

# Adult Issues in Fragile X Syndrome

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# Updated Information from FORWARD

- Somewhat biased sample – adults coming to FXCRC clinics
- Data still being analyzed

# Objectives

**(1) To characterize employment and program participation, residence, and engagement in social activities in adults with FXS**

**(2) To evaluate barriers to participation, and predictors of employment status, residence and social participation in adults with FXS**

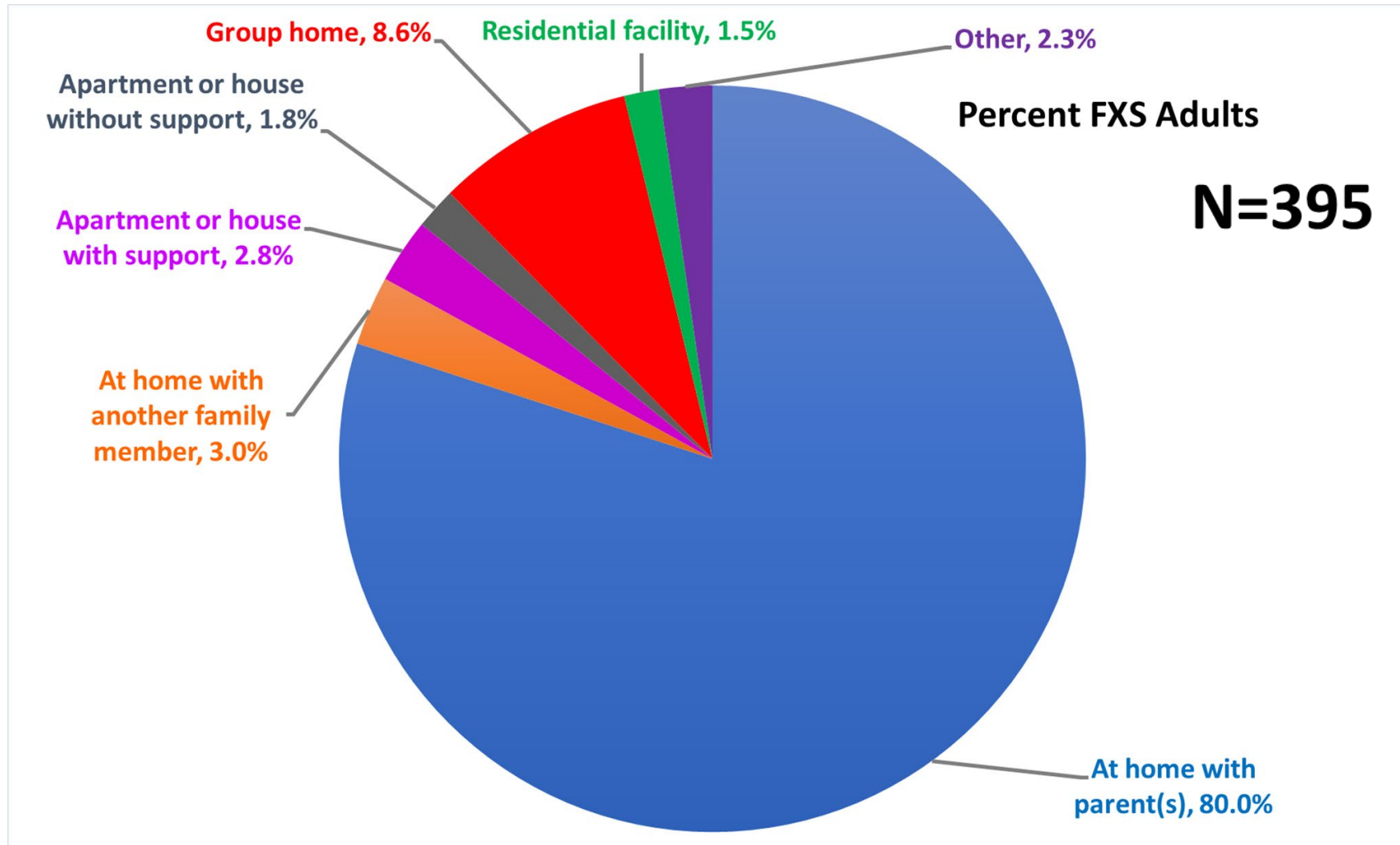
# Demographics of FXS Adult Study Participants in FORWARD

