

ICI POLICY FORUM

INSTITUTE *on* COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA



INSTITUTIONAL BIAS IN LONG-TERM SERVICES AND SUPPORTS FOR PEOPLE WITH IDD

Tuesday, Oct 3, 2023

Discussants: Brian Begin & Sheryl Larson, ICI; Agnes Cole 22/23 MN LEND Fellow

Michael Gamel-McCormick, Disability Policy Director, U.S. Senate Special Committee on Aging;

Heidi Hamilton, Disability Services Director, Minnesota Department of Human Services

Facilitator: Julie Bershadsky, ICI

POLICY RESEARCH BRIEF

INSTITUTIONAL BIAS IN LONG-TERM SERVICES AND SUPPORTS FOR PEOPLE WITH IDD

INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

Research Issue

The Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) program is Medicaid's institutional option for people with IDD who need long-term services and support (LTSS). The Medicaid Home and Community-Based Services (HCBS) Waiver option allows people to get services at home or in their preferred community setting rather than in an institution. The 2014 HCBS Settings Rule ensures that people receiving HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting. While ICF/IID services are guaranteed, HCBS Waiver-funded services are not. States are not allowed to have waiting lists for ICF/IID services, but they can have waiting lists for HCBS Waiver-funded services. This results in an institutional bias in long-term supports and services for people with IDD.

Study Background

The Residential Information Systems Project (RISP.umn.edu) at the University of Minnesota has tracked the size and type of living arrangements for people with IDD who get Medicaid or state-funded LTSS since 1977. This brief is based on Fiscal Year 2019 RISP survey results. It also cites findings from the National Core Indicators In-Person Survey.

POLICY FORUM

This Policy Forum for this issue of Policy Research Brief will be **Tuesday, October 3rd, 2023 at 1:00 p.m. Central on Zoom.** [Register here.](#)

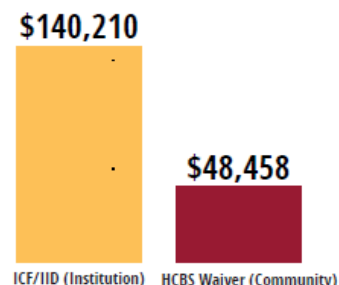
The Policy Forum is a web-based presentation and facilitated

discussion exploring research published in the most recent *Policy Research Brief*. Please visit the website, z.umn.edu/icpolicyforum, for details and to view previous forums.

Key Findings

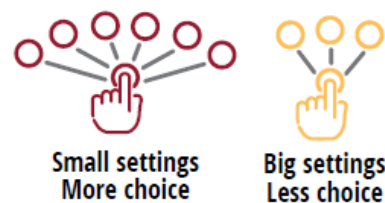
It costs more to support a person in an institution than in the community.

In 2019, average annual per person spending was \$140,210 for people in ICF/IID settings compared with \$48,458 for HCBS Waiver recipients.



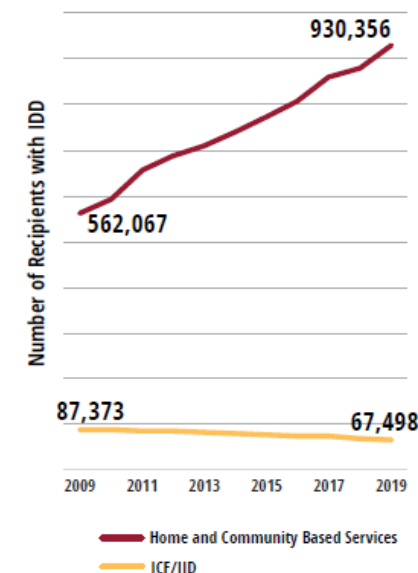
People in smaller community settings have more choice.

Research using the National Core Indicators In-Person Survey shows that people living in smaller community settings have more choices in what time they eat and go to bed, what they do with their free time and how they spend their money. They also have more say in who supports them and where they live and work.



