

Adrienne Villagomez<sup>1</sup>, Anne Wheeler<sup>2</sup>

<sup>1</sup>University Of North Carolina, Chapel Hill, NC, <sup>2</sup>RTI International, Research Triangle Park, NC

## Abstract

This study explored self- and parent-reported self-determination (SD) in 86 adolescents and adults (56 males; 30 females) with full mutation fragile X syndrome (FXS). Individuals with FXS completed the Arc's Self-Determination Scale (Adolescent and Adult versions, Wehmeyer, 1995). Parents completed the Self-Determination Questionnaire (Carter et al., 2013), which covered a range of skills and perceptions of importance of SD and supports and barriers to SD. Measures of IQ, adaptive behavior, ASD, and anxiety were also collected. Age, adaptive behavior, and social avoidance predicted scores on the autonomy domain of the self-report measure and gender predicted scores on the remaining 3 domains. Parent-reported self-determined behaviors were predicted by adaptive behavior. Most parents rated all self-determined behaviors as "very important" for their child. Many parents identified emotional support, behavioral support, and providing opportunities as important areas of support for their child's development of SD. Parents reported anxiety, self-efficacy, communication, and cognitive functioning as the most significant barriers to their child's development of SD. Findings from the present study highlight the importance of considering functional skills in predicting (and promoting) the development of SD in individuals with FXS. It also underscores the need for parent-report measures and additional research on the role of the family in the development of SD.

## Introduction

- Self-determination is a key strategy to reduce disparities faced by individuals with I/DD<sup>3</sup>
- The issue of health autonomy for individuals with I/DD is increasingly important. This is particularly true for individuals with FXS given rise in clinical trials.
- Although FXS is the most common known genetic cause of ID and ASD, no studies have examined factors associated with SD.
- FXS occurs in 1 in 4,000 males and 1 in 6,000 females. One-third of males and 13% of females meet criteria for ASD.
- Limited research on SD in individuals with ASD. One study suggests lower levels of autonomy<sup>2</sup>
- Research suggests that environmental factors (e.g., opportunities) contribute to SD<sup>6</sup>
- Parents of children with disabilities less likely to provide opportunities (choices, decisions, goals) than parents of children without disabilities.<sup>7</sup>
- Despite the importance of parent role, there are few studies on parent perceptions<sup>6</sup>
- In one study, disability status, ID, and free-and-reduced lunch status predicted parent ratings of importance of SD<sup>1</sup>
- The present study explored self- and parent-reported SD and also examined parent perceptions of importance, supports, and barriers.

## Methods

### Participants

- 56 males (22 adolescents 12-17 years; 34 adults 18-40 years) and 30 females (12 adolescents and 18 adults).
- Majority identified as Caucasian (84%). 5% identified as African-American; 2% Hispanic or Latino; 2% Other; 2% Asian or Pacific Islander; Missing 5%.
- Mean age was 20.76 years ( $SD = 6.77$ ; range 12 - 40 years).
- Over half of parents (55%) reported an income of >\$65,000. 37% of families did not report an income.
- Parents were highly educated (35% college/some post college; 21% graduate degree). 21% reported some college; 6% reported a high school degree.

### Procedures

- Study was part of the *Decisional Capacity and Informed Consent in FXS* project.
- Self-reported SD was collected using the Arc's Self-Determination Scale (Adolescent and Adult versions)<sup>5</sup>
- Parents completed the SD Questionnaire<sup>1</sup>
- Qualitative data collected on perceptions of barriers to SD and strategies to encourage SD.
- Standardized measures of intellectual ability (SB-5), adaptive behavior (SIB-R), autism spectrum disorder (ADOS-2 and SCQ), and anxiety and social avoidance (ADAMS) were collected.

