The President's Committee for People with Intellectual Disabilities (PCPID)
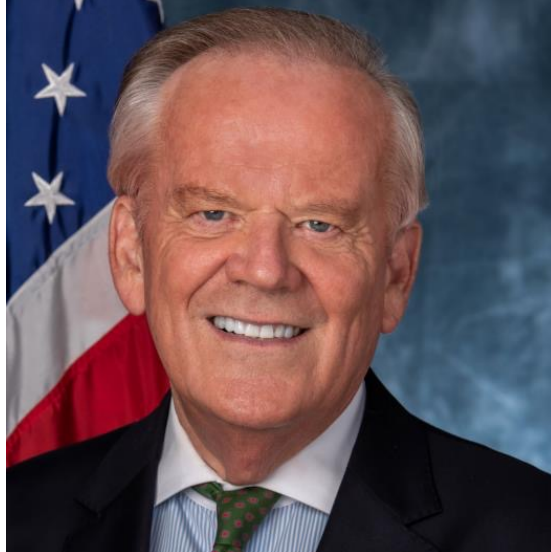
Business Meeting

July 28, 2022
12:00 PM to 4:00 PM EST

ACL
Administration for Community Living

Call to Order, Welcoming Remarks, and Meeting Overview

Jim Brett

PCPID Chair

Welcome Remarks from Administration for Community Living

Alison Barkoff
Acting Administrator
Administration for Community Living

Jill Jacobs
Commissioner, Administration on Disabilities
Administration for Community Living

Results from Internal PCPID Member Survey and Public Input; Overview of Past PCPID Reports Issued

David Jones

Director, Office of Intellectual and Developmental Disabilities
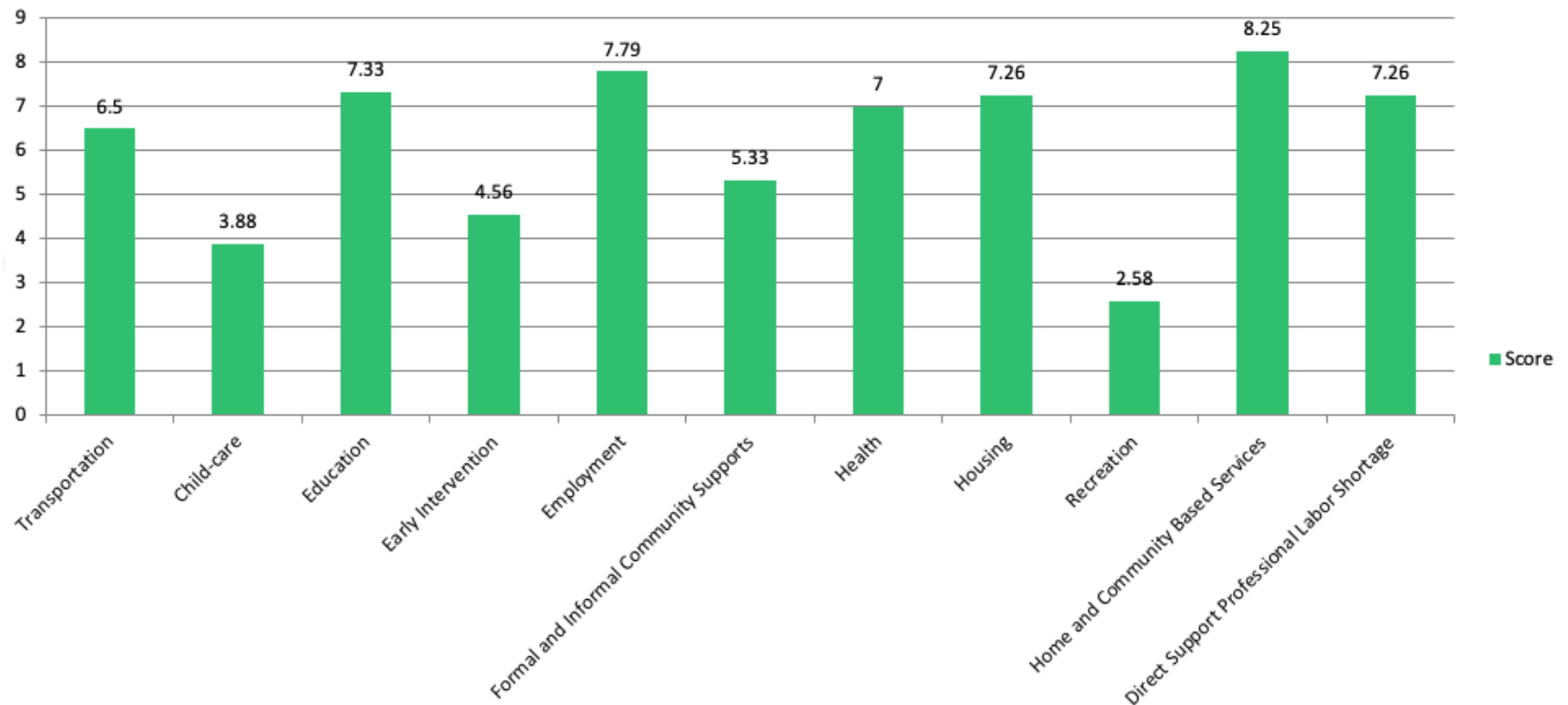
Administration for Community Living

I. PCPID Member Survey

PCPID Member Feedback – Narrative Questions

- **Q1**: What are the biggest policy barriers to community living for people with intellectual disabilities?

- **Q2**: What are innovative practices within federal, state, or local programs that promote effective delivery of services and supports for people with intellectual disabilities?

- **Q3**: What has been the greatest impact of the COVID-19 pandemic on people with intellectual disabilities?

- **Q4**: What are important issues facing individuals with intellectual disabilities who are a part of racial and ethnic minorities, economically disadvantaged communities, and/or rural communities?

PCPID Member Feedback – Ranking Issues [Q5]

From the list below, please rank the areas PCPID should focus on as it relates to the lives of people with intellectual disabilities - Please rank 1 (highest priority) to 9 (lowest priority). Please enter a numerical ranking for each topic area.

Topic Area	Score
Transportation	6.5
Child-care	3.88
Education	7.33
Early Intervention	4.56
Employment	7.79
Formal and Informal Community Supports	5.33
Health	7
Housing	7.26
Recreation	2.58
Home and Community Based Services	8.25
Direct Support Professional Labor Shortage	7.26

PCPID Member Feedback – Administrative Feedback

- **Q6:** Please check off which dates you are available to meet virtually this summer for a full committee meeting.

- **Q7:** Would you be interested in chairing a workgroup during your term?

II. Public Input Feedback to PCPID

III. PCPID Published Reports

Historical Published PCPID Reports (2011– 2017)

- **2017** – America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities, and the U.S. Economy

- **2016** – Strengthening an Inclusive Pathway for People with Intellectual Disabilities and Their Families

- **2015** – Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities

- **2012** – Managed Long-Term Services and Supports

- **2011** – People with Intellectual Disabilities: Critical Supports that Promote Independence, Full and Lifelong Community Inclusion

Briefing on Emerging Issues – Leading Three Takeaways

Home and Community Based Services (HCBS)

Nancy Thaler
Senior Policy Advisor
Administration for Community Living

Employment

John Butterworth
University of Massachusetts Boston
Institute for Community Inclusion

Jean Winsor
University of Massachusetts Boston
Institute for Community Inclusion

Education

Catherine Fowler
University of North Carolina Charlotte
Cato College of Education

Housing

Sheryl Larson
University of Minnesota
Institute on Community Integration

Direct Support Professional Workforce Crisis

Amy Hewitt
University of Minnesota
Institute for Community Inclusion

Home and Community Based Services (HCBS)

Nancy Thaler

Senior Policy Advisor

Administration for Community Living

Overview of HCBS Topics to be Covered

- People Served

- People Waiting for Services

- The Workforce Crisis

- Quality and the HCBS Rule

People Served in the HCBS Waiver Program

- 1.8 million people receiving 1915 (c) services

- 267 approved 1915 (c) waivers in 46 states & DC

- Participants with ASD/ID/IDD and who are Medically Fragile comprise over 50% of the participants and utilize 67% of expenditures.

