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Language Skills Influence Transition Planning in Adolescents with Fragile X Syndrome

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Abstract

Individuals with fragile X syndrome (FXS) and their parents have a range of experiences navigating the crucial transition period between adolescence and adulthood. Semi-structured interviews of 47 mothers of adolescents with FXS (mean child age = 15.89 years) were analyzed to identify mothers' changing expectations during the adolescent period and parent goals related to work and postsecondary education. Mothers' work and education goals were explored in relation to child factors such as language skills and autism characteristics. Lower language skills were associated with lower likelihood of reporting vocational goals. Results suggest that adolescents with FXS with lower language ability are less likely to have vocational plans for adulthood during this critical period and may need greater transition planning assistance.

Key Words: fragile X syndrome, transition planning, language, vocation, autism

Introduction

Fragile X syndrome (FXS), a neurodevelopmental disorder caused by a mutation of the X chromosome, is the most common inherited cause of intellectual disability and is estimated to affect about 1 in 7,000 males and 1 in 11,000 females (CDC; Hunter et al., 2014). In addition to intellectual disability, FXS is associated with high levels of anxiety, hyperactivity, hallmark physical characteristics, and challenges in the areas of executive functioning, language, and attention (Abbeduto et al., 2021a; Brady et al., 2020; Hooper et al., 2008; Raspa et al., 2017; Wheeler et al., 2013). Individuals with FXS, particularly males, often have impairments in adaptive behavior skills with relative weaknesses in interpersonal skills (Dykens et al., 1993;

Thurman et al., 2022). It is estimated that approximately one half of individuals with fragile X syndrome have a co-occurring diagnosis of autism spectrum disorder (ASD) with prevalence being higher in males than females (Abbeduto et al., 2014; Bailey et al., 2006; Haebig et al., 2020; Klusek et al., 2014; Roberts et al., 2020). Co-occurrence of autism is associated with differential behavioral and cognitive outcomes such as increased language impairment, higher rates of challenging behavior, fewer social relationships, and reduced daily living skills and independence in adulthood (Abbeduto et al., 2007; DaWalt et al., 2019; Hartley et al., 2011; Kaufmann et al., 2017; Smith et al., 2012; and Thurman et al., 2022). The profile of impairments seen in FXS has implications for not only future vocational access and independence in adulthood, but also potentially for the process of transition planning during adolescence. Given the importance of this critical period of planning before students exit the secondary education system, it is necessary to better understand how various factors relate to transition expectations.

Communication in FXS

Individuals with FXS present with a wide range of communication abilities and outcomes which are related to educational and independence outcomes in adulthood (Abbeduto et al., 2021b; Brady et al., 2020; Hartley et al., 2011). Most males with FXS have some degree of language impairment, and language skills are associated with the severity of cognitive impairment, of which there is also considerable variability (Abbeduto et al., 2007). A subgroup of children with FXS remain minimally verbal or nonspeaking and demonstrate limited expressive language growth into adolescence (Brady et al., 2006; Brady et al., 2020). Levy et al., (2006) estimate one-third of males remain minimally verbal; however, they based this estimate on a sample of 15 participants. Receptive and expressive vocabulary skills are a relative strength for those with FXS and continue to show growth from childhood to adolescence (Brady et al.,

2020; Hoffmann et al., 2019). Grammatical comprehension and syntactic complexity, however, are considered a relative weakness and show more of a plateau pattern into adolescence (Abbeduto et al., 2007; Brady et al., 2020). Language impairments are generally more severe in those with co-occurring ASD, which is compounded by differences in social communication and social reciprocity that are characteristic of ASD (Abbeduto et al., 2019; Smith et al., 2012; Sterling et al., 2018; Warren et al., 2010). Additionally, females with FXS show greater variability in language skills, with some females being minimally affected (Brady et al., 2020). Some studies show higher scores for females with FXS in individual language domains such as receptive and expressive vocabulary or expressive syntax, however overall language growth trajectories are similar across both sexes (Brady et al., 2020; Komesidou et al., 2017; Sterling & Abbeduto, 2012).

Mothers of children with FXS have expressed challenges, frustrations, and management of expectations surrounding their children's communication skills in early childhood. A qualitative study of the same cohort of mother-child pairs in the current study examined mothers' perceptions, concerns, and expectations for their children with FXS and found that many mothers took on a role as therapist for their children and employed a multitude of strategies including augmentative and alternative communication (AAC), bookreading, daily routines, and prompting to facilitate their child's communication development (Brady et al., 2006). At the same time, when asked about expectations for their child's communication, many mothers noted that they expected to be their child's long term caregiver and tried not to have many expectations for the distant future such as full time work or college (Brady et al., 2006). Understanding how changing expectations from early childhood to adolescence may also be influenced by communication and

language skills may provide a more complete picture of parents' experiences and transition expectations for adulthood.

Vocational and Educational Outcomes in Fragile X Syndrome

Characteristics associated with FXS, such as language and communication impairment, challenging behaviors, and executive functioning difficulties, are closely related to independence and vocation in adulthood (Abbeduto et al., 2021b). Expressive language skills, and expressive syntax in particular, are associated with parent reports of independence related to daily living, community participation, and self-determination (Abbeduto et al., 2021b). However, Abbeduto and colleagues (2021b) argue that more research is needed to disentangle the role of language development in independent functioning because young adults who have greater capacity for independent work may in turn be exposed to more language learning environments, pointing to a bidirectional relationship between language and independence. Young adults with FXS and their parents both express concerns about the transition process from adolescence to adulthood, including limited availability of daytime occupational programming and resources for finding an appropriate job (van Remmerden et al., 2020). Many adults with FXS experience social isolation and limited time engaging in recreational activities, patterns which are magnified in those with co-occurring ASD (DaWalt et al., 2019). Indeed, independence in adulthood is negatively associated with co-occurring ASD for males with FXS and positively associated with functional daily living skills and language skills (Hartley et al., 2011; Thurman et al., 2022; Usher et al., 2020).

