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Friendships and Social Participation as Markers of Quality of Life of Adolescents and Adults with Fragile X Syndrome and Autism

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Abstract

Friendships and social participation are key domains of quality of life for individuals with intellectual disabilities. The present study examined the friendships, social and recreational activities, and family social networks of individuals with intellectual disabilities from two distinct diagnostic groups: individuals diagnosed with fragile X syndrome (n=81) compared with those diagnosed with autistic disorder (n=226). Within each diagnostic group, individuals in two developmental stages were compared: adolescence and adulthood. Quality of life in friendships and social participation domains was notably low for individuals with fragile X and those with autism. Individuals with fragile X had more friendships and a less negative social impact on the family than individuals with autism. Across both groups, adolescents spent less time with friends and neighbors, and more time exercising, than did adults.

Keywords

quality of life; friendships; social participation; fragile X syndrome; autism; adulthood

Past outcome studies for individuals with intellectual disabilities (ID) have focused on documenting achievement of traditional markers of adulthood such as maintaining employment and living independently. Studies consistently find that many individuals with developmental disabilities have poor outcomes based on these conventional benchmarks (Henninger & Taylor, 2012; Howlin & Moss, 2012). More recently, however, increasing attention has been placed on understanding the quality of life (QOL) for persons with disabilities across the lifespan (Billstedt, Gillberg, & Gillberg, 2011; Schalock, 2004; Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016). QOL is a concept that reflects an individual's overall well-being and thus encompasses multiple domains such as emotional well-being, physical health, safety, and rights. Particularly important to consider when studying individuals with ID are the core QOL domains of friendships and social participation and how they may be experienced depending on stage of life (Murphy, 2009; Schalock, 2004). Notably, social inclusion has been identified as a particularly important QOL domain for which individuals with ID may be at risk due to the challenging behavior with the condition (Murphy, 2009). As such, these key markers of QOL, friendship and

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social participation, are the focus of the current study. Specifically, we examined friendships, social and recreational activities, and family social networks of adolescents and adults with ID from two different groups: individuals with fragile X syndrome (FXS) and individuals with autistic disorder (AD). Importantly, as previous research has demonstrated variable findings for social functioning across the lifespan (Levy and Perry 2011), we compared results for adolescents and adults in both diagnostic groups.

Friendships

Previous studies have indicated that adolescents and adults with ID tend to have restricted social networks and that their friendships are limited (Emerson & McVilly, 2004; Lippold & Burns, 2009; Tipton, Christensen, & Blacher, 2013), and this may be particularly acute for those with FXS and those with autism. Up to 50% of individuals with FXS are estimated to also have a co-occurring diagnosis of autism (Demark, Feldman, & Holden, 2003; Kaufmann et al., 2004; Philofsky, Hepburn, Hayes, Hagerman, & Rogers, 2004) and even when they do not meet the criteria for an autism diagnosis, many of those with FXS have symptoms associated with ASD. Specifically, due to the difficulties in social reciprocity and communication associated with autism, individuals with a diagnosis of autism or FXS may be at particular risk for a lower QOL in the friendships domain. For example, in a study of children between the ages of 5 and 17 years, children with autism spectrum disorders had fewer mutual friends and fewer best friends than children who had ID but no autism diagnosis (Solish, Perry, & Minnes, 2010). Difficulties in friendships for individuals with autism also have been shown to persist into adolescence and adulthood (Seltzer et al., 2003). A recent study using data from the National Longitudinal Transition Study-2, found that over half (55.4%) of high school students with autism did not spend time with friends in the previous year (Liptak, Kennedy, & Dosa, 2011). Less is known, however, about how the friendships of individuals with autism compare to individuals with other types of ID, such as FXS, and particularly those with FXS who do not have a co-occurring diagnosis of autism, across the life course.

Social Participation

Another important component of quality of life for individuals with ID is social participation. The concept of social participation encompasses community integration, participation in social activities, having a role in the community, and access to support networks (Schalock, 2004). Past work indicates that individuals with ID may have lower QOL in terms of social participation than individuals without disabilities. For example, children with ID have been shown to participate in social and recreational activities at lower rates than children without disabilities; further, when children with disabilities do participate in social activities, they tend to engage in those activities with their parents instead of with peers (Solish et al., 2010). Similarly, using a British birth cohort of individuals who were 43 years of age at follow-up, Hall and colleagues found that adults with ID were less likely to regularly spend time with friends and less likely to be involved in community groups (church, school, sports, or local government groups) compared to individuals without disabilities, although there were no differences in informal social participation such as going to pubs or social clubs (Hall et al., 2005).

Questions remain whether there are differences in social participation for individuals with different types of intellectual and developmental disabilities across the lifespan. Esbensen and colleagues found that compared to a well-matched sample of adults with Down syndrome, adults with ID and autism experienced less social contact with friends (Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010). However, two studies contrasting adults with ID with and without the triad of impairments characteristic of autism (i.e. impairments in social interaction, communication, and repetitive behaviors) did not find differences in engagement with and frequency of community activities, after controlling for adaptive behavior (Totsika, Felce, Kerr, & Hastings, 2010; Felce, Perry, Lowe, & Jones, 2011). Notably in both the Totsika et al (2010) and Felce et al (2011) studies, individuals in the autism group had characteristics of autism but had not received a formal diagnosis of ASD. Also, few studies have investigated social participation at multiple stages in the life course. When examining deficits in social reciprocity in individuals with ASD, reduction in deficits