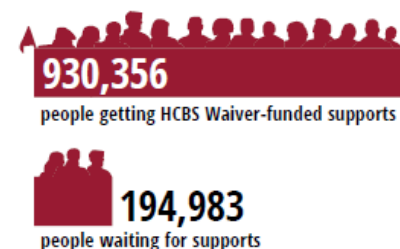
The number of HCBS Waiver recipients grows every year while the number ICF/IID recipients continues to decline.

In 2019, there were 930,356 HCBS Waiver recipients compared to 67,498 people in ICF/IIDs.



Many states have long waiting lists for HCBS Waiver-funded services.

In 2019, 194,983 people living in their own homes or with a family member in 30 states were waiting for HCBS Waiver-funded supports.



Policy Recommendations

- Continue to reduce use of expensive ICF/IID settings.
- Eliminate Medicaid's institutional bias by making HCBS an entitlement.
- Continue to promote the use of HCBS that support person-centered services, full community inclusion and individual choice.
- Enforce all provisions of the 2014 Medicaid HCBS Rule to promote person-centered services, full community inclusion and individual choice.

Published, September 2023.

Editors: Agnes Cole, Brian Begin, and Sheryl Larson

Graphic design: Connie Burkhardt

Larson, S.A., Neidorf, J., Pettingill, S., Sowers, M. (2022). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. DOI: 10.13140/RG.2.2.23116.08320.

Ticha, R., Hewitt, A., Nord, D. & Larson, S.A. (2013). System and individual outcomes and their predictors in services and support for people with IDD. *Intellectual and Developmental Disabilities*, 51, 316-332.

Policy Research Brief: z.umn.edu/rbprb

This project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services, Cooperative Agreement #90DNPA0001-05 with supplemental

funding from the National Institutes on Disability, Independent Living and Rehabilitation Research Grant #90RT5019. Grantees undertaking projects under government sponsorship are encouraged to freely express their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDILRR policy.

The University of Minnesota is an equal opportunity educator and employer. This document is available in alternative formats upon request.

The University of Minnesota stands on *Miní Sóta Makhózhé*, the rightful homelands of the *Dakkhóta Oyáte*. We recognize the U.S. did not uphold its end of these land treaties. It is the current and continued displacement of the *Dakkhóta Oyáte* that allows the University to remain today.

Ongoing oppression and discrimination in the United States has led to significant trauma for many people of color, immigrants, people with disabilities, and other oppressed persons. At ICI, we affirm our commitment to address systemic racism, ableism and all other inequalities and forms of oppression to ensure inclusive communities.

Research Issue: Medicaid's Institutional Bias

ICF/IID

- Intermediate Care Facility for Individuals with Intellectual Disabilities
- Medicaid's institutional option for people with IDD
- Participating states must serve all eligible people who request this service
- Federal level of care requirement
- Rules require active treatment but not community inclusion

HCBS Waiver

- Medicaid Home and Community Based Waiver
- Pays for services for people living in their own home, with family members, or in other small community settings
- Eligibility defined by states
- Waives Medicaid rules requiring states to serve everyone who is eligible
- Can have waiting list
- 2014 HCBS Rules require
 - person centered plans
 - Community participation and inclusion

Study Background

Residential Information Systems Project

- National longitudinal study of living arrangements for 1.4 million people getting IDD services
- Annual survey of State IDD agencies and large state-run facilities
- Funded by the Administration on Community Living
- University of Minnesota



