Illinois Community Living Report

A project of IPADD
Illinois Parents of Adults with Developmental Disabilities
Our expectation is that every person with a developmental disability, supported appropriately, can live a safe, meaningful, and connected life in their home community. To achieve this goal, Illinois must:

1. Commit immediately to raising the state fiscal investment in Home and Community-Based Services (HCBS) from our current rank of 46th in the nation (per capita) to at least a mid-range ranking.

2. Shorten, and eventually eliminate, the PUNS (Prioritization for Urgency of Need for Services) waiting list, which currently holds the names of 19,461 Illinois citizens with developmental disabilities who want to receive HCBS for their care.

3. Make equitable rate adjustments for community services across regions, settings, and HCBS waivers so that all individuals (including those with medical, behavioral, or mental health challenges) can afford quality care and services in their homes or communities.

To this end, IPADD will continue to draft, promote, and monitor public policy in the State of Illinois and hold its legislators accountable.
Dear Illinois Citizens:

In many arenas of Illinois government, the 2019 Spring Session of the 101st General Assembly was like a breath of fresh air. Compared with the contentious budget impasse years and its aftermath, many agencies and departments have reason to remain hopeful. This sense of hope has been slower to reach the developmental disability community.

A 3.5% rate increase promised to providers, which was approved by the General Assembly and expected to take effect on July 1, 2019, has been delayed due to complicated interactions between the State and the federal Centers for Medicare and Medicaid Services (CMS). At the time of this writing, the rate increase has not been implemented. Questions remain about when it will go into effect and also whether or not the increase can become retroactive to July 1st. These are uncertain times for providers.

Regardless, we are confident that Illinois has potential for growth and we remain optimistic for the future. We have watched patiently as the Illinois General Assembly recalls its ability to function smoothly and prioritize the people of Illinois, especially those in need of human services who long for a place in their own homes and their own communities.

This year we honor five legislators who received a 100% score and sponsored five or more of our bills. These top performers are Rep. Gabel, Sen. Gillespie, Rep. Hurley, Sen. Muñoz, and Sen. Murphy. We thank these five for going above and beyond the call of duty.

Sincerely,

Laurie Jerue
Co-Founder

Ellen Garber Bronfeld
Co-Founder

Deb Hamilton
Legislative Affairs
Ten bills were selected from the 2019 Spring Session of the Illinois 101st General Assembly. None of the bills were vetoed by Governor Pritzker and all ten bills have already been signed into law. Bills were selected for their relevance to home and community living for Illinois citizens with developmental disabilities.

Notable among this year's crop of bills were SB2087 for a 5-year customized employment pilot program, HB3299 for facility access to sex education and related resources, HB3483 to tighten communication between DHS, ISCs, and individuals on the PUNS database, and HB3343 to allow people who are elderly, disabled, and/or homeless to use SNAP (Supplemental Nutrition Assistance Program) benefits at participating establishments which sell hot meals.

Since the progress of the State of Illinois relies on good leadership, we have once again reported the scores of top leaders in the House and Senate, as well as a score for the Governor.

Voting on each bill has been weighted equally, with each bill worth 10% of the overall score for a maximum score of 100%. IPADD was in favor of all ten bills this year, meaning that each "yea" vote earned a legislator ten percentage points. No points were given for legislators who were absent or non-voting, regardless of the reason. This report does not include raw data, but legislative votes are a matter of public record and can be viewed on the Illinois General Assembly (ILGA) website.