Additionally, in a national survey of caregivers of individuals with FXS ranging in age from 22 to 63 years, the majority of male adults with FXS were residing with their parents and needed moderate to significant daily living support (Bailey et al., 2010; Hartley et al., 2011).

Fewer female adults with FXS needed a high level of assistance with daily living skills; however, about half of female adults included in the survey were also residing with their parents (Bailey et al. 2010; Hartley et al., 2011). Issues related to the transition into adulthood such as guardianship, employment, social skills, and independence in daily living have been identified as priorities for the field of fragile X research due to the lack of knowledge in this area (Riley et al., 2017).

Families and adolescents with FXS typically begin the process of planning for the transition into adulthood in high school, when students' individualized education programs (IEP) are expected to include postsecondary goals and describe transition services related to those goals (IDEA, 2004). These formalized transition plans include measurable postsecondary goals that are updated annually, an age-appropriate transition assessment, description of related transition services, and appropriate service coordination with outside agencies. However, despite the best practices mandated by IDEA, many parents express concerns about communication and coordination with professionals in the IEP and transition planning process (Snell-Rood et al., 2020). Further, students with the most significant communication and cognitive needs are typically less involved in the IEP/transition planning process than other peers (Davenport et al., 2021; Johnson et al., 2020).

Role of Parents in Transition Planning

Considering the need for more research investigating transitions into adulthood in the FXS population, parents can provide a particularly valuable perspective. Parents of individuals with FXS often play a central role in their children's lives well into adulthood and frequently take on the role of advocate, caregiver, and coordinator of their child's daily activity and vocation (Kamga et al., 2020). Research related to transition supports for other populations, such

as autistic adolescents, highlight the importance of both the family and young adult having a concrete plan in place with clear goals while acknowledging that level of impairment and parents' informed expectations can impact the transition process (Curtiss et al., 2021; Hatfield et al., 2018).

Recent qualitative studies exploring parent perspectives and concerns during the adult transition period highlight the difficulty of navigating institutional, financial, and social barriers to transition planning (Feinstein & Pollack, 2016; Gauthier-Boudreault et al., 2020; Kamga et al., 2020; and Van Remmerden et al., 2020). Difficulties cited include anxiety in finding appropriate living and work accommodations, lack of support from schools and other social welfare systems, and trouble managing the work of transition planning on top of daily caregiving burdens (Feinstein & Pollack, 2016; Kamga et al., 2020). Other studies have echoed these concerns, and in an analysis of 13 parent interviews, parents specifically cited co-occurring ASD, cognitive disability, and number of children with FXS in the home as factors affecting their child's transition to adulthood (Gauthier-Boudreault et al., 2020).

In the current study, we explored mothers' expectations and future goals for their children with FXS to answer the following questions: 1) how do mothers of adolescents with FXS describe their expectations for the future and how those expectations have changed over time, and 2) are child language skills and autism characteristics associated with differences in mothers' reports? We interviewed mothers of adolescents with FXS and analyzed the interviews for themes related to transition planning. These interviews capture maternal perceptions and experiences in the critical period of planning, before their children are exiting high school and potentially entering the workforce. Thus, the resulting data are uniquely situated to provide insight into factors that may impact the transition process itself, rather than looking solely at

outcomes in adulthood. Next, we investigated how two child-related factors—language ability and autism characteristics—are associated with reported perceptions and expectations. As documented in other qualitative studies, language skills and autism are two primary concerns that parents cite related to their child’s transition to adulthood (Gauthier-Boudreault et al., 2020) and are related to the independence and daily living skills of adolescents and adults with FXS (Abbeduto et al., 2021b; Raspa et al., 2018; Thurman et al., 2022). In line with these reports, we hypothesized that individual differences in language and autism characteristics would be associated with maternal expectations related to adulthood.

Method

Participants

Forty-seven adolescents with FXS (10 girls) and their mothers participated in an ongoing longitudinal study of development and family adaptation in fragile X syndrome (citations masked for blind review). Participants ranged from age 12.1 years to 18.0 years at the time of data collection for the current study, and mothers’ ages ranged from age 34.7 to 55.1 years. During the interview 30 out of 47 mothers reported that they were the primary caregiver in the home during their discussion of parenting roles and responsibilities. One mother reported that the father was the primary caregiver. Information about the primary caregiver in the home for the remaining 16 participants was not reported. Both mother and child genotypes were confirmed through blood sample analyses. All adolescents had full mutation FXS. Forty-one mothers carried the FMR1 premutation, one mother was mosaic with full mutation alleles, two mothers were mosaic with both premutation and full mutation alleles, and three carried the full mutation.

Participants were recruited from developmental clinics, doctors’ offices, through a national research registry at the [masked for review], FXS family support group networks,

advertising at national conventions, and an FXS parent email list. All families completed study procedures in-person in their homes during a visit that lasted approximately four hours. The current study was approved by the Human Subjects Committee of the [masked for review]. All families provided informed consent and assent before participating.

Assessment Measures

Autism Characteristics

The *Childhood Autism Rating Scale, Second Edition, Standard Version* (CARS2-ST; Schopler et al., 2010) was used to quantify autism characteristics in adolescent participants. The CARS2-ST was completed by trained clinicians and research assistants based on in-person observation and other standardized test results during in-home visits and was scored after the administration of all other study procedures. Total raw scores from the CARS2-ST were used to quantify autism characteristics. Higher raw scores indicated elevated symptoms of autism. Age-specific thresholds have high sensitivity and specificity in identifying ASD (Dawkins et al., 2016).

Language and Communication Skills

The Vineland Adaptive Behavior Scales, 2nd Edition Interview Form (VABS-II; Sparrow et al., 2005) was used to measure language skills in adolescent participants. The VABS-II is a measure of adaptive behavior for individuals from birth through old age administered by completing a semi-structured interview with a parent/caregiver. For the current study, we used the raw score from the Communication subdomain which includes receptive language, expressive language, and written language subscales. Demographic characteristics including participant scores on both the CARS2-ST and the VABS-II Communication subscale are reported in Table 1.