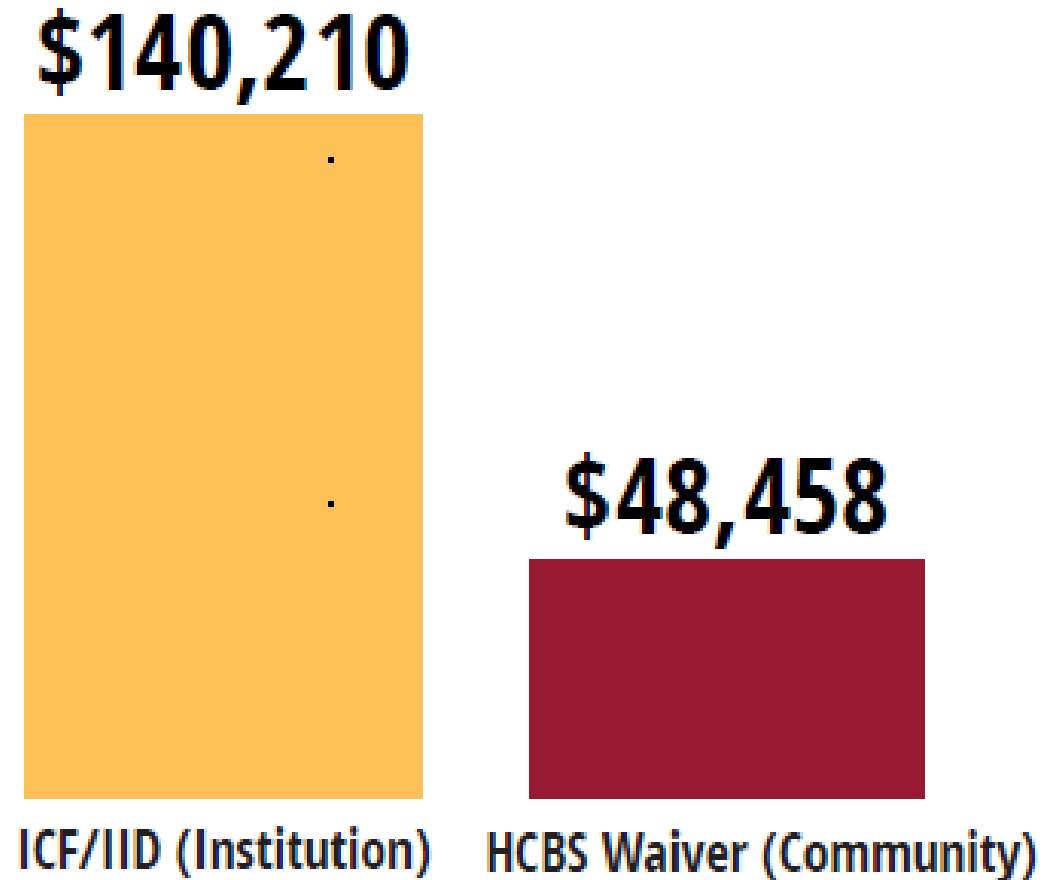
National Core Indicators

- Annual in person survey of adults getting IDD services
- HSRI and NASDDDS
- Funded by state memberships



Key Findings

It costs more to support a person in an institution than in the community.



People in smaller community settings have more choice.

HCBS settings are smaller.

People per non-family setting:

11.0 – ICF/IID

2.0 – HCBS Waiver setting



**Small settings
More choice**

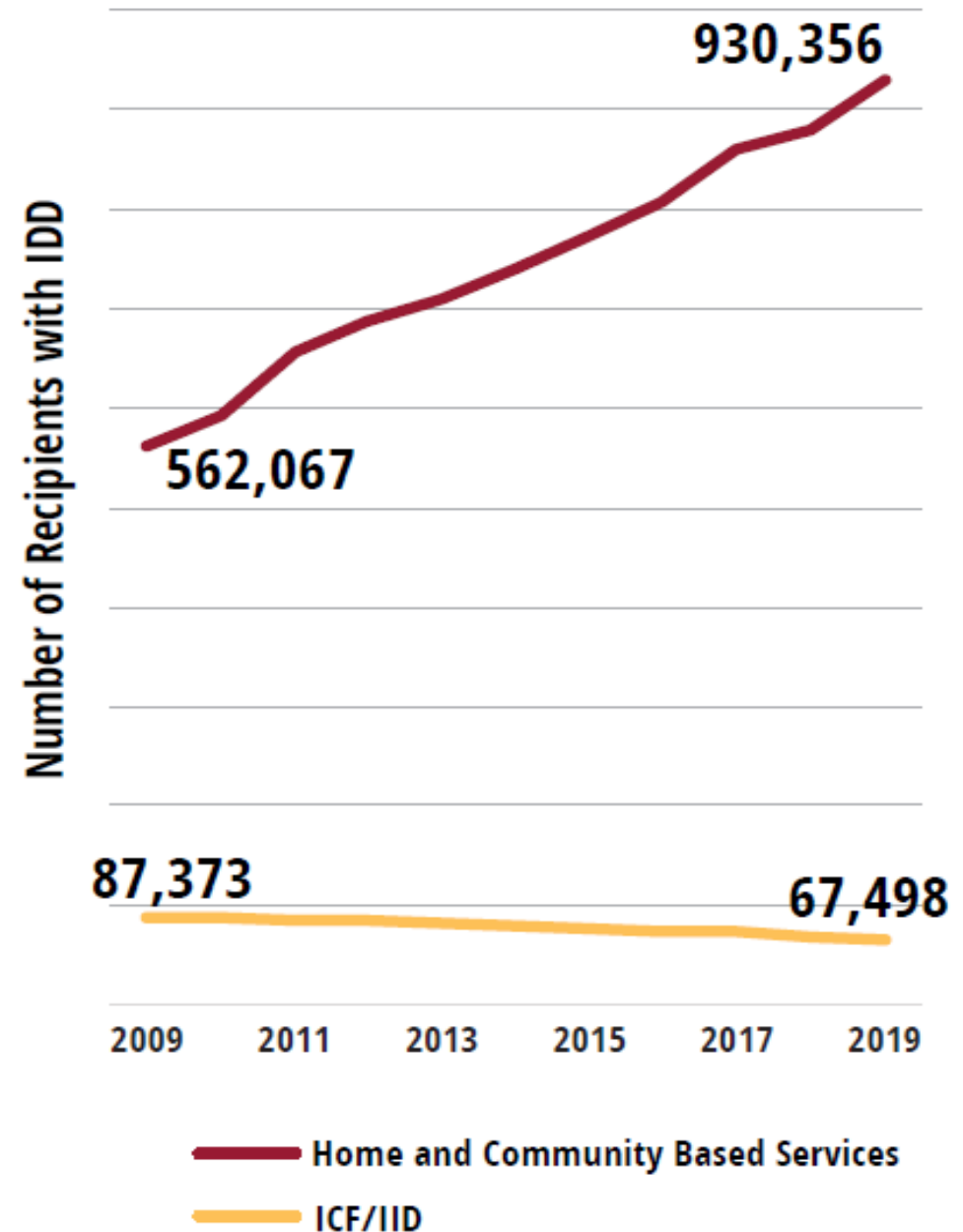


**Big settings
Less choice**

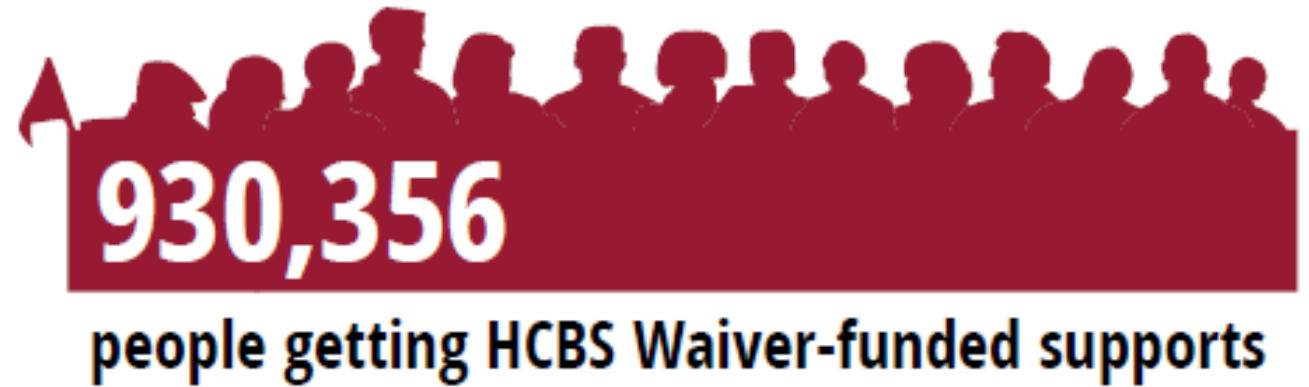
The number of HCBS Waiver recipients with IDD is nearing one million.

The number of ICF/IID recipients continues to decline.

Most people now chose HCBS Waiver funded services.