Congratulations to this year’s top scorers in the Illinois General Assembly, Rep. Gabel, Sen. Gillespie, Rep. Hurley, Sen. Muñoz, and Sen. Murphy, who received a 100% score and also sponsored five or more of our bills.
AT A GLANCE: COMMUNITY LIVING SCORES

LEADERSHIP SCORES

Illinois Leadership Community Living Scores

Goveror JB Pritzker (D) 100
Speaker of the House Michael Madigan (D) 80
House Majority Leader Greg Harris (D) 100
House Republican Leader Jim Durkin (R) 80
President of the Senate John Cullerton (D) 100
Senate Majority Leader Kimberly Lightford (D) 90
Senate Republican Leader William Brady (R) 80

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

TOP GENERAL ASSEMBLY SCORES

Rep. Gabel (D)
Sen. Gillespie (D)
Rep. Hurley (D)
Sen. Muñoz (D)
Sen. Murphy (D)

BOTTOM GENERAL ASSEMBLY SCORES

Rep. Mazzochi (R)
Sen. Syverson (R)
<table>
<thead>
<tr>
<th>Bill</th>
<th>Title</th>
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<th>Description</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>SB2087</td>
<td>CUSTOMIZED EMPLOYMENT PILOT</td>
<td>+</td>
<td>Establishes a 5-year pilot program to serve a minimum of 25 individuals with a developmental disability, coordinated with DRS.</td>
<td>HOUSE: 5/23/19 SENATE: 3/27/19</td>
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<tr>
<td>HB3299</td>
<td>DD SEX EDUCATION</td>
<td>+</td>
<td>Gives access to sex education and related resources to support the right to sexual health and healthy sexual practices.</td>
<td>HOUSE: 3/27/19 SENATE: 5/30/19</td>
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<tr>
<td>HB3483</td>
<td>PUNS DATABASE</td>
<td>+</td>
<td>Tightens communication between DHS, ISCs, and individuals on the PUNS database, including information available on the website.</td>
<td>HOUSE: 4/10/19 SENATE: 5/22/19</td>
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<td>SB1321</td>
<td>MEDICAID OMNIBUS</td>
<td>+</td>
<td>Addresses Medicaid eligibility churn and regulates MCOs, requiring yearly reports to be published on the HFS website.</td>
<td>HOUSE: 5/30/19 SENATE: 5/30/19</td>
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<td>SB1136</td>
<td>CMS EMPLOYMENT</td>
<td>+</td>
<td>Requires CMS to conduct annual presentations for State agencies to increase the number of employees with disabilities.</td>
<td>HOUSE: 5/21/19 SENATE: 5/31/19</td>
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<td>SB1214</td>
<td>PHLEBOTOMY TRAINING</td>
<td>+</td>
<td>Charges the Department of Public Health to make available training materials to ensure phlebotomists effectively treat individuals with I/DD.</td>
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<td>SB111</td>
<td>DENTAL ANESTHESIA</td>
<td>+</td>
<td>Amends the Illinois Insurance Code to expand dental anesthesia coverage up to age 26 for people with a developmental disability.</td>
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<td>HB3671</td>
<td>ACCOMMODATE SERVICE ANIMALS</td>
<td>+</td>
<td>Protects both the rights of housing providers and people with disabilities who use assistance animals for a disability-related need.</td>
<td>HOUSE: 5/30/19 SENATE: 5/22/19</td>
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<tr>
<td>HB3343</td>
<td>SNAP RESTAURANT MEALS</td>
<td>+</td>
<td>Allows people who are elderly, disabled, and/or homeless to use SNAP benefits at participating establishments which sell hot meals.</td>
<td>HOUSE: 3/29/19 SENATE: 5/17/19</td>
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<td>SB1387</td>
<td>ABLE ACCOUNT CLEAN-UP</td>
<td>+</td>
<td>Allows State Treasurer to enter into agreements with other states and gives guardians ability to manage ABLE accounts with less red tape.</td>
<td>HOUSE: 5/26/19 SENATE: 3/7/19</td>
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+ on a blue field indicates the bill is scored positively by IPADD
2019 ILLINOIS GENERAL ASSEMBLY SCORES

SENATE

Superior (91-100%)
Aquino  Belt  Collins  Crowe
Cullerton, J. (Senate President)  Cullerton, T.
Cunningham  Ellman  Gillespie  Glowiak
Harmon  Harris  Hastings  Holmes  Hunter
Koehler  Link  Martinez  McGuire  Mulroe
Muñoz  Murphy  Peters  Sims
Van Pelt  Villivalam