- **ASD/ID/DD**
  - 114 waivers for 741,600 people (41.2%)
  - Expenditures in the top quartile states
  - $68,000 - $123,000

- **Medically Fragile**
  - 25 waivers for 162,000 people (.9%)
  - Expenditures in the top quartile of states
  - $68,000 to $184,000

- **Children SED**
  - 17 waivers - no of people unknown
  - Expenditures unknown

Leading Three HCBS Key Takeaways

- Waiting Lists to Enroll in Medicaid HCBS Services
  - Impact of State Budgets

- Access to Service
  - Impact of the Direct Care Crisis

- Quality of Services – and the HCBS Rule
  - Choice
  - Inclusion
  - Rights

Waiting List – Using Several Data Points

7.43 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2018
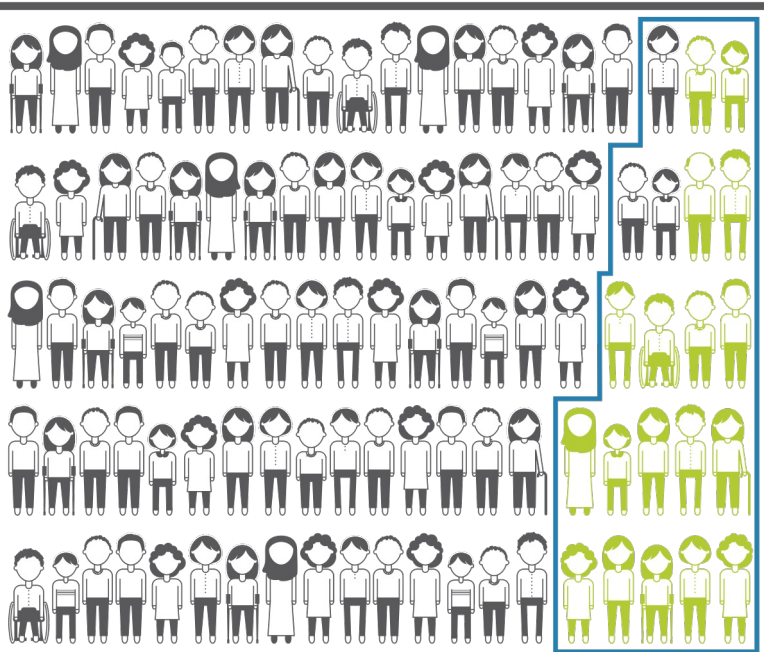
21% 1.55 million people with IDD were known to or served by state IDD agencies

18% 1.31 million people with IDD received long-term supports or services through state IDD agencies

FY 2018 RISP Infographics

What proportion of people with IDD get publicly funded supports?

not receiving supports

receiving supports

For every person with IDD getting publicly funded supports, four more people with IDD do not.
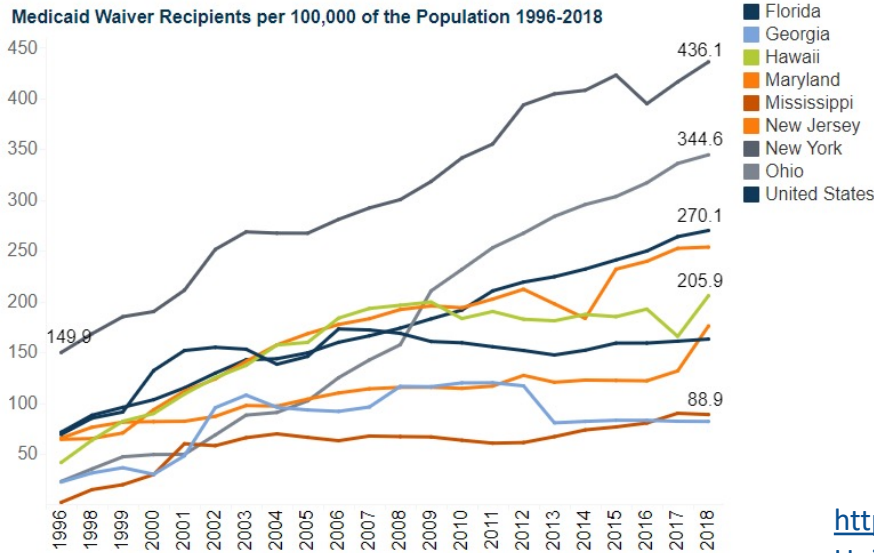
https://risp.umn.edu/infographics
University of Minnesota Institute on Community Integration

Number of People with ID/D Receiving Services in the Community – a State by State Picture

Medicaid Waivers include 1115 Demonstration Waivers, 1915(a, b, and b/c Managed Care Waivers) and 1915(c) Home and Community Based Waivers.

Select one or more: ▼
(Multiple values) ▼

Bar charts of waiver recipients are available to select specific years. Waiver includes: 1115; 1915 (a) (b) (b/c); 1915 (c). Click on a line to view data. Download options on lower right.

Medicaid Waiver Recipients per 100,000 of the Population 1996-2018

Legend:
- Florida
- Georgia
- Hawaii
- Maryland
- Mississippi
- New Jersey
- New York
- Ohio
- United States

Data labels: 436.1, 344.6, 270.1, 205.9, 149.9, 88.9

https://risp.umn.edu/infographics
University of Minnesota Institute on Community Integration

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The HCBS Workforce Crisis

- 1.3 million new workers will be needed by 2029

- The demand for services is growing faster than the labor pool

- People are at risk. The workforce shortage is limiting the ability of federal programs to safely maintain people in their homes and communities.

PROJECTED POPULATION GROWTH BY AGE GROUP, 2016 TO 2060

■ 18 to 64 Years Old   ■ 65 Years and Older
■ 85 Years and Older

198%

92%

15%

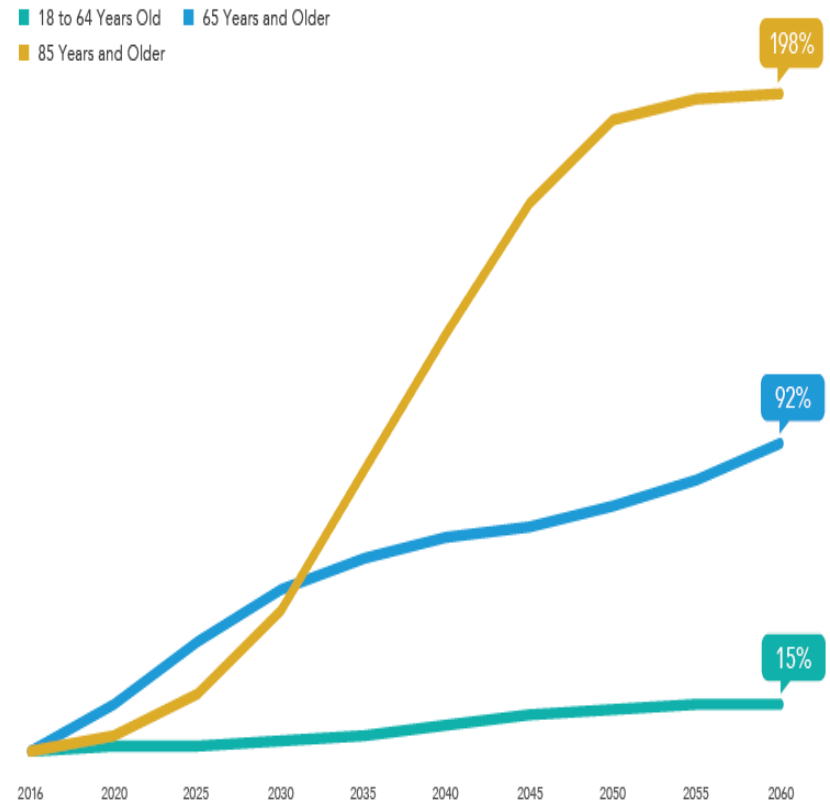2016 2020 2025 2030 2035 2040 2045 2050 2055 2060

Chart Source: U.S. Census Bureau. 2017. 2017 National Population Projections Datasets, Projected Population by Single Year of Age, Sex, Race, and Hispanic Origin for the United States: 2016 to 2060. https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html; analysis by PHI (July 2020).

