financial Wellness in Illinois:

2021 Project Snapshot

In 2021, 26 more trainers joined the 44 trainers already presenting the financial wellness curriculum to people with DD and families across the state providing them new insights and resources to use their money towards living how they want and enjoying life. The goal was to increase awareness, understanding, and implementation of financial education by providing virtual Train the Trainer sessions where participants learned how to implement financial wellness training and received resources on how to set and achieve financial goals, how public benefits and work programs can create a safety net, and how to create and manage a budget and monthly expenses to help pay bills and to save for the future. There were trainer support network monthly meetings where the trainers were offered support and had an opportunity to come together to learn and share from each other. Public webinars were held on topics that included; Identity theft and online shopping, extra costs of living with a disability, and housing opportunities for people with disabilities. It is important to note that understanding and managing finances are essential for all of us, but especially important for people with disabilities as it leads to a better quality of life.

Customized Employment Training Series:

2021 Project Snapshot

Marc Gold & Associates brought a Customized Employment training series to Illinois in early 2021. This was a series of trainings on Discovery, Customized Job Development and Systematic Instruction that are critical to supporting individuals with developmental disabilities to obtain and retain employment in their communities. The training sessions were followed by Community of Practice events where attendees had the opportunity to refresh and augment their knowledge on customized employment. Also as part of this project, there were two webinars geared specifically towards Illinois Department of Human Services Staff from the Division of Developmental Disabilities (DDD) and Division of Rehabilitation Services (DRS). Finally, there was a webinar developed and held for self-advocates, family members, and allies. As a direct result of this project, in 2021, 30 people completed both the Discovery and Customized Job Development training and received their ACRE certificate of Achievement. This certificate from the Association of Rehabilitation Educators indicates that the individual has exhibited competency in employment services with an emphasis on customized employment.

Ray Graham Association

Empowering people with disabilities to reach, grow, and achieve.

Medical Advocacy:

2021 Project Snapshot

www://

Ray Graham developed a health resume tool to facilitate people being better to self-advocate for healthcare personalized to them. The health resume is downloadable from ICDD's website. Anyone can complete their own health resume and share it at a doctor, lab, or hospital visit as a PDF document or by showing a QR code that their provider can scan. An additional 138 individuals completed a healthcare resume during 2021. Everyone served by Ray Graham has completed a health resume and each of Ray Graham's 30 CILA homes has an IPad with each resident's health resume so that it is easily accessed and updated. The project has made exciting systems impact. Edward-Elmhurst Health has approved the health resume for inclusion in its EPIC medical record system. EPIC is used by the majority of hospitals, and Rush Medical Center is also in discussion to use it in their medical records. Another development was the DDD Medical Director becoming interested in the health resume. The health resume will be embedded in Illinois' HRST (Health Risk Screening Tool) for over 400 CILA providers to be able to complete a health resume for CILA residents statewide.

Association for Individual Development

AID CARES:

2021 Project Snapshot

www://

The **Community Action for Referenda to Ensure Stability** or **CARES** project brought knowledge to communities 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 CARES Toolkit includes a manual, postcard and door hanger in English, Spanish, and pictorial versions. The CARES website www.377cares.org contains the Toolkit as well as a PowerPoint presentation describing the 377-information process. The project through AID (Association for Individual Development) provided guidance to two communities interested in using the Toolkit and pursuing a local 377 Board.

377 CARES TOOLKIT

Milton Township in DuPage County had a referendum on the April 2021 ballot. People in Wheeling and Cook County learned the process and available resources from the CARES Toolkit.

START EARLY™
Champions for Early Learning

Inclusion Everywhere:

2021 Project Snapshot

www://

Start Early's policy team was funded to explore the issue of how to provide IDEA IEP (school district Individual Education Plan) services to children in community based organizations (CBO) such as child care, Head Start, and pre-K. Children attending a CBO often have to be bussed to their local home school requiring a shift in setting and bussing, or families decide to decline the IEP services. The project developed an informational packet and filmed family/provider interviews to showcase the issue. It engaged over 60 key stakeholders in more than 18 interviews and focus group sessions. They met with the executive directors/presidents of a number of the key school district management associations including the IL Superintendents Association, the IL Federation of Teachers, the IL Principals Association and the IL Superintendents Association. The project's focus dovetails with recommendations of the Governor's Illinois Commission on Equitable Early Childhood Education and Care Funding (The Commission). The work under this grant is coordinating with and reporting to the Early Childhood Transformation Team, which is leading the effort to move The Commission recommendations forward.

Health for All:

2021 Project Snapshot

The focus of the Infiniteach public health campaign, **Health for All**, is to increase vaccine uptake under the broader umbrella of general health and well-being. The Health for All site, www.idd.health, includes a variety of features, such as:

- **Resources database:** searchable database that includes 700 resources and organizations from across IL, focusing on COVID, general health, mental health, transportation, social services, and more
- **Expert videos:** interviews with experts from Rush University, conducted by project Peer Coaches, that cover topics such as vaccine safety, tips for getting a vaccine, mental health, self-care, and more
- **Peer Coach Content:** a collection of blog posts, infographics, and other content developed by our Peer Coaches
- **Communication options:** the site offers a spectrum of communication options, including SMS (texting questions for an expert or Peer Coach to answer); email; or responding to survey questions

During the last quarter of 2021, Infiniteach delivered 1,481 text messages, had 1,400 visitors to https://www.vaxforall.com.

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

$1,519,9361.55

Systems Change

$931,008.05

Administrative

$523,140.31

Grant Total for Federal Fiscal Year 2021:
$2,973,509.91

Meet the Council

2021 Council Members

Membership consists of 60% people with DD and family members. Members: Curtis Harris (Cook), Nathan Joerndt (Livingston), Ana Cruz (Madison), John Porter Jr (Livingston), 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).

Council Staff Listing

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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

Join the ICDD Listserv

Join the ICDD listserv by emailing ICDDInfo@illinois.gov

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

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

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Helpful Links

ICDD Website
ICDD Listserv
Contact Us

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