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

Evidence from the National Core Indicators

NATIONAL CORE INDICATORS™

Featured Core Indicators

...s Lonely
...proportion of people who ...el lonely

READ MORE

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

READ MORE

Allowed to Use ... Phone or Intern... Any Time
The proportion of peo... whose basic rights are... respected by others

READ...

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 Fetal Alcohol Spectrum Disorder (FASD)?

- 1973: FAS was first described as a **specific cluster of birth defects resulting from alcohol exposure in utero.**

- The US Surgeon General issued the **first public health advisory in 1981 that alcohol during pregnancy was a cause of birth defects.**

- In 2002, Congress mandated that the CDC develop **diagnostic guidelines for FAS** and related disorders
  - Through this effort, **practical clinical approaches were endorsed**
    - FAS readily identified,
    - diagnosed with greater accuracy,
    - referral for appropriate services.

- The terminology "**FASD**" has recently been used by advocates, educators, and federal agencies to cover **the range of outcomes associated with all levels of prenatal alcohol exposure.**

- Outward appearance and demeanor of individuals with FASD differs:
  - Characteristic facial features, growth restriction, poor motor skills, learning disorders, difficulty with social relationships, poor mood regulation, impulsivity, attention deficits, poor memory, and inappropriate sexual behavior

--Sokol RJ, Delaney-Black V, Nordstrom B. Fetal Alcohol Spectrum Disorder. *JAMA.* 2003;290(22):2996–2999. doi:10.1001/jama.290.22.2996
--Watson, E., Kinscherff, R. (2018) Innovative cross disciplinary partnership enables rapid and accurate FASD diagnosis and referrals to support services. [handout] *8th International Research Conference on Adolescents and Adults with FASD. April 19-21, 2018*
--Williams, J., Vincent C. Smith, the COMMITTEE ON SUBSTANCE ABUSE. Pediatrics Nov 2015, 136 (5) e1395-e1406; **DOI:** 10.1542/peds.2015-3113