[Table 1 here]

Interview Collection

Maternal expectations for their child and their child's future were gathered through a semi-structured interview. The interview protocol was designed by the research team and administered by trained research staff in the family's home. The original interviews were constructed by a researcher with experience conducting ethnographic interviews and years of experience working with families with FXS. Questions in the interview protocol were designed to elicit discussion on a range of topics, including family relationships, support, behavior and teaching strategies used in the home, goals for the future, and perceptions of parenting style. Most of the questions were the same as those administered in previous interviews with a few additions. For example, we asked mothers to describe their parenting style and if their parenting had changed over time. This reflection on changes in parenting style was a new addition. They were also asked about their goals and expectations for their child for the future. Specifically, we asked, "What expectations and goals do you have for ____?" We did not ask specific questions about future work or living situations, however themes about these topics emerged in several of the interviews (as described below). The interviews were collected as part of a larger assessment with both the child and mother. The interview protocol with the full list of interview questions are available at [anonymized OSF link for review] <https://tinyurl.com/2s4m9ukp>. Interviews were digitally recorded and later transcribed into a Word document.

Interview Analysis

Interview transcripts were analyzed using an inductive coding process which included open, axial, and selective coding (Strauss & Corbin, 1990). In the open coding phase, interviews

were examined for discrete concepts that emerged from the text. Researchers identified concepts and named them as they emerged from each transcript. Once all interviews were coded for these emerging concepts, codes were categorized based on common themes and relationships in the axial coding process. Potential categories were continually refined by examining relationships between individual codes, and subcategories were created as necessary through code notes and debriefing with others on the research team. For example, when asked about expectations for the future, parents frequently discussed specific plans that they made surrounding future employment situations for their child. Even though some mothers discussed plans for their child to work independently, continue with postsecondary education, work with vocational support, etc., these codes all centered around the common category of vocational plans. In selective coding, researchers collected all major defined categories and summarized those categories into the broader theme of parent perceptions, roles, and strategies or planning used with their adolescent child. Authors [masked] and [masked] completed independent coding on six interviews based on these themes to refine code definitions and created consensus files that were subsequently used as gold standard files for training other coders. The individual codes and their corresponding categories generated through this process are described in Table 2.

[Table 2 here]

Two research assistants were trained to fidelity on the final coding scheme using the gold standard training files. During the training phase, all discrepancies were reviewed and discussed with author [masked] or [masked] for consensus. Once research assistants reached 80% agreement on three interviews in a row, 32% (15 of 47) of subsequent interviews were randomly

selected and coded for reliability by author [masked]. Percent agreement was calculated for all reliability files (average percent agreement = 83%) and kappa coefficients were calculated to assess interrater reliability across codes in all categories. The average Kappa coefficient was 0.86 (SD = 0.09, range: 0.69 – 1.0).

Results

Data Reduction and Analysis

We first described the frequencies of the codes of interest to assess which codes were commonly occurring. Based on the information from the descriptive analysis, we then examined whether child-specific factors such as language or autism characteristics were related to a) whether mothers reported expectations related to work and b) whether they reported higher or lower expectations. Due to the heterogeneity of specific work and education plans put in place by mothers, codes in this category were collapsed into a binary variable reflecting whether or not mothers reported having work or education plans in place for their child. This binary variable is used in all subsequent analyses. Codes related to parental expectations were combined into a three-level factor indicating lower expectations, no reported change, and higher expectations. Two of the 47 respondents (child ages 12.0 and 13.3) were removed from subsequent analyses in order to limit the sample to adolescents ages 14 years and older. Many students begin formal transition planning between the ages of 14-16 years; therefore, parents of younger children may be less likely to engage in such planning or goal-setting.

A logistic regression model was used to explore child factors associated with the presence or absence of work and education planning. To examine factors related to changing parental expectations, multinomial logistic regression analysis was used. Both the logistic and multinomial logistic regression models yielded odds ratios (OR), representing the change in

likelihood of parents reporting a particular theme for every ten unit increase in the child's Vineland or one unit increase in CARS scores. To improve the interpretability of the Vineland results, we used an increment of ten points as the unit of analysis. $OR < 1$ indicate lower odds of the reported theme while $OR > 1$ indicate higher odds for every incremental score increase. All models controlled for child age to account for any differences in goals or expectations related to age. Likelihood ratio tests showed that regression models including maternal education level and household income did not significantly differ from models controlling only for child age when assessing the relationship of CARS scores on maternal expectations ($p = 0.139$) and work expectations ($p = 0.529$) and the relationship of Vineland scores on maternal expectations ($p = 0.156$) and work expectations ($p = 0.148$). As a result, they were not included in the subsequent regression models. Sex differences in interview responses were not accounted for in the regression models, however, the frequency of interview responses by child sex can be accessed at [anonymized OSF link for review] <https://tinyurl.com/2s4m9ukp>.

Goals and Planning for Work and Post-Secondary Education

Mothers reported a variety of work and education expectations for their adolescent children with FXS (see Figure 1A). More than one third of mothers (40.4%) reported that they expected their children to work independently after they left or graduated from their current educational program. Many mothers who expected their child to work independently also recognized adaptations that their child may need to be successful, such as shorter shifts or work that matched their child's strengths. For example, one parent stated "I know [he] will be able to have a job someday, not a full-time job. I mean maybe, you know, twelve hours a week doing I don't know what. But I know he can have a job". In contrast, only eight mothers (17.0%) reported that they expected their child to engage in some form of supported work, and only one

parent reported that they did not expect their child to be employed. Seven mothers (14.9%) reported they expected or made plans to enroll their child in some form of post-secondary education. Educational plans ranged from vocational or technical schooling, online courses, adapted college programs, and two-year or four-year degree-seeking college programs. Notably, the adolescents whose mothers reported post-secondary education plans all demonstrated low autistic traits on the CARS2-ST (range = 19.0 – 22.5). Many mothers, regardless of reported expectations, identified potential barriers to their child either working independently or being able to maintain work after high school, such as speaking status, difficulty identifying their child's interests, or identifying potential employers that were a good fit for their child. One mother who saw their child working with some form of job support noted, "Being nonverbal, that's not gonna change at fifteen. So we're now looking into programs that will allow her to have an aide with her that she would be able to do."