Many states have long waiting lists for HCBS Waiver-funded services.



Policy Recommendations

1. Continue to reduce use of expensive ICF/IID settings.
2. Eliminate Medicaid's institutional bias by making HCBS an entitlement.
3. Continue to promote the use of HCBS that support person-centered services, full community inclusion and individual choice.
4. Enforce all provisions of the 2014 Medicaid HCBS Rule to promote person-centered services, full community inclusion and individual choice.



Discussion Question

What stands in the way of implementing these policy recommendations?



Discussion Question

How can we ensure that people with IDD who need HCBS get the services they need?

Links

Policy Forum slides and recording:

<http://z.umn.edu/icipolicyforum>

Policy Research Brief:

<https://ici.umn.edu/series/10>

Better Care Better Jobs:

<https://www.casey.senate.gov/news/releases/casey-dingell-introduce-bill-to-provide-historic-permanent-investment-in-home-care-for-seniors-and-people-with-disabilities>

HCBS Access Act:

<https://www.aging.senate.gov/press-releases/casey-holds-hearing-on-caregiving-crisis-introduces-new-legislation-to-begin-eliminating-home-care-services-waiting-list>

Supporting our Direct Care Workers and Family Caregivers Act:

<https://www.casey.senate.gov/news/releases/casey-colleagues-introduce-bill-to-support-direct-care-workforce-and-family-caregivers>

Thank You

Institute on Community Integration

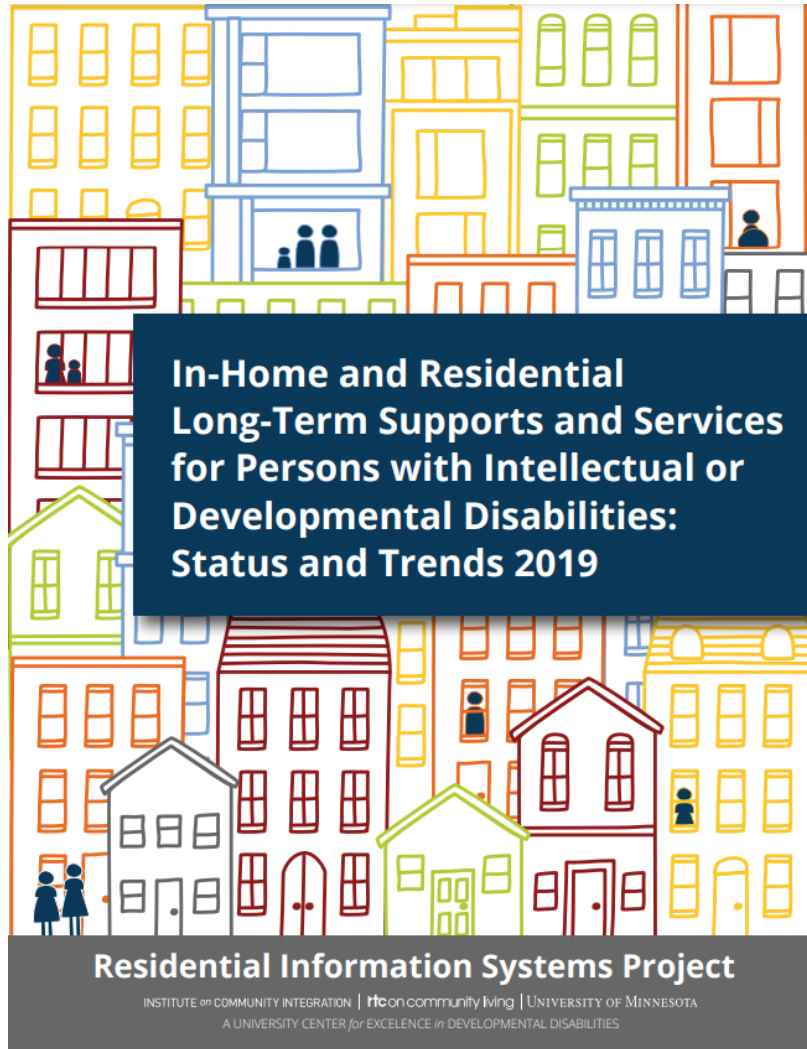
Brian Begin: begin036@umn.edu
Sheryl Larson: larso072@umn.edu
Agnes Cole: dmnetwork2016@gmail.com
Julie Bershadsky: bers0017@umn.edu

