

Going Home Coalition

Speak Up Speak Out Summit
10.19.2022



Going Home Coalition



The Arc of Illinois



Illinois Council on
Developmental
Disabilities



Today's Presenters...

Carole Rosen



Tia Nelis



Jae Jin Pak



Mission

The Going Home Coalition is a diverse statewide network of self-advocates, families, community service providers and allies. We purposefully advocate to create systems change, transition from institutional living through increasing community capacity, and empower fair and equal choices and opportunities for people with intellectual and developmental disabilities.



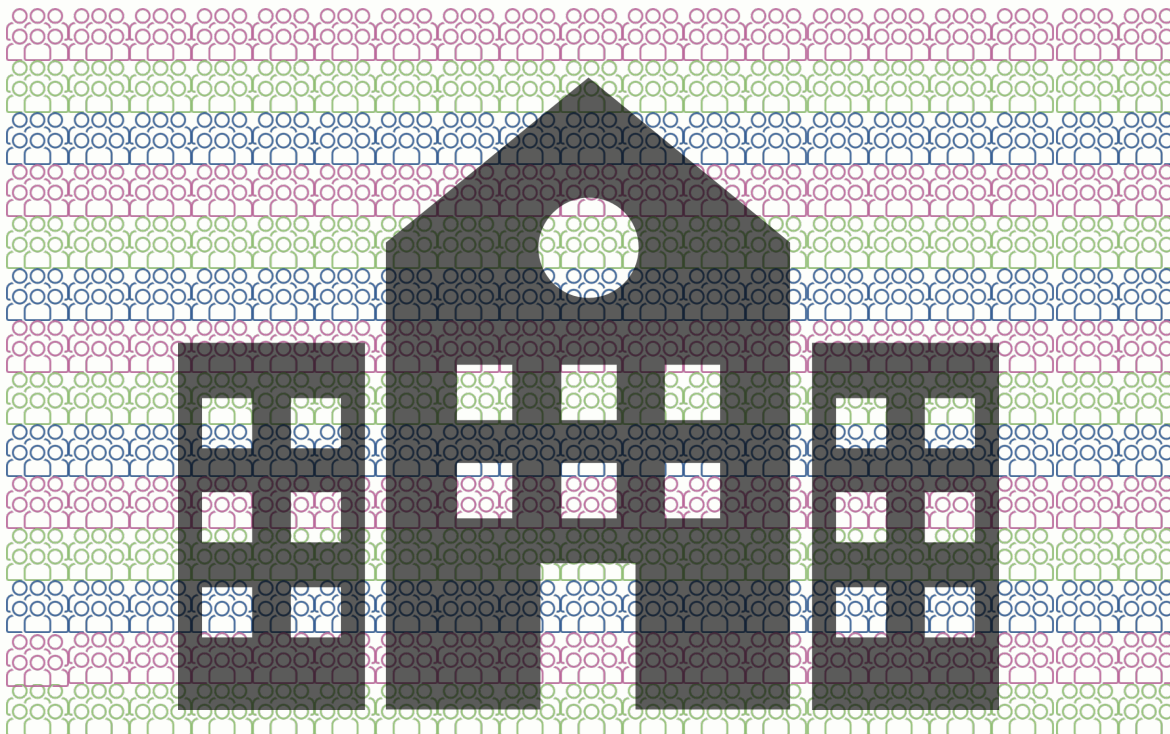
Vision

The Going Home Coalition's vision for people with disabilities in Illinois is to live in a truly individualized person-centered system with the supports and services they choose. Everyone, no matter what challenges they may face, has the right to live a full life in the community. Community is strengthened by diversity, inclusion, and accessibility.



Illinois currently has 7 fully operational state institutions housing 1,645 people.¹

<https://www.dhs.state.il.us/page.aspx?item=61088> Accessed 05/05/2022



Choate: 228
37 forensic

Kiley: 198

Fox: 72

Ludeman: 316

Mabley: 115

Murray: 254

Shapiro: 462

\$286,000

Average Annual Cost to Support One Person
in an Illinois Institution in FY 2019¹



¹ Tanis, E.S., Lulinski, A. & Wu, J., Braddock, D. & Hemp, R. (2021). The State of the States in Intellectual and Developmental Disabilities, Department of Psychiatry, University of Colorado. www.stateofthestates.org.