19

Quality and the HCBS Rule

1. The setting was selected by the individual.

2. The individual participates in unscheduled and scheduled community activities in the same manner as individuals not receiving Medicaid HCBS services.

3. The individual is employed or active in the community outside of the setting.

4. The individual has his/her own bedroom or shares a room with a roommate of choice.

5. The individual chooses and controls a schedule that meets his/her wishes in accordance with a person-centered plan.

6. The individual controls his/her personal resources.

7. The individual chooses when and what to eat.

8. The individual chooses with whom to eat or to eat alone.

9. Individual choices are incorporated into the services and supports received.

10. The individual chooses from whom they receive services and supports.

11. The individual has access to make private telephone calls/text/email at the individual's preference and convenience.

12. Individuals are free from coercion.

13. The individual, or a person chosen by the individual, has an active role in the development and update of the individual's person-centered plan.

14. The setting does not isolate individuals from individuals not receiving Medicaid HCBS in the broader community.

15. State laws, regulations, licensing requirements, or facility protocols or practices do not limit individuals' choices.

16. The setting is an environment that supports individual comfort, independence and preferences.

17. The individual has unrestricted access in the setting.

18. The physical environment meets the needs of those individuals who require supports.

19. Individuals have full access to the community.

20. The individual's right to dignity and privacy is respected.

21. Individuals who need assistance to dress are dressed in their own clothes appropriate to the time of day and individual preferences.

22. Staff communicates with individuals in a dignified manner.
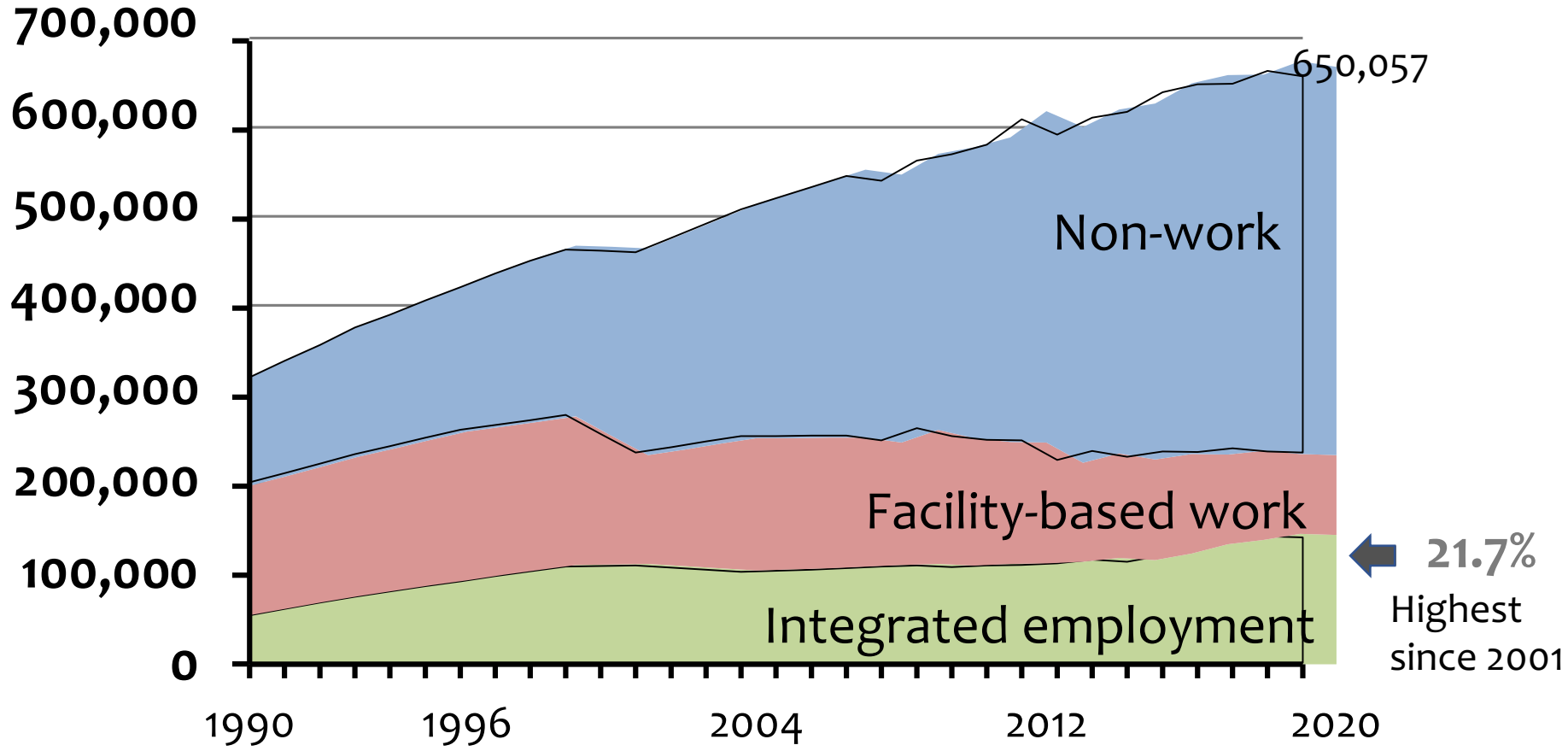
EMPLOYMENT

Employment Emerging Services and the New Reality

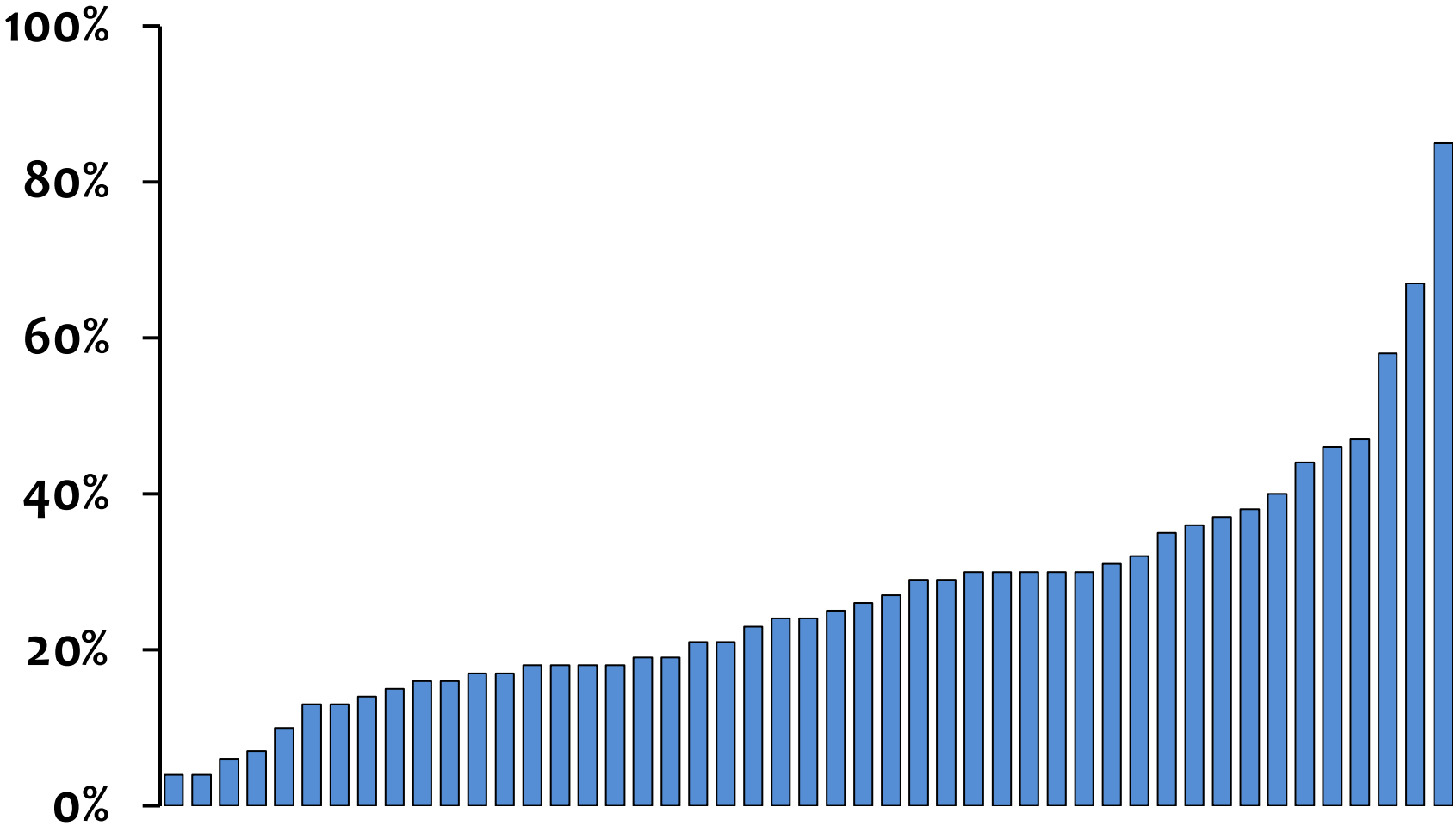John Butterworth
Jean Winsor

July 28, 2022

Number in Employment and Day Services

Chart: Number in Employment and Day Services, 1990–2020

- Y-axis: 0 to 700,000 (in increments of 100,000)
- X-axis: 1990, 1996, 2004, 2012, 2020