CHILD PRESENTING WITH THE 3 DIAGNOSTIC FACIAL FEATURES OF FAS

short palpebral fissure length

thin upper lip

smooth philtrum
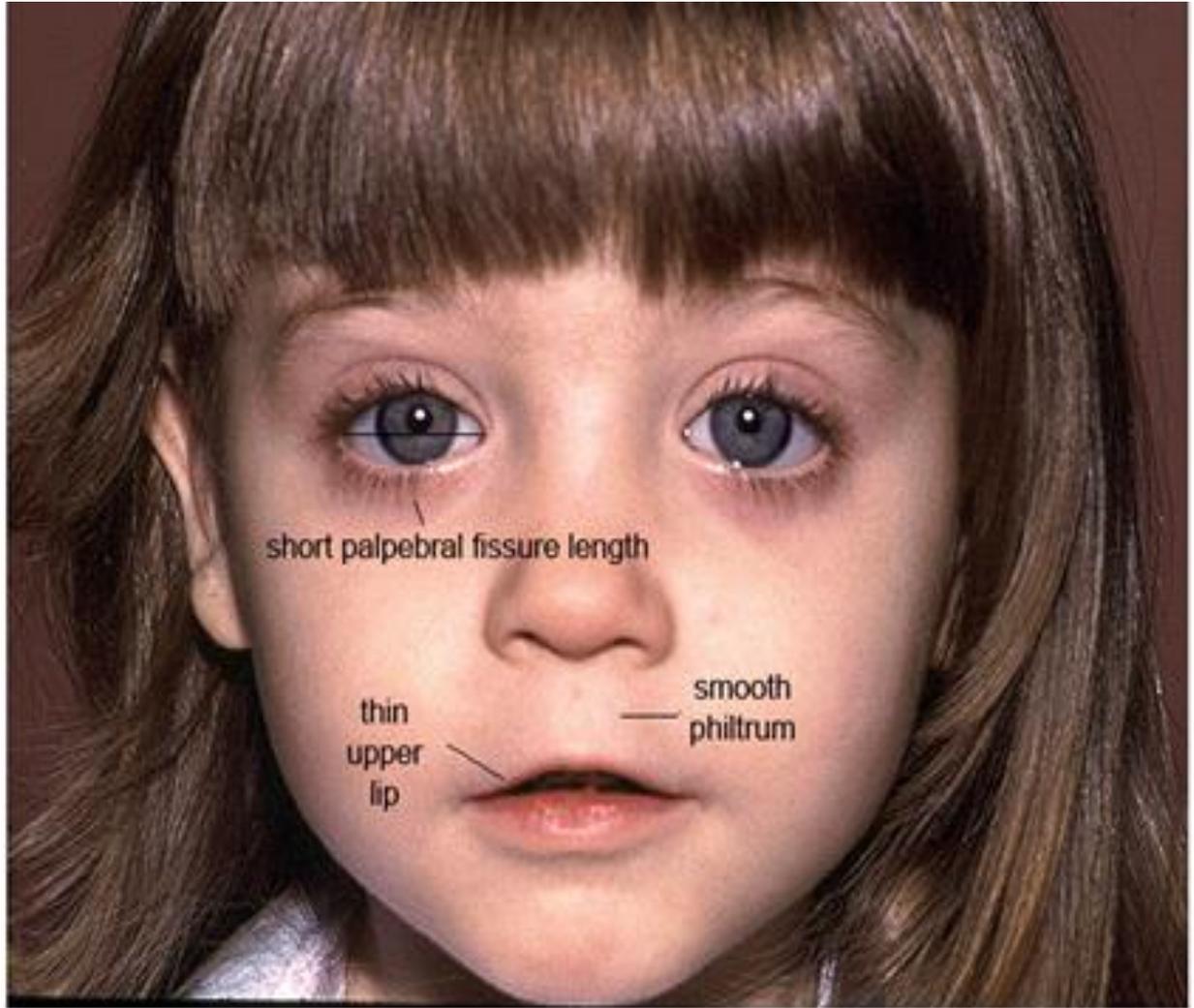
Janet F. Williams et al. Pediatrics 2015;136:e1395-e1406

PEDIATRICS

Epidemiology

- FASD is one of the most common causes of developmental delay and ID
  - Vastly underrecognized
- There have been many studies on prevalence rates
  - 1980s and 90s:
    - FAS: 0.5 to 2 cases per 1000 live births
  - More recent studies:
    - FAS: 6-9 cases per 1000 live births
    - FASD: 24-48 cases per 1000 live births

- Rates up to 9% per 1000 live births among vulnerable populations
  - Such as certain American Indian and other racial/ethnic minority populations
  - Possibly related to isolation and socioeconomic impoverishment

--Centers for Disease Control and Prevention (CDC) Fetal alcohol syndrome—Alaska, Arizona, Colorado, and New York, 1995–1997. *MMWR Morb Mortal Wkly Rep*. 2002;51(20):433–435pmid:12056499

--Williams, J., Vincent C. Smith, the COMMITTEE ON SUBSTANCE ABUSE. Pediatrics Nov 2015, 136 (5) e1395-e1406; **DOI:** 10.1542/peds.2015-3113

What Is NCI?

