

A New Population-Level Data Source for Research in Adults with FASD

Evidence from the National Core Indicators



Featured Core Indicators

Person is Lonely
The proportion of people who feel lonely

Person has Paid Job in the Community
The proportion of people who have a job in the community

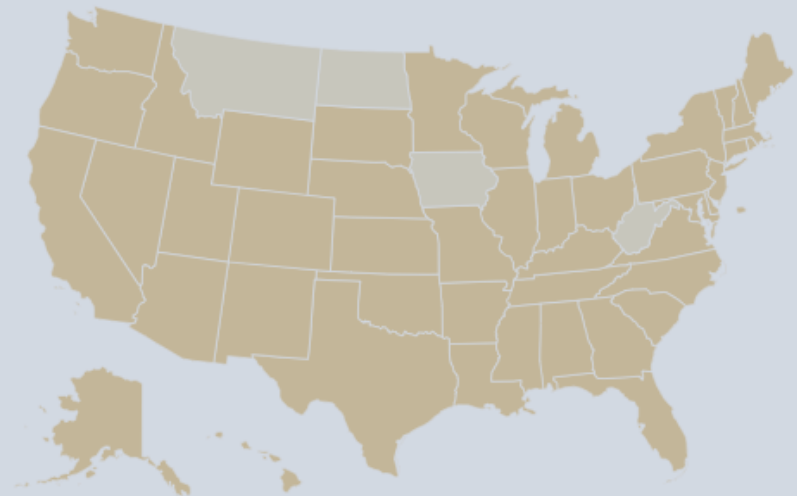
Allowed to Use Phone or Internet Any Time
The proportion of people whose basic rights are respected by others

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Participating NCI States

Select a participating state to view its profile

NCI States



LEARNING OBJECTIVES

01

Population Insights

Discuss the current lack of population level data on Fetal Alcohol Spectrum Disorder (FASD)

02

Data Source

Describe National Core Indicators as a source of FASD monitoring data in the US including subjective and person-centered outcomes

03

Study Findings

Describe and discuss the methodology and results of a secondary data analysis study using NCI

BACKGROUND/RATIONALE

Limited population-level information about the characteristics, living circumstances, experiences, and needs of community-living adults with FASD



What Is NCI?

A voluntary effort by public developmental disabilities agencies to measure and track their own performance



