

Using Data from National Core Indicators™ to Inform Three ID/DD Policy Areas: Supports for People with Autism, Importance of Friendships, and Staff Stability



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Agenda



- Introduction to National Core Indicators
- Outcomes For Adults On The Autism Spectrum
- What do NCI data tell us about the relationship between friendship and life outcomes for adults with IDD?
- Reflections on recent data from the NCI Staff Stability Survey

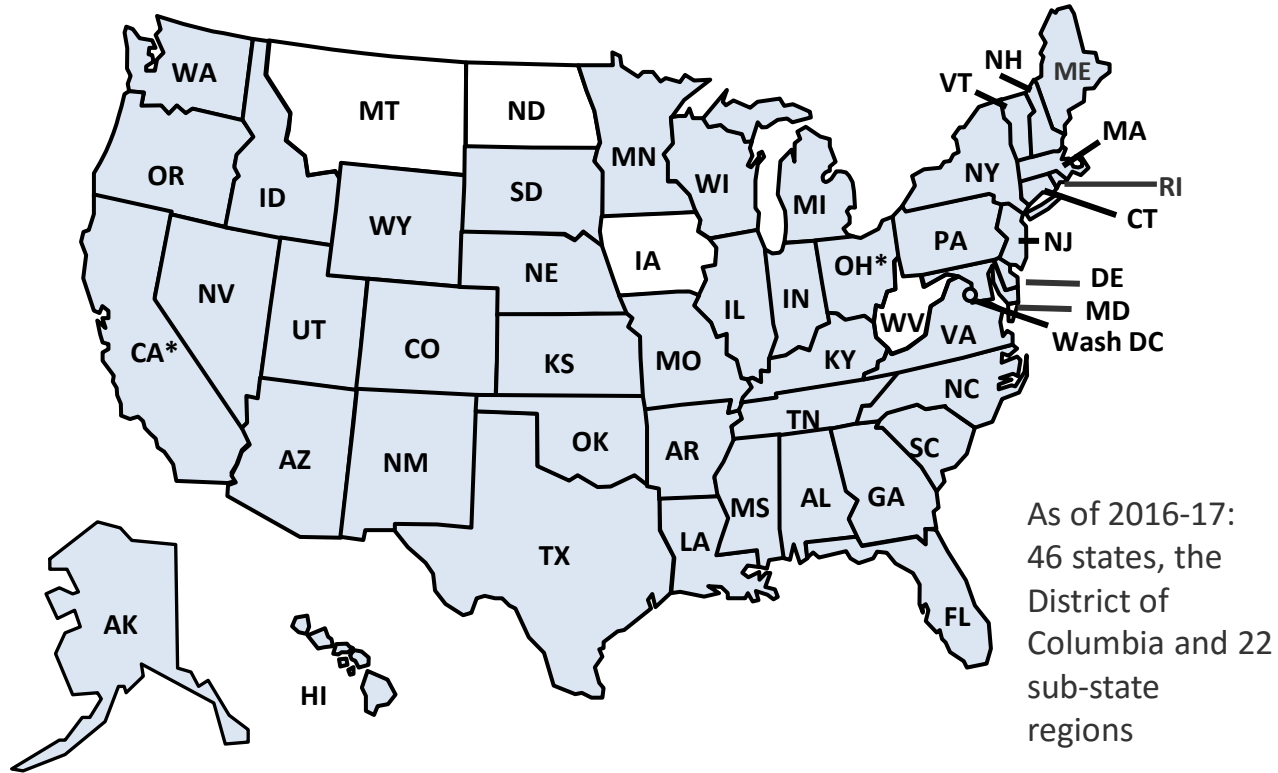


What is NATIONAL CORE INDICATORS (NCI)?

- NASDDDS, HSRI & State DD Directors
 - Multi-state collaboration
 - Launched in 1997 in 13 participating states – now in 47 states (including DC) and 22 sub-state areas
- Goal: Measure performance of public systems for people with intellectual and developmental disabilities by looking at **outcomes**
 - Help state DD systems assess performance by benchmarking, comparing to other states
 - Domains: employment, community inclusion, choice, rights, health, safety, relationships, service satisfaction etc.



National Core Indicators^(TM) State Participation



Adult Consumer Survey



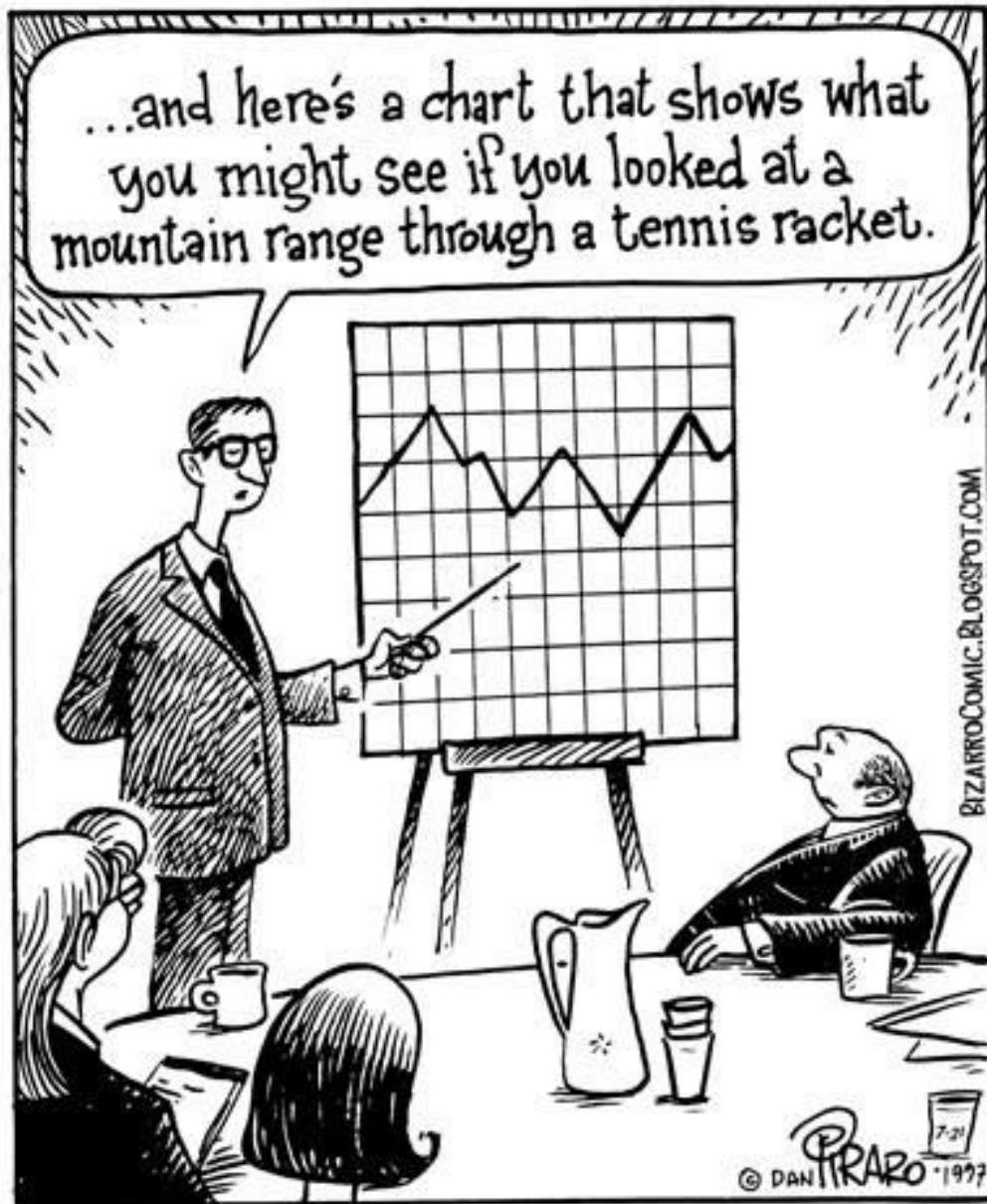
- Standardized, face-to-face interview with a sample of individuals receiving services
 - Background Information - includes health information
 - Section I (no proxies allowed)
 - Section II (proxies allowed)
- No pre-screening procedures
- Conducted with adults only (18 and over) receiving at least one service in addition to case management
- Section I and Section II together take 50 minutes (on average)



Data for This Presentation:

- NCI Consumer Survey Data, 2014-15
 - 32 States & Washington DC
 - 25,820 individual surveys
- Staff Stability Survey Data, 2014
 - 10 states
 - 17 states in 2015







What Do We Know About People with Autism?

Terminology Preferences

- Within the autism and Autistic communities, a wide variety of different linguistic preferences exist, with many individuals on the autism spectrum preferring the use of “identity-first” language rather than “person-first”.
- **Within this presentation, we will alternate between “person on the autism spectrum” and “autistic person”.**
- See <http://autisticadvocacy.org/home/about-asan/identity-first-language/> for more details.



Autism Spectrum Disorder

- Prevalence estimates of ASD are rising
 - Autistic people represent higher percentage of population than previously recognized.
- Proportion of Autistic people with co-occurring intellectual disabilities (ID), by some estimate, is as high as 60%
 - However, some question the applicability of standardized tests for people with ASD.



Autism and State I/DD Service Systems



- In some states, Autistic people are eligible for ID/DD services.
 - Often due to concomitant ID diagnosis, functional limitations, and/or state eligibility criteria that goes beyond ID
 - Recently, some states adopting “autism waivers.”
- However, the number of individuals enrolled is small.
 - Hewitt et al. (2012) estimated that only 8.1% of the individuals receiving public I/DD services have been assigned an ASD diagnosis.