	<b>Total (n=541) N (%)</b>	<b>Males (n=413) N (%)</b>	<b>Females (n=127) N (%)</b>	<b>p Male vs female</b>
<b>Age: Mean (SD)</b>	27 (9.1)	26.8 (8.7)	27.4 (10.2)	0.52
<b>Age: Range</b>	18 – 65	18 – 64	18 – 65	
<b>Child race/ethnicity</b>				
<b>White</b>	478 (88.4)	365 (88.4)	113 (89)	0.90
<b>Black</b>	35 (6.5)	30 (7.3)	5 (3.9)	0.18
<b>Hispanic</b>	39 (7.2)	29 (7.0)	10 (7.9)	0.81
<b>Asian</b>	16 (3.0)	10 (2.4)	6 (4.7)	0.18
<b>Other</b>	18 (3.3)	14 (3.4)	4 (3.2)	0.89
<b>Total co-occurring conditions: Mean (SD)</b>	2.78 (1.4)	3.00 (1.37)	1.97 (1.15)	<.0001
<b>SRS-2<sup>b</sup> t-score: Mean (SD)</b>	67.2 (11.2)	68.81 (10.14)	61.58 (12.77)	<.0001
<b>SCQ<sup>c</sup> total raw score: Mean (SD)</b>	17.0 (5.2)	16.80 (5.17)	17.77 (5.42)	0.11
<b>Family income</b>				0.49
<b>Less than \$25,000</b>	23 (4.3)	15 (3.6)	8 (6.3)	
<b>\$25,000 - \$49,999</b>	44 (8.1)	36 (8.7)	8 (6.3)	
<b>\$50,000 - \$74,999</b>	45 (8.3)	37 (9.0)	8 (9.5)	
<b>\$75,000 - \$99,999</b>	54 (10.0)	42 (12.1)	12 (8.7)	
<b>\$100,000 - \$149,999</b>	61 (11.3)	50 (12.1)	11 (13)	
<b>\$150,000 or more</b>	94 (17.4)	72 (17.4)	21 (16.5)	
<b>Prefer not to answer</b>	58 (10.7)	45 (10.9)	13 (10.2)	
<b>Missing</b>	162 (29.9)	116 (28.1)	46 (36.2)	

<sup>b</sup>SRS-2 = Social Responsiveness Scale, 2nd edition

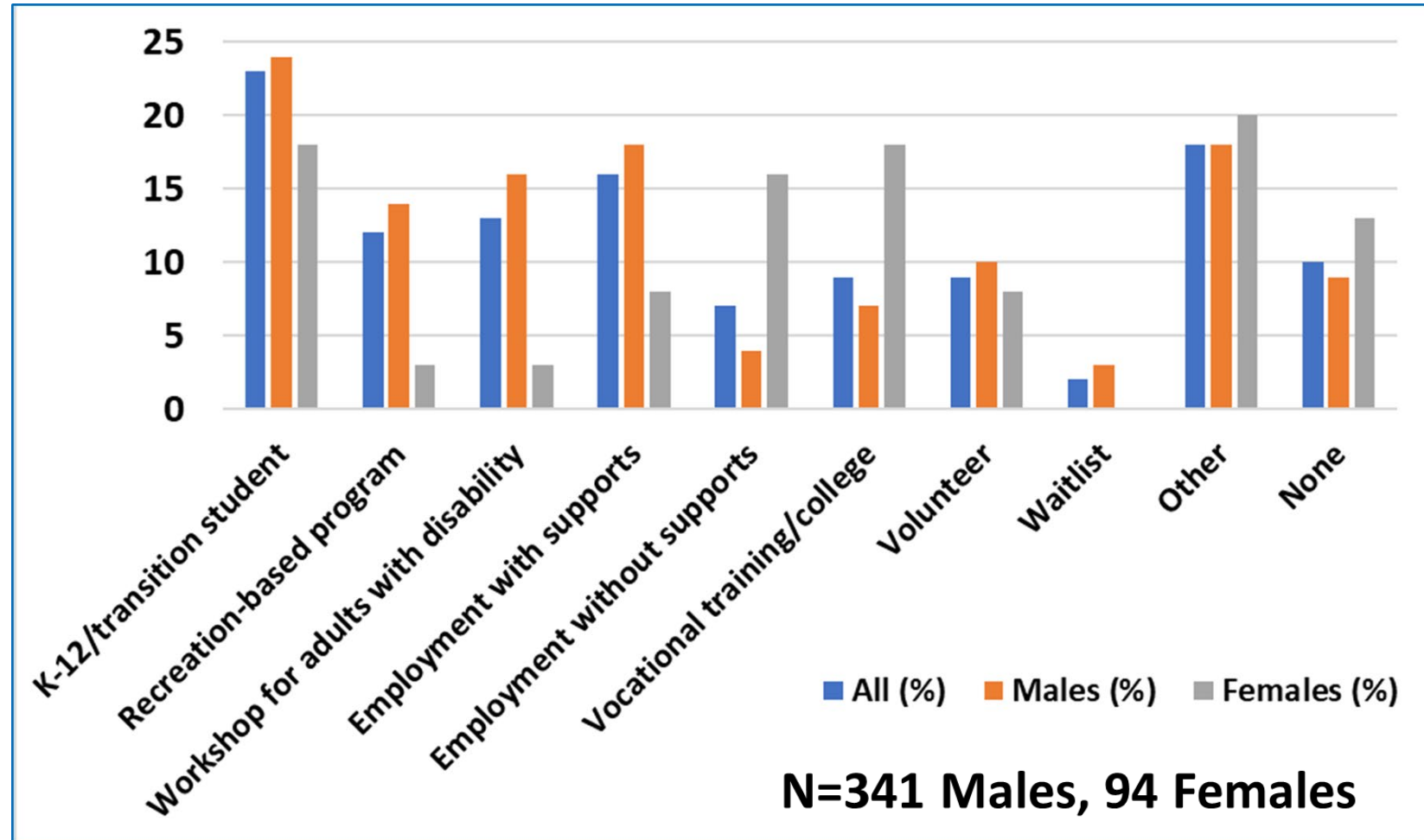
<sup>c</sup>SCQ = Social Communication Questionnaire