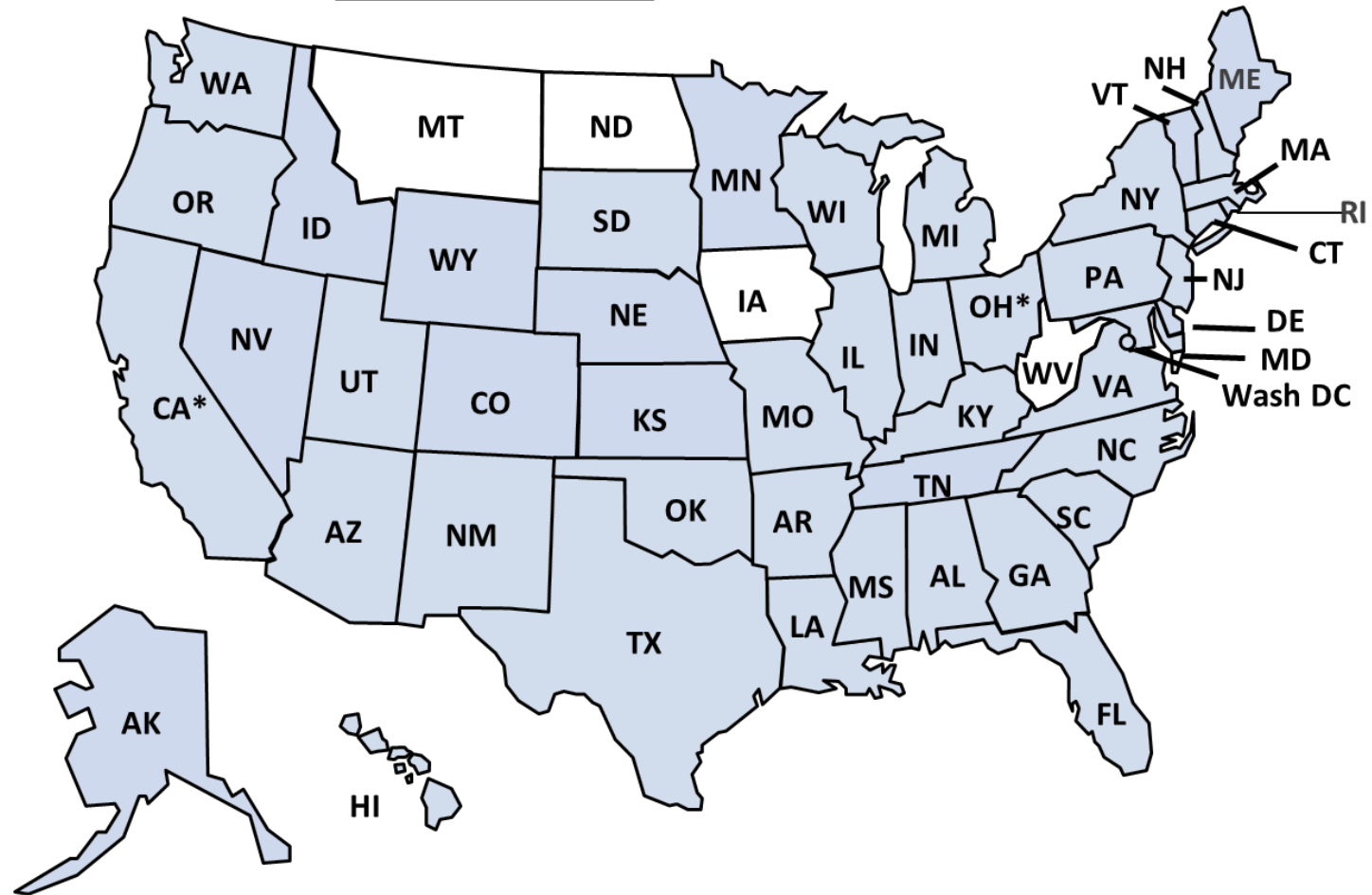
NATIONAL
CORE
INDICATORS™

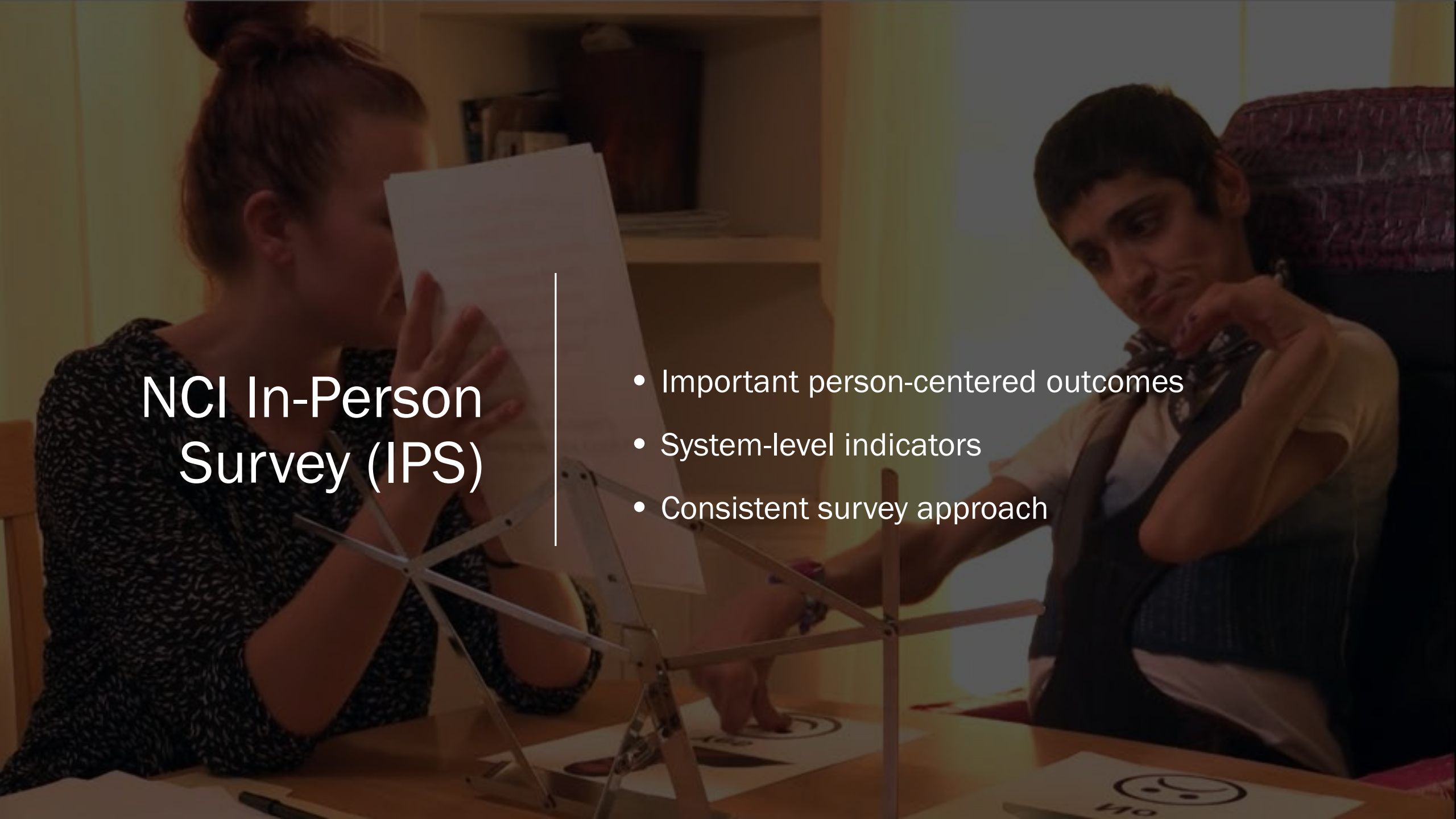
NASDDDS



Human Services
Research Institute

NCI – State Participation





NCI In-Person Survey (IPS)

- Important person-centered outcomes
- System-level indicators
- Consistent survey approach

STUDY

1. Which demographic and personal characteristic variables are closely associated with FASD among US adults who participate in NCI?
2. Does the population w/ FASD experience different outcomes compared to the their NCI counterparts w/o FASD?

Methods: Data and sample

Total NCI N: 39,304


Two cycles (2015-16 and 2016-17; FASD was first added in the 2015-16 cycle)

414 adults (age 18+) with on-record diagnoses of FASD

About 1.2% of total N

BI-12 What other conditions are noted in this person's record?

CHECK ONE COLUMN FOR EACH ROW. This is very important for data analysis purposes.

No	Yes	Don't Know	
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Mood disorder (e.g., depression, mania, bipolar disorder, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Anxiety disorder (e.g., obsessive disorders, panic disorders, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Behavior challenges (e.g., aggression, self-injurious behavior, pica, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Psychotic disorder (e.g., schizophrenia, hallucinations, etc.)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Other mental illness/psychiatric diagnosis
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Autism spectrum disorder (e.g., autism, Asperger syndrome, pervasive developmental disorder)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Cerebral palsy (spastic quadriplegia/diplegia)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Brain injury
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Seizure disorder/neurological problem
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Chemical dependency
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Down syndrome
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Prader-Willi syndrome
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Fetal alcohol spectrum disorder (FASD) 
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Limited or no vision – legally blind
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Hearing loss – severe or profound
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 99	Other disabilities not listed:

Sample characteristics

	FASD	NCI Non-FASD	P
N	414	39,304	-
Age	34.9 (yrs) ± 13 (SD)	42.7 ± 15	<.01
Gender = Female	37.1%	42.1%	<.05
Race/ethnicity			
Caucasian	57.6%	71.2%	<.01
African American	23.0%	17.5%	<.01
American Indian or Alaska Native	9.2%	1.1%	<.01
Hispanic/Latino	4.3%	3.9%	NS
Other race/ethnicities, multi-race	5.1%	5.1%	NS