Autism and State I/DD Service Systems

- **DSM-5** eliminated separate categories of autism disorder
 - Removed diagnoses of
 - pervasive developmental disorder,
 - Asperger's syndrome,
 - childhood disintegrative disorder
 - autistic disorder.
 - Instead there will be **one diagnostic category for the autism spectrum**
- Single diagnostic category may result in increased access to services
 - for those who may have met the functional eligibility criteria for I/DD systems but have been excluded because of their presenting diagnosis



Sweeping Changes Over Past Several Decades

- Developmental Disabilities Assistance and Bill of Rights Act
 - Americans with Disabilities Act (ADA)
 - Individuals with Disabilities Education Act (IDEA)
 - Rehabilitation Act of 1973.....
- Led to growth of community-based settings for people with disabilities
 - Goal: aim to encourage “full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society”



Autistic Individuals Lag Behind

- Autistic people do not appear to have benefited to the same extent as those without autism.
 - Research has shown:
 - Poorer adult life outcomes in areas such as:
 - Independent living
 - Community inclusion
 - Research has shown that teens with ASD fare worse than other students with intellectual disabilities.
 - physical well-being, social support and psychological well-being



**What do NCI data show about
Autistic adults receiving state
I/DD services?**

NCI Sample of Autistic Individuals

- Subsample identified in the 2014-2015 Consumer Survey:
 - Diagnosis of “Autism Spectrum Disorder (i.e., Autism, Asperger Syndrome, Pervasive Developmental Disorder)” identified in background
 - ❖ Information on diagnoses taken from agency records
 - ❖ The total number of records indicating the presence of ASD was 4,187 (16% of total sample)

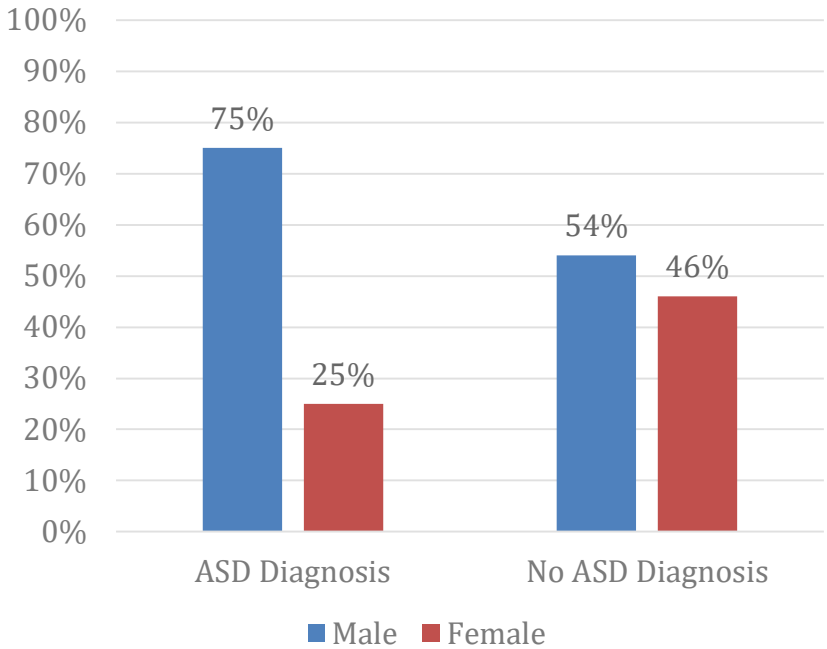
All relationships shown are significant at the $p \leq .05$ level



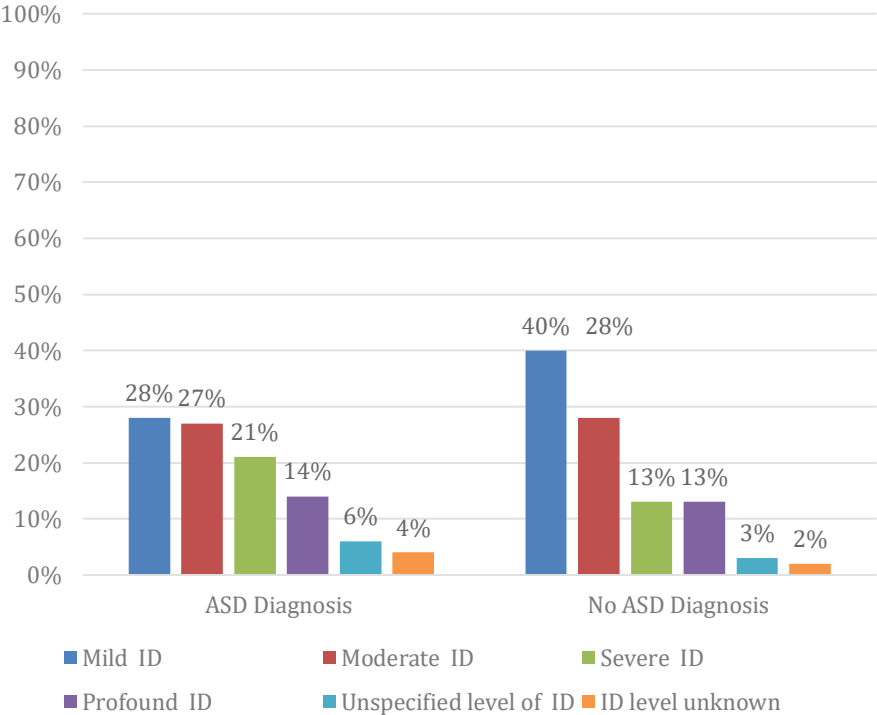
Demographics



Gender

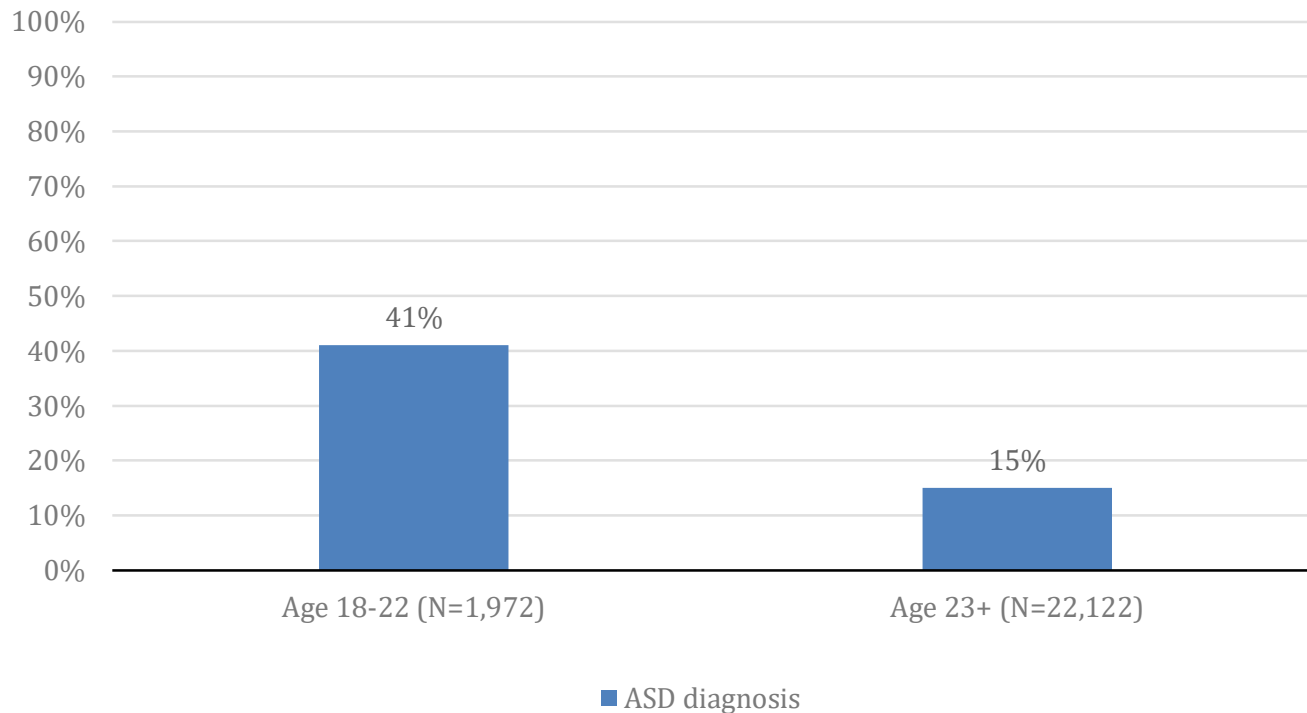


Level of ID



Younger Individuals Are More Likely to Have ASD Diagnosis

Percent of Respondents Between Ages 18-22 and Age 23+ with ASD Diagnosis



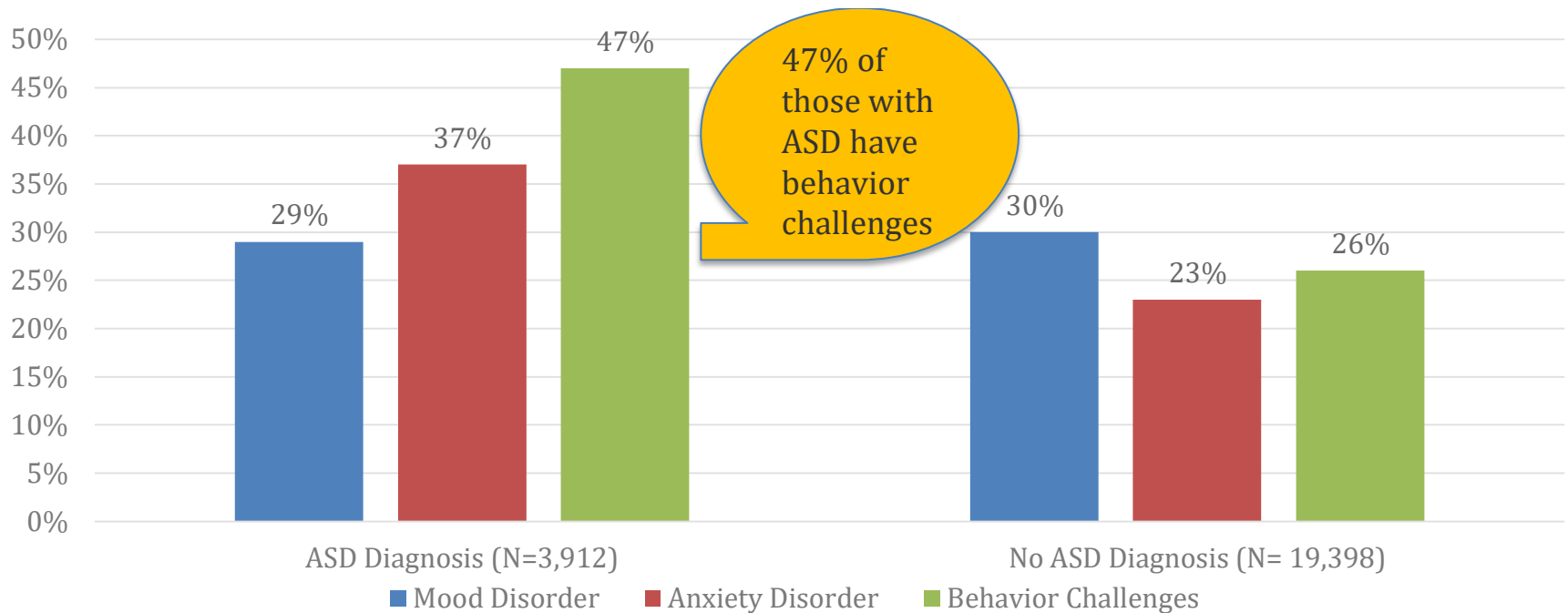
Average age of respondents with ASD Diagnosis: **33.8**