# Residence of Adults with FXS in FORWARD

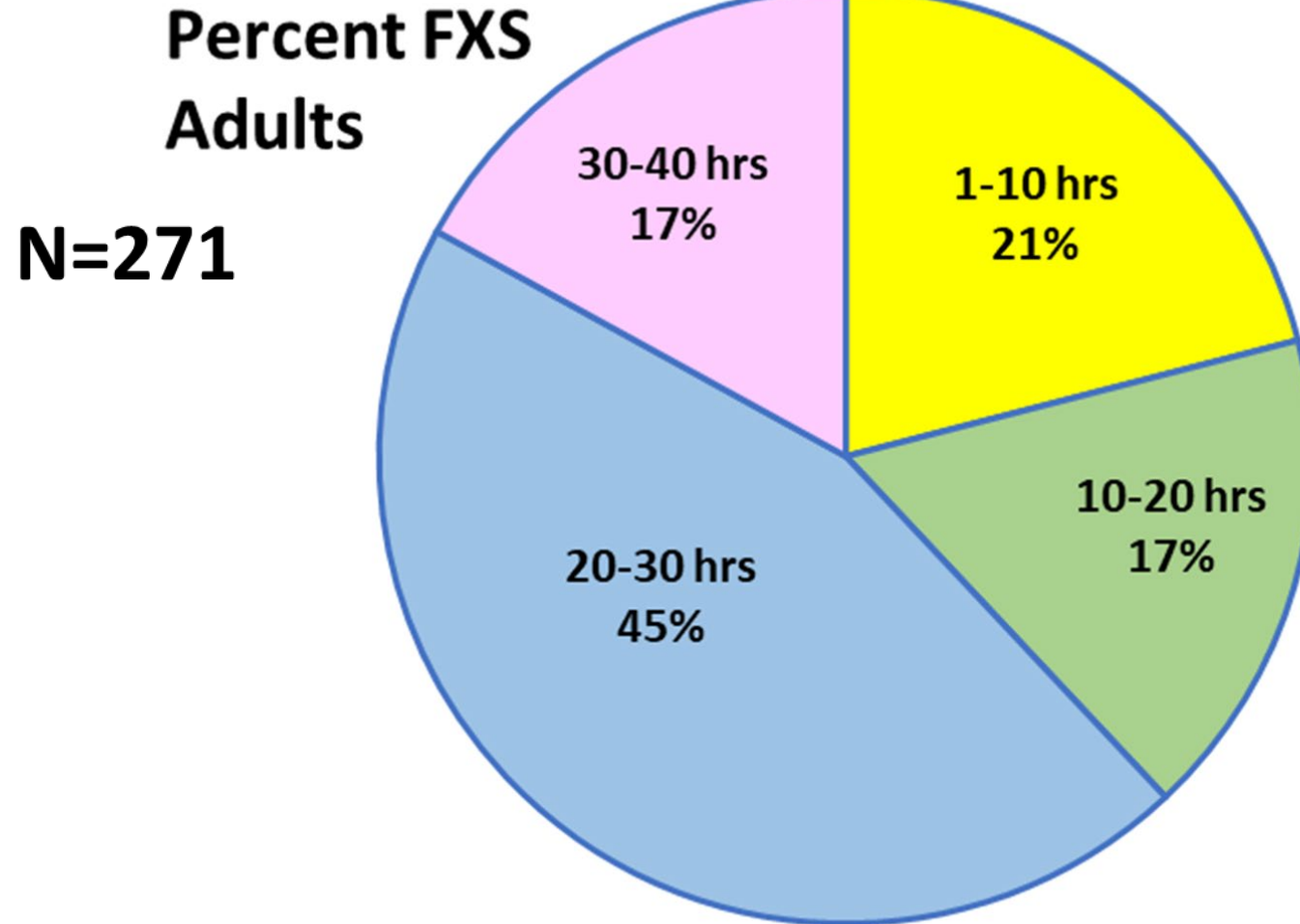


# Employment Status of Adults with FXS in FORWARD

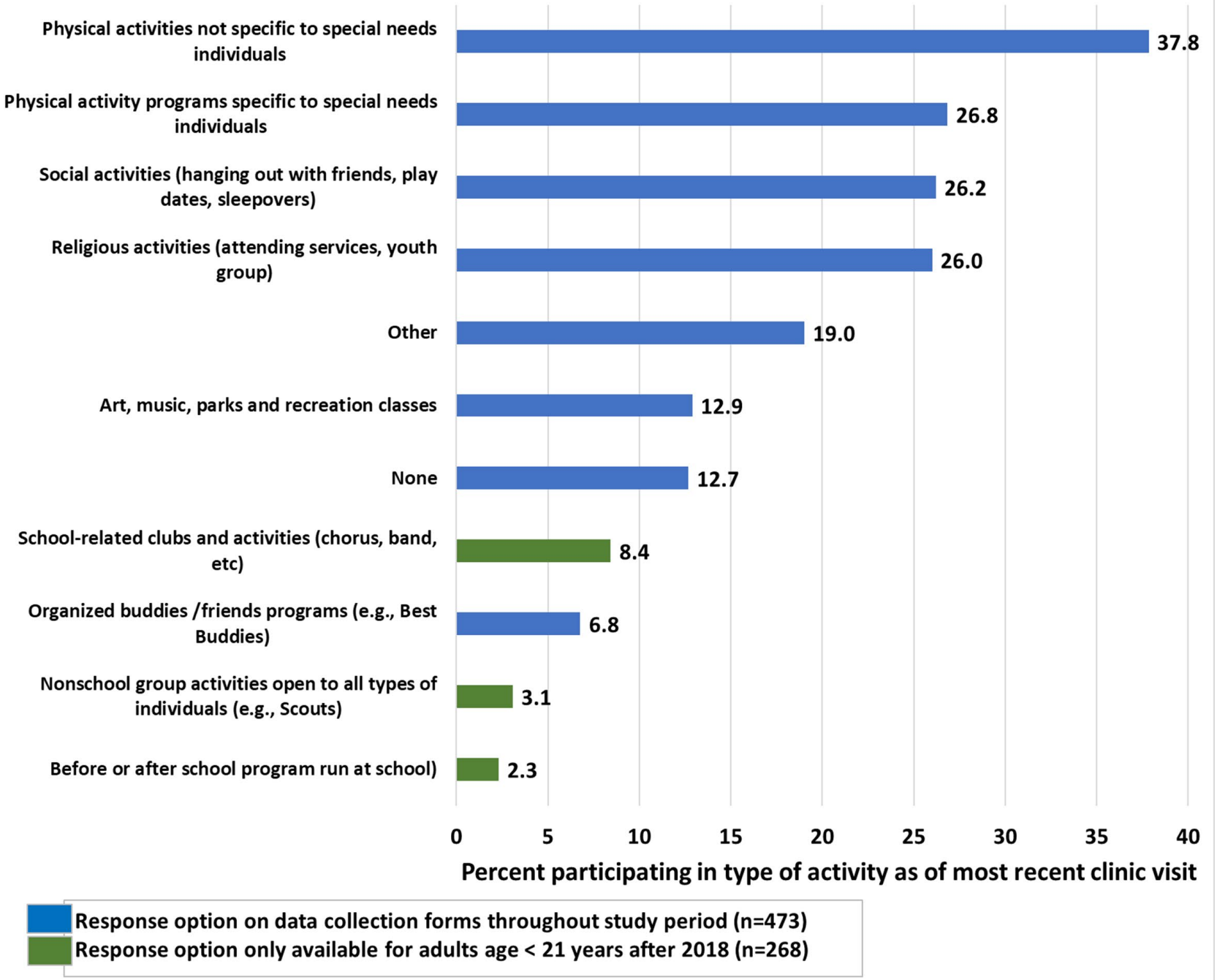
- More males than females were attending a recreation-based program ( $p = 0.001$ ), a workshop for adults with special needs ( $p < 0.0001$ ) or employed with supports ( $p = 0.03$ ).
- Females were more likely employed without supports ( $p < 0.0001$ ) or in a vocational training program or college ( $p < 0.0001$ ).