Categories (stacked areas, bottom to top):
- Integrated employment
- Facility-based work
- Non-work

Annotations:
- 650,057 (2020 total)
- 21.7% — Highest since 2001

Source: ICI National Survey of State IDD Agencies

State Employment Leadership Network

ICI ThinkWork!

Participation in integrated employment services

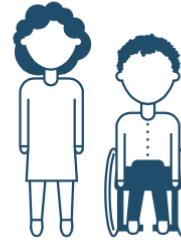

Source: ICI National Survey of State IDD Agencies

Do not have a job
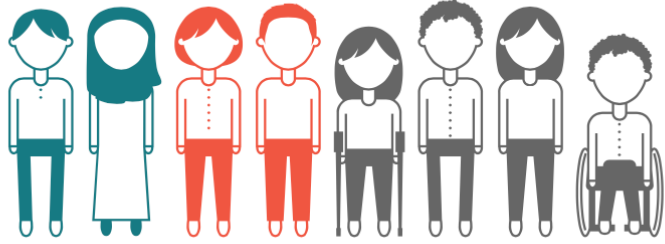
Have a job

Want a job
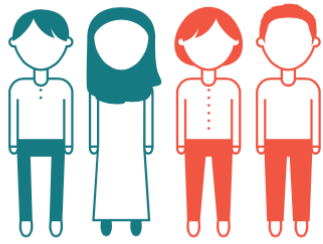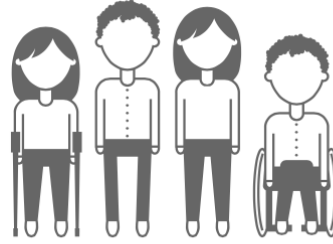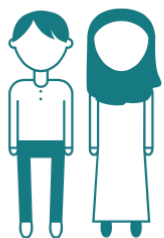
Don't want a job

Have goal

No goal

Source: National Core Indicators

ICI ThinkWork!

What Families Said Was Helpful During COVID-19 and Wish to Keep/Adapt/Expand

Peer to Peer	Self Advocacy Peer to Peer	More Individualized	Person Learned New Skills

Source: Fall 2020 Innovation Roundtable discussions from the Community of Practice for Supporting Families project

NASDDDS
National Association of State Directors
of
Developmental Disabilities Services

State Employment Leadership Network

ICI ThinkWork!

Systems:
What We Have – What People Want

Program Model

Hours and activities defined by program

Individualized Person-Centered Model

Work; socialization; continuous adult learning; civic participation; support hours flexible and defined by person
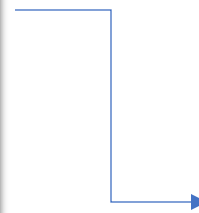
State Employment Leadership Network

ICI ThinkWork!

Employment is a basic part of how we connect many of the "important to" aspects of life such as relationships and social roles, status, routines, places to go, enjoyable or activities that allow for increased opportunity in life.

Our work is not isolated from the rest of lives, rather it is woven into it

Employment Relates to Everything

The ID system needs:

1. A clear pathway from non-work to work

2. Belief that people can work and responsive goals and action steps

3. A fundamental shift in how we approach supports

State Employment Leadership Network

ICI ThinkWork!

John Butterworth

john.butterworth@umb.edu

Jean Winsor

Jean.winsor@umb.edu

www.ThinkWork.org

www.selnhub.org

www.StateData.info

Additional Resources

[Employment: How we measure success](#)
State Employment Leadership Network

[Guidance for conversations: Identifying and designing pathways towards rewarding employment](#)
State Employment Leadership Network

[Agency Change Toolkit: Ten elements of organizational transformation](#)
Institute for Community Inclusion, UMass Boston

[Community Life Engagement Toolkit](#)
Institute for Community Inclusion, UMass Boston

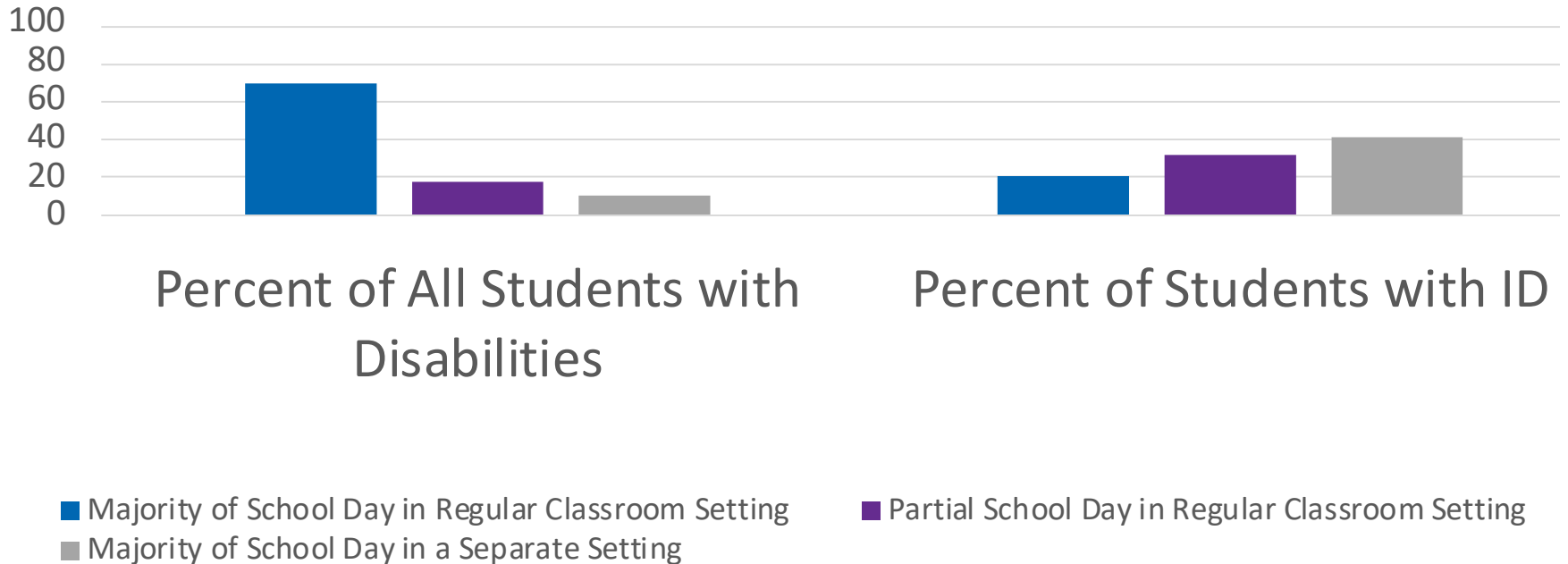[Weathering the pandemic: Employment and day service delivery](#)

Rie Kennedy-Lizotte & John Butterworth

EDUCATION

PCPID/ EMERGING ISSUES: EDUCATION

Catherine Fowler, PhD/ UNC Charlotte and

National Technical Assistance Center on Transition: the Collaborative

Educational Environments of Students with Intellectual Disabilities

Percent of All Students with Disabilities | Percent of Students with ID

■ Majority of School Day in Regular Classroom Setting ■ Partial School Day in Regular Classroom Setting
■ Majority of School Day in a Separate Setting