Excellent (81-90%)
Anderson  Barickman  Bennett  Bertino-Tarrant  Bush
Castro  Curran  DeWitte  Fine  Fowler  Hutchinson
Jones, E.  Landek  Lightford  Manar  McConchie
Morrison  Oberweis  Schimpf  Stadelman  Steans
Tracy  Wilcox

Good (71-80%)
Brady  McClure  Plummer  Rose  Stewart  Weaver

Mediocre (61-70%)
Rezin  Righter  Sandoval

Poor (0-60%)
Syverson
2019 ILLINOIS GENERAL ASSEMBLY SCORES

HOUSE

Superior (91-100%)
- Andrade
- Arroyo
- Burke
- Connor
- Conroy
- Crespo
- Davis
- Didech
- Edly-Allen
- Evans
- Feigenholtz
- Flowers
- Ford
- Gabel
- Gong-Gershowitz
- Gordon-Booth
- Greenwood
- Halpin
- Harper
- Harris
- Hernandez, B.
- Hernandez, E.
- Hoffman
- Hurley
- Kalish
- Mah
- Manley
- Martwick
- Mayfield
- Morgan
- Mussman
- Ortiz
- Pappas
- Ramirez
- Rita
- Robinson
- Scherer
- Slaughter
- Smith
- Stava-Murray
- Stuart
- Thapedi
- Turner
- Villa
- Villanueva
- Walker
- Welch
- West
- Williams, A.
- Willis

Excellent (81-90%)
- Ammons
- Bristow
- Carroll
- Cassidy
- Costa
- Howard
- D'Amico
- Kifowit
- Lilly
- Marron
- Mason
- McCombie
- Meyers-Martin
- Moeller
- Moylan
- Reick
- Sommer
- Swanson
- Tarver
- Walsh
- Windhorst
- Yednock
- Zalewski

Good (71-80%)
- Bailey
- Batinick
- Bourne
- Bryant
- Buckner
- Butler
- Caulkins
- Chesney
- Davidsmeyer
- DeLuca
- Demmer
- Durkin
- Guzzardi
- Halbrook
- Hammond
- Jones
- Keicher
- Madigan (Speaker of the House)
- McAuliffe
- McDermed
- McSweeney
- Meier
- Miller
- Morrison
- Murphy
- Parkhurst
- Severin
- Sosnowski
- Spain
- Unes
- Weber
- Wehrli
- Welter
- Wheeler
- Wilhour
- Yingling

Mediocre (61-70%)
- Bennett
- Brady
- Cabello
- Frese
- Grant
- Skillicorn
- Ugaste

Poor (0-60%)
- Mazzochi
OUR MISSION STATEMENT

IPADD’s mission is to provide Illinois parents, self-advocates, adult siblings, and others who care about adults with developmental disabilities a dedicated online platform for networking, information, advocacy, and support.

OUR PHILOSOPHY

We believe every person with a developmental disability, supported appropriately, can live a safe, meaningful, and connected life in their home community. In order to achieve this reality, Illinois must increase its fiscal investment in Home and Community-Based Services (HCBS), shorten the waiting list for services, and make equitable rate adjustments for community services.

TAKE THE NEXT STEP

• Share this report with your co-workers, friends, and family
• Find your state legislators at tinyurl.com/IPADDfind
• Meet with your state legislators and discuss vital issues
• Follow the Illinois General Assembly at ilga.gov

CONNECT WITH IPADD

Connect with IPADD at ipaddunite.org

For general IPADD inquiries, email questions@ipaddunite.org

For questions about this report, email scorecard@ipaddunite.org

Front Cover Photo Courtesy of Former Illinois State Representative Steve Andersson
Report, Graphics, and Front Cover Design Courtesy of Marcus Hamilton
Website Design Courtesy of Ann Myrna

2015 HCBS Raw Data Located in State of the States in Developmental Disabilities Project