The code for *Lack of Plans for the Future* included explicit statements about lack of work or education plans. Four mothers (5.7%) explicitly stated that they didn't know whether their child would be able to have a job in the future. One parent commented, "...vocational work, he has no interest in that. So I haven't seen anything that we could tap into as far as his interest. So it's a blur at this point. I don't know." Additionally, fourteen mothers did not make any comments about plans for future work or education for their children. The four mothers who made explicit statements about lack of plans for the future and the fourteen who did not make any comments about future vocational plans were collapsed into a larger group, shown in Figure 1B as "No work/education plans". Overall, 29 mothers (61.7%) discussed goals or expectations related to work or education, while 18 mothers (38.3%) did not.

Mothers' Parenting Style and Expectations for the Future

In regard to parenting style, 17 mothers (36.2%) discussed how they had become more relaxed as their children had gotten older, and only two mothers reported they had become less relaxed. Five mothers (10.6%) stated that they felt more capable as parents as time has passed, and nine mothers' responses (19.1%) reflected a fear of the future. When asked how their parenting style and expectations had changed over time, eight (17.0%) reported that they had higher expectations for their child as they've grown, while 11 mothers (23.4%) reported lower expectations (see Figure 1B). Some mothers who reported higher expectations reflected upon specific milestones or moments of developmental progress. When discussing how she has higher expectations for her child, one mother said, "The next five years he may surprise me because I never thought that he would even be able to talk. So in the next five years it may look a little different. But I've learned to deal with the right now." Others discussed how in early childhood their expectations were unclear, but seeing their child progress changed their outlook. For example, one mother stated, "I think they've increased as I've seen her mature and her do more ... I think my expectations really changed because I saw what she was capable of and when she had that drive and that passion, what a difference she could make."

Mothers who reported lower expectations similarly noted the importance of developmental milestones such as developing spoken language. One mother stated, "...I probably would have said years ago one of my goals for him is that he'll talk. And I'm just slowly coming to terms with that's probably not going to happen. And it's like really okay. It doesn't break my heart as much as it used to." The process of letting go of specific goals was a common theme. One mother responded, "...[there] used to be a time that I thought that he would be able to live at best in an assisted living home. I now know that's not gonna happen. I've had

to lower the expectation.” For a more comprehensive sample of interview quotes and their corresponding interview codes, see Table 3.

[Table 3 here]

[Figure 1 here]

Child Factors Related to Maternal Expectations

Factors Related to Work and Education Expectations

Vineland Communication subscale raw scores significantly predicted the likelihood of mothers reporting work and education expectations, such that for every ten-unit increase in VABS-II scores, the odds of mothers reporting work expectations are 1.27 times higher (95% CI: [1.067, 1.57], $p = 0.0125$). Thus, adolescents with higher language scores had a higher likelihood of their mother reporting future work or education plans. The association between CARS2-ST scores and likelihood of mothers reporting work expectations did not reach significance. For every one-unit increase in CARS2-ST scores (indicating more autistic traits), the odds of mothers reporting work expectations are 0.93 times as high (95% CI: [0.83, 1.02], $p = 0.123$). See Table 4 for full logistic regression models.

Factors Related to Changing Expectations for the Future

We next examined whether language or autism characteristics were related to mothers' changing expectations. There were no significant relationships between language or autism characteristics and reports of increased expectations. Vineland Communication subscale raw scores did not significantly predict the likelihood of mothers reporting lower expectations ($p = 0.292$). The association between CARS2-ST scores and the likelihood of mothers reporting lowered expectations also did not reach significance ($p = 0.175$). See Table 5 for full multinomial regression models.

Discussion

The aims of the current study were to explore maternal perceptions and expectations for the future in adolescents with fragile X syndrome. Using a mixed methods approach, we identified common themes based on mothers' reported experiences and examined their relationship to child factors, namely language ability and autism characteristics.

Experiences of Mothers of Adolescents with Fragile X

Mothers of adolescents with FXS reported a wide range of experiences and plans for the future as they looked toward transitioning into adulthood. Responses related to planning for future work or education opportunities were consistent with prior qualitative studies of adolescents with FXS (Feinstein & Pollack 2016; Kamga et al., 2020; and van Remmerden et al., 2020). Many mothers expressed that they were in the process of trying to identify potential employment options or employment supports for their children. Similar to the respondents in previous studies, some explicitly cited feelings of uncertainty or anxiety surrounding this process, while others did not (Feinstein & Pollack 2016; Kamga et al., 2020; and van Remmerden et al., 2020). While vocational plans ranged from independent work, additional education, supported work, and unemployment, a considerable subset of mothers did not report any plans or goals related to employment or education. These results may reflect recent evidence suggesting a gap in best practices for transition planning for students with disabilities, including a shift in the burden of transition planning to families rather than practitioners, a lack of integration of vocational rehabilitation services or similar pre-employment agencies, and poor communication between stakeholders (Snell-Rood et al., 2020).

Additionally, many mothers noted that they've shifted their expectations as their child has aged, with some reporting higher expectations and others reporting lower expectations.

Discussions of changing expectations often centered around previous goals or expected milestones that were either met or not met, and mothers indicated how their child's developmental progress impacted their view of the future. Mothers frequently reflected that when their children were younger, they had little information about what to expect, therefore other siblings, family members, or individuals in the community with FXS were their most accessible frame of reference.