Predictors of Post-School Success for Students with Intellectual Disabilities

Inclusion in General Education

Community Experiences

Career Awareness

Work Experiences

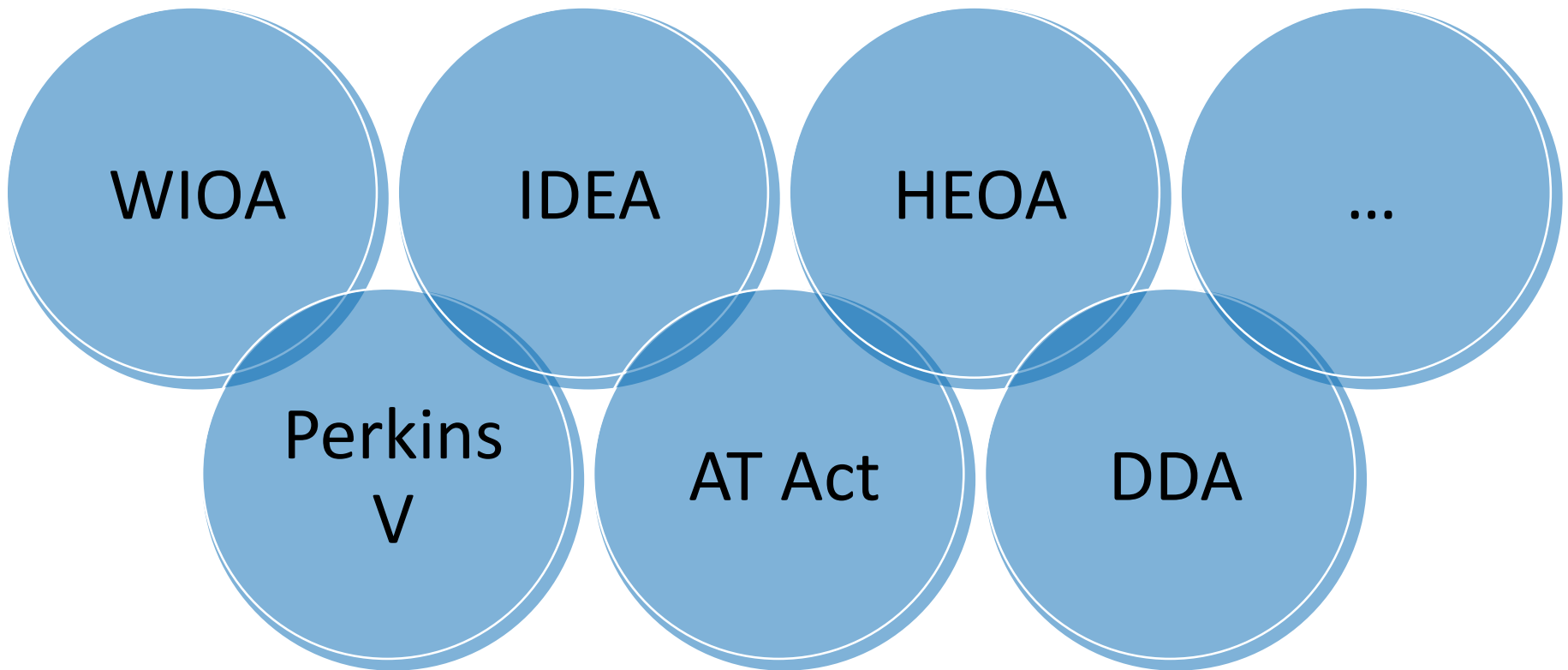**Paid Work**

Career and Technical Education

Autonomy

Empowerment

Communication (including AT)

Family Expectations

Capitalizing on Opportunities

WIOA

IDEA

HEOA

...

Perkins V

AT Act

DDA

3 Key Take Aways

Interdisciplinary and Interagency Coordination are Critical

Investing in Work Based Learning Experiences in Integrated Settings is Essential

Young People Must Have Access to Communication Tools

NTACT
THE **COLLABORATIVE**

Resources Relevant to Students with ID

→ Work-Based Learning for Students with High Support Needs

→ Predictor Implementation Self-Assessment and List of Predictors of Post-School Success

→ Developing School-Community-Business Partnerships

→ National Report on Employment Services (ICI)

→ Perkins State Plans and Data Explorer (OCTAE)

→ Inclusive Postsecondary Education (ThinkCollege)