# Hours Spent in Adult Programs or Employment



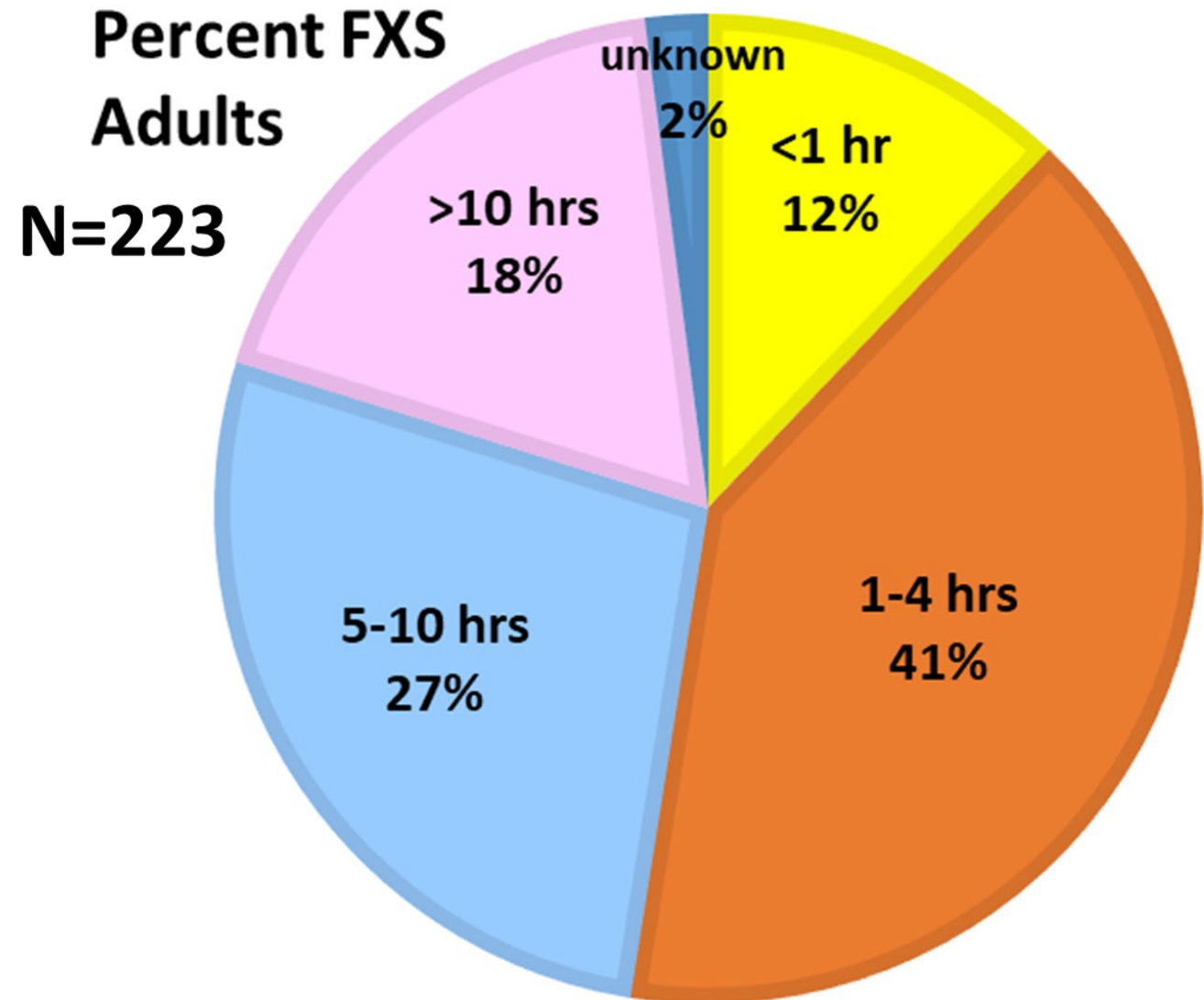
# Social Participation of Adults with FXS in FORWARD





