Illinois Department of Human Services
Division of Developmental Disabilities

Sarah Myerscough-Mueller
Interim Director, Division of Developmental Disabilities
Mission, Values, Vision

The Division of Developmental Disabilities oversees Illinois’ system of programs and services specifically designed for individuals with intellectual and developmental disabilities.

• **Mission**
  Supporting people to attain their wants, needs and dreams.

• **Vision**
  We believe in opportunities for those we serve so they can maximize control over their life choices to achieve personal success including:
  • Having relationships with family and friends
  • Being healthy and safe
  • Contributing to the community
  • Making decisions
  • Engaging in competitive employment
DDD System Overview

FY 22 Budget: ~ $2.3 billion
Staff Total: ~ 4,100

- Community Based System of Care
  - Administers 3 Home and Community Based (HCBS) Medicaid Waivers
    - Children’s Residential Waiver
    - Children’s Support Waiver
    - Adults with Developmental Disabilities (DD) Waiver
- Institutional System of Care
  - Funds and provides placement for Intermediate Care Facilities for Individuals with I/DD (ICF/DD)
  - Operates 7 State Operated Developmental Centers (ICF/DD)
- Grant Funding
  - Funds grant programming including Respite, Epilepsy, Dental, etc.
- *Ligas* Consent Decree
Developmental Disabilities
Persons in Service by Living Arrangement
as of: June, 2022

- State-Op Dev. Centers: 1,604
- Private ICF/DDs (all ages): 4,292 includes MCDDs
- Children's Residential: 157
- CLF: 329
- CILA: 11,134
- At Home: HBS (adults): 10,637
- At Home: HBS (Children): 898
- At Home: Day Program only: 1,393

Private ICF/DDs include: SLC, MCDD (former SNF/Ped), and ICFDDs. Children's Residential includes Group Homes (170) and CGs (190). HBS = Home Based Services. CLF = Community Living Facility (670,676,670). Private ICFDDs and State-operated facilities are actual persons as of June, 2019. All other counts are persons “authorized” for
Adults with Developmental Disabilities by Living Arrangement
End of Year Persons
FY2010 to FY2022
(Adults - age 18 and over only)

- Adult Residential includes CILA codes: 60D, 61D, 65H.
- Adults at home include HBSS (adult, type H) and those receiving day program only (type D).
- Private ICFDD includes all categories of DD long term care - age 18 and older. Includes MCDDs.
- State-Op facilities include all 7 facilities. Choate is only the DD population.

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<tbody>
<tr>
<td>Adult Residential: CILA</td>
<td>8,943</td>
<td>9,334</td>
<td>9,515</td>
<td>10,038</td>
<td>10,441</td>
<td>11,243</td>
<td>11,410</td>
<td>11,430</td>
<td>11,359</td>
<td>11,406</td>
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<tr>
<td>Adults at Home: HBSS &amp; Day Pgm (only)</td>
<td>6,893</td>
<td>8,481</td>
<td>8,486</td>
<td>9,261</td>
<td>9,765</td>
<td>9,755</td>
<td>9,668</td>
<td>9,831</td>
<td>10,043</td>
<td>10,353</td>
<td>10,796</td>
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<tr>
<td>Private ICFDD (age 18 &amp; over only)</td>
<td>6,435</td>
<td>6,409</td>
<td>6,276</td>
<td>5,962</td>
<td>5,594</td>
<td>5,044</td>
<td>4,891</td>
<td>4,876</td>
<td>4,792</td>
<td>4,672</td>
<td>4,473</td>
<td>4,277</td>
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<tr>
<td>State Operated Facility</td>
<td>2,111</td>
<td>2,034</td>
<td>1,965</td>
<td>1,811</td>
<td>1,761</td>
<td>1,686</td>
<td>1,653</td>
<td>1,660</td>
<td>1,661</td>
<td>1,673</td>
<td>1,613</td>
<td>1,612</td>
<td>1,604</td>
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I/DD Community System Data Points

We have invested approximately $470 million in new Home and Community Based Services (HCBS) spending since FY 16 (52% increase).

• In FY 16, we were spending just over $900 million on HCBS services and supports.

• In FY 22, we are estimated to have spent close to $1.4 billion on HCBS services and supports which included an additional investment of $170M.