Follow-up on Education

→ www.transitionta.org

→ ntact-collab@uncc.edu

→ Catherine Fowler, chfowler@uncc.edu

HOUSING

Housing and Residential Services for People with IDD

July 28, 2022

Sherri Larson, Ph.D. Director,

Residential Information Systems Project

University of Minnesota

Institute on Community Integration

Key Issues

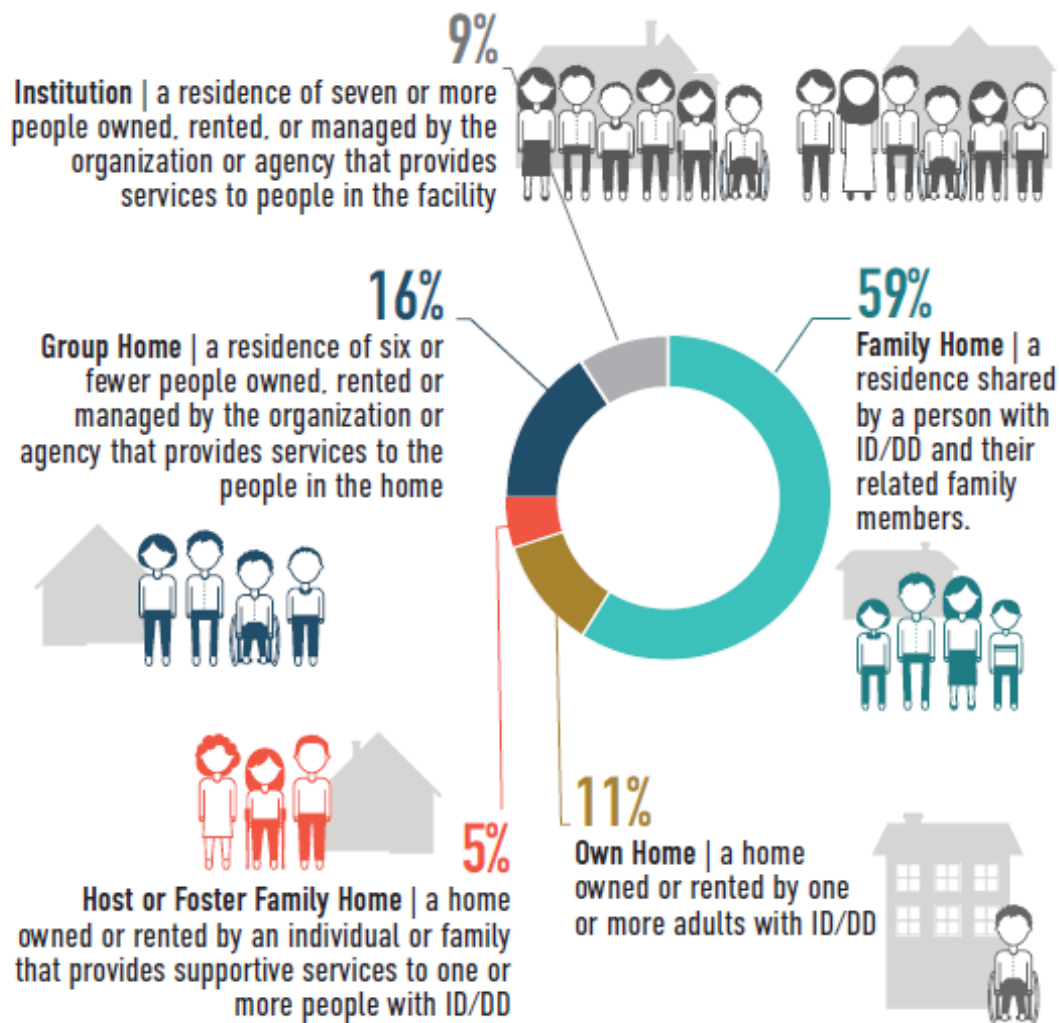Supporting Families

Access to Supports
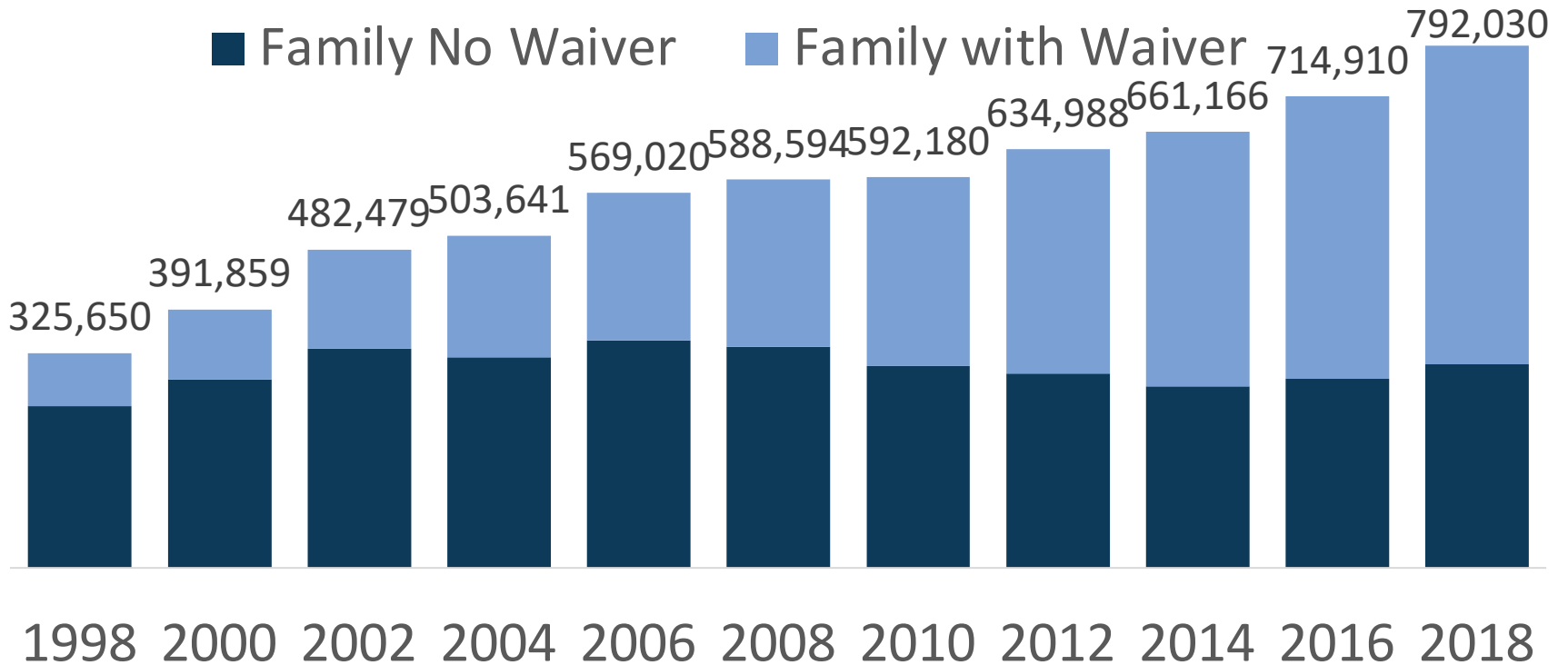
Housing

I. Supporting Families

Living Arrangements

- Most people with IDD live with family members
  - 85% of people with IDD in the United States
  - 59% of long-term supports and services recipients
- Huge state variations
- Deinstitutionalization continues

9%
Institution | a residence of seven or more people owned, rented, or managed by the organization or agency that provides services to people in the facility

16%
Group Home | a residence of six or fewer people owned, rented or managed by the organization or agency that provides services to the people in the home

59%
Family Home | a residence shared by a person with ID/DD and their related family members.

5%
Host or Foster Family Home | a home owned or rented by an individual or family that provides supportive services to one or more people with ID/DD

11%
Own Home | a home owned or rented by one or more adults with ID/DD

Growth in Medicaid Waiver Support for People who Live with a Family Member

II. Access to Supports

Access to Supports (2018)

- State IDD Agencies serve
  - 46% of adults with IDD
  - 11% of children with IDD
- 200,000+ people were waiting for Medicaid Waiver funded supports
- Adult prevalence estimates are very old
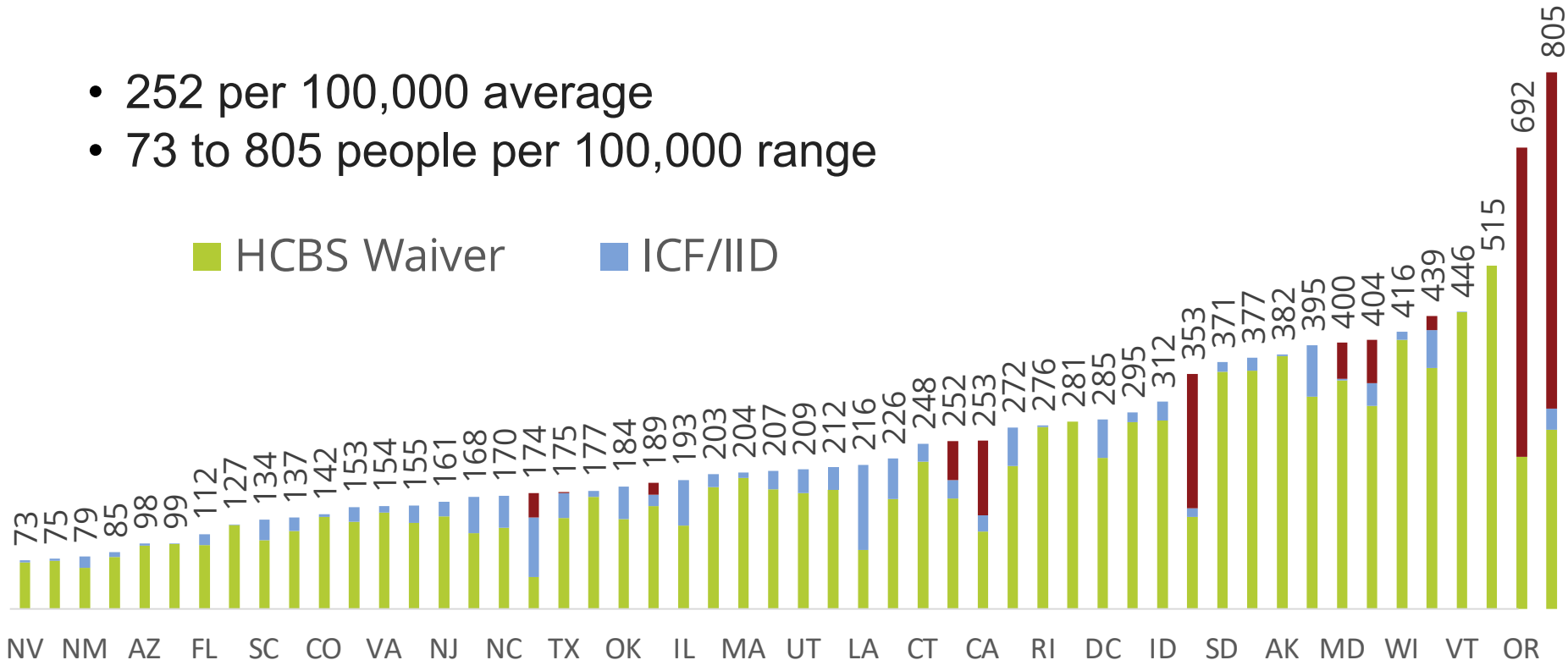