Average age of respondents without ASD Diagnosis: **43.3**



More Individuals with Autism Have a Mental Health Diagnoses

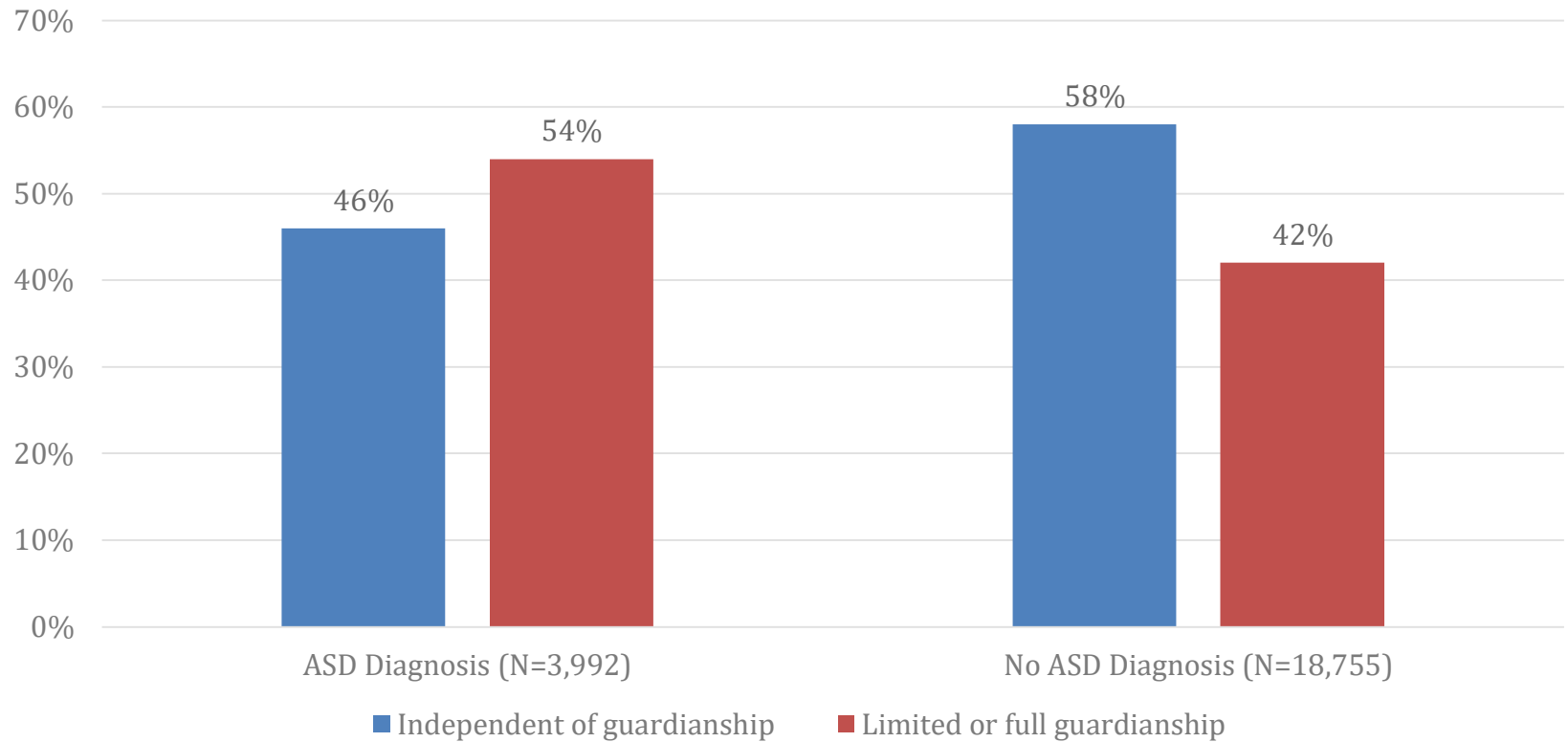
Proportions of Adult Consumer Survey respondents with reported mental health diagnoses, behavior challenges, by ASD diagnosis



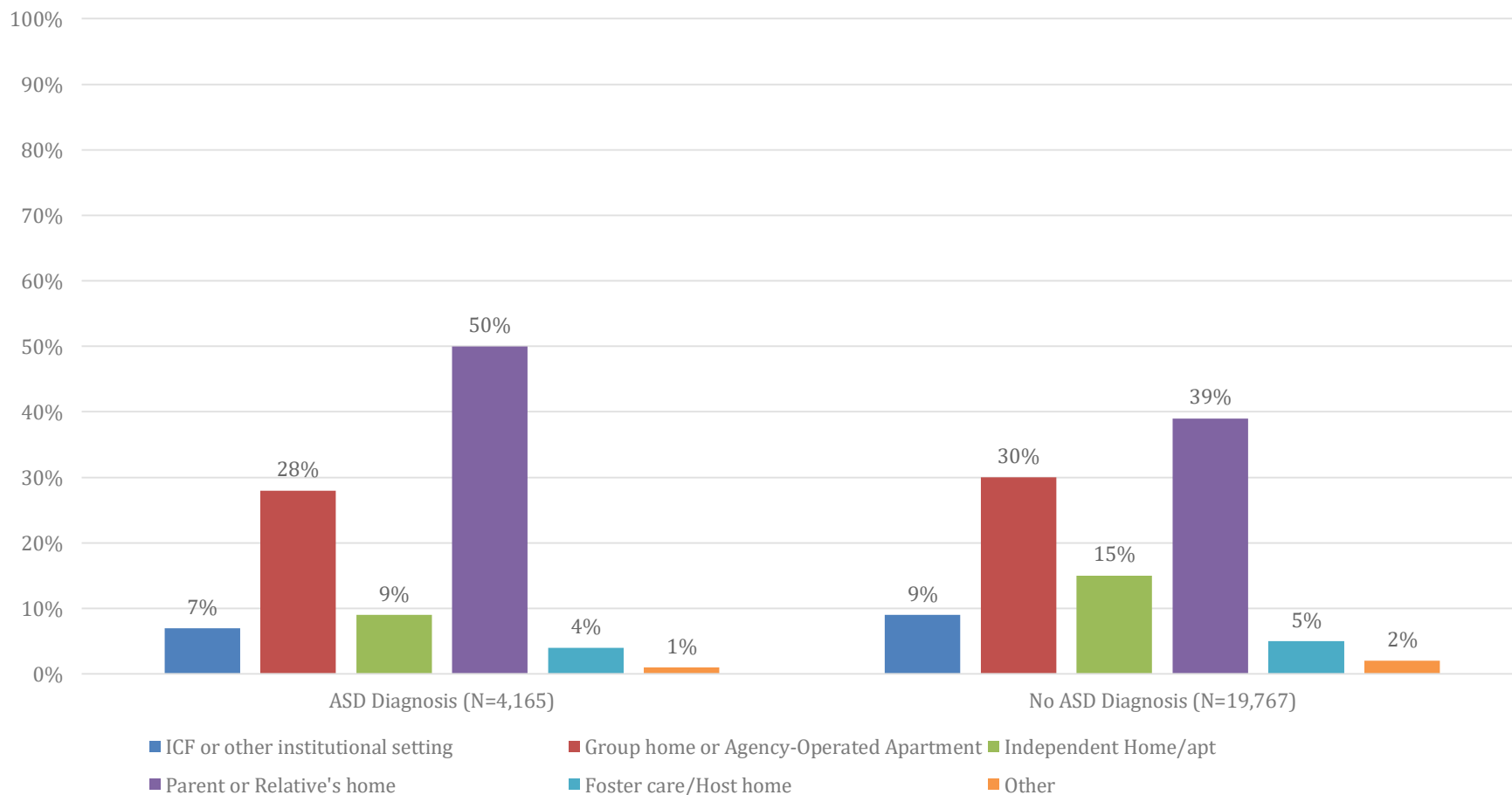
Autistic individuals were far more likely to be reported as receiving **medications** for anxiety, mood, behavior or psychotic disorders: **ASD Diagnosis: 65% No ASD Diagnosis: 46%**