\$134,110

Highest Average Topline Rate For 1 Person CILA
As Of June 30th 2021¹



¹<https://www.dhs.state.il.us/page.aspx?item=138124>.





185

As of 04/13/2022, the number of individuals and guardians have indicated that they would like to transition to a community provider.

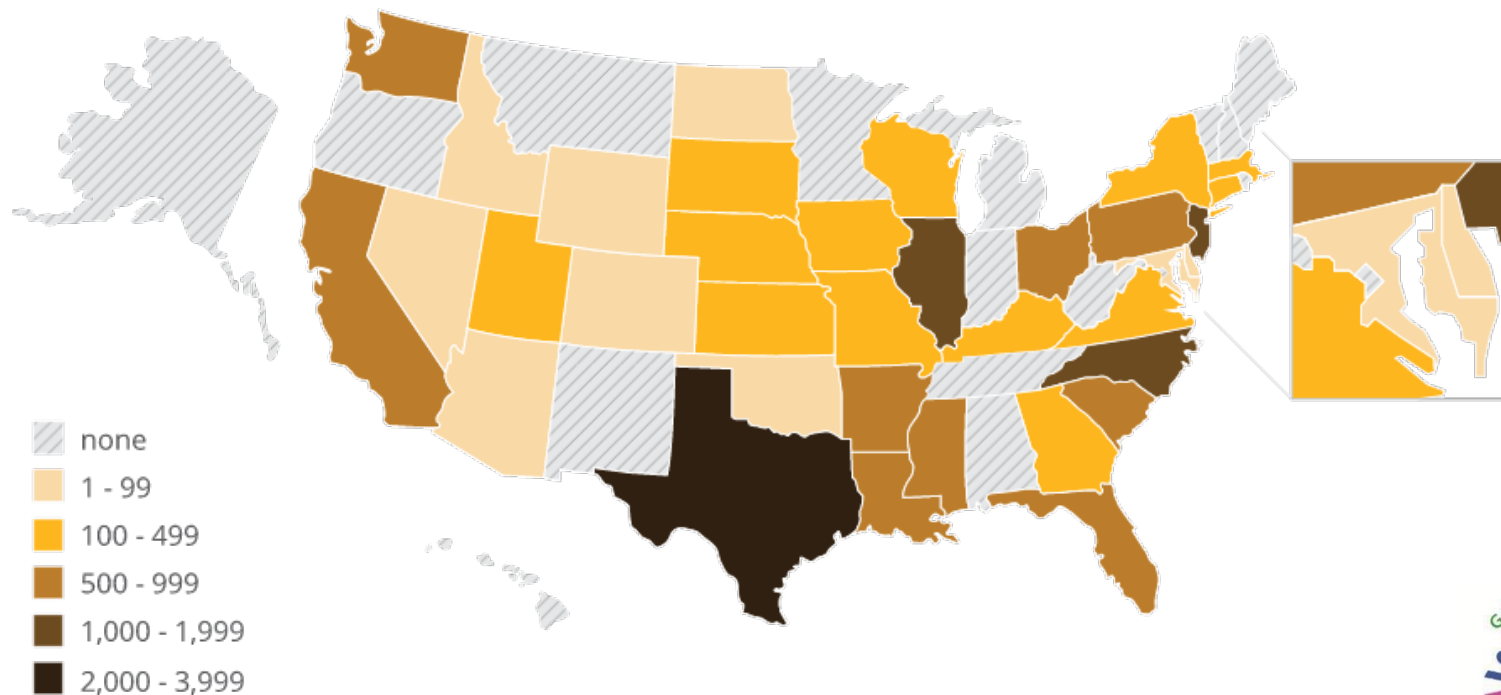
04.13.2022 Director Allison Stark; The Arc of Illinois Conference



Number of people in large public residential IDD facilities (PRFs)

In 1977, there were 154,638 people with IDD living in 327 large PRFs in every US state.

By 2018, there were 17,557 people with IDD living in 115 PRFs in 34 states.



Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>. Retrieved 9/14/2022 FY2018 RISP Infographics | How many people with IDD live in large state-run IDD facilities? | Institute on Community Integration Publications ([umn.edu](https://risp.umn.edu))



Going Home Coalition Members



Participants

- Access Living
- The Arc of Illinois
- Blue Tower Solutions
- Butterflies for Change
- Center for Independent Futures
- Centerstone
- Chicagoland Autism Connection and Trailblazers
- Community Choices
- CTF Illinois – Frankfort
- Garden Center Services
- Equip for Equality
- Illinois Council on Developmental Disabilities
- Illinois State University
- Individual Advocacy Group – Quad Cities
- Institute on Public Policy for People with Disabilities
- Illinois Self Advocacy Alliance
- McManus Consulting, Mosaic
- National Association for Down Syndrome (NADS)
- New Star + Possibility Partners
- Niswander Training and Consulting
- Progress Center for Independent Living
- Pui Tak Center
- Ray Graham Association
- Statewide Independent Living Council
- Supporting Illinois Brothers and Sisters (S.I.B.S.) Network
- Trinity Services
- United Cerebral Palsy (UCP)
- University of Illinois Institute on Disability and Human Development (UIC – IDHD).



PURPOSE



Purpose

Empowering Coalition members through teaching them advocacy skills and supporting self determination. Participants are advocating for inclusion, independence, individualized person-centered supports, employment opportunities, fair wages for support staff, affordable housing and accessibility to create systems change.



Going Home Coalition Teaches Advocacy

Advocacy is defined as any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others.



https://mffh.org/wp-content/uploads/2016/04/AFI_what-is-advocacy.pdf

Going Home Coalition Teaches Advocacy

Participants learn how to tell their story

Set up and run meetings

How to write agendas

Coalition advocacy priorities

How to identify their legislators

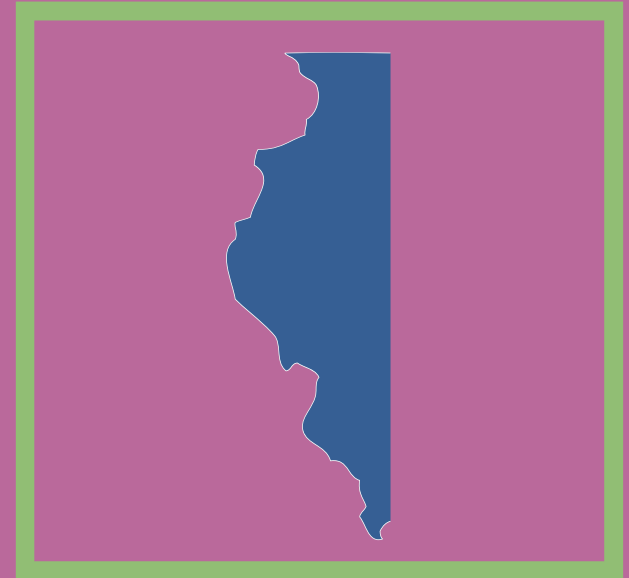
Meet with elected officials

Advocate for positive change



Advocacy Trainings

- Aspire
- Community Choices
- CTF Charleston
- CTF Frankfort
- El Valor
- Envision
- Futures Unlimited
- Keshet
- Mosaic of Rockford
- Individual Advocacy Group - East Moline
- Individual Advocacy Group
- INCIL
- Ray Graham
- Trinity Services (2)
- People First (2)
- Total Link
- Sertoma Center
- Springfield Public School District 186 (presentation archived on their website)



Policy, Informational Meetings

- Secretary; Illinois Department of Human Services
- Director; Division of Developmental Disabilities
- Deputy Director of the State Operated Developmental Centers
- Deputy Director of the Ligas Consent Decree
- DDD Senior Public Service Administrator
- Acting Supervisor of the Transitional Services Unit
- Inspector General of the Office of the Inspector General
- Barry Smoot (Retired OIG Investigator; Author of *Failure to Protect*)