P value: T test for age, chi square tests for the rest of the table

Sample characteristics

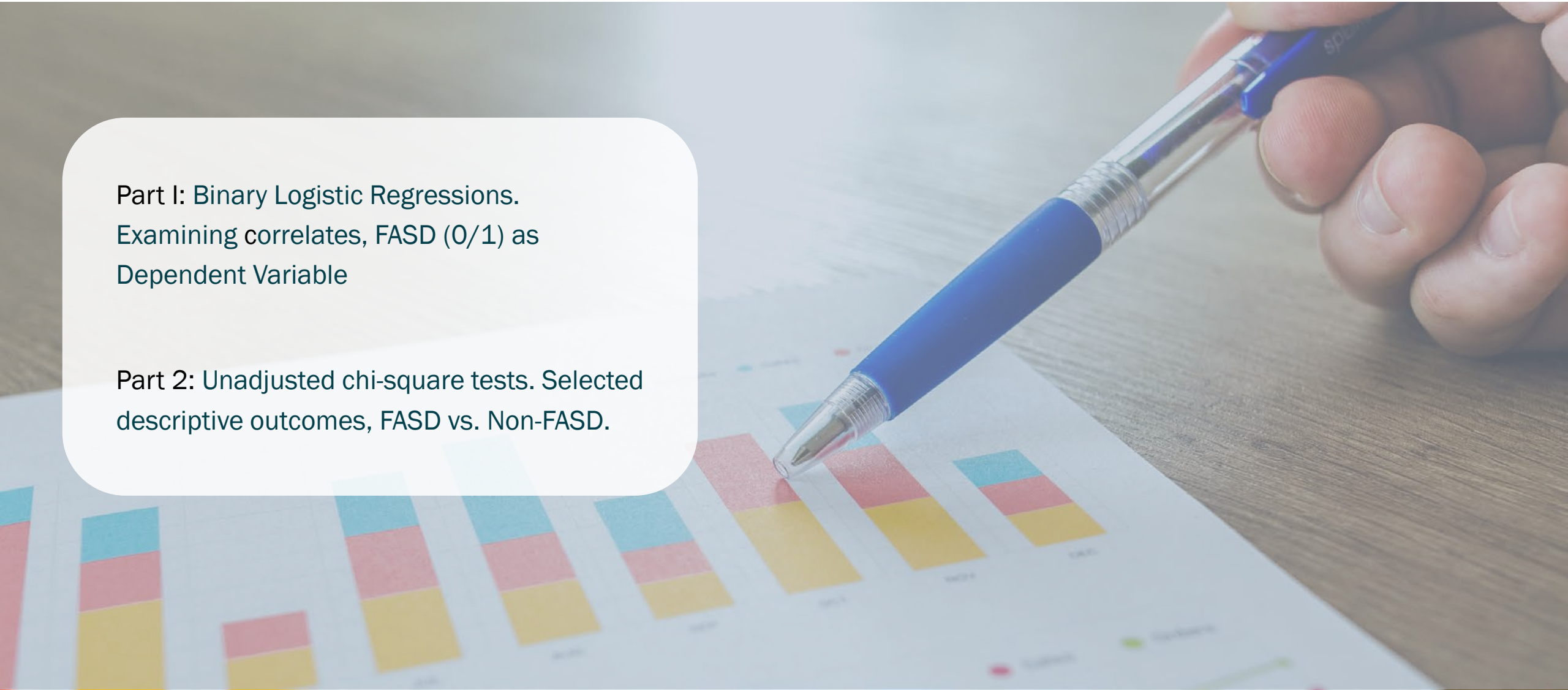
	FASD	NCI Non-FASD	P
Residence type			.015
Intermediate Care Facilities	7.3%	7.2%	
Group residential settings	37.4%	32.5%	
Own home or apartment	20.2%	18.9%	
Parent/relative's home	31.2%	38.1%	
Foster care/host home	3.9%	3.3%	
Has legal guardian	61.1%	54.0%	<.01

P value: Chi square test

Statistical Analysis

Part I: Binary Logistic Regressions.
Examining correlates, FASD (0/1) as
Dependent Variable

Part 2: Unadjusted chi-square tests. Selected
descriptive outcomes, FASD vs. Non-FASD.



Part 1 Results: Significant ($p < .05$) correlates of FASD

(slide 1 of 2)

	aOR	95% CI
Younger age, 18-34 vs. 35+ (ref)	2.37	1.78, 3.17
American Indian or Alaska Native (reference: Non-Hispanic White)	8.20	4.99, 13.47
Black/African-American	1.80	1.28, 2.52
Hearing or vision problems	2.05	1.46, 2.89
Nonverbal	0.44	0.27, 0.72
Mental illness (mood disorder, anxiety disorder, psychotic disorder, etc.)	2.29	1.68, 3.13
Ambulatory	0.24	0.08, 0.68
Behavior challenges	1.74	1.24, 2.45

Note: Based on logistic regression. List of significant predictors continued next slide.