More Individuals with Autism Have Guardians

Guardianship status of Adult Consumer Survey respondents by ASD diagnosis

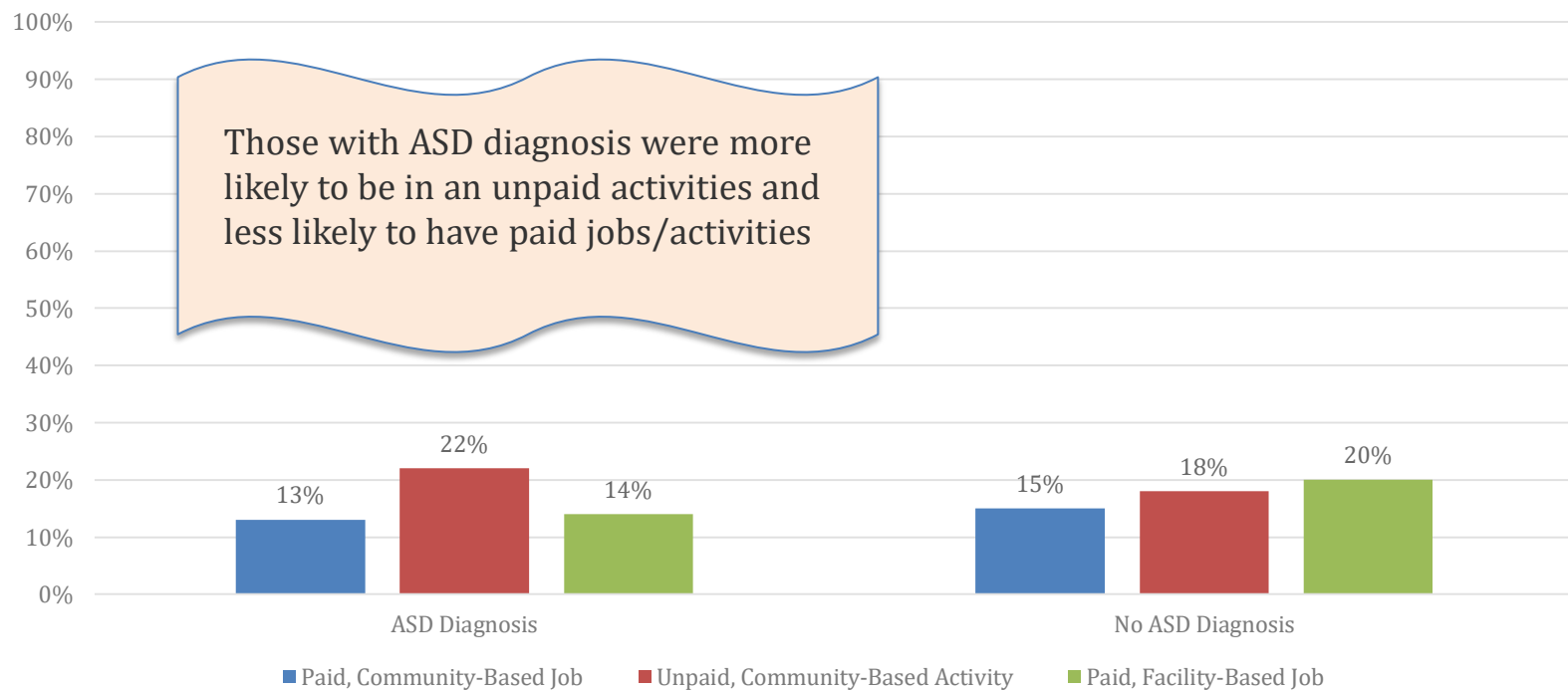


People with Autism Less Likely to Live in Their Own Home/Apartment



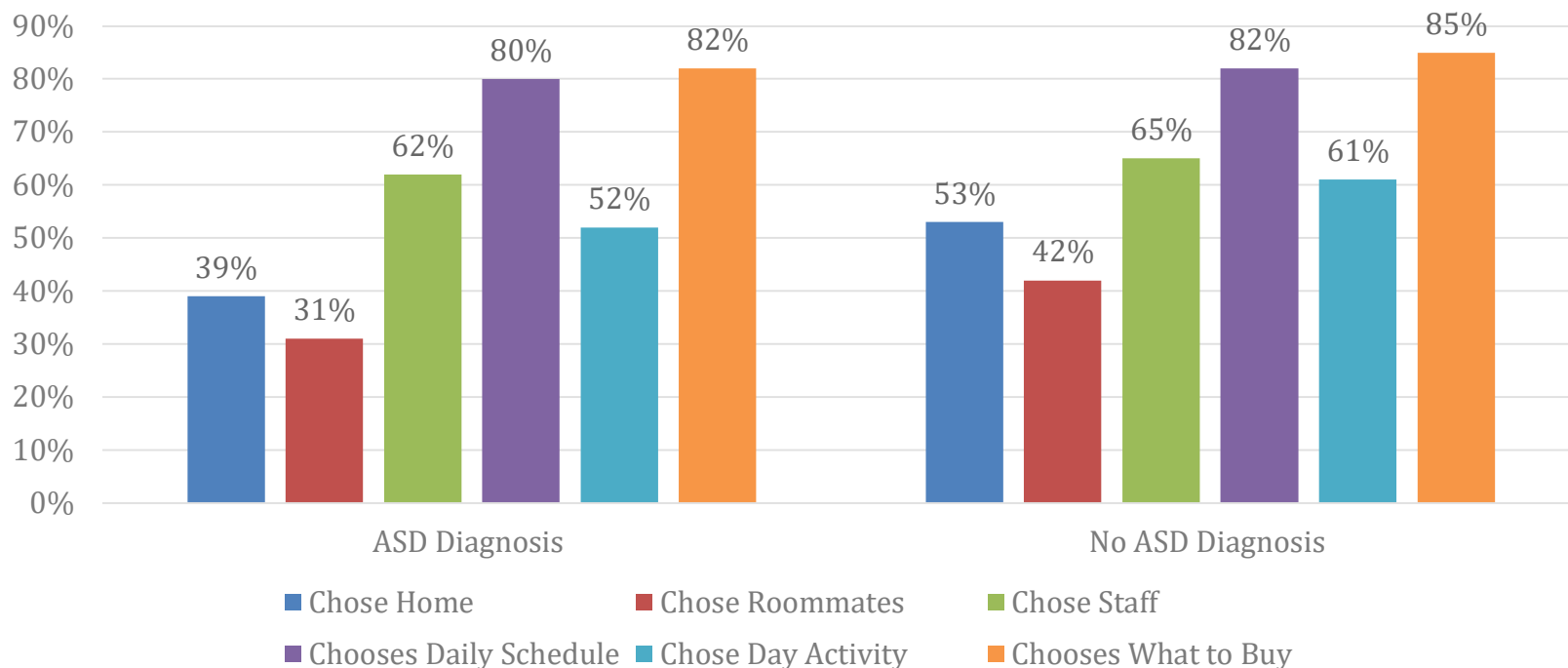
Autistic Adults Are Less Likely to be Employed

Employment among Adult Consumer Survey respondents by ASD diagnosis



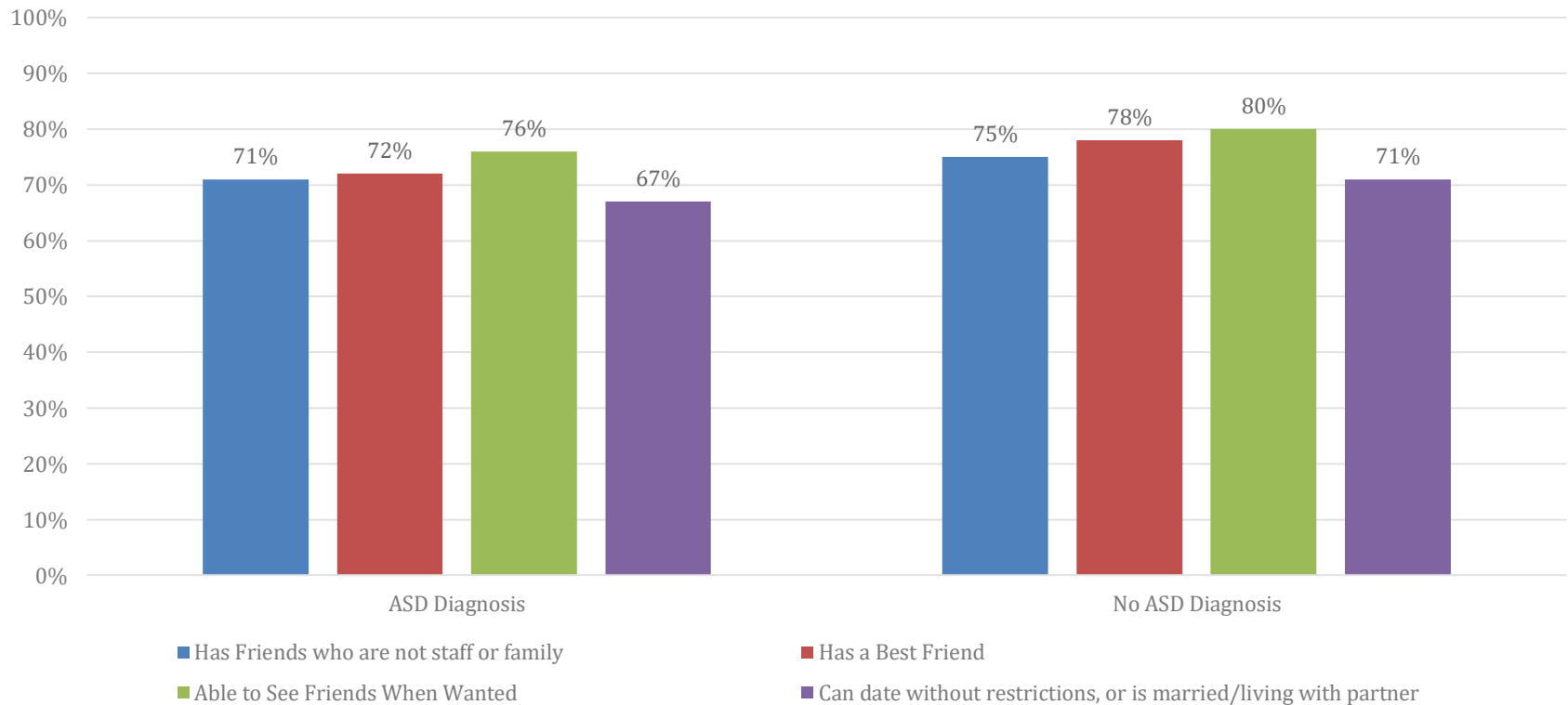
Autistic Adults Are Less Likely to Make Choices About Their Lives

Proportions of Adult Consumer Survey respondents with and without ASD diagnosis reporting at least some input into choices



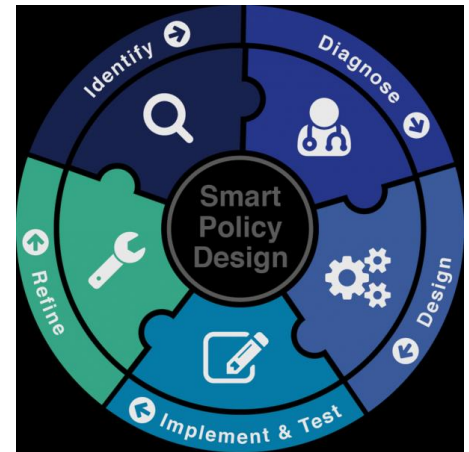
Of those with ASD Diagnosis: using a self directed supports option: 14%
Of those with No ASD Diagnosis: using a self directed supports option: 10%