Legislative Meetings

Senator Scott Bennett

Senator Terri Bryant

Senator Deb Conroy

Senator Michael Hastings

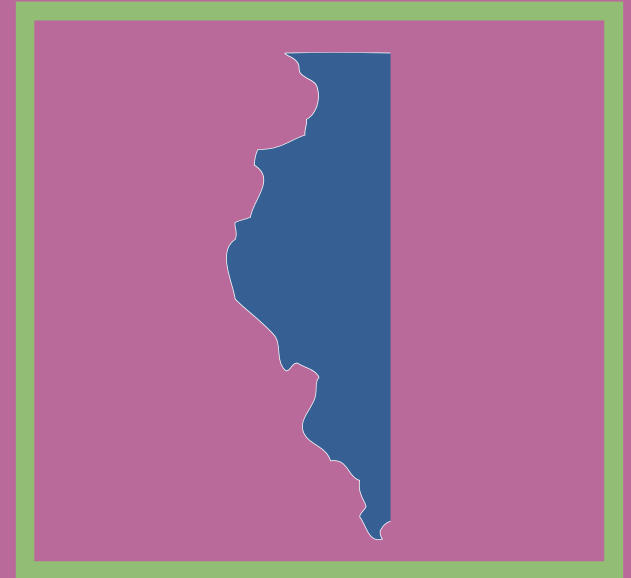
Senator Steve Stadelman

Representative Jason Barickman

Representative Charlie Meier

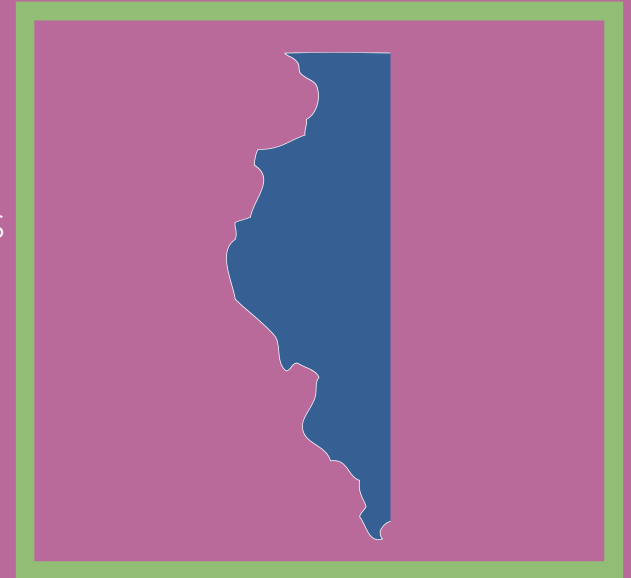
Representative Bob Morgan

Representative Maurice West



Legislative Meetings

- Senator Dick Durbin
- Senator Tammy Duckworth
- Jerod Lockhart Mayor's Office for People with Disabilities
- Mercedes Mondragon Governor's Office
- Carter Harms Legislative Associate of the Governor's Office
- Jabari Knox Policy Associate of the Governor's Office
- First Assistant Deputy Governor Lizzie Whitehorn
- Deputy Governor Sol Flores
- Congresswoman Jan Schakowsky
- Congresswoman Marie Newman



Letter to Governor Pritzker



Dear Governor Pritzker,



Media Campaign

Letters to the Editor

Letter:

Illinois doesn't make navigating life easy for people with intellectual, developmental disabilities. Lack of funding makes life hard for state residents Kimberly Johnson, published July 20, 2021 in The Beverly Review (serving Chicago neighborhoods Beverly, Morgan Park, and Mt. Greenwood);

Circulation 5,500

Kimberly Johnson, published July 21, 2021 in The Chicago Tribune;

Circulation 238,103

Total Circulation 243,603



Media Campaign

Letters to the Editor

Letter:

For 13 years, a Palos Park woman did not know she had an institutionalized sister. After reconnecting, she became both guardian and advocate.

Katherine Hamann. Reporter Bill Jones expanded Katherine's letter after it was printed in The Daily Southtown, a subsidiary of The Chicago Tribune serving the south suburbs and city of Chicago;

Circulation 24,583

Reprinted in The Chicago Tribune

Circulation 238,103

Reprinted in Disability Scoop

80,000 plus

Total LTE circulation: 586,289



Media Campaign

Press Releases

Used Media Consultant: Michelle Arnold

April 26, 2021: 2021 Going Home Virtual Advocacy Day Urges Full State Funding for People with Intellectual and Developmental Disabilities Real Funding Can Transform Lives and Provide Real Choices for Everyne.

The Vedette, Monee, Ill. April 23, 2021;

Circulation: 4,000

The Southern Illinoisan, Carbondale, Ill. Calendar Listing;

Circulation: 32,000

Total press release circulation: 36,000



Going Home Coalition Advocacy Day





SUCCESSSES

Vincent Smith

I support the Going Home Coalition because I want to see people move out of institutions. I spoke about this at Going Home Rallies and a press conference. I talked about how I was able to finally get a place and live on my own. I have traveled all over Illinois talking about this.