A voluntary effort by public developmental disabilities agencies to measure and track their own performance
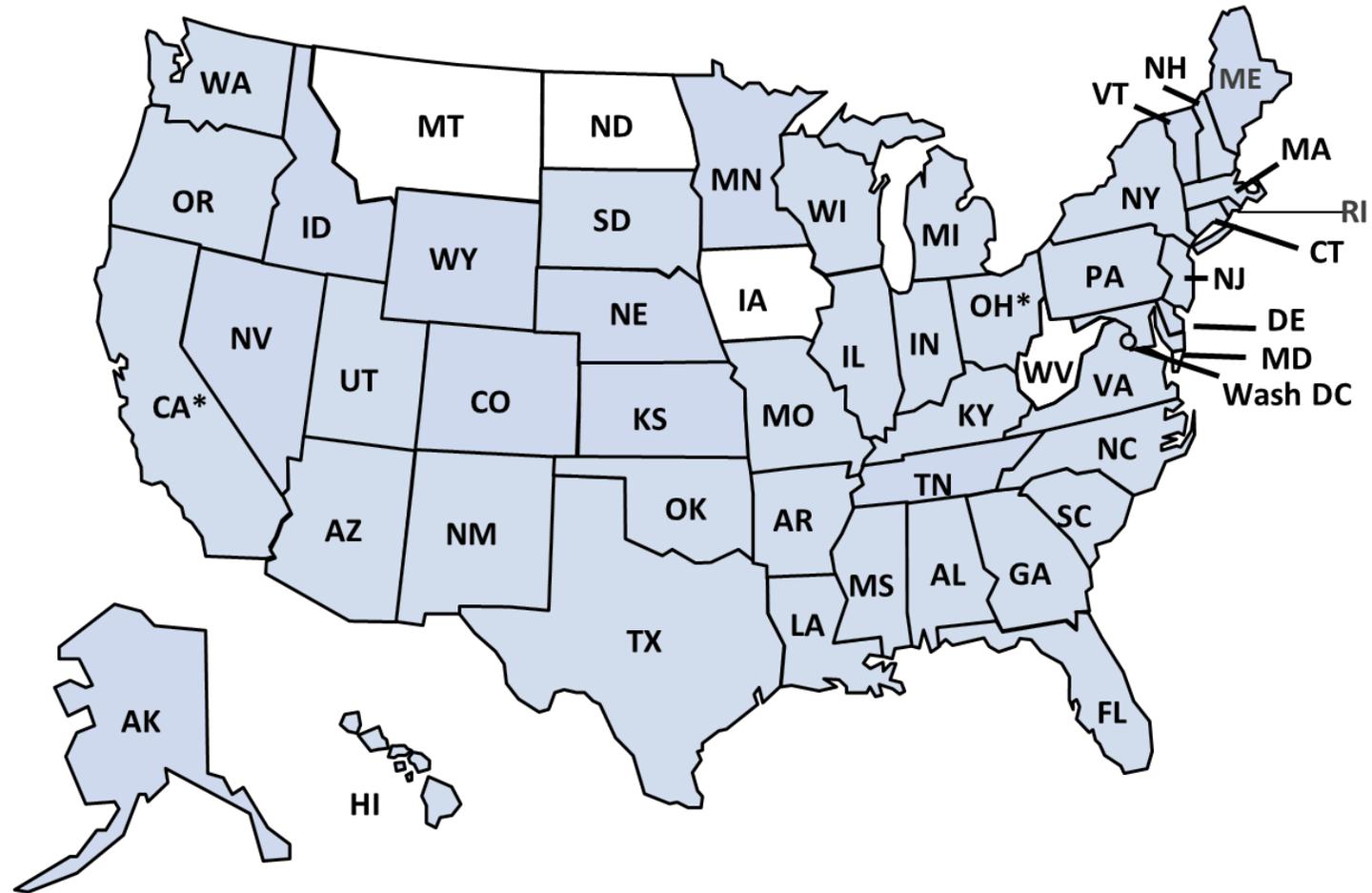
NATIONAL CORE INDICATORS™
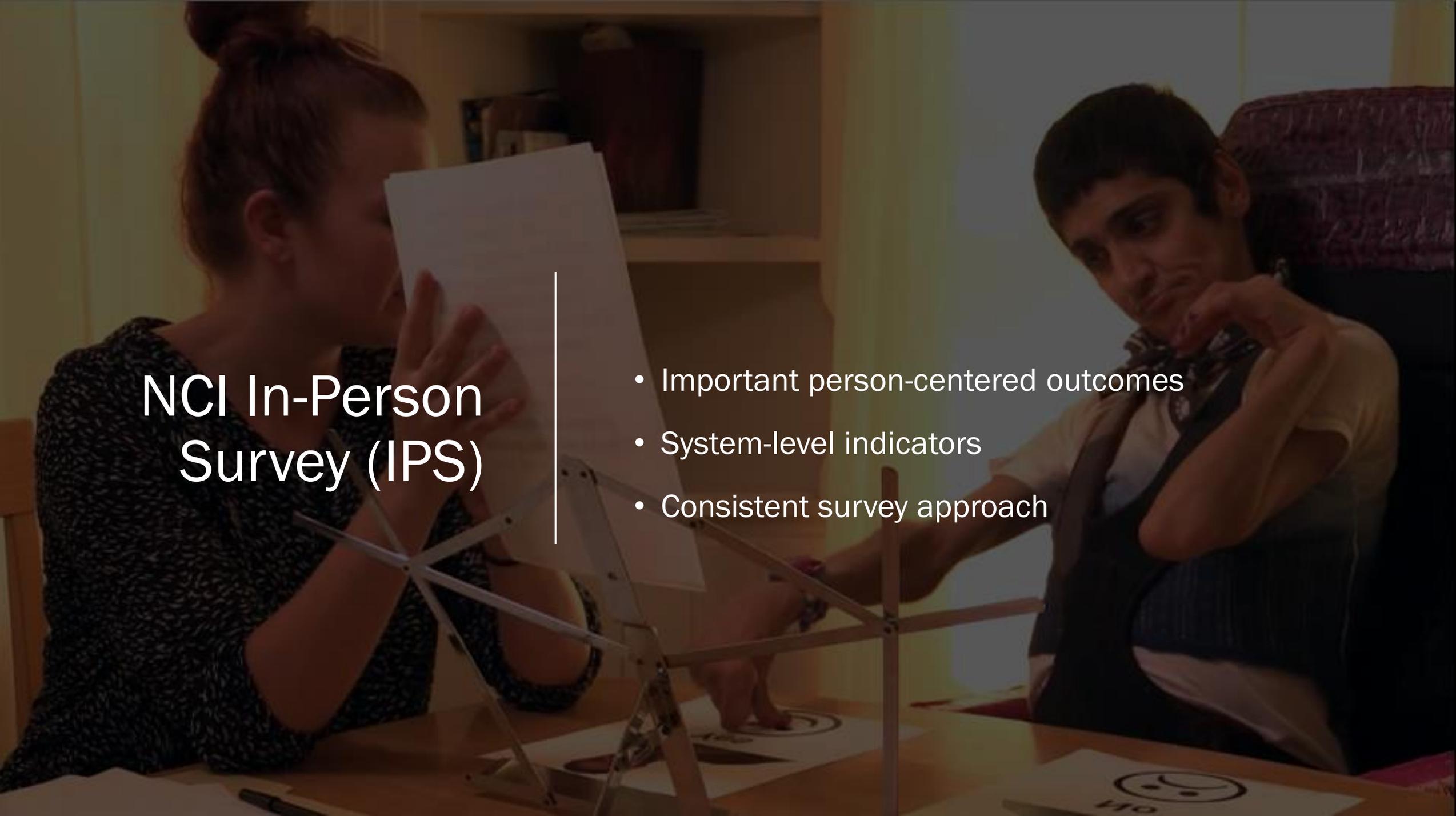
NASDDDS