Autistic Adults Less Likely to Have Friends



Key Policy Initiatives that will Enhance Outcomes for Autistic Adults

- Research
- Long Term Services and Supports
- Housing
- Employment
- Legal Autonomy and Supported Decision-making



Research

- Significant disparities in autism research funding allocation
- In 2010, of NIH's \$217M in Autism Research, only 1.5% went towards adults and only 2.45% towards services research
- Need for Participatory Action Research models



Long Term Services and Supports

- CMS HCBS Settings Rule
- Significant gap for Autistic people who do not meet institutional LoC
- Emerging use of state 1915i state plan authority to meet need for this population
- Family support



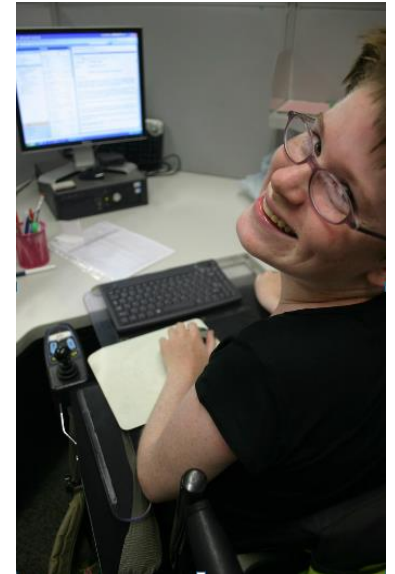
Housing



- Settings rule encouraging a shift towards supported living, shared living models;
- States need to establish rental subsidy programs to make supported living viable;
- Congregate models frequently replicate the dynamics of an institution;

Employment

- Five states (VT, MA, OR, RI, NY) have or are committing to phasing out sheltered work;
- Growing *Olmstead* litigation around integrated employment;
- Integrated Day Services often key to the employment discussion;
- S. 1604, the Transition to Independence Act



Legal Autonomy and SDM

- Article 12 of the UN CRPD
- Texas recently became first state to adopt SDM Law;
- ASAN Model Legislation on Healthcare Supported Decision-Making
- Liability issues remain to be sorted out, especially in financial and healthcare SDM





What Do NCI Data Show About Friendship and Life Outcomes for Adults With IDD?

Types of Friendships

- Expanded friendships
 - Reported being friends with people other than staff and family
- Limited friendships
 - Those reported having no friends
 - Those who reported having friends who were all either family or staff



Sample

“Do you have friends you like to talk to or do things with?”

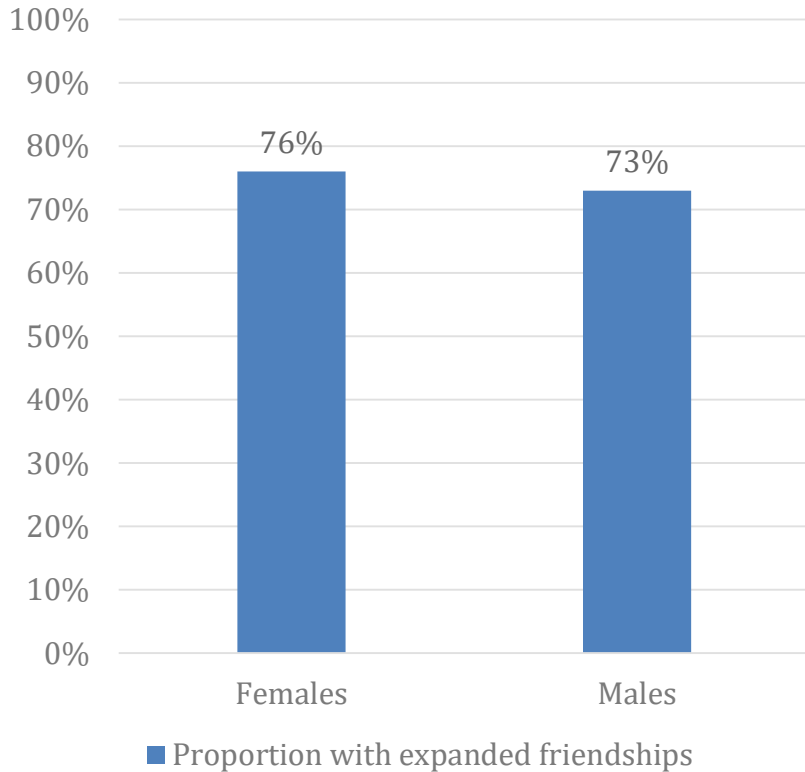
- Yes, has friends who are not staff or family
 - Yes, all friends are staff or family, or cannot determine
 - No, does not have friends
 - Don't know
- No proxy responses permitted
 - Only individuals who responded to this question were included in the sample
 - Respondents for whom this question was left blank or coded as “Don't know” were excluded from the final dataset.
 - The final dataset includes 16,626 people.