# Hours Spent in Social Activities

- There was no difference in social participation between males and females with FXS
- The top two barriers to social participation were lack of community resources and behavioral issues, with 39% of parents indicating that each was either a moderate or huge barrier. Parents of males were more likely to indicate both of these as barriers (lack of community resources,  $p = 0.03$ ; behavioral issues,  $p < 0.0001$ ). Transportation limitations were cited more often by parents of females ( $p = 0.05$ ).

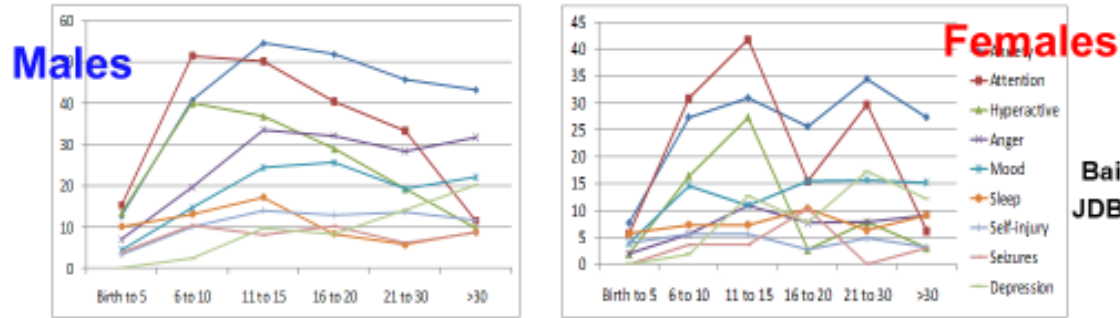


# Family Support

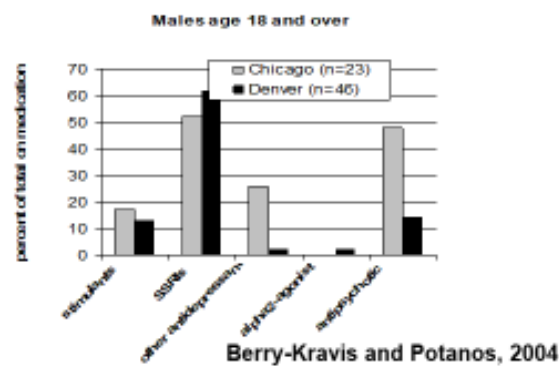
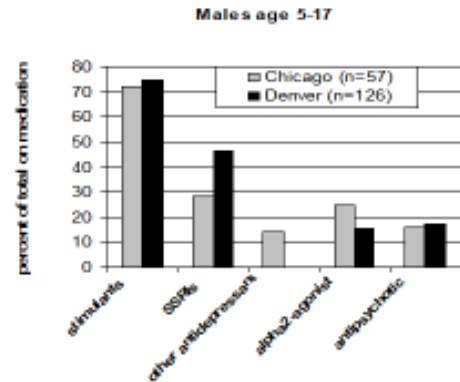
- On average, families reported 1.33 types of supports (SD = 1.55), with a range of none (40%) to eight (1%).
- More common supports were face-to-face support (30%) or respite care, babysitting, or au pair (23%).
- Some families reported using internet support (13%), a lawyer (11%), or a social worker (10%).
- Parents of males reported using child counseling and respite care, babysitting, or an au pair ( $p < 0.0001$ ) more often than females.
- Parents of females more frequently used a mentor,  $p = 0.005$ .