## Results

### Predictors of self-reported self-determination

- Gender did not moderate relationship between predictor variables (i.e., age, ASD, adaptive behavior, FSIQ, social avoidance, anxiety) and self-reported SD.
- Gender was a significant predictor of scores on the Self-Regulation, Psychological Empowerment, and Self-Realization domains on the SDS.
- Social avoidance ( $\beta = -.28, p = .04$ ), adaptive behavior ( $\beta = .48, p < .00$ ), and age ( $\beta = .31, p = .03$ ) significantly predicted Autonomy scores ( $R^2 = .42, F(6, 43) = 5.27, p < .00$ ).
- Social avoidance ( $\beta = -.027, p = .03$ ) and adaptive behavior ( $\beta = .59, p < .00$ ) significantly predicted total SD scores.

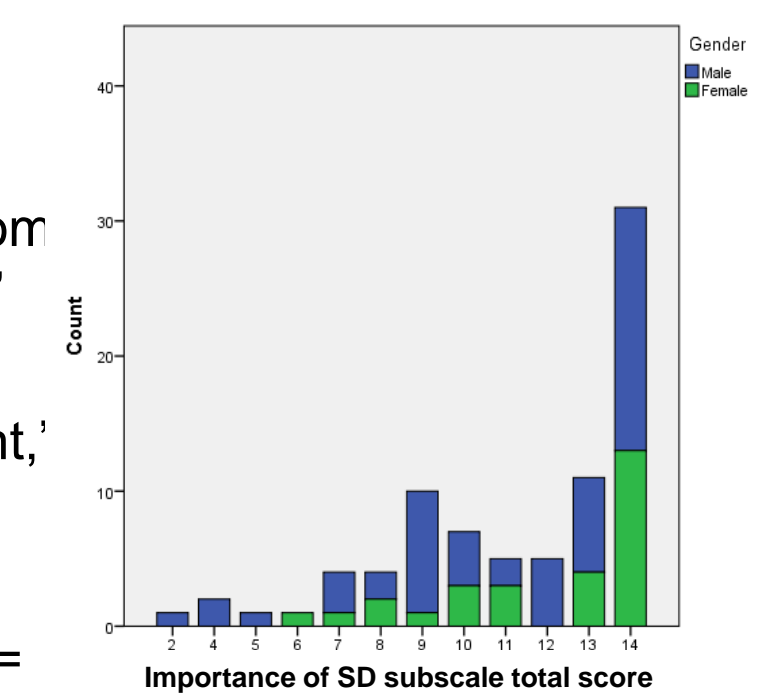
### Predictors of parent-reported self-determination

	b	SE b	$\beta$	t	p
(Constant)	11.16	3.36		3.32	0.00
Age	0.04	0.10	0.04	0.41	0.69
FSIQ	-0.03	0.03	-0.10	-1.02	0.31
ASD	-0.29	1.79	-0.02	-0.16	0.87
Adaptive Behavior	0.13	0.02	0.58	5.44	<b>0.00</b>
Generalized Anxiety	0.08	0.18	0.05	0.46	0.65
Social Avoidance	-0.32	0.19	-0.18	-1.70	0.10

- Adaptive behavior significantly predicted parent-reported SD behaviors ( $R^2 = .39, F(6, 65) = 6.98, p < .00$ ).