• In FY 23, the budget includes an additional $209M investment.
FY 23 Budget Investments

• 700 new adult PUNS selections
• 100 children’s PUNS selections (for the Children’s Support Waiver)
• Reinstates the quarterly Independent Service Coordination (ISC) agency visit schedule.
• Funding parity with DCFS for Children’s Group Homes
• Implements a 2% COLA for all DDD grant lines as well as ISC agencies and Community Living Facilities (CLFs).
• Implements Guidehouse recommendations
  • $1.00/hour DSP and ICF Aide wage increases
  • 15% regionality for Chicago, Cook and collar counties
  • CILA Rate Calculator
HCBS Waivers

• The DDD is the Operating Agency for 3 HCBS Waivers
  • Adults with Developmental Disabilities
  • Children’s Residential
  • Children’s Support

• The DDD received approval from the federal Centers for Medicare and Medicaid Services (CMS) for the renewals of all three waivers and all changes went into effective July 1, 2022.

• It is a federal requirement that waivers be renewed every 5 years.

• The DDD is currently working with the Department of Healthcare and Family Services (HFS) on updates to all 3 waivers via the waiver amendment process.
Children’s Residential Waiver

- Eligibility: Children and young adults 3-21 years of age with developmental disabilities
- Services available:
  - Children’s Group Home
  - Behavior Intervention and Treatment
  - Adaptive Equipment
  - Assistive Technology
Children’s Support Waiver

• Eligibility: Children and young adults 3-21 years of age with developmental disabilities

• Services available:
  • Home Based Support Services
  • Service Facilitation
  • Personal Support
  • Behavioral Intervention and Treatment
  • Training and Counseling for Unpaid Caregivers
  • Adaptive Equipment
  • Assistive Technology
Adults with DD Waiver

- Eligibility: Young adults and adults 18 and older with developmental disabilities
- Services available:
  - Residential Habilitation
  - Home Based Support Services
  - Community Day Services
  - Supported Employment
  - Adaptive Equipment
  - Assistive Technology
  - Remote Supports
  - Personal Support
  - Home Modifications
  - Vehicle Modifications
  - Behavioral Services (Psychotherapy and Counseling)
PUNS List

- The State’s database that registers children and adults with I/DD who want or need HCBS waiver-funded DD services.
- As funding is available, based on appropriation, individuals are selected from PUNS for funded services based on time waiting.
- There are two categories of people on the PUNS List:
  - Seeking Services: Children and adults who currently need or desire funded services – PUNS selections are made from the Seeking category only.
  - Planning for Services: Children and adults who do not currently need or desire funded services but may in the future.
- Since 2018, the DDD sends “early notice letters” to notify individuals of their anticipated selection from the PUNS List (roughly 6 months prior to selection letters)
- In July, the DDD selected 1,293 adults from the Seeking Services category based on funding in the FY23 Budget. This follows Reasonable Pace requirements under the Ligas Consent Decree.
- In July, for the first time in over 10 years, the DDD selected 147 children from the Seeking Services category based on funding in the FY23 Budget. These 147 children now have access to services and supports of their choosing under the Children’s Home-Based Support Services Program within the Children’s Support Waiver.
CILA and Adult HBSS Enrollments
FY10 to FY22
end of year persons

This graph displays persons authorized for CILA (60D) as compared to Adult Home-based persons (Client Type H). Enrollments as of June 30th. Adults at home authorized for "Day Program Only" are NOT included here.
Ligas Consent Decree

- June 15, 2011 – State entered into a Consent Decree settling Ligas v. Hamos
- Class Members:
  - Adults with I/DD living in state-funded, private intermediate care facilities (ICF) with 9 or more residents who wish to move to a community-based setting and receive community-based services
  - Adults living at home wishing to receive community-based services
- Consent Decree focus:
  - A person-centered, coordinated, integrated community-based system
  - Programs, activities and services and supports provided in the most integrated setting that meets the choices and needs of individuals
- Compliance activities:
  - Reasonable Pace
  - Annual Implementation Plan
  - Guidehouse Rate Study
Ligas Consent Decree