# Age Related Changes in Therapy for FXS

## Medication Use With Age in FXS



Bailey et al.  
JDBP 2012



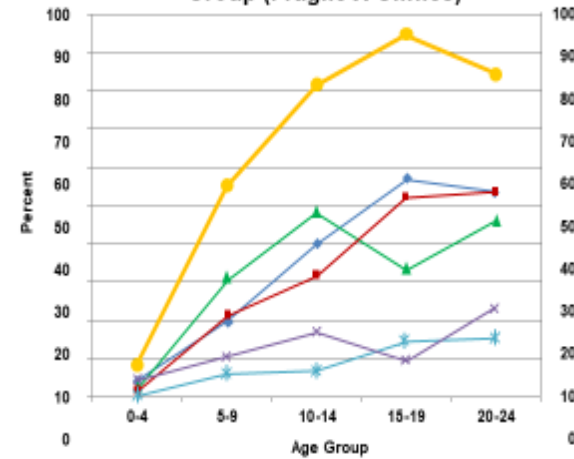
Berry-Kravis and Potanos, 2004

Medications for attention and hyperactivity when younger  
Evolves to anxiety medications and those for aggression when older

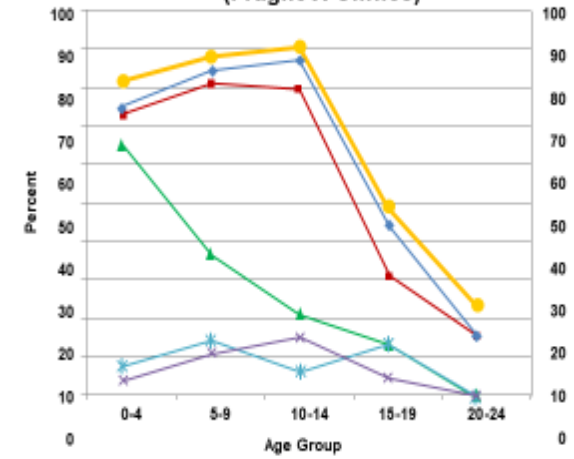
## Use of Pharmacologic Therapies and Services Change As Patients with FXS Age

- Patients from the Fragile X Clinical and Research Consortium (FXCRC) database had increasing use of pharmacologic therapies and decreased use of services as they age