Communication Skills Impact Transition Expectations

Communication skills significantly predicted likelihood of future work expectations, such that adolescents with lower communication skills had a lower likelihood of parent reported work or education expectations. Communication challenges may pose particular barriers to families in planning work after high school because job coaching support and assistive technology are particularly critical for those with lower language abilities. Identifying, securing, and adapting those supports to a workplace setting can be a frustrating and logistically challenging process for families, as described in depth by caregivers in Feinstein and Pollack (2016). Feinstein and Pollack (2016) also related their similar findings to a phenomenon called “tunneling”, where immediate concerns such as behavior challenges, schooling, and the daily acts of caregiving make it difficult to focus on long-term planning. Thus, parents of children with higher support needs such as language impairment may need additional support from professionals and institutions, such as increased inclusion of family advocates or representatives from integrated employment services in the transition planning process, or counseling on vocational options and access in order to navigate the transition process. Speech-language pathologists (SLPs), in particular, play an important role in helping students access supports related to communication needs, such as continued AAC device access and counseling for families. SLPs are also uniquely

positioned to help students promote workplace interaction skills, self-advocacy skills, and compensatory communication strategies for different workplace settings (Perryman et al., 2020). SLP involvement during the transition planning process may help to facilitate earlier vocational planning and calibrate family expectations for the future.

Some mothers in the current study also reflected that they feared their child being taken advantage of in outside settings, highlighting the importance of trusted support professionals and systems outside of the home. Interestingly, while we expected that supported employment goals would be more prevalent among our participants, particularly with those adolescents who have higher communication needs, only eight mothers reported plans for supported employment such as a structured vocational program or job coach. Taken together with these trends, we suggest that the association between lack of vocational planning and communication skills is not a function of the child's *ability* to work but is more indicative of a breakdown in the planning process itself. This interpretation is consistent with previous work documenting transition IEP quality in students with autism and other disabilities, wherein inclusion of parent concern, student input, measurable goals, vocational rehabilitation coordination, and communication and social skill considerations were often lacking (Johnson et al., 2020; Snell-Rood et al., 2020).

Intersection of Fragile X Syndrome and ASD

Based on statements from parent interviews and previous literature documenting daily living outcomes for individuals with co-occurring FXS and ASD, we examined whether mothers' interview responses were related to degree of autism characteristics. Autism characteristics were not significantly associated with either changes in maternal expectations or likelihood of reporting vocational goals. This finding was surprising, considering the body of evidence demonstrating poorer vocational and daily living outcomes for individuals with FXS

and co-occurring ASD (Abbeduto et al., 2021b, DaWalt et al., 2019, Hartley et al., 2011) and increased parent anxiety related to ASD symptoms (Gauthier-Boudreault et al., 2020). One potential explanation for the nonsignificant relationship between transition expectations and ASD characteristics is that the measure used in the current study, the CARS, may have reduced sensitivity in individuals with FXS compared to other diagnostic instruments such as the Autism Diagnostic Observation Schedule, Second Edition (Haebig et al., 2020; Lord et al., 2012). These results require further investigation with larger sample sizes and multiple methods of assessing autism characteristics. Additionally, future research should investigate the interaction among ASD characteristics and language skills as they relate to transition experiences and the potential impact of other domains such as adaptive behavior, executive function, or self-regulation. Given the high rate of co-occurrence in these two disorders, future research should continue to explore the specific obstacles faced by individuals with FXS and individuals with ASD.

Limitations and Future Directions

This study provides novel insight into individual differences in adolescents with FXS that relate to parent perceptions of the transition process. A strength of the current study is the focus on reporting mothers' views about their plans for the future as identified from their interviews. Our approach allowed us to identify themes that may not come up in more specified methods such as a questionnaire. Thus, parent-reported themes were data-driven and not constrained by survey questions or theoretical assumptions of the research team, decreasing measurement bias. A few limitations and potential future directions should also be noted, however. First, while the scope of this paper focused on child-based factors impacting the transition process, there are many other external influences worth exploring in future studies. Future research with larger sample size and greater diversity in terms of racial/ethnic background and SES are needed to

help elucidate how socioeconomic factors impact the planning process for families. In addition, stakeholders such as family members and individuals with FXS should participate in creating interview questions. Environmental factors such as geographic region, school district, and community resources can be a major barrier to vocational support access for families. Feinstein and Pollack (2016) describe long wait-lists for services, uneven implementation of policies, and overall scarcity of support as barriers to transition planning, which should be further investigated in relation to vocational outcomes. Further, networks of support such as extended family, disability advocacy groups, and connections within the community may play a role in accessing vocational resources and forming parent attitudes about future goals. This is especially relevant as not all of the mothers in this study identified themselves as the primary caregiver, therefore roles and responsibilities related to planning for the future may differ. Future research should engage caregivers in identifying potential solutions or resources for engaging in earlier and more effective transition planning in adolescence.

Second, although the themes identified in the current paper were driven by parent responses, even within individual code categories mothers may have a variety of reasons for providing those responses. For example, while some mothers who cited lower expectations for their child described feelings of sadness and grief, others described feelings of acceptance and contentment about their child's development. These two examples provide qualitatively different experiences within the broader "lower expectations" theme that could be teased apart in future investigations. Follow-up investigation could elicit more in-depth discussion about attitudes surrounding transitions to adulthood and specific barriers that parents believe contribute to their planning or expectations. Additionally, responses in the *No Work/Education Plans* category could reflect that mothers were unsure about work goals, did not expect their child to work at all,

or that vocation planning was not yet part of their planning for the future. Gathering more information from teachers, therapists, and support personnel may paint a more complete picture of an individual child's transition plans because teacher perceptions are not always aligned with parent perceptions, particularly for students with higher support needs (Carter et al., 2012).