PCP Process
• Person-Centered Planning is a federal requirement in the HCBS Settings Rule for people receiving Medicaid waiver services
• In 2017, Illinois transitioned the responsibility of writing the Personal Plan to ISC agencies. The requirement had previously been the responsibility of service providers.
• Service providers are now responsible for writing Implementation Strategies that reflect what is written in the Personal Plan.
• The Division contracted with the Institute on Disability and Human Development at the University of Illinois at Chicago (UIC) to evaluate the person-centered planning process and make recommendations to improve the process for all stakeholders.
• An Evaluation of Person-Centered Planning in Illinois Adult DD Waiver Services was released in early May. Strengthening training, communication and coordination are key themes of the report.
• Recommendations that are in process including the creation of an Implementation Strategies template as well as updates to the Discovery Tool and Personal Plan templates.

An Evaluation of Person-Centered Planning in Illinois Adult DD Waiver Services: 
https://www.dhs.state.il.us/page.aspx?item=144102
In addition to the PCP Report, the DDD contracted with the UIC Institute on Disability and Human Development to evaluate the capacity of the I/DD system around those individuals with additional support needs:

- Complex Medical Needs
- Insulin-Dependent Diabetics
- High Behavioral Support Needs
- Autism or Other Sensory Support Needs
- People who are deaf/hard of hearing
- People who are blind/visual impairment
- Physical accessibility support needs

The Community Capacity Report was released in June and includes DDD recommendations as well as service provider recommendations.

Community Capacity Report:
https://www.dhs.state.il.us/page.aspx?item=144695
Guidehouse Rate Study

• Guidehouse Rate Study was released in December 2020
• Rate Study Cost (estimated): $745M
• The Study makes recommendations and lays out priorities around the adult residential (CILAs, ICFs) and day services systems (plus additional ancillary services).
• Much of the $209M included in the FY 23 Budget is going to implement the next round of recommendations from the Rate Study.
• In order to implement the recommendations, a Waiver Amendment is required for the Adult DD Waiver specifically.
Guidehouse Rate Study

• The FY 23 Budget includes implementation of the following Guidehouse recommendations:
  • Increases the DSP and ICF Aide wage reimbursement to $17.00/hour (from $16.00/hour) across Illinois.
  • Regionality: Increases the DSP wage reimbursement to $19.55/hour (from $16.00/hour) in Chicago, Cook and the collar counties.
  • Implements the Guidehouse-recommended CILA Rate Calculator including
    • Using the Health Risk Screening Tool (HRST);
    • Adjusting base nursing and medication administration hours based on the recipient’s needs; and
    • Updating rates/percentages for room & board, transportation, employee-related expenses (ERE), program and administration.
**DSP Residential Wages**

(Excludes Fringe)

*Chicago & collar counties wages increase from $11.46 to $19.55.*

*Downstate wages increase from $11.46 to $17.00.*

<table>
<thead>
<tr>
<th>Year</th>
<th>Downstate DSP Wage</th>
<th>Chicago Area DSP Wage</th>
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<tbody>
<tr>
<td>FY18</td>
<td>$11.46</td>
<td>$11.46</td>
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<tr>
<td>FY19</td>
<td>$12.00</td>
<td>$12.00</td>
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<tr>
<td>FY20 (Jul)</td>
<td>$12.42</td>
<td>$12.42</td>
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<tr>
<td>FY20 (Jan)</td>
<td>$13.00</td>
<td>$13.00</td>
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<tr>
<td>FY21 (Jul)</td>
<td>$14.00</td>
<td>$14.00</td>
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<tr>
<td>FY21 (Jan)</td>
<td>$14.50</td>
<td>$14.50</td>
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<tr>
<td>FY22 (Jan)</td>
<td>$16.00</td>
<td>$16.00</td>
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<tr>
<td>FY23 (Jan)</td>
<td>$17.00</td>
<td>$19.55</td>
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Independent Service Coordination Agencies

- Individuals and families work with a local ISC agency
- The ISC helps with registration on the PUNS database and then with accessing and entering services (waiver and otherwise) across the DD system
- ISCs serve a critical role in the Person-Centered Planning process completing the Discovery Tool and the Personal Plan for each waiver recipient
- 8 ISC agencies and 12 ISC regions
  - Service Inc. of Illinois (3 regions)
  - Community Alternatives Unlimited
  - Community Service Options
  - Suburban Access, Inc.
  - Prairieland Service Coordination Inc. (3 regions)
  - Champaign County Regional Planning Commission
  - Central Illinois Service Access
  - Southern Illinois Case Coordination Services
ISC Updates