Over the years I think this has made an impact on legislators.

I have made visits with legislators and testified at hearings.

We are moving forward, making people aware of the issues – what matters to us and what we want. I believe that people need to know how people with disabilities feel. It's important to share our personal stories.

I enjoyed going to Springfield for the Going Home Coalition. After the rally I was able to take care of personal business. I went to the Governor's office and I visited my Senator to talk about my community. I also experienced calling a legislator from the floor. When you do this, you can see who cares about your issues.

I visited an SODC with the Going Home Coalition when we met with Director Stark at Kiley. It was horrible there, like a jail. We need to get people out of institutions and into the community. And we need people to have enough to live on. I think our meetings make a difference. I hope they continue so we can keep talking.



Bob Peterson

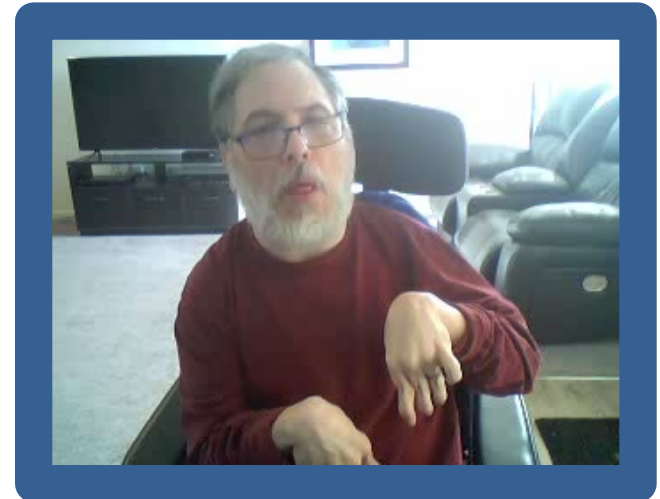
When I think of all the people I have worked with through the years and projects, working with legislators and legislation we worked on – the Going Home Coalition is a unique program that allows us to do advocacy but also teaches you about legislators and how to work with them. We all learn about legislation and become sort of like a family. It's important that new people keep joining and that the concept keeps going. The Going Home Coalition gives people with all kinds of disabilities a voice.

We can better our lives and better the disability system.

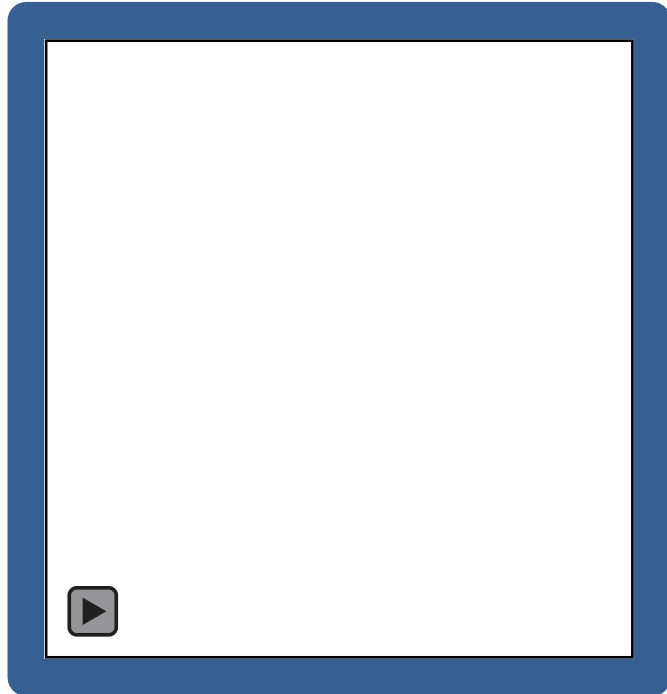
When we come together we show people our power that when people work together there is power in numbers. We all have a reason why we want to better people's lives in the DD system. Some of the things we all believe in: DD issues are human rights issues. We want to live in the community and close institutions. We want to work and have regular jobs. I lived in an SODC and I figured this would be my way of changing my life and encouraging legislators to get rid of institutions. I didn't think it would lead to a long career. The more involved I got and the more I learned, the more I realized that it's a lifetime commitment.

“Having a disability is a lifetime commitment.”

The Going Home Coalition gives people with disabilities a vehicle to learn advocacy and to do advocacy.