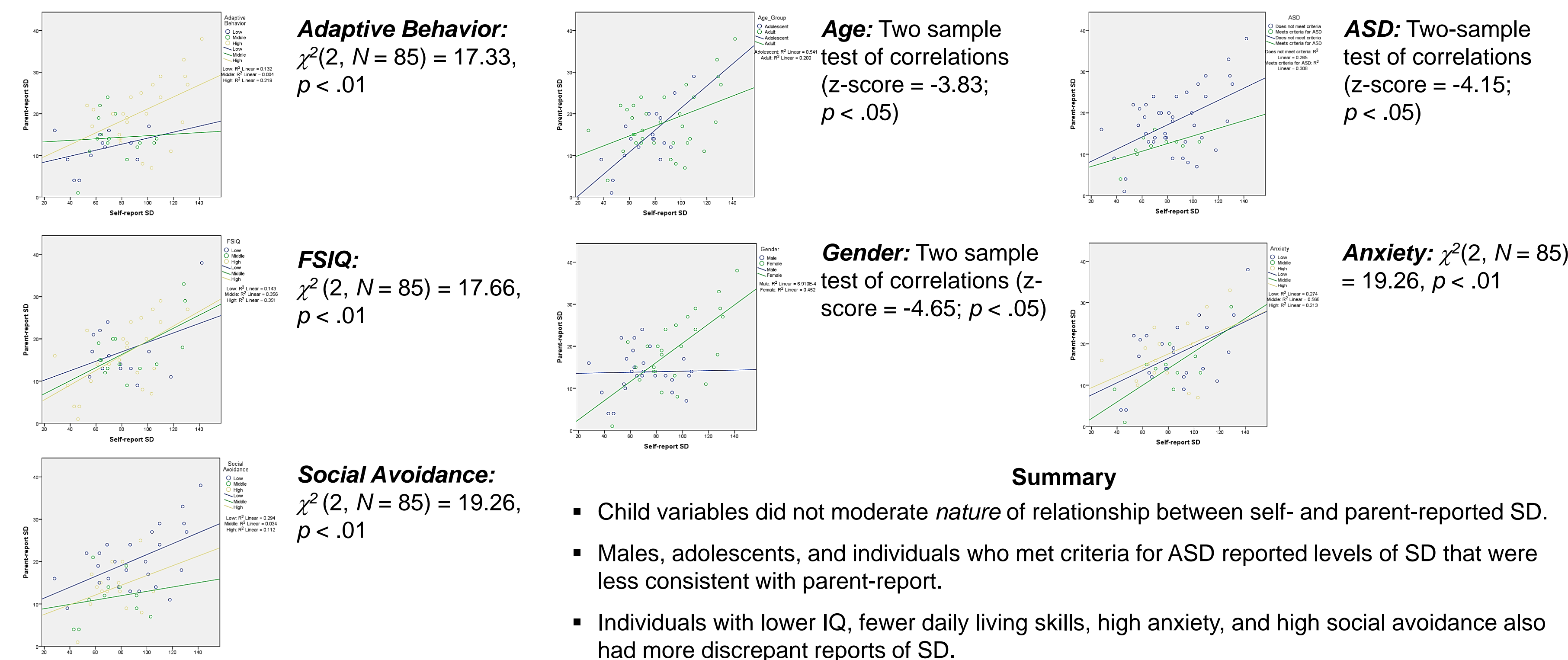
### Parent-reported importance of self-determination

- Independent *t*-tests conducted to examine if parents who rated all SD skills as "very important" differed from parents who did not rate all skills as "very important."
- Parents of children with more daily living skills were more likely to rate all SD behaviors as "very important,"  $t(77) = 2.96, p < .00$ .
- Parents who rated their children's SD higher were more likely to rate all skills as "very important,"  $t(78) = 2.20, p = .03$ .