Other Presenters

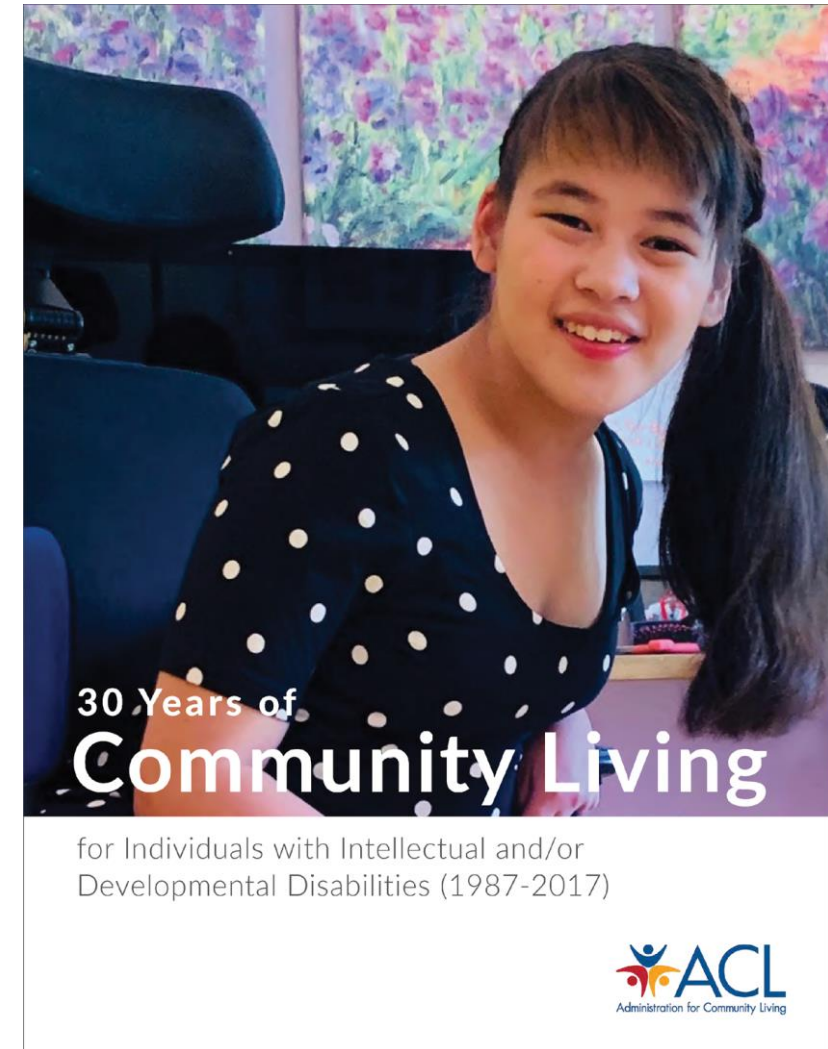
Michael Gamel-McCormick:
 Michael_gamel-mccormick@aging.senate.gov
Heidi Hamilton:
 heidi.hamilton@state.mn.us

The RISP project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services Cooperative Agreement #90DNPA0001-01 with supplemental funding from the National Institutes on Disability, Independent Living and Rehabilitation Research Grant #90RT5019. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDRR policy.

The University of Minnesota is committed to the policy that all persons shall have equal access to its program, facilities, and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance status, veteran status, or sexual orientation.



risp.umn.edu



acl.gov/30years

Resources

Larson, S.A., Neidorf, J., Pettingell, S., Sowers, M. (2022). Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. DOI: 10.13140/RG.2.2.23116.08320.

Ticha, R., Hewitt, A., Nord, D. & Larson, S.A. (2013). System and individual outcomes and their predictors in services and support for people with IDD. *Intellectual and Developmental Disabilities*, 51, 316-332.



z.umn.edu/FIEmployment



z.umn.edu/impact352