Sarah Demissie



The News-Gazette

July 20, 2021

Disabled Need Greater Support

I am a person with autism who lives in Champaign. Advocating for my rights and the rights of others is important to me. I want Illinois legislators to know that people with intellectual and developmental disabilities deserve to live full lives in their communities. I am fortunate to have choices about where I work, where I live, the activities I participate in and what my day looks like. Because I receive state funding, I work with community service providers to move into my own apartment, secure a job with the University of Illinois, and facilitate advocacy and leadership classes and projects for myself and others with these types of disabilities.

A lot of nondisabled people in Illinois don't understand that some people with these disabilities are not able to choose these things. Why? People with intellectual and developmental disabilities are part of their communities, contribute to their communities and are the experts in their own lives. They should have the right to make decisions about their own lives. The state does not properly fund services for people with disabilities. Some people are on a waiting list for services and funding. I was on the wait list for 12 years. Some people with disabilities live in state-run institutions and have to wait for services because the state doesn't have the funding available to help them leave.

If Illinois legislators agree to fully fund community living services for people with these types of disabilities, then we can all choose the lives we want to live.

SARAH DEMISSIE

Champaign
Circulation 22,000



Press Release

News +++ Information +++ News +++ Information



ENGINEER
Intermolecular in San Jose
the follow

Instagram

118 Followers



<https://www.instagram.com/goinghomeillinois/>

Facebook

737 people like this
791 people follow this

Going Home: A Full Life in the Community
Published by Michelle Calkins · November 1, 2021 ·

Arts of Life: Tag <https://www.facebook.com/artsoflife>

Going Home Coalition Member Spotlight:
Arts of Life advances the creative arts community by providing artists with intellectual and developmental disabilities a collective space to expand their practice and strengthen their leadership.



Arts of Life
Nonprofit organization

Like

NEED EXTRA HELP ORDERING COVID TESTS?

Americans are able to order free, at-home COVID-19 tests at COVIDTests.gov.

Those without internet access and those needing assistance may order by calling 1-800-232-0233.

Tests will usually ship within 7-12 days of ordering.

The Disability Information and Assistance Line (DIAL) is an additional resource, connecting people with disabilities to COVID-19 vaccination and testing in their communities. DIAL support can be reached by calling 888-677-1199 or by emailing DIAL@USAgingsandDisability.org. ACL's COVID Website <https://acl.gov/COVID-19>. DIAL's Website <https://acl.gov/DIAL>.

RT PCR TEST
24/7 TESTS AVAILABLE AT HOME



Going Home: A Full Life in the Community
Published by Michelle Calkins · August 18, 2021 ·

TRIVIA ANSWER:
27,000 children and adults with developmental disabilities depend on service.

55 People reached 0 Engagements - Distribution score [Boost post](#)

Like Comment Share

Comment as Going Home: A Full Life in the...

Going Home: A Full Life in the Community
Published by Michelle Calkins · August 17, 2021 ·

TRIVIA TUESDAY:
How many children and adults with developmental disabilities depend on services?

49 People reached 0 Engagements - Distribution score [Boost post](#)

Like Comment Share

Comment as Going Home: A Full Life in the...



Going Home: A Full Life in the Community
Published by Carole Lozoff Rosen · December 13, 2021 ·


Many people with intellectual and developmental disabilities pay for their services (day and residential) with money from the Medicaid waiver. There is a new rule in the United States about Medicaid waivers. It is called the Home and Community-Based Services Settings Rule. The rule says that services must be done in a way that helps people be part of their communities. Providers of Medicaid waiver services must follow this rule. You can learn more about the rule by watching the What the HCBS Settings Rule Means for You video. <https://www.youtube.com/watch?v=1oONwteTJUY>

The Illinois Department of Human Services (IDHS) Division of Developmental Disabilities (DDD) needs to make sure that Medicaid waiver providers are following the new rule by March 2023. DDD knows that your life, services, and voice matter. DDD needs to hear from you!

DDD asks you to take this survey about your life. It will help DDD make waiver services better for all people getting home and community-based services in Illinois. You can ask a trusted person to help you. It can be a support person, family member, guardian, or friend. You can take the survey online, <https://www.dhs.state.il.us/page.aspx?module=17...> or you can print this form, complete it, and send it to Meg Cooch at 600 East Ash Street, Building 400, 1st Floor, Springfield, IL 62703.