HSRI 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?

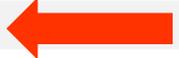# Methods: Data and sample

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	
☐ 1	☐ 2	☐ 99	Mood disorder (e.g., depression, mania, bipolar disorder, etc.)
☐ 1	☐ 2	☐ 99	Anxiety disorder (e.g., obsessive disorders, panic disorders, etc.)
☐ 1	☐ 2	☐ 99	Behavior challenges (e.g., aggression, self-injurious behavior, pica, etc.)
☐ 1	☐ 2	☐ 99	Psychotic disorder (e.g., schizophrenia, hallucinations, etc.)
☐ 1	☐ 2	☐ 99	Other mental illness/psychiatric diagnosis
☐ 1	☐ 2	☐ 99	Autism spectrum disorder (e.g., autism, Asperger syndrome, pervasive developmental disorder)
☐ 1	☐ 2	☐ 99	Cerebral palsy (spastic quadriplegia/diplegia)
☐ 1	☐ 2	☐ 99	Brain injury
☐ 1	☐ 2	☐ 99	Seizure disorder/neurological problem
☐ 1	☐ 2	☐ 99	Chemical dependency
☐ 1	☐ 2	☐ 99	Down syndrome
☐ 1	☐ 2	☐ 99	Prader-Willi syndrome
☐ 1	☐ 2	☐ 99	Fetal alcohol spectrum disorder (FASD)
☐ 1	☐ 2	☐ 99	Limited or no vision – legally blind
☐ 1	☐ 2	☐ 99	Hearing loss – severe or profound
☐ 1	☐ 2	☐ 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

	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

Outcome	FASD	Non-FASD
Took part in the last service planning meeting	98.2%	97.4%
Met services coordinator	97.7%	95.4%
* Treated with respect by staff	88.1%	92.6%
* Able to contact coordinator	83.1%	87.4%
Able to choose services	73.8%	76.6%
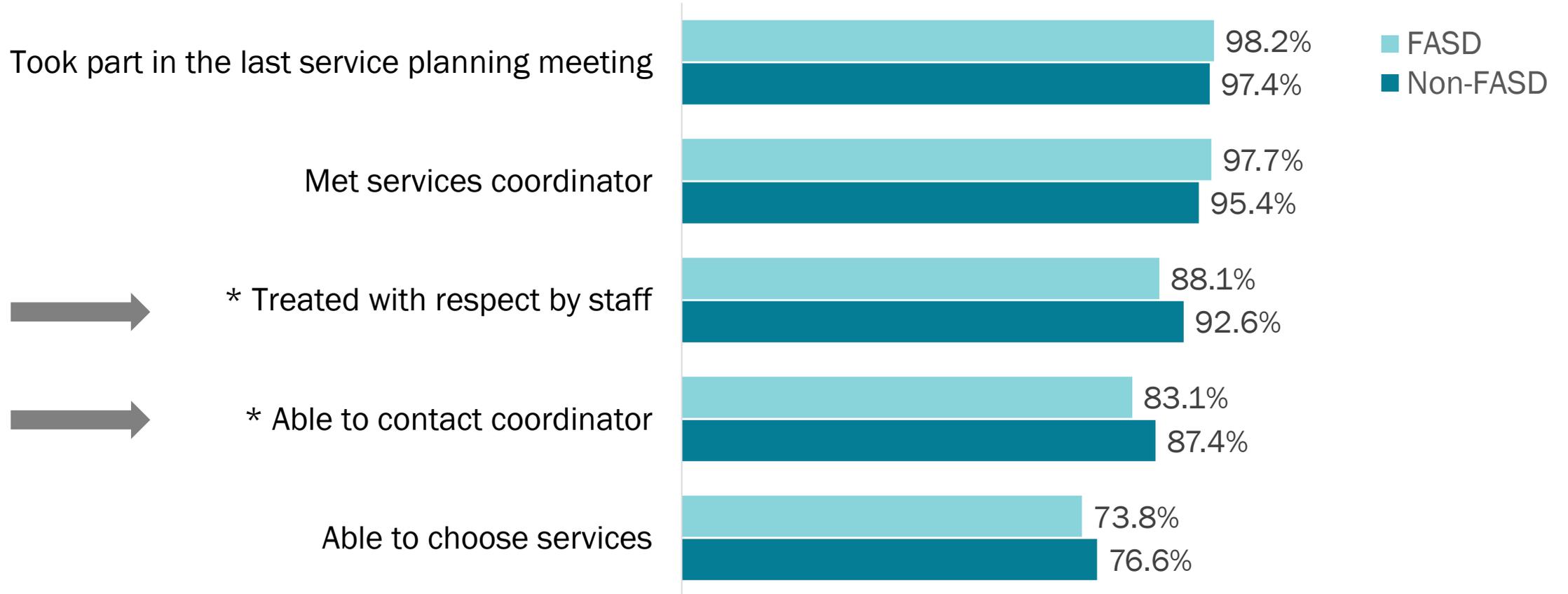
*Significant differences (chi square p<.05)