### Psychopharmacological Medications by Age Group (Fragile X Clinics)



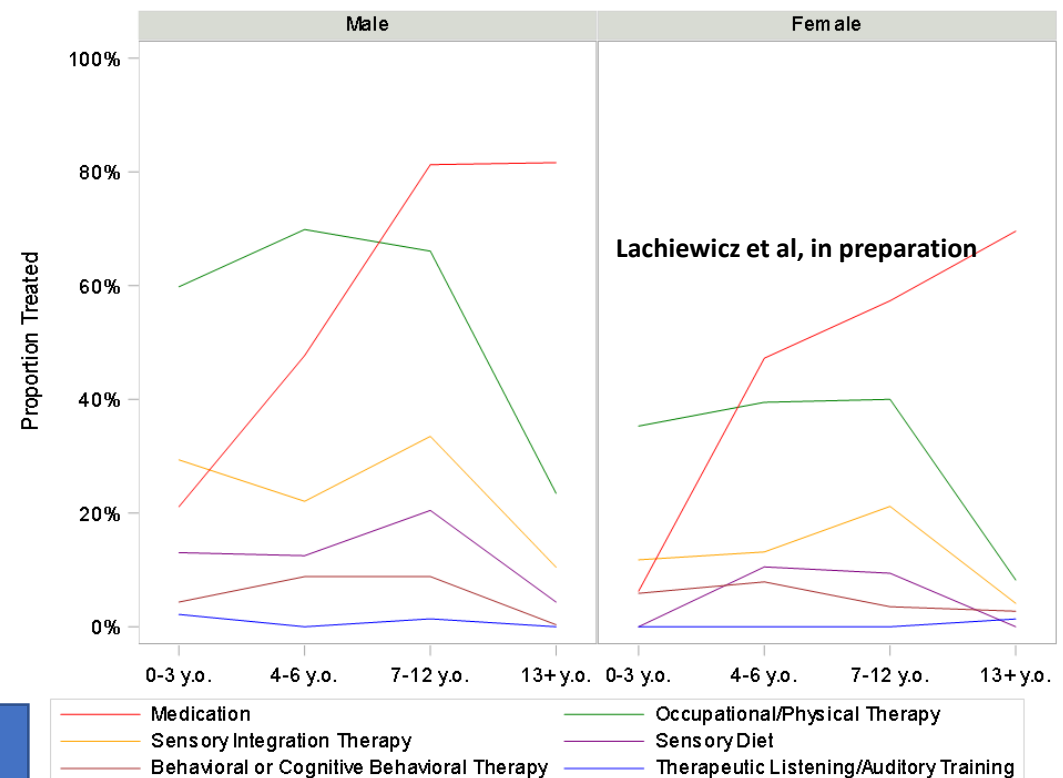
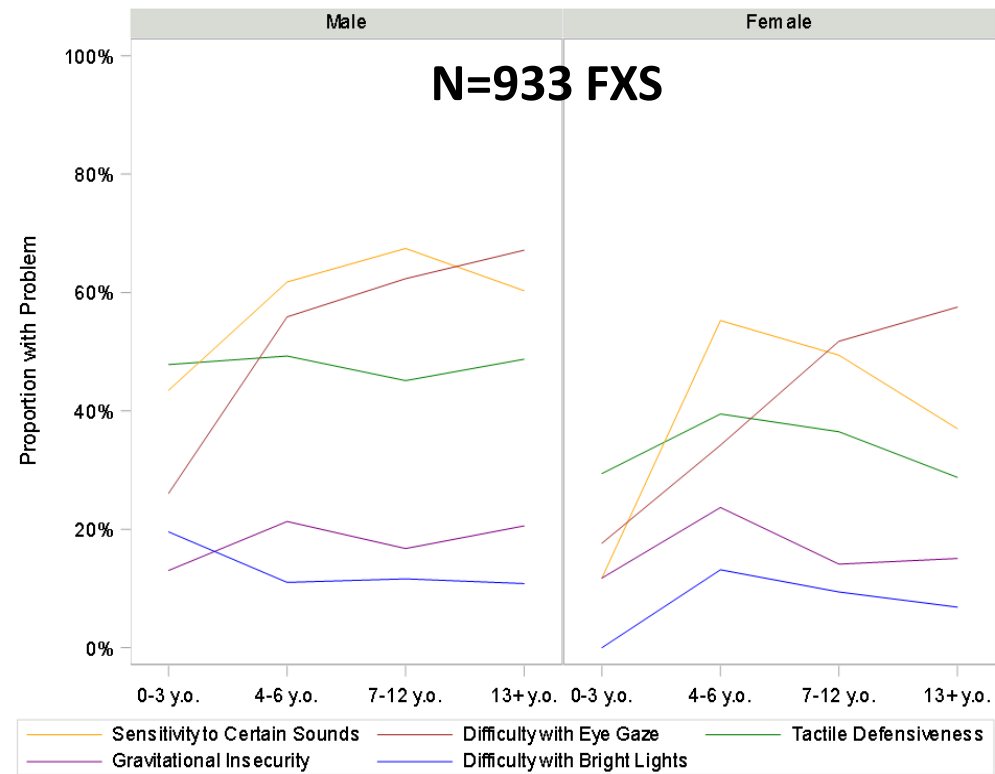
### Use of Services by Age Group (Fragile X Clinics)



Kidd et al. 2013.  
Manuscript in preparation

# Sensory Issues in FXS from FORWARD

Hypersensitivity/overreaction to stimuli in 73% M, 54% F; limiting in 48% M, 36% F



- Awareness for school program and therapy planning (don't force eye contact)
- Need for OT and sensory integration techniques
- Need for therapy programs in adolescent and adult life

# Conclusions From FORWARD

- **Most adults with FXS were living at home likely due to the relatively young age of the cohort and bias toward those still living with the family getting care at FXS clinics.**
- **There is high variability in the types of programs and numbers of hours of attendance.**
- **Adult females are more likely than males to have competitive employment and attend higher education programs.**
- **Types and amount of social participation is also highly variable, with behavioral issues and lack of resources being the biggest barriers to social participation.**
- **This study suggests target areas to improve adult life in FXS and data from larger cohorts with longer longitudinal follow up will help better understand living arrangements, employment, and social participation for adults with FXS across the lifespan.**
- **As always, further work is needed**

# Acknowledgements

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<sup>1</sup>Rush University Medical Center, Chicago IL; <sup>2</sup>RTI International, Research Triangle Park NC; <sup>3</sup>National Fragile X Foundation, MacLean VA



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