Finally, the current study's investigation of parent attitudes and expectations in adolescence can be extended longitudinally into adulthood to identify associations between parent expectations and individual vocational outcomes. Based on the current findings associating child language skills and maternal vocational goals, future studies can examine whether parent goals or expectations during the start of the transition period moderate the relationship between child skills and vocational outcomes.

Conclusions

The current findings suggest that mothers of adolescents with fragile X syndrome and higher support needs, such as lower language ability, are less likely to have vocational plans in place for the future. Although autism characteristics did not significantly predict parent vocational goals in the current sample, previous work documenting parent concerns and independence outcomes in adulthood suggest that autistic traits or an ASD diagnosis may impact the transition process to some degree (Curtiss et al., 2021; Davenport et al., 2021; Hatfield et al., 2018; Johnson et al., 2020; Snell-Rood et al., 2020). Future research with larger sample sizes can disentangle these findings, which are of significant interest considering the high co-occurrence of FXS and ASD. Parent interview responses across all participants reveal heterogeneous experiences and attitudes surrounding their child's development and transition into adulthood that warrant further exploration using qualitative or mixed methods designs to fully capture caregiver and adolescent experiences. These findings point to the need for greater support for

caregivers and adolescents navigating the transition process, particularly adolescents with greater communication needs.

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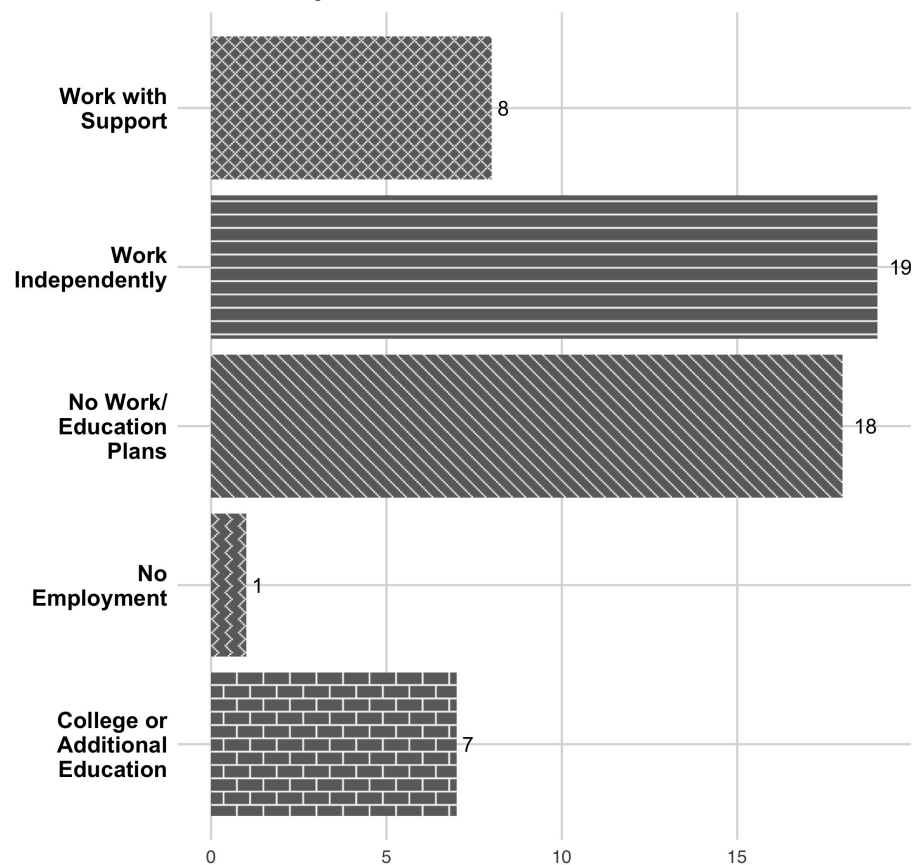
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Figure Captions

Figure 1. Frequency of coded responses across all interviews. Interview codes are not all mutually exclusive. Pairs of codes that are mutually exclusive include “No work/education plans” and all other vocational codes, “More relaxed” and “Less relaxed”, and “Higher expectations” and “Lower expectations”.