No significant differences for Relationships outcomes

Has friends
- FASD: 80.9%
- Non-FASD: 77.6%

Can see family when wants to
- FASD: 80.8%
- Non-FASD: 84.3%

Can see friends when wants to
- FASD: 74.0%
- Non-FASD: 79.4%

Can date
- FASD: 70.4%
- Non-FASD: 71.1%

Often lonely
- FASD: 11.9%
- Non-FASD: 10.9%

Legend:
- FASD
- Non-FASD
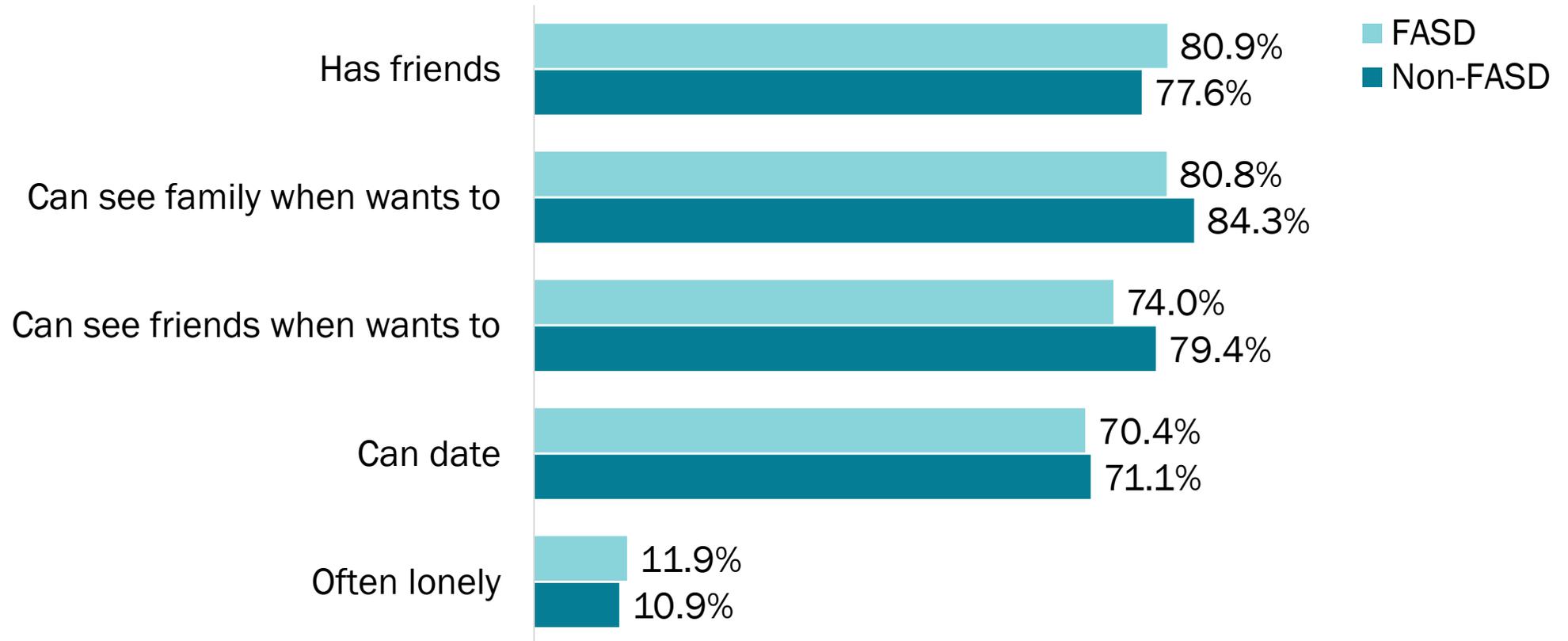
Significant differences within three Rights and Respect outcomes