All relationships in this presentation are significant at the $p \leq .05$ level

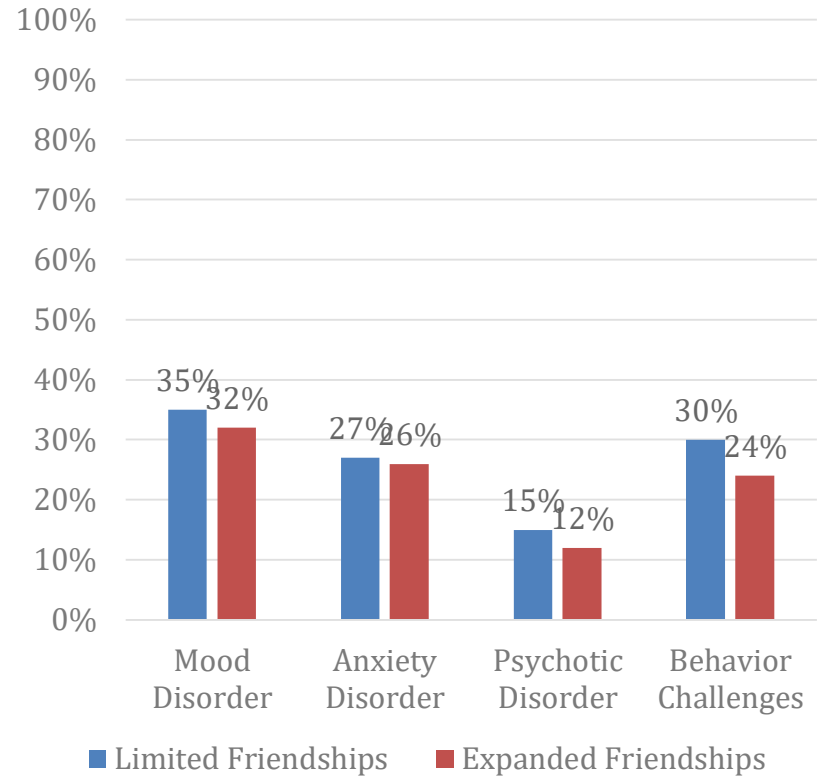


Demographics

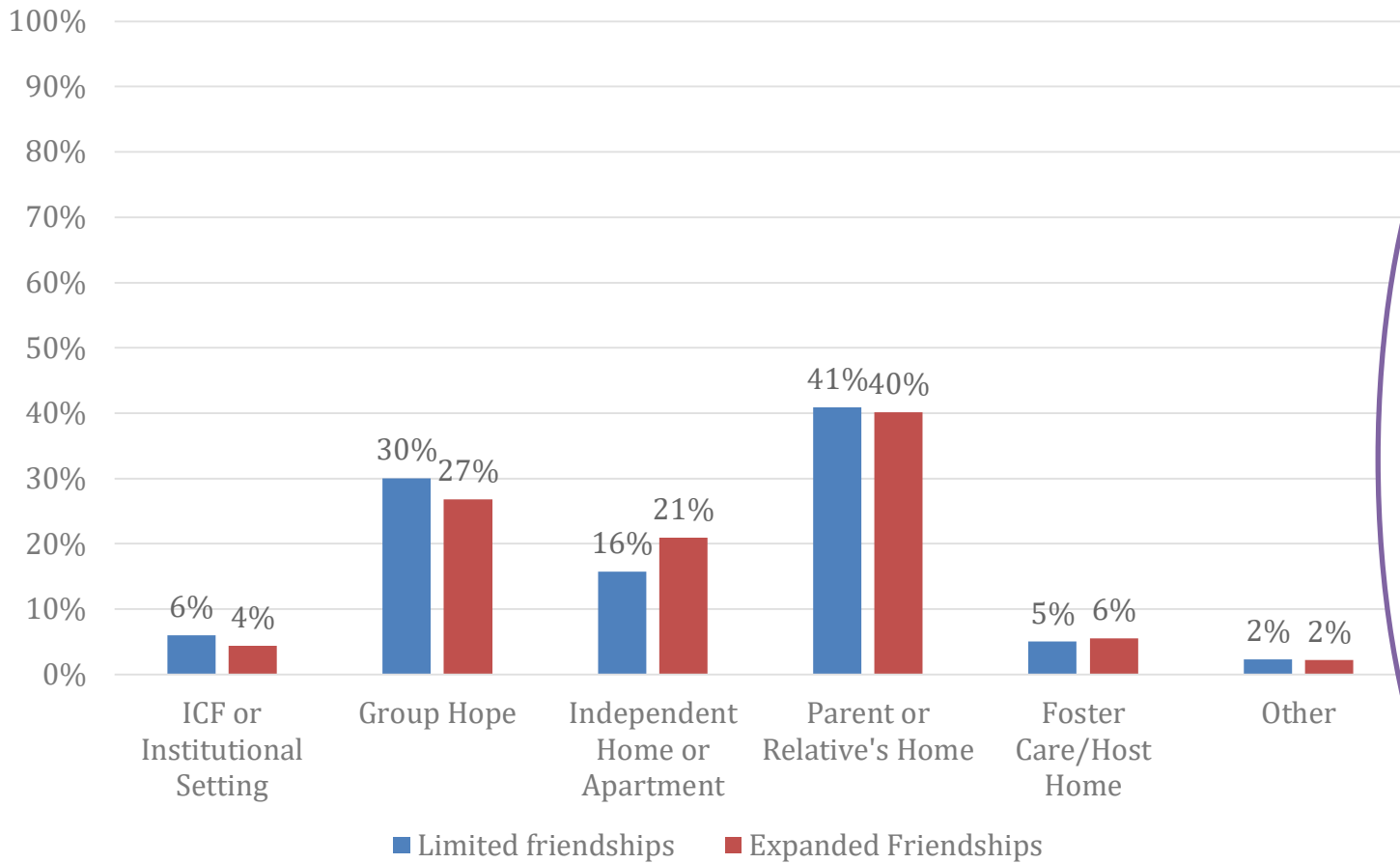
Expanded Friendships by Gender



Mental Illness/Psychiatric Diagnosis by Friendship Status



Type of Residence by Friendship Status

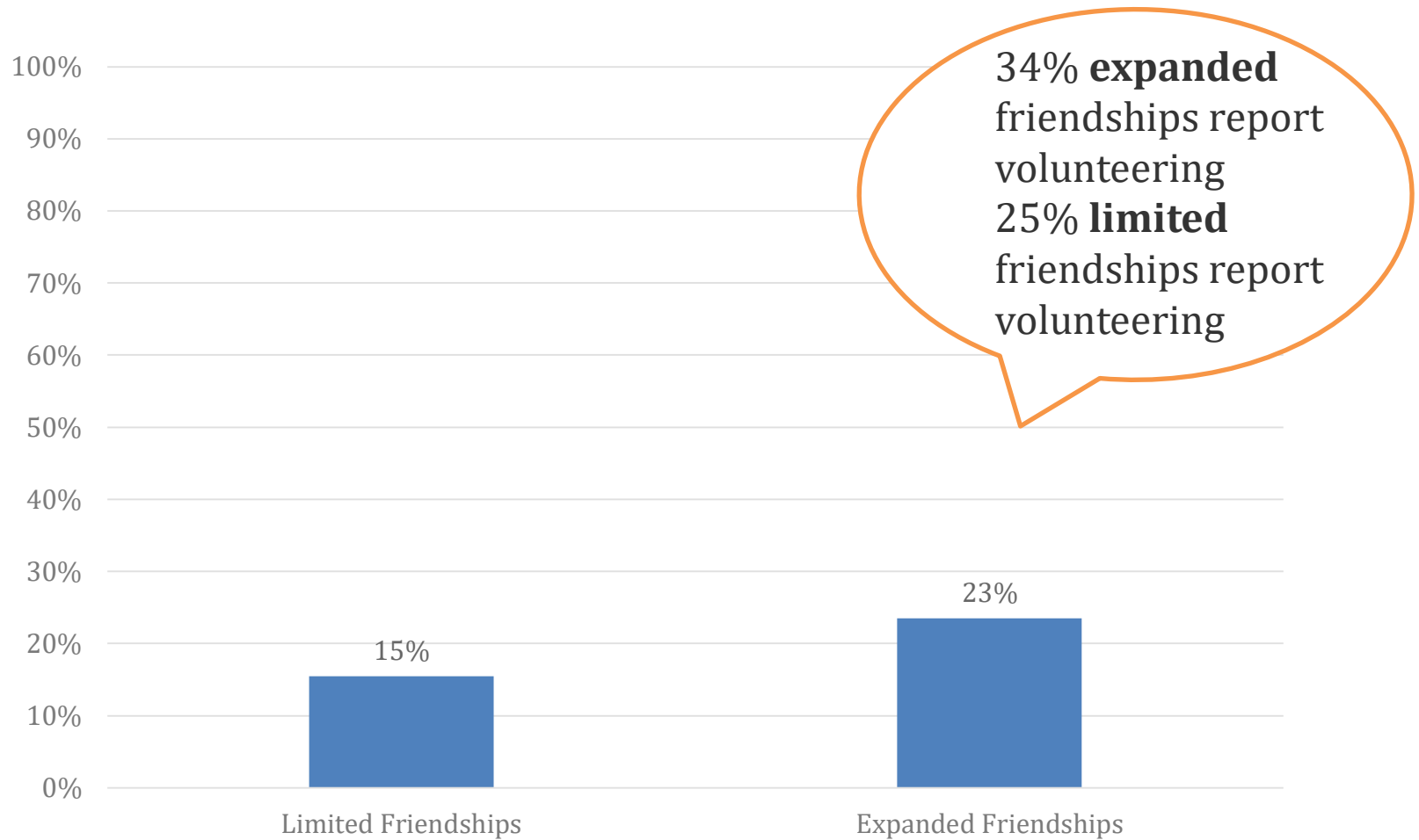


91%
expanded friendships
said they like where they live.

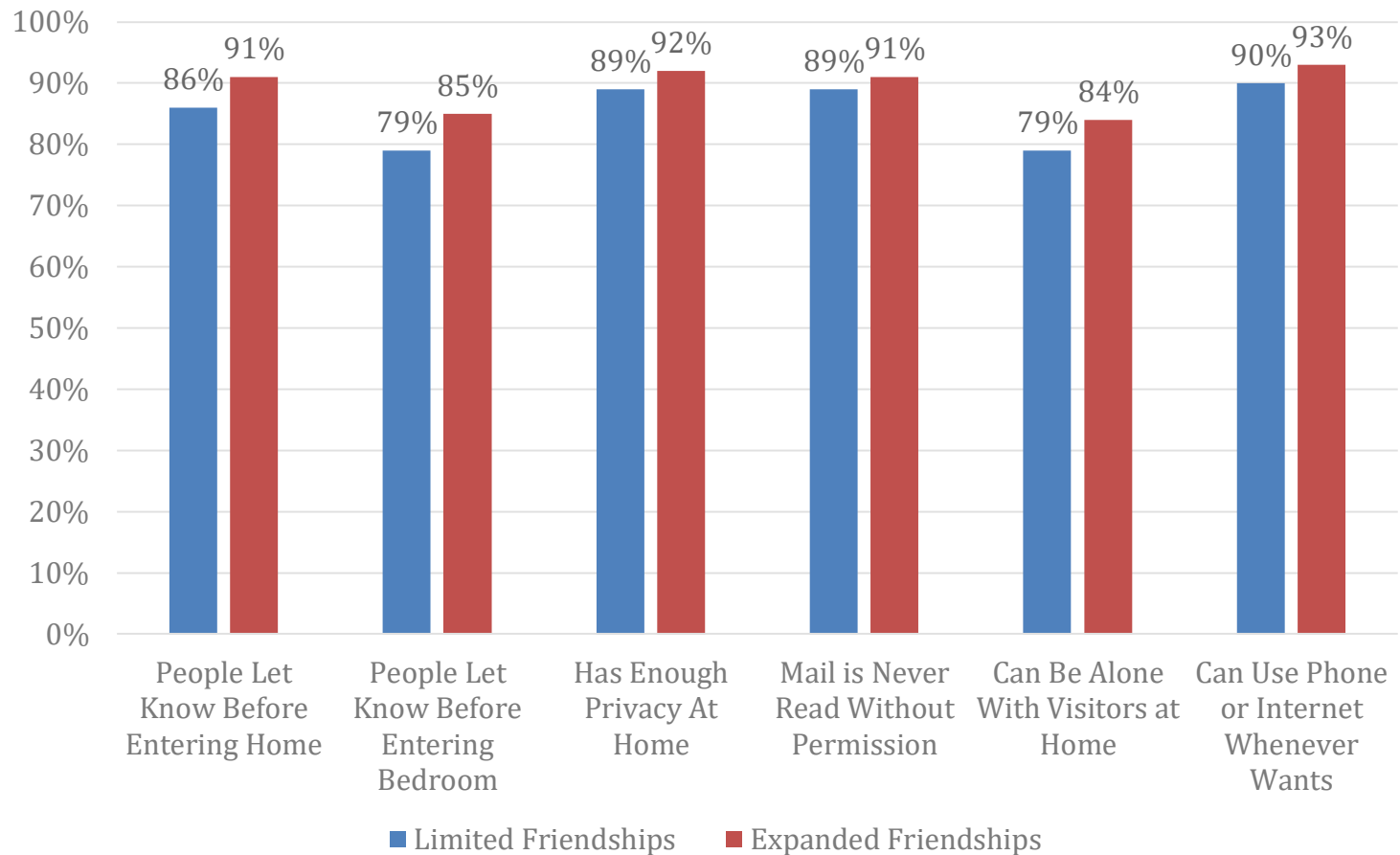
89%
limited friendships
said they like where they live.



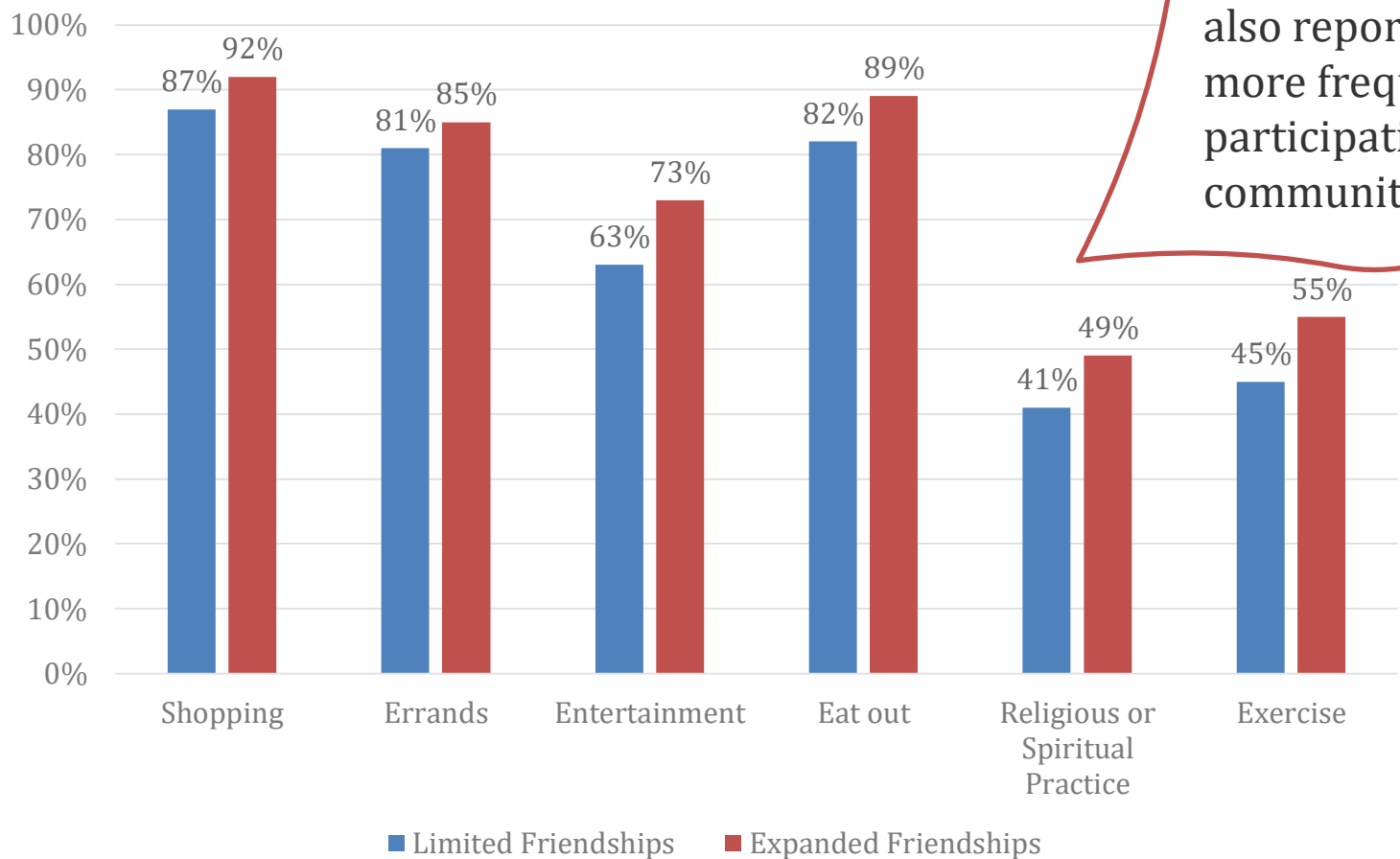
Paid Job in Community by Friendship Status