Figure 1. Frequency of Coded Responses

A. Work Expectation Codes



B. Parenting Style Change Codes

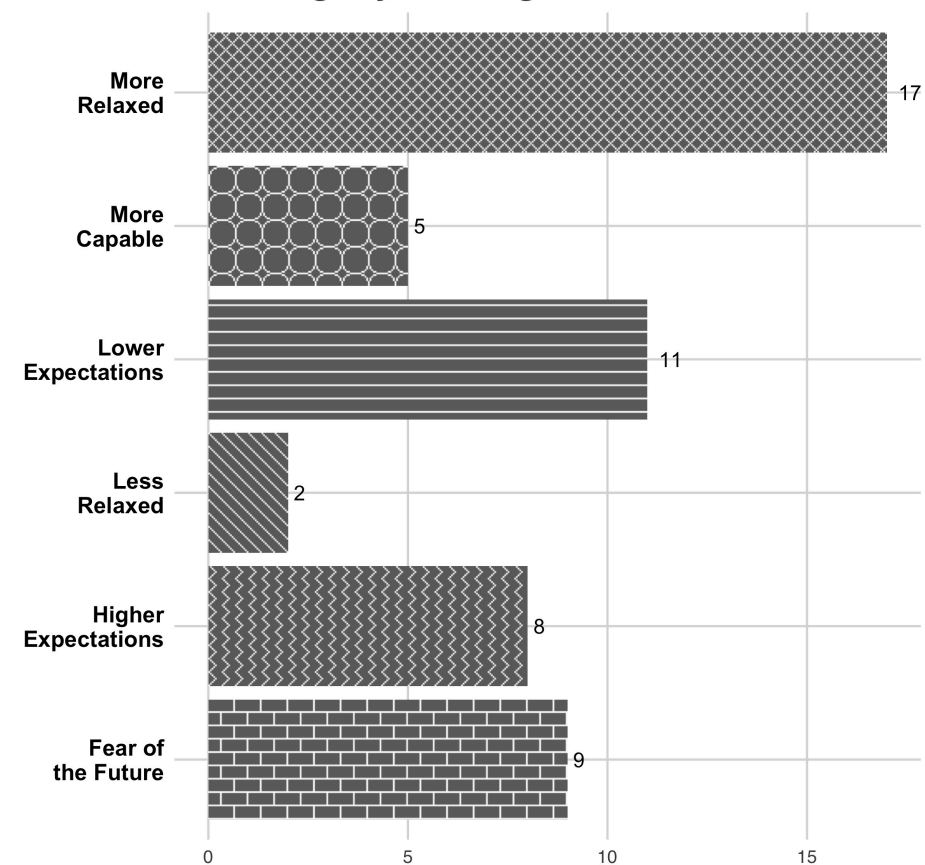


Table 1. Participant demographics

	Child <i>n</i> = 47	Mother <i>n</i> = 47
Age (years)		
Mean (SD)	15.89 (1.16)	46.58 (4.82)
Range	12.05 – 18.0	34.72 – 55.07
Sex		
Male (n)	37	0
Female (n)	10	47
Race		
Native Hawaiian or Pacific Islander (n)	0	1
Black (n)	2	2
White (n)	42	43
More than one race (n)	3	1
Ethnicity		
Hispanic/Latino (n)	3	3
Not Hispanic/Latino (n)	44	44
CARS2-ST Total Score		
Mean (SD)	25.32 (6.49)	-
Range	17 – 39	-
VABS-II Communication Raw Score		
Mean (SD)	128.45 (40.23)	-
Range	50 – 198	-

Note: CARS2-ST = Childhood Autism Rating Scale, Second Edition, Standard Version. Raw scores range from 15 to 60, with higher scores indicating higher ASD characteristics. VABS-II = Vineland Adaptive Behavior Scales, 2nd Edition Interview Form. Communication subdomain raw scores can range from 0 to 212.

Table 2. Semi-structured interview codes and descriptions

Code	Definition
Change in Parenting Style or Feelings	
Higher Expectations	The mother reports she has higher expectations for the child or has “toughened up” on the child.
Lower Expectations	The mother reports that she has lower expectations for the child than before.
More Relaxed	The mother reports that she or the father have become more relaxed in their parenting style.
Less Relaxed	The mother reports that she or the father have become less relaxed or more proactive in their parenting style

More Capable	The mother reports that she or the father have become more capable in their parenting style by learning and applying a new parenting skill.
Fear of the Future	The mother reports that she has apprehension for the future.
Work and Post-Secondary Education Expectations	
Work Independently	The mother expects the child to obtain a job and be capable of working without help; this is the default code if the parent desires the child to work but does not specify necessity of support.
Work with Support	The mother reports the child has limitations, such as being non-speaking, that would require more support at work.
Unemployed	The mother does not expect the child to work.
Post-Secondary College	The mother reports they are planning on enrolling the child in college classes or in a formal program that teaches a technical skill.
Lack of Plans for the Future	The mother reports she does not know whether the child will be able to work or have a job in the future.

Table 3. Examples of interview responses related to changes in parenting style or feelings and work and postsecondary education expectations

Higher expectations (n = 8)

I think my expectations really changed because I saw what she was capable of and when she had that drive and that passion, what a difference she could make.

I didn't think he would be able to do anything in the community. But the school takes him on trips and getting him acclimated to that environment. Like he used to be deathly afraid of escalators, but now he's taking escalators. So there's room for improvement. He used to not be able to handle any crowds at all. But he's doing better with that. So I think there's hope for him.

It has changed because I think we've realized what he can do. He was the one that was much more severely affected than our other son. So I think for a long time we kinda cut him some slack because there was a lot of physical things he just could not do for a long time. But that's changing now that we see how capable he is.

If you asked me five years ago what he was gonna do, I'd say he'd live with us forever or live with me forever. But I think having [son] and [other FXS sibling] doing things now and seeing what they can do and them being in the adult world and knowing what's out there and seeing other parents and other adult kids with intellectual disability doing things, that's what's changed. So it's kinda gotten bigger I guess. It's not just "you're gonna be with me forever because I'm gonna take care of you" there's a lot that they can do so.

Lower expectations (n = 11)

There's a huge difference between the mom that I was and the mom that I am with him. ... I don't expect as much. ... and I just shrug my shoulders and walk away from it. ... used to be a time that I thought that he would be able to live at best in an assisted living home. I now know that's not gonna happen. I've had to lower the expectation.

I always thought he'd have a better communication system which he doesn't have. I thought he'd have wider range of interest ... but yeah it goes back to the goals again. I'm happy with the simple things.

I think where it's changed is years ago we saw community college. We saw possibly college for her. That's not a possibility anymore.

Probably because I have a sister who has fragile X [syndrome]. And she's a bit higher functioning than he is. So I think my expectation on her path that she's gone versus maybe his path that he's going to go. It's a little different. But it kind of is what it is. I think it's just changed as I've understood where he's functioning and his skill set that he has.

So I guess I have had to step back and acknowledge maybe she wasn't as advanced in her growth or wasn't moving as fast or quickly through that as I thought she would.

More relaxed (n = 17)

I've probably become more relaxed over time and less frustrated over time is my thought and understanding his behaviors more and understanding his needs more.

I may have been stricter when he was younger so in that regard I probably discipline even less. You know I kinda just try and deal with the behavior and then move on.

I would say yes because I don't sweat the small stuff anymore. You know they say you pick and choose your battles.

I would say that I've really learned I have to be flexible. And I have to be a lot more patient and as I'm getting older I feel like I have less.

Less relaxed (n = 2)

Yeah I've had to get more stricter with [son] because I'm Mom this nice person and everybody's told me "you're too easy on him" so I've had to toughen up.