## Results (continued)

### Relationship between self- and parent-reported self-determination

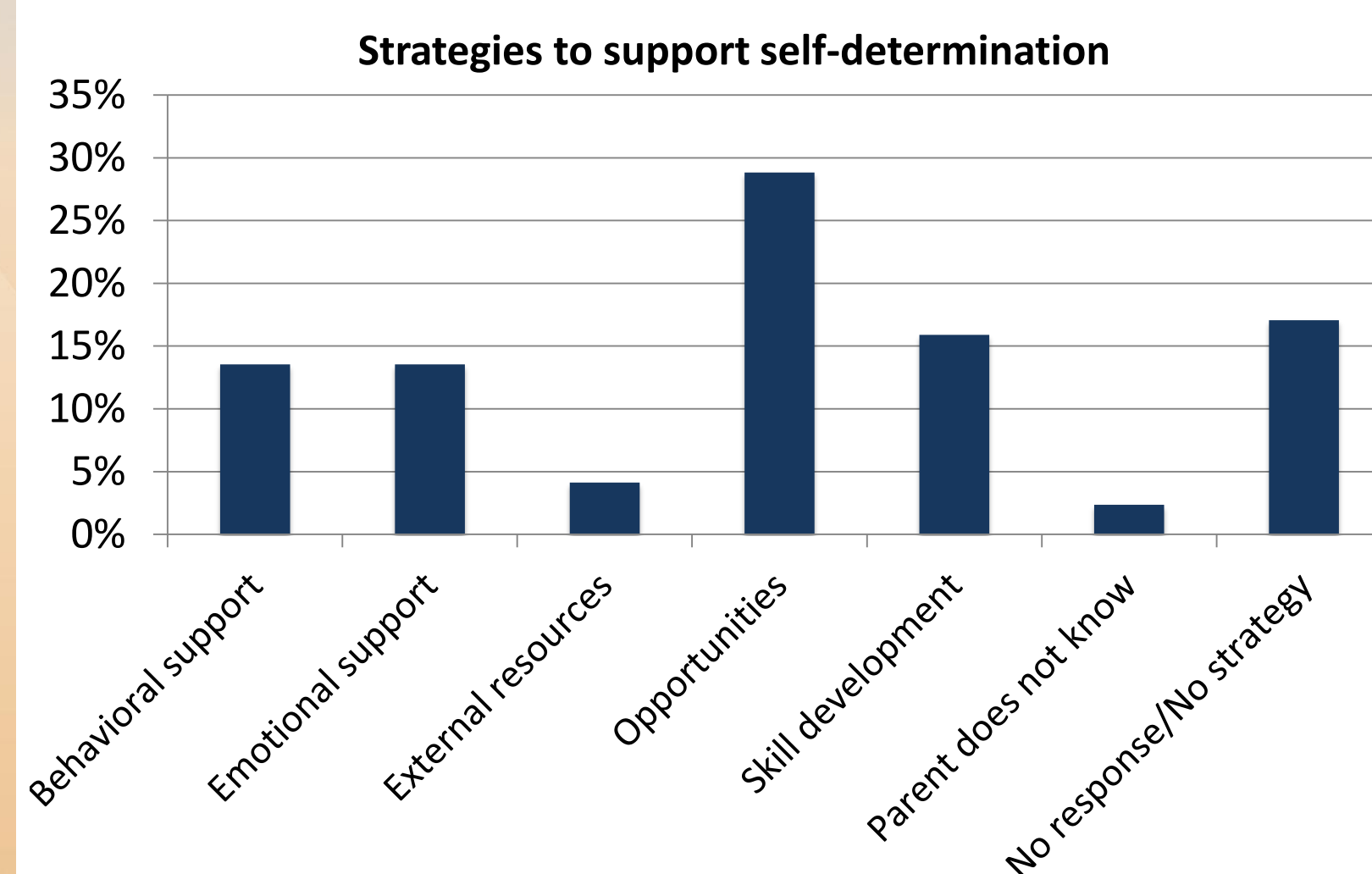


### Summary

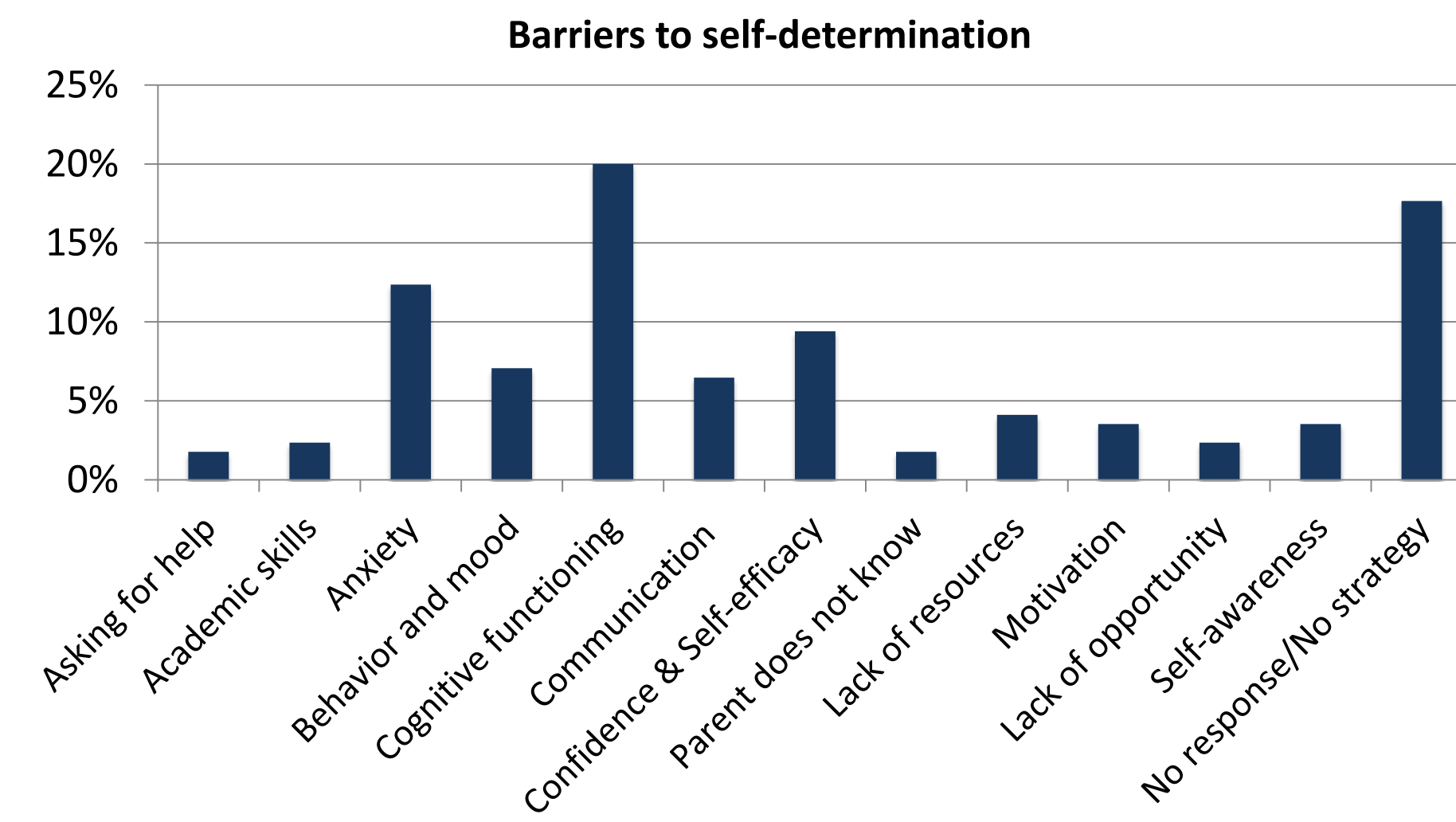
- Child variables did not moderate nature of relationship between self- and parent-reported SD.
- Males, adolescents, and individuals who met criteria for ASD reported levels of SD that were less consistent with parent-report.
- Individuals with lower IQ, fewer daily living skills, high anxiety, and high social avoidance also had more discrepant reports of SD.

## Results (continued)

### Parent perceptions of strategies to support self-determination



### Parent perceptions of barriers to self-determination



## Discussion

- Given heterogeneity among individuals with I/DD, research that explores intra-individual differences in SD is important.
- The present study used raw scores and did not make comparisons to the norm sample.
- Adaptive behavior is the most consistent predictor of SD in adolescents and adults with FXS.
- Parents of males may not prioritize higher-order, more advanced skills as much as parents of females.
- Parent-report of supports were consistent with quantitative findings.
- Few parents referred to adaptive behavior as a barrier. More likely to reference anxiety, behavior and mood, self-efficacy, communication, and cognitive functioning.
- High nonresponse rate suggests that many parents have difficulty identifying supports and challenges related to their child's development of SD.
- Findings from present study highlight the importance of future efforts emphasizing parent participation from both a measurement and intervention standpoint.
- Lack of variability in race, income, and education status of caregivers in the present study limits generalizability.
- Hypotheses that anxiety and ASD would predict SD were not supported. Exploring adaptive behavior as a mediating variable is a next step.
- Future directions include increasingly accessible standardized measures and complimentary parent- and teacher-report scales.
- Future research includes family systems, parenting styles, and environmental variables.

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