ISC Monitoring Visits
• The ISC will complete a minimum of four face-to-face visits per year, for each individual served through DD waiver programs.
  • At least one visit for the development of the discovery process/personal plan
  • Quarterly Monitoring Visits
    • 2 at the person’s residential home
    • 1 at the person’s day program (if DDD funded). Additional options: privately funded day programs, School IEP meetings
  • No visits should take place at an employment site
ISC Updates

ADA/Olmstead Outreach

- Annually, ISCs will visit ICF/DDs and SODCs to engage with the individuals living there.
- The ISC will engage the Guardian prior to outreach. The ISC will send a formal letter and follow up by telephone call.
- During the meeting, the ISC will share information on Developmental Disability services available to the individual, including HCBS Waiver funded services and offer to register the individual on PUNS if interested in HCBS and living in an ICF/DD.
- The ISC will complete the PUNS registration as applicable or requested (ICF only).

DDD ADA/Olmstead Outreach Webpage:
https://www.dhs.state.il.us/page.aspx?item=143873
Housing Navigator

- Housing Navigators (HNs) will be hired at 7 ISC agencies
- HNs will train and work with current ISC Case Managers to support individuals to apply for affordable housing. They will also track interest.
- HNs will provide landlord outreach, relationship building and work to create a master list of housing options in various communities.
- HNs will be responsible for outreach and developing educational information about the program to distribute to individuals and families in the waiver and on the PUNS list.
- HNs will participate in pilot activities and Technical Assistance as part of the pilot program in conjunction with ICDD.
- After 2 years ICDD will release a report on the success of dedicated Housing Navigators housed at ISCs.
HCBS Settings Rule

• The federal HCBS Settings Rule requires all states to come into compliance by March 17, 2023, in order to maintain HCBS Waiver funding.

• The rule is designed to make sure that the services people receive provide the opportunity for integration and access to the community, choice, individual rights, and independence.

• “Maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting.”

• The Settings Rule applies to ALL HCBS waiver funded services including home-based, CDS and CILA services, among others.
HCBS Settings Rule

- State must validate all provider-controlled sites for compliance including children and adult residential and day sites.

- The DDD in the process of validating roughly 2,300 DDD waiver sites for compliance (onsite or desk validation).
  - The DDD has provided regular provider webinars, a weekly Settings specific email communication and is holding weekly office hours to answer provider questions.
  - The DDD is working to update our rules as well as policies and procedures for ongoing compliance post March 2023.
  - The DDD is partnering with ICDD for technical assistance for providers through the Council on Quality and Leadership.

- The DDD believes that ALL sites can meet the Settings requirements with support and interest.
FY23 DDD Priorities

- HCBS Waivers/Amendments
- PUNS List/PUNS selection
- Ligas Consent Decree compliance
- Guidehouse Rate Study investment
- HCBS Settings Rule compliance
- Development of new DSP Training
- Supports Waiver
New DSP Training

- DDD has contracted with the UIC Institute on Disability and Human Development to support development of a new DDD DSP Training.
- DDD has created a diverse group of stakeholders including partnering departments/divisions, associations, DSPs, self-advocates and others.
- The workgroup is assessing current DSP Training and is making recommendations for changes to ensure training is based on:
  - Nationally validated competency areas and topics
  - DSP code of ethics
  - Appropriate for additional programs to use such as ISBE Career Tech Education Pathways, community college tracks for CNAs and/or caseworkers and vocational rehabilitation (if desired)
- Go Live Date: FY24
Supports Waiver

- During the spring 2021 legislative session, the General Assembly passed, and Governor Pritzker signed Public Act 102-0043 (Senate Bill 2294).

- The Act requires IDHS to work with HFS and stakeholders to study the development and implementation of a supports waiver for young adults with developmental disabilities.

- Specifically, the Act requires IDHS to look at the following as potential components of a supports waiver:
  - Age of individuals
  - Number of individuals
  - Services to be provided
  - Funding to be provided (caps, etc.)
  - Transition process to the Adult DD Waiver
  - Waiver type
Thank you!