And so I would say in certain areas it's gotten stricter

More capable (n = 5)

I've grown with him. ... I've had to force myself not to treat him differently.

I think what's changed from like [other sibling] to [son] is just knowing more, knowing what works, knowing different. Yeah just being more educated...

But I think I have grown more into it and realizing how important the planning and coordination is. ... and maybe when he was younger it almost seemed more exhausting for some reason. I think because if you didn't do a great job with that then the other things didn't go smoothly.

Fear of the future (n = 9)

I've always been the primary caretaker and the one who has to navigate school and his life ... I don't see it changing. And that's a little scary.

I think our biggest fear for the future is when we're gone what will happen to him.

And now the future is looking at us. So yeah it's a little more I guess real and scary.

Work independently (n = 19)

I do want him to be able to have a job one day and be able to be out of the house for the day and be able to do things on his own.

I know [he] will be able to have a job someday, not a full-time job. I mean maybe twelve hours a week doing I don't know what. But I know he can have a job.

At her IEP meeting, we discussed one of the things she had conveyed to them was a early childhood certificate. So you can go work at a day care once you turn eighteen and how she could do that. ... because that will give her time to figure out if school is the route to go, job is the route to go or part-time job, part time school.

Work with support (n = 8)

We would both like for him to have a job of some sort as an adult. ... And of course he would need some support with that probably like a job coach or something.

We're hoping for independence to a certain degree because I know he won't fully be independent. ...work independence to some degree, with supports.

Being nonverbal that's not gonna change at fifteen. So we're now looking into programs that will allow her to have an aide with her that she would be able to do.

Unemployed (n = 1)

I really don't want him to have a job outside of working with [dad] around the house. And [dad]'s a general contractor. And so once the kids are in school all day he'll go back to picking up some smaller job/s and stuff not any big ones and our plan all along has been that he would just work with [dad] because then we know how he'll be treated.

Post-secondary college (n = 7)

I expect her to go to college, I know that she's undecided on what she wants to do and that's fine.

We were thinking about possibly doing an online type thing so that I can help him with class work. Or somebody can help him with class work and then auditing like a community college type class that's of high interest.

I think that we've made a smart choice with the vocational school that she'll be attending because she will still be required to do the academic rigor to be able to go to college if she chooses.

Lack of plans for the future (n = 4)

I have no clue whether he'd be able to do a job.

I don't think of him even ever driving a car. I mean working a job I want to see it. But I don't.

But like vocational work he has no interest in that. So I haven't seen anything that we could tap into as far as his interest. So it's a blur at this point. I don't know.

Table 4. Logistic regression analysis of predictors of maternal work and education expectations

Predictor	<i>b</i>	<i>SE</i>	Wald	Odds ratio	95% CI		<i>p</i>
					<i>LL</i>	<i>UL</i>	
Language skills							
Intercept	-7.09	6.516	-1.088				.885
Vineland communication ^a	.024	.01	2.497	1.27	1.067	1.565	.013*
Chronological age (years)	.292	.378	.772	1.339	.642	2.906	.44
Autism characteristics							
Intercept	.798	5.516	.145				.885
CARS2-ST	-.078	.051	-1.543	.925	.833	1.02	.123
Chronological age	.111	.345	.322	1.117	.564	2.238	.748

^a Vineland Communication subscale raw scores were analyzed in 10 point increments

Table 5. Multinomial logistic regression analysis of predictors of changes in maternal expectations

Predictor	No change vs.	<i>b</i>	<i>SE</i>	Wald	Odds ratio	95% CI		<i>p</i>
						<i>LL</i>	<i>UL</i>	
Language skills								
Intercept	Higher	-1.521	7.227	-.21				
	Lower	-8.73	7.578	-1.152				
Vineland communication ^a	Higher	.063	.112	.564	1.065	.855	1.326	.573
	Lower	-.01	.095	-1.053	.905	.752	1.09	.292
Chronological age (years)	Higher	-.04	.431	-.082	.965	.415	2.246	.935
	Lower	.553	.452	1.226	1.739	.718	4.215	.22
Autism characteristics								
Intercept	Higher	.78	6.862	.114				
	Lower	-13.139	7.776	-1.69				
CARS2-ST	Higher	-.058	.076	-.755	.944	.813	1.01	.451
	Lower	.081	.059	1.358	1.084	.965	1.218	.175
Chronological age	Higher	-.04	.426	-.095	.961	.417	2.212	.925
	Lower	.619	.461	1.344	1.857	.753	4.579	.179

^a Vineland Communication subscale raw scores were analyzed in 10 point increments

Supplementary Table 1. Percentage of Maternal Interview Responses by Child Sex

Interview Code	Male (N = 37)	Female (N = 10)	Total (N = 47)
Change in Parenting Style or Feelings			
Higher Expectations	7 (18.9%)	1 (10%)	8 (17.0%)
Lower Expectations	8 (21.6%)	3 (30%)	11 (23.4%)
More Relaxed	13 (35.1%)	4 (40%)	17 (36.2%)
Less Relaxed	2 (5.4%)	0 (0%)	2 (4.3%)
More Capable	5 (13.5%)	0 (0%)	5 (10.6%)
Fear of the Future	7 (18.9%)	2 (20%)	9 (19.1%)
Work and Post-Secondary Education Expectations			
Work Independently	14 (37.8%)	5 (50%)	19 (40.4%)
Work with Support	7 (18.9%)	1 (10%)	8 (17.0%)
Unemployed	1 (2.7%)	0 (0%)	1 (2.1%)
Post-Secondary College	4 (10.8%)	3 (30%)	7 (14.9%)
Lack of Plans for the Future	3 (8.1%)	1 (10%)	4 (8.5%)

Note: Codes are not exclusive nor exhaustive, therefore percentage of participants whose mothers reported themes within each category do not add up to 100%.