	FASD	Non-FASD
Have place to be alone in home	95.9%	94.6%
Can use phone/internet when want to	87.3%	89.2%
* Can be alone with friends/visitor	74.4%	82.6%
Can lock bedroom if want to	52.8%	55.1%
* Has a key to home	49.7%	56.7%
* Rules against having friends/visitors	46.9%	35.4%
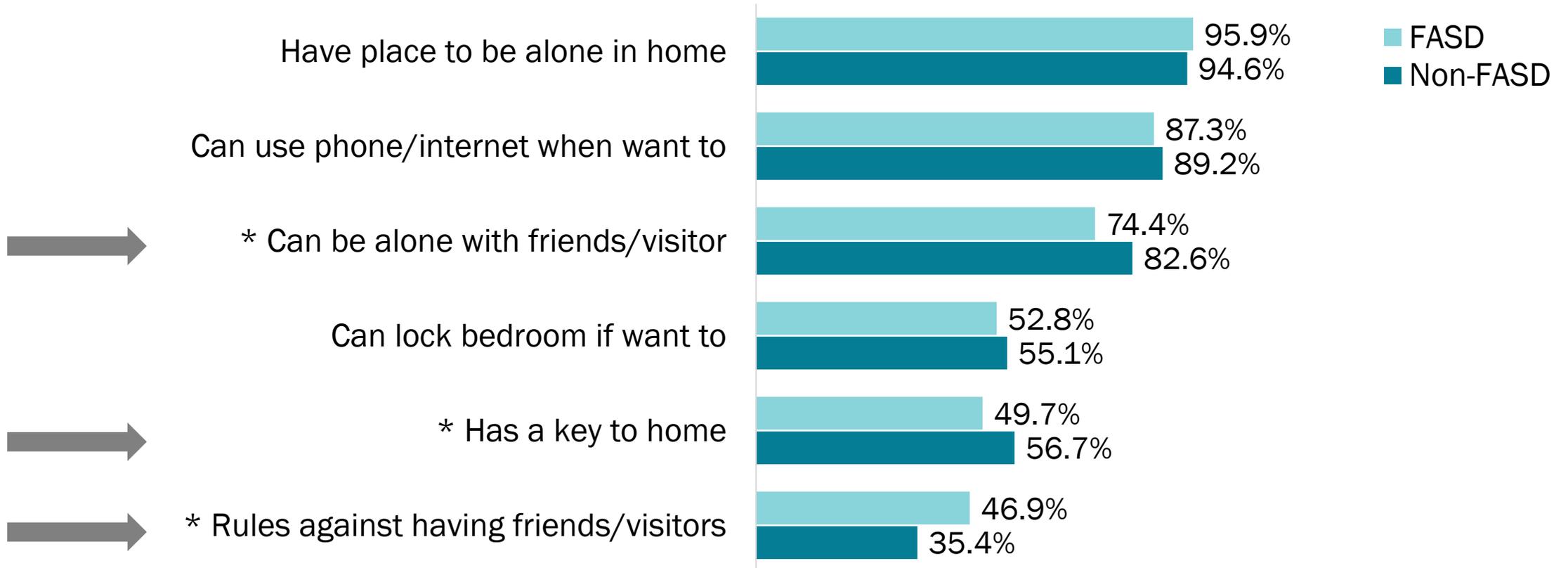
*Significant differences (chi square p<.05)

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

1. Limitations of study

2. Research opportunities

3. Particular support needs

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

Popova, S., Lange, S., Probst, C., Gmel,G., Rehm, J. (2017), Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. Lancet, 5: e290-299. doi:10.1016/S2214-109X(17)30021-9

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- 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.

NCI™

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