Rights and Respect by Friendship Status



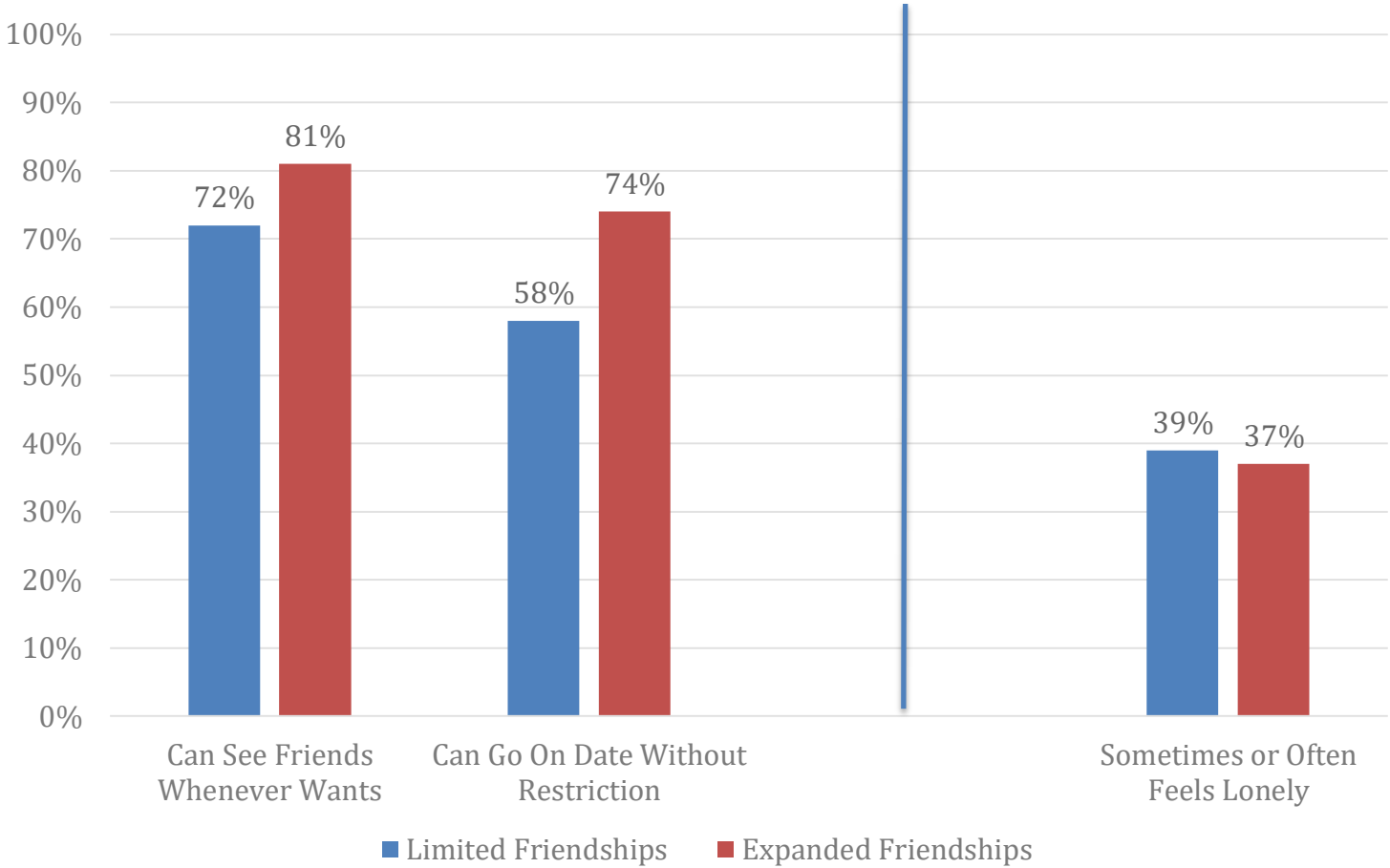
Participation in Community Activities by Friendship Status



Exp. Friendships also reported more frequent participation in community



Relationships by Friendship Status



State Policy Highlight

- MA DDS “Widening the Circle,”
 - Educates people (advocates, staff, etc.) about benefits of expanded friendships.
 - Provides resources to help engage and sustain friendships
 - Example: toolkit for supporting friendships at work.
 - <http://thearcofmass.org/building-friendships-at-work-toolkit/>



NCI Staff Stability Survey



Direct Support Professionals (DSPs)



Issues Being Faced by DSP Workforce

- Low supply and high demand for DSPs accentuated by:
 - Low salaries
 - Erratic/unpredictable hours: Part time
 - Few benefits
 - High levels of emotional and physical stress
 - High injury rate



Providers

- Providers are affected:
 - DSPs working several jobs
 - DSPs going without beneficial trainings
 - High vacancy rates/turnover rates
 - People unprepared for the realities of the job
 - High turnover rates: extra incurred costs to providers:
 - Overtime for workers to cover
 - Training
- Most likely impact outcomes and Q o L for individuals receiving services.



Why is Data Collection Important?

- Research demonstrates that stability of workforce and relationships has direct impact on the lives of the people supported
- Legislatures more frequently request data before approving increases based on the need for a competent, skilled workforce
- Lack of consistent national data about direct service workforce
- Encourage perspective that DSP is a career, beyond simply a job.



How Can States Use the NCI Staff Stability Data?

- NCI Project
- Generally, data gathered with this tool can be used on **state level** to:
 - Compare state workforce data with those of other states.
 - Benchmark!
 - Inform policy and program development regarding direct support workforce improvement initiatives
 - Monitor and evaluate the impact of workforce initiatives
 - Attempt to answer those two questions
 - Provide context for consumer and family outcomes
 - Build systems to more effectively collect, analyze, and use DSP workforce data



Oregon

- Information gained will increase Oregon's ability to:
 - Track the impact of the 4% rate increase that went into effect 1/1/2016 for 24 hour residential providers (provide baseline)
 - Evaluate Oregon's workforce status and trends compared to other states to provide context for workforce improvement strategies; and
 - Assess the impacts of federal and state policy changes, including implementation of the Department of Labor Administrative Rule.



Ohio

- Ohio plans to use NCI Staff Stability Survey data to track workforce data pre- and post- a wage increase for HCBS providers.
- Separated responses from private ICF –I/DD providers from HCBS I/DD Providers.
- Context specific to each state can be accommodated.



Minnesota

- Providers plan to seek a rate increase this legislative session.
- Goal is to provide information for state legislators and provider organizations on the overall picture of DSPs in Minnesota.



2014 Data

10 states

- Arizona (AZ)
- Washington, D.C. (DC)
- Georgia (GA)
- Kentucky (KY)
- Maine (ME)
- Ohio (OH)
- South Carolina (SC)
- Texas (TX)
- Utah (UT)
- Vermont (VT)

2015 Data

to be released soon

AL	OR
AZ	PA
DC	SC
GA	SD
IN	TN
KY	TX
MN	UT
MO	VT
OH	

17 states



Response rates

	Number of responses*	Valid responses **	Total number of providers	Response rate	Meets 95% confidence interval and 5% margin of error	# Responses needed to reach 95% confidence interval and 5% margin of error^
AZ	49	42	363	13%		187
DC	31	25	94	33%		76
GA	51	44	368	14%		189
KY	163	147	204	80%	YES	134
ME	18	16	84	21%		70
OH	365	292	1766	21%	YES	316
SC	16	15	57	28%		50
TX	53	49	535	10%		N/A
UT	31	28	97	32%		78
VT	16	15	16	100%	YES	16

*Please note that the following cases were deleted and not included in this column: Those that had logged in to the data entry system but had answered no questions

**Please note that the following cases were considered invalid: Those that reported providing no services and those that reported employing no DSPs