Nonsignificant variables include: Gender, legal guardianship status, intellectual disability status, BMI, self-reported overall health

Significant correlates of FASD (slide 2 of 2)

	aOR	95% CI
Autism Spectrum Disorder	1.572	1.12, 2.21
Cerebral Palsy	1.676	1.14, 2.46
Brain Injury	4.303	2.85, 6.49
Down Syndrome	2.455	1.64, 3.69

Note: Based on logistic regression. Continued from table on previous slide. Nonsignificant variables include: Gender, Legal guardianship status, Intellectual disability status, BMI, self-reported overall health



Part 1: Variables that are nonsignificant

- Gender (female)
- Intellectual disability (most NCI participants have ID)
- BMI
- Self-reported overall health
- Legal guardianship status

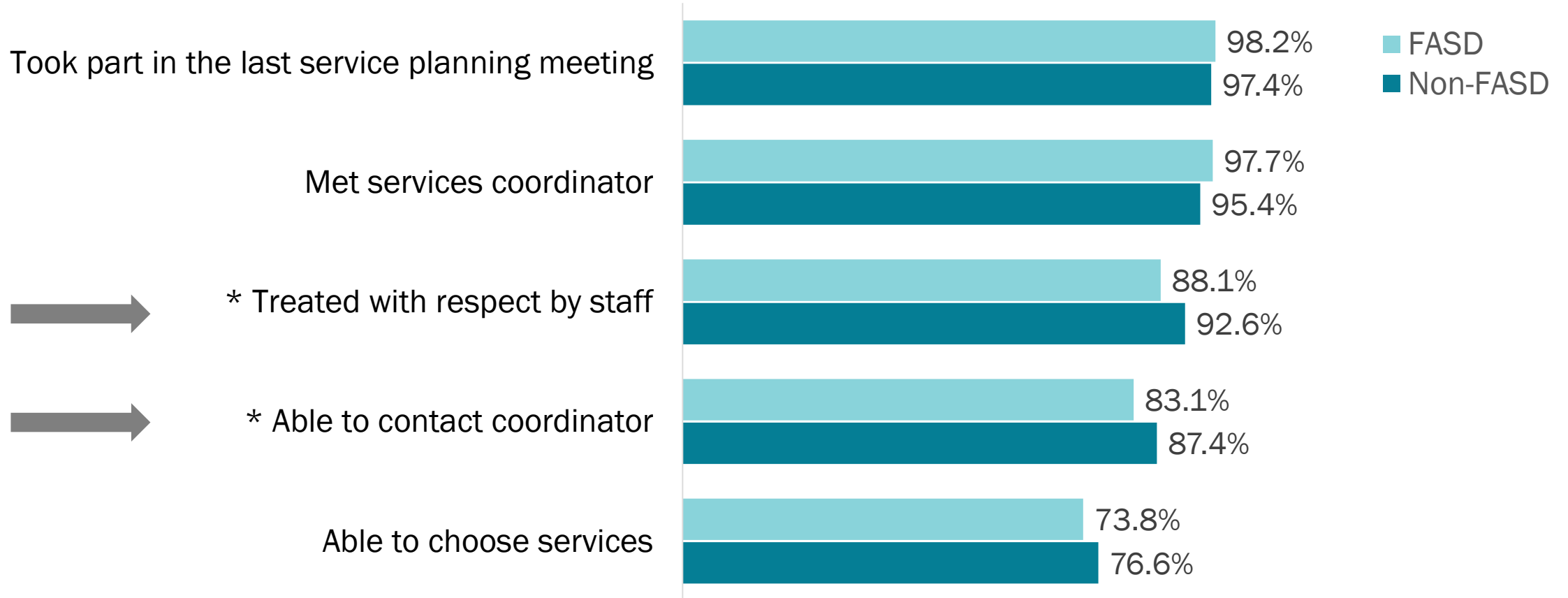
Part 2: Health outcomes

	FASD	NCI Non-FASD	P
Has primary care provider	97.3%	98.0%	NS
Physical exam in the past year	85.1%	86.7%	NS
Poor health	3.3%	3.1%	NS
Takes medication to treat mood, anxiety, psychotic issues	65.3%	49.2%	<.01
Takes medication to treat behavior problems	42.6%	25.0%	<.01