New CMS Rules for Providers
#2c: Your Personal Style

You have the freedom to furnish and decorate your room or house within the limits of the lease or other agreement.



YOUTUBE.COM
HCBS ACT: What the HCBS Settings Rule Means for You

@GoingHomeLifeintheCommunity

Facebook.com/GoingHomeLifeintheCommunity



Self Advocate Spotlights

Jillian Gilruth
Nathan Joerndt
Ryan Murray
Susan Mary O'Connor
Terry Teasley



MY ABILITY
IS STRONGER
THEN MY
DISABILITY!!

I AM NO DIFFERENT
FROM YOU!!


Website



@goinghomeillinois

Going Home Illinois | Full Life Disability Community Living

Website



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Take Action

SHOW YOUR SUPPORT AND CONTACT YOUR LEGISLATORS TODAY!


Find Your Representatives

Enter your address to find out who represents you.


Street*

Zip Code*

[Submit](#)




In partnership with the Illinois Council on Developmental Disabilities. This communication is supported in part by grant number CIDA 91430 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.



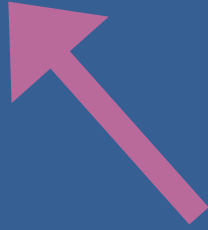
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Contact Information

815 464-1832 - Phone
info@thearcofil.org - Email

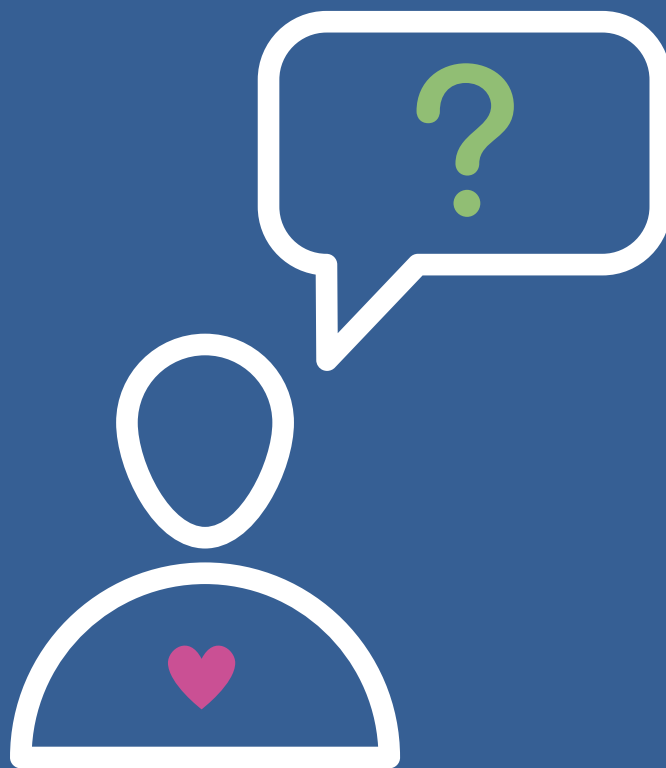
[Going Home Illinois Website](#)

[Going Home Coalition Facebook Page](#)

[Going Home Coalition Instagram Page](#)



Thank You & Questions



Resources - Reports

Equip for Equality (2005). Clyde Choate Developmental Center: How an archaic system results in tragic consequences for people with disabilities. Available: <https://www.equipforequality.org/wp-content/uploads/2014/04/Clyde-Choate-Developmental-Center-How-an-Archaic-System-Results-in-Tragic-Consequences-for-People-with-Disabilities.pdf>

Department of Justice (2009). Choate Developmental Center Findings Letter. Available https://www.justice.gov/sites/default/files/crt/legacy/2010/12/15/Choate_findlet_11-09-09.pdf

Summary of Guidehouse Study. Available https://assets.website-files.com/5cd9df65ab1379f2c10d883a/6040fbfdee757806062812d1_GuidehouseRecommendationSummary.pdf

Full Guidehouse Study. Available. <https://3m4psa58y9z2v1hgruw7ram5-wpengine.netdna-ssl.com/wp-content/uploads/2020/12/Final-Guidehouse-Rates-Report-12.08.2020.pdf>, November 9,



Resources – Statistical Data

Tanis, E.S., Lulinski, A. & Wu, J., Braddock, D. & Hemp, R. (2021). **The State of the States in Intellectual and Developmental Disabilities**, Department of Psychiatry, University of Colorado. [Illinois \(stateofthestates.org\)](https://stateofthestates.org)

Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>.