7.43 million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2018
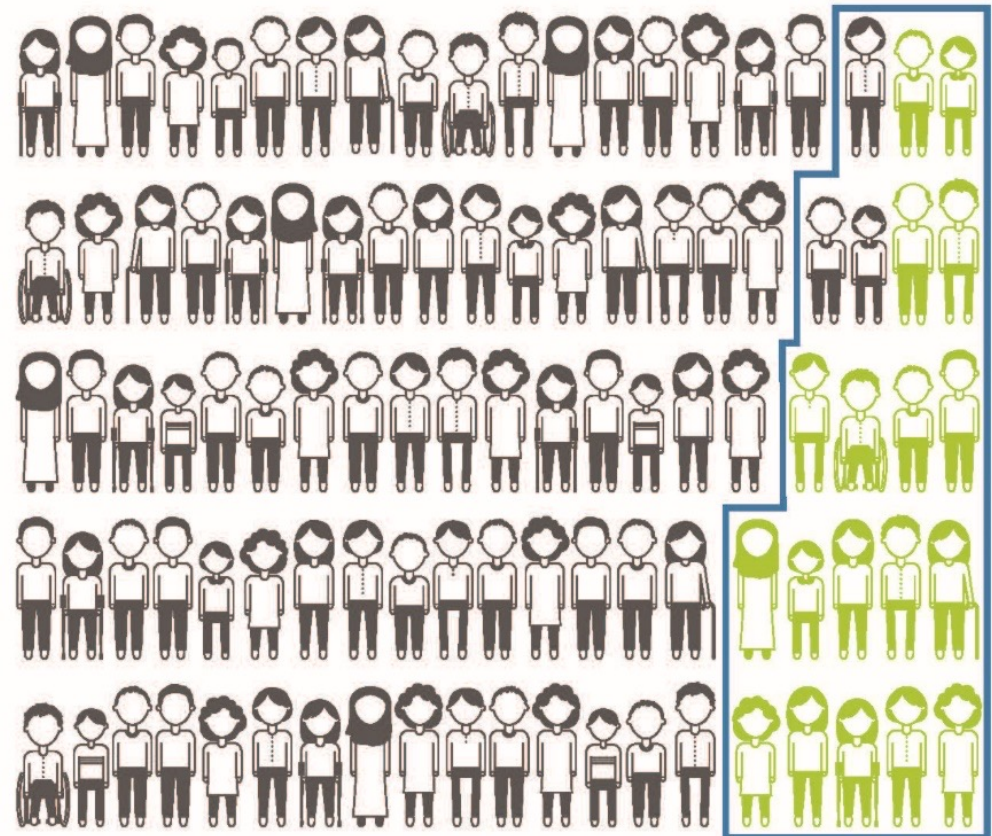
21% 1.55 million people with IDD were known to or served by state IDD agencies

Adult LTSS Recipients per 100,000 by State

- 252 per 100,000 average
- 73 to 805 people per 100,000 range

Legend: ■ HCBS Waiver ■ ICF/IID

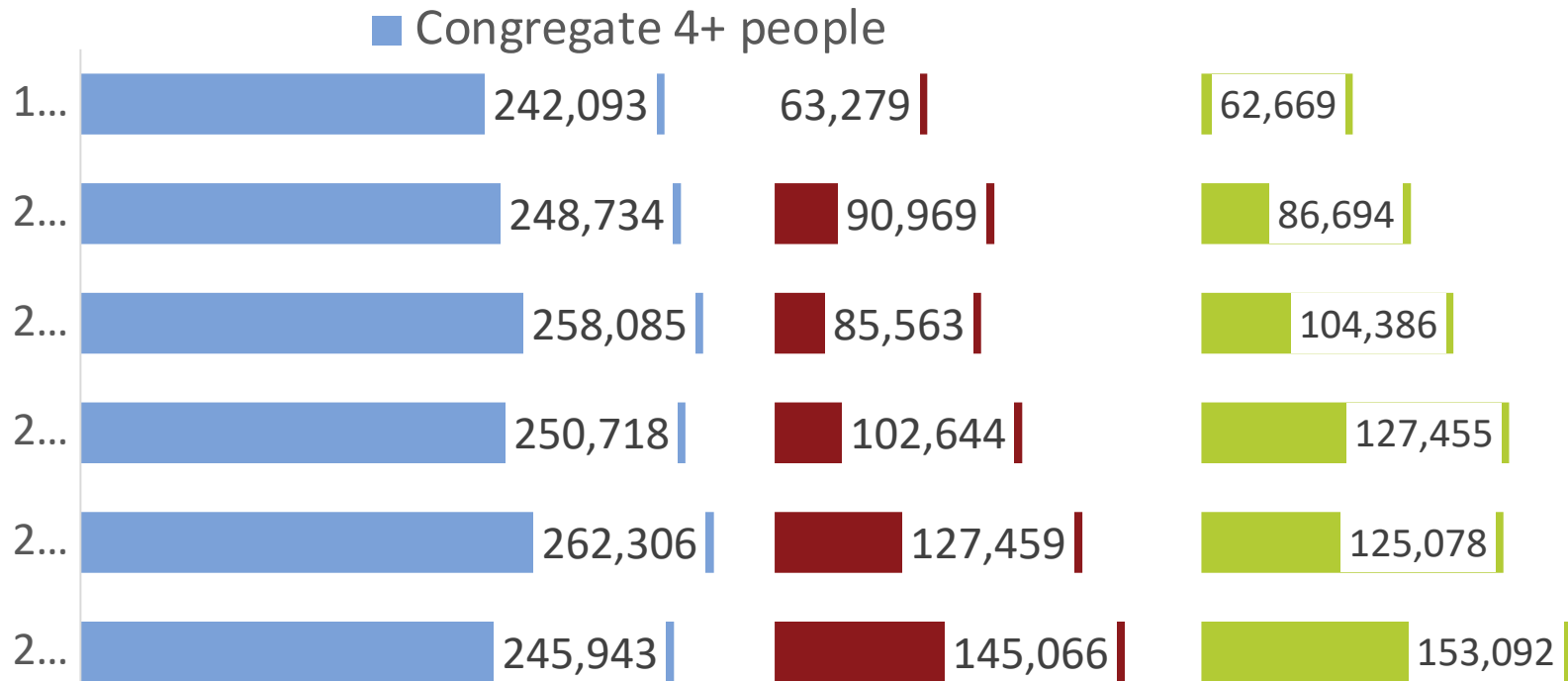| State	Value
NV	73
NM	75
AZ	79
	85
FL	98
	99
SC	112
	127
CO	134
	137
VA	142
	153
NJ	154
	155
NC	161
	168
TX	170
	174
OK	175
	177
IL	184
	189
MA	193
	203
UT	204
	207
LA	209
	212
CT	216
	226
CA	248
	252
RI	253
	272
DC	276
	281
ID	285
	295
SD	312
	353
AK	371
	377
MD	382
	395
WI	400
	404
VT	416
	439
OR	446
	515
	692
	805

RISP

III. Individualized Supports

Individualized Supports

- Required for Medicaid Home and Community Based Services funding

- People in smaller settings have more choice, are more satisfied and have better outcomes.

- Settings that best support individualized services
  - A person's own home with supports as needed
  - A host or foster family home
  - Family Home
  - Small group settings of three or fewer people getting supports

Living Arrangements Other than Family Home

Legend: ■ Congregate 4+ people

1...	242,093	63,279	62,669
2...	248,734	90,969	86,694
2...	258,085	85,563	104,386
2...	250,718	102,644	127,455
2...	262,306	127,459	125,078
2...	245,943	145,066	153,092

The size of congregate settings continues to decrease but some families want to build new congregate settings such as intentional communities or farmsteads.