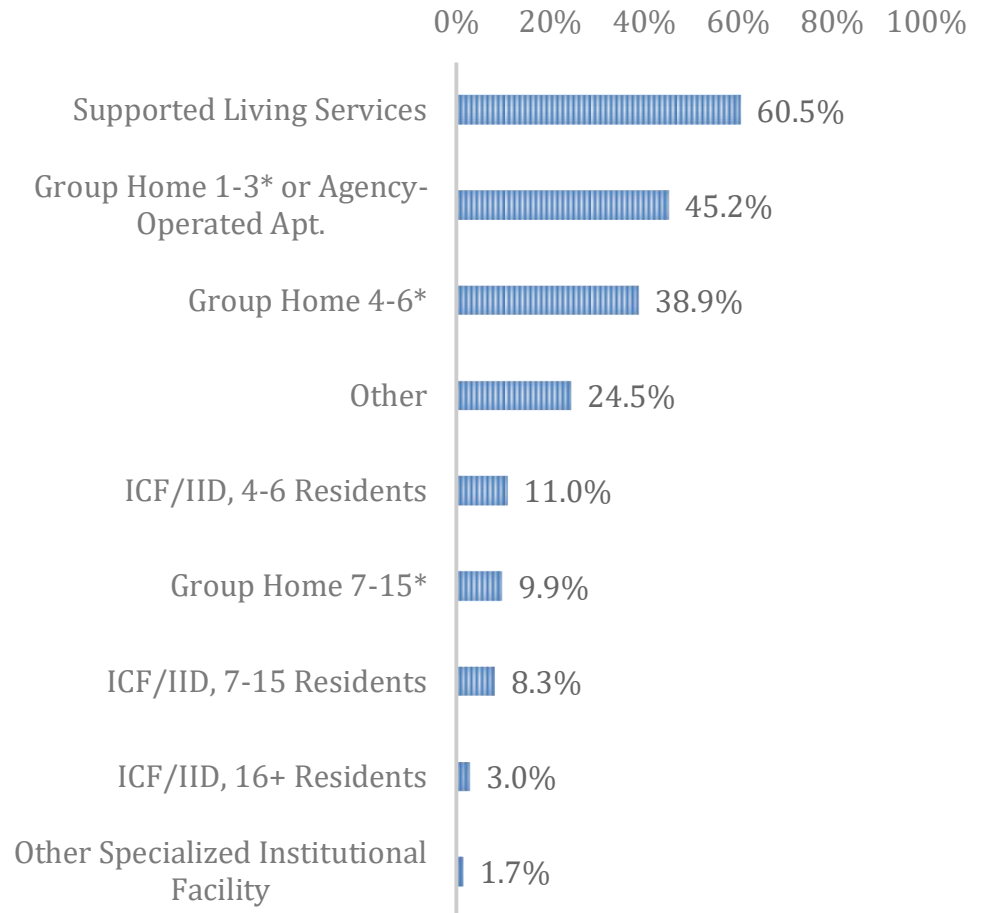
NOTES

- Data presented in following slides are average of 10 participating states
- Refer to the period of Jan 1, 2014-Dec 31, 2014
- Important to note that in the report, data are shown aggregated by state.



Residential

- Residential supports: 77% of responding agencies

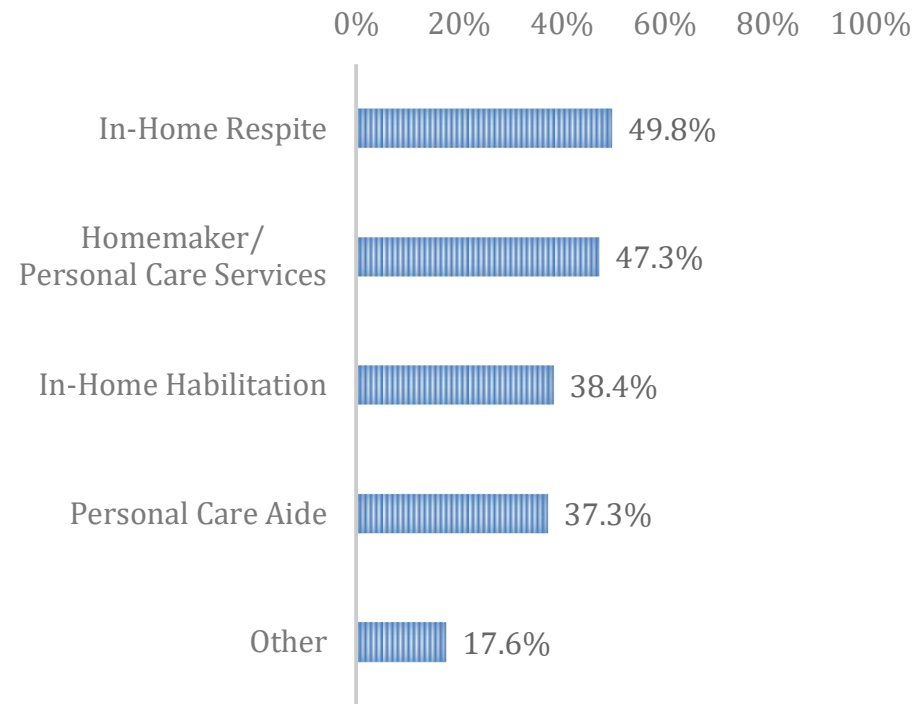


* range refers to # of people with disabilities living in residence



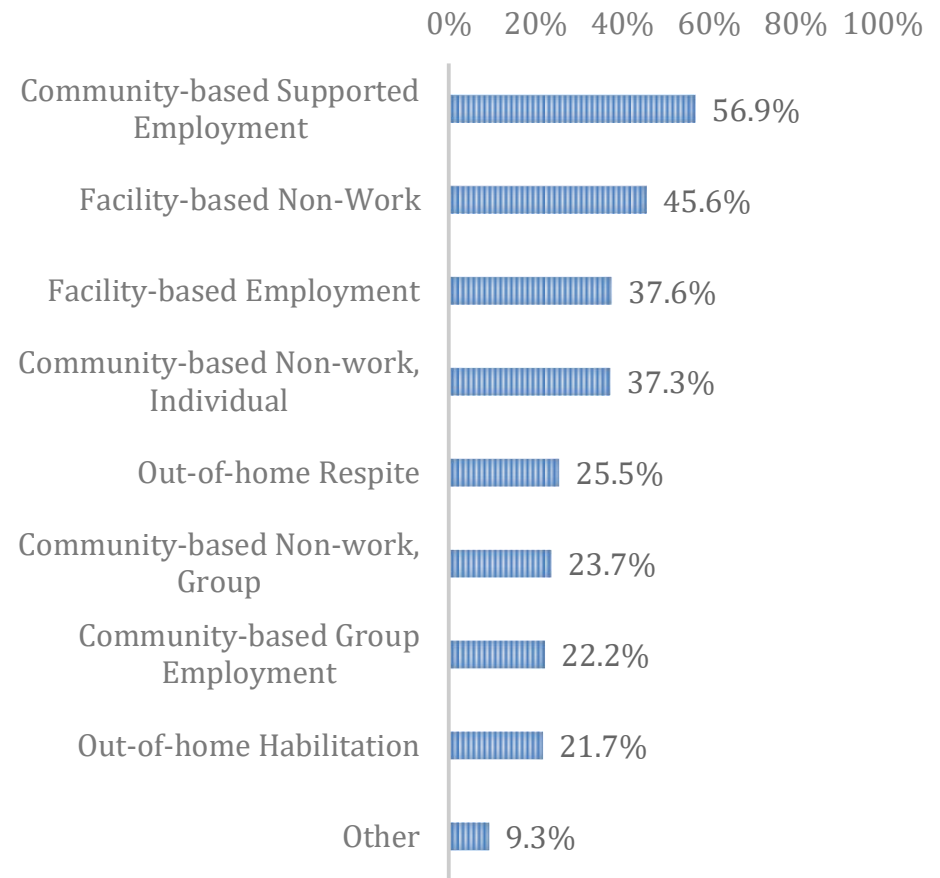
In-home

- In-home supports:
59% of responding agencies



Non-residential

- Non-residential supports: 76% of responding agencies



TENURE: CURRENT DSPs

As of Dec. 31, 2014....

35.5% of DSPs had been in their positions for less than 12 months.

- 673 providers employed 54,608 DSPs
 - 18.9% had been in their DSP positions less than 6 months
 - One state: 33.5% of DSPs had been in positions less than 6 months
 - 16.6% had been in the DSP positions between 6-12 months
 - 63.3% had been in the DSP position 12+ months

May not add to 100% because of missing responses



TENURE: SEPARATED DSPs

As of Dec. 31, 2014

- 22,998 DSPs separated between Jan. 1, 2014 and Dec. 31, 2014

59.%
had
been in
DSP
position
less
than 12
months

- 37.2% had been in their DSP positions less than 6 months.
- 22.2% 6-12 months
- 41.4% 12+ months

Two states: About 73% of separated DSPs had been in their positions for less than 12 months



Turnover Rates

(Number of DSPs on staff as of Dec. 31, 2014)

÷

(Number of DSP separated between Jan. 1, 2014 and Dec. 31, 2014)

- Average turnover rate: 44.4%
- Range from: 21.5%--80.2%

The good kind
of turnover

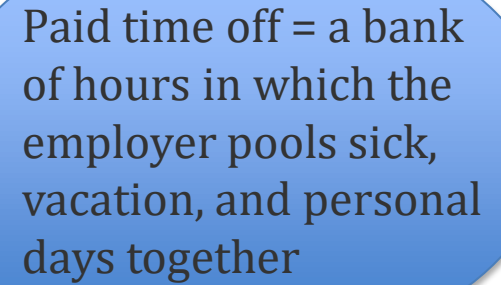


Wages

- Across all participating states and service types, DSPs received an average hourly wage of **\$11.11**.
 - Range: \$9.62/hr.-\$13.70/hr.
 - \$10.55 for DSPs residential supports.
 - \$10.93 for DSPs in-home supports.
 - \$11.10 for DSPs non-residential supports.
- Broken out by organization type, average hourly wages were
 - higher public/government provider agencies than at private, for-profit and private, non-profit agencies.



Benefits



Paid time off = a bank of hours in which the employer pools sick, vacation, and personal days together

- 43% offer paid sick time:
 - 24% offer it as paid time off
 - 19% offer it as paid sick time.
- 43% offer paid vacation time:
 - 24% offer it as paid time off.
 - 19% offer it as paid vacation time.
- 30% offer paid personal time off:
 - 24% offer it as paid time off.
 - 6% offer it as paid personal time.



Challenges Encountered

- Accuracy and completeness of list of email addresses varied by state
 - Affected the “sampling.”
 - Affected ability to assess “representativeness” of data
- Email filters catching email with survey
- Terminology differences
- Lack of standardized method for follow up with providers
- We aren’t capturing some critical components of the DSP workforce
 - Overtime, awake rate
 - Frontline supervisors



Questions?

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