Here is the webpage with **infographic:** FY 2018 RISP Infographics | How many people with IDD live in large state-run IDD facilities? | Institute on Community Integration Publications ([umn.edu](https://icip.umn.edu))

Vasudevan, V., Lulinski, A., Heller, T., Owen, R., Rizzolo, M.C., Spassiani, N., Schmidt, A.J., & Friedman, C. (2015). **An Evaluation of the Jacksonville Developmental Center Closure.** Chicago: Institute on Disability and Human Development, University of Illinois at Chicago. Retrieved: https://eppu.ahslabs.uic.edu/wp-content/uploads/sites/26/2017/04/jacksonville-closure_report.pdf.



Resources – Press

Hundsorfer, B. (2022, March 9) Prosecutor alleges he accessed confidential documents in attempt to derail State Police investigation. *Capital News Illinois*. Retrieved from: <https://www.capitolnewsillinois.com/NEWS/administrator-of-state-run-developmentally-disabled-center-accused-of-obstructing-investigation>

Hundsorfer, B. (2022, March 10). Man accused of sexual misconduct with patient at state-run facility charged with child molestation in unrelated case. *Capital News Illinois*. Retrieved from: <https://capitolnewsillinois.com/NEWS/man-accused-of-sexual-misconduct-with-patient-at-state-run-facility-charged-with-child-molestation-in-unrelated-case>.

Hundsorfer, B. (2022, March 14). Charges filed against man accused of abusing developmentally disabled woman at state-run facility. *Capital News Illinois*. Retrieved from: <https://www.capitolnewsillinois.com/NEWS/charges-filed-against-man-accused-of-abusing-developmentally-disabled-woman-at-state-run-facility>



Resources - Press

McManus, E. (2022, March 17, No. 223). Legislative Session Ending - Choate Abuse Scandal - Objections to ICFDD Vax Rule. *McManus Consulting; Ed's Newsletter*. Retrieved from:
<https://www.linkedin.com/pulse/eds-newsletter-legislative-session-ending-choate-abuse-ed-mcmanus/?trackingId=EFkWB4uquN0wx1Ux6bwSgQ%3D%3D>

McManus, E. (2022, March 31). Choate Developmental Center abuse scandal timeline. *Capitolfax*, Retrieved from:
[Choate Developmental Center abuse scandal timeline](#)

McManus, E. (2022, March 30). Abuse Scandal at Choate Developmental Center. *Linked In*;. Retrieved from:
<https://www.linkedin.com/pulse/abuse-scandal-choate-center-ed-mcmanus/?trackingId=4iC9NxOrJe4sbnGsRIS9zw%3D%3D>

McManus, E. (2022, April 4). Abuse Scandal at Choate Developmental Center. *Linked In*;. Retrieved from:
<https://www.linkedin.com/pulse/eds-newsletter-another-choate-worker-indicted-violence-ed-mcmanus/?trackingId=OdvOVz9Sovb%2BT8G8hkpN%2Fw%3D%3D>



Resources - Press

Chicago Sun Times

Brutal beatings, abuse plague state-run mental health facility, investigation reveals

[choate-mental-health-developmental-center-blaine-reichHard-illinois-department-human-services](#) Circulation 57,222

Southern Illinoisan

[Culture of cruelty persists despite decades of warnings at Illinois-run mental health facility | State & Regional | thesouthern.com](#)

Circulation 21,270

ProPublica

A Disabled Young Patient Was Sent to Get Treatment. He Was Abused Instead. And He Wasn't the Last. *Capitol New Illinois*.

Retrieved from: <https://www.propublica.org/article/illinois-choate-mental-health-abuse-beatings> Circulation 5,200,000

Capitol New Illinois

[Pritzker calls for changes after “awful” reports of abuse at developmental center Capitolnewsillinois.com](#)

News Conference - 09/06/2022 Gov. Pritzker addressed Choate. (link is [here](#) and his comments begin at 35:10)

ProPublica

Chilling Audio Provides Rare Glimpse Into Abuse at Troubled Illinois Residential Facility. *Capitol New Illinois*.

Retrieved from: [911 Call Reveals Abuse at Choate — ProPublica](#) Circulation 5,200,000