Challenges

Prioritize supports for people living with <u>family</u> members or in <u>individualized</u> settings

<u>Access</u> to supports differs within and across states

200,000 + people are waiting

Providing individualized supports requires affordable accessible <u>housing</u>

Supplementary Resources

Resources

Residential Information Systems Project https://risp.umn.edu/

30 years of Community Living https://acl.gov/30years

IMPACT newsletter (https://ici.umn.edu/series/14)

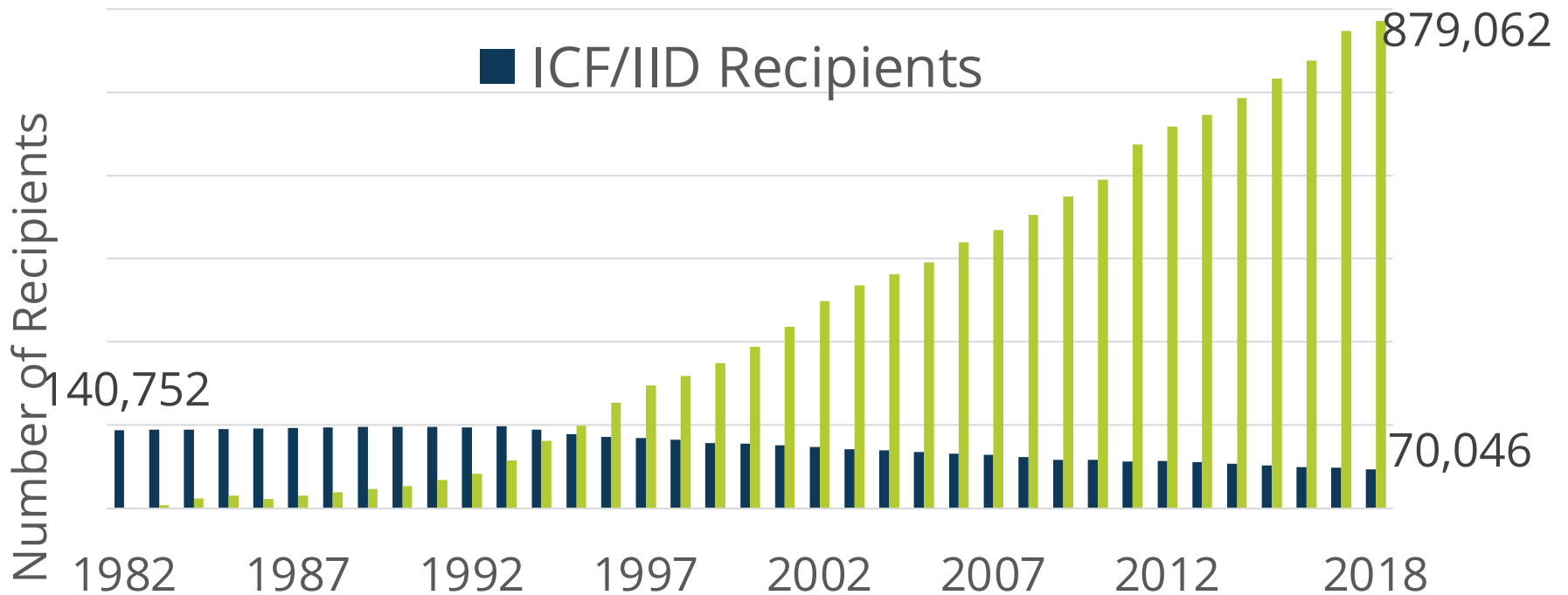ACL's Housing and Services Resource Center https://acl.gov/HousingAndServices

Institute on Community Integration Policy Research Briefs and Policy Forums
http://z.umn.edu › icipolicyforum

Charting the Lifespan for Families of Individuals with IDD
https://supportstofamilies.org/

ICF/IID Use Declines as HCBS Waiver Use Explodes

Contact Information

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612.624.6024 larso072@umn.edu

Research and Training Center on Community Living
Institute on Community Integration (UCEDD)
University of Minnesota, Twin Cities

Office 1-338

2025 East River Parkway, Minneapolis, MN 55414

DIRECT SUPPORT PROFESSIONAL WOFKORCE CRISIS
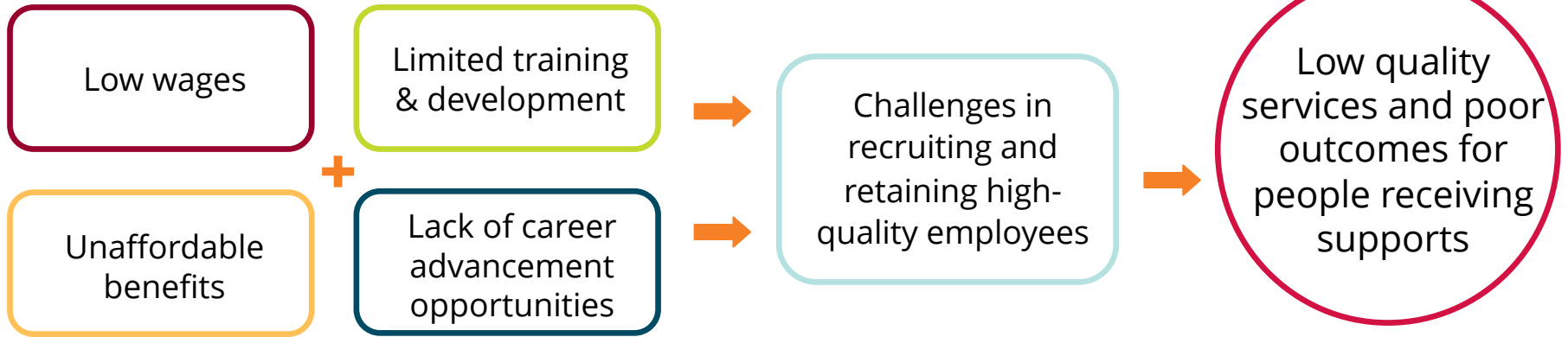
Direct Support Professional Workforce Crisis

Amy Hewitt

University of Minnesota

Institute on Community Inclusion

A 30 year National Problem

Low wages

Limited training & development

+

Unaffordable benefits

Lack of career advancement opportunities

→ Challenges in recruiting and retaining high-quality employees

→ Low quality services and poor outcomes for people receiving supports

Things we know about DSPs

Primary wage earners	**~70%** (Hewitt et al 2021)
Disproportionately women	**84%**
Disproportionately BIPOC	**55.4%** (NCI, 2020)
Mean wage	**$13.61** (Nat'l NCI, 2022)
Rely on public assistance	**~50%** (PHI, 2020)
PT/FT status	
Part time	**31%** (Nat'l NCI, 2020)
Full time	**69%** (Nat'l NCI, 2020)
Turnover rate	**40%** (Nat'l NCI, 2020)
Terminated from their positions	**17%** (Nat'l NCI, 2020)
Vacancy rate	**12.3%** (FT); **16.4%** (PT) (NCI, 2020)
Education	**73%** education beyond h.s.; **27%** h.s. only (Hewitt et al 2021)

Direct care job openings 2018 - 2028
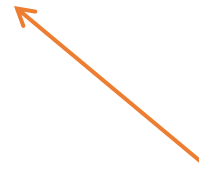
PRE-pandemic!

8.2 Million

Then COVID-19……

- Only 30% reported extra money working as essential workers
  - Of those majority $1 – 2

- Disparities evident in wages and household incomes

- Disruption and change
  - work patterns, schedules, locations, type

- Extreme hours worked

- Majority had decline in work-life status (worse or much worse 54%)

- Mental health and wellness challenges
  - Physical and emotional burnout 50%
  - Anxiety 47%
  - Sleep difficulties 38%

Policy Research Brief
Policy Forum

Source: Hewitt et al, 2021

Mental health support

- Employee assistance
- Ensure health plans have robust mental health coverage
- Wellness training and support programs
- Financial, childcare and caregiver community connections

Other recommendations

Ensure the DSP workforce is identified as essential workers with same benefits in every state, DC and US territory

Identify, address and eliminate wage disparities at organizational, state and national levels within this workforce

Professional recognition and wage equity for all DSPs

Pay wage that correlates with skills and enhance wages through career paths that recognize new skill development with higher wages

Eliminate wage compression through better methods for getting wage increases to DSPs

Find solutions in lessons learned from other female dominated professions (e.g., nursing, teaching, social work)

Contact Information

Amy Hewitt - University of Minnesota

- **Email:** hewit005@umn.edu

UNIVERSITY OF MINNESOTA

Driven to Discover®

Crookston Duluth Morris Rochester Twin Cities

PCPID Member Question and Answer to the Panel Presenters

Break

15 minutes

Public Input Feedback to PCPID

PCPID Member Reflection on Emerging Issues

- As a committee member, what do you believe is the leading issue(s) that needs to get addressed by the PCPID and why?

- Committee Members Nominate Topics

Break

5 minutes

PCPID Committee Member Online Voting

Closing Remarks

Jill Jacobs
Commissioner, Administration on Disabilities
Administration for Community Living

Jim Brett
Chair, PCPID

THANK YOU