P value: Chi square test

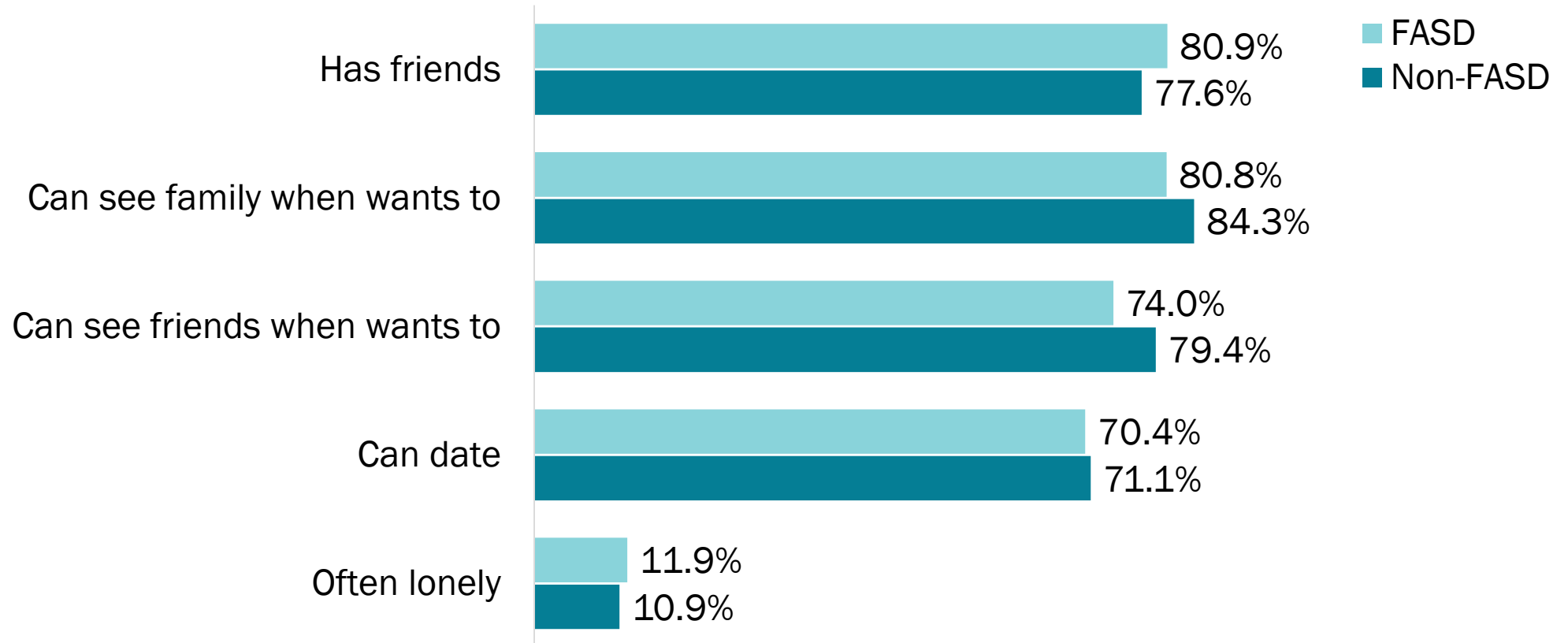
Part 2

Service Coordination outcomes

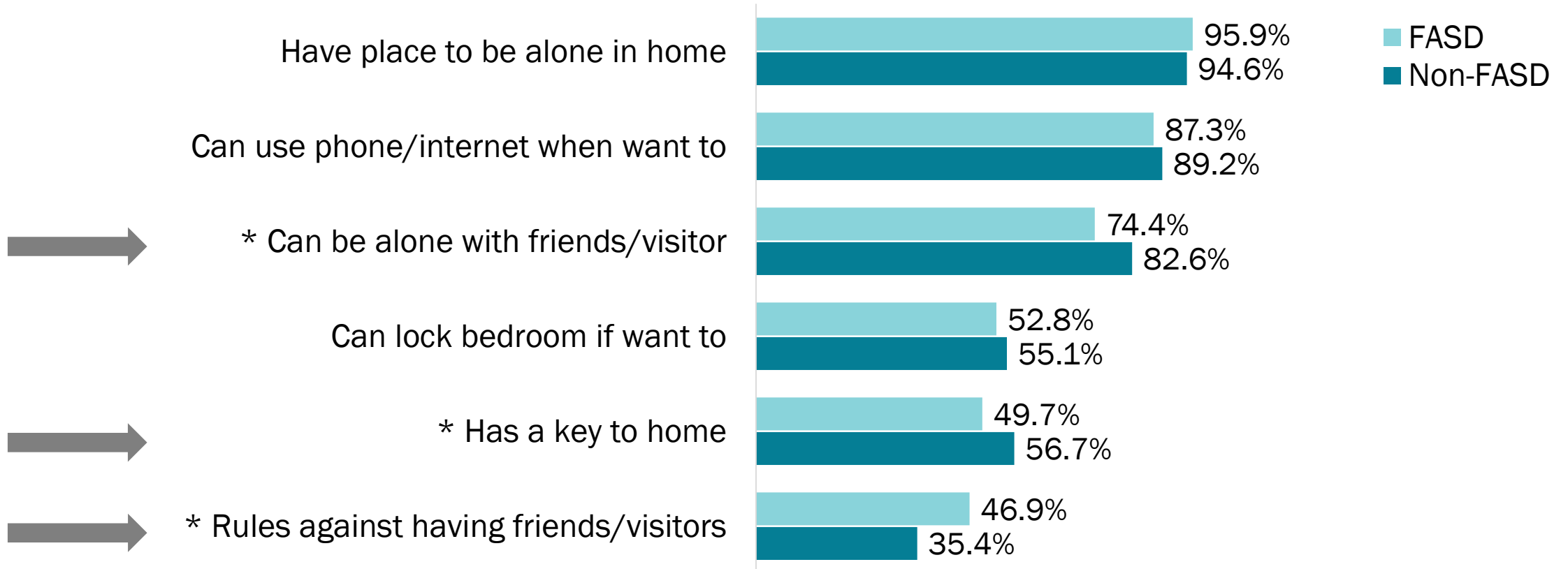


*Significant differences (chi square $p < .05$)

No significant differences for Relationships outcomes



Significant differences within three **Rights and Respect** outcomes



*Significant differences (chi square p<.05)

Discussion

1

Younger = more likely to have FASD dx on file

2

Race/ethnic disparities may be worth further investigation

3

Hearing/vision problems, mental illnesses dx significantly associated w/ FASD

Discussion, continued

4

In the NCI sample, FASD is correlated with being verbal; non-ambulatory

5

Common comorbid conditions associated with FASD:

- ASD
- CP
- Brain Injury
- DS

6

Preliminary analyses of experience/outcomes suggest certain differences to the general NCI population in the following areas:

- Service coordination
- Relationships
- Rights and Respect

Conclusions

- Health:
1. Limitations of study
 2. Research opportunities
 3. Particular support needs



Satisfaction:
Percentage of respondents who report that...

They like where they live – 89%

They like where they work in a paid community job – 92%

Services are helping them to live a good life – 91%

References

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- Roozen, S., Peters, G.-J. Y., Kok, G., Townend, D., Nijhuis, J. and Curfs, L. (2016), Worldwide Prevalence of Fetal Alcohol Spectrum Disorders: A Systematic Literature Review Including Meta-Analysis. *Alcohol Clin Exp Res*, 40: 18–32. doi:10.1111/acer.12939
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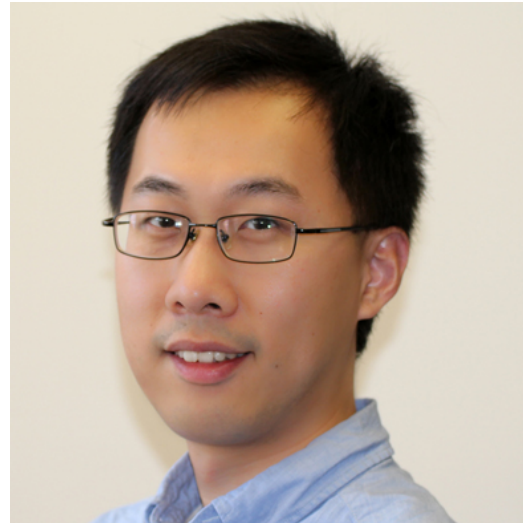
CONTACT US



Alexandra Bonardi

abonardi@hsri.org

NCI Project Director



Henan Li

hli@hsri.org

NCI Research Associate



Dorothy Hiersteiner

dhiersteiner@hsri.org

NCI Research Associate

Questions?

- We discussed the current lack of population level data on Fetal Alcohol Spectrum Disorder (FASD)
- Described National Core Indicators (NCI) as a source of FASD monitoring data in the US including subjective and person-centered outcomes
- Described and discussed the methodology and results of a secondary data analysis study using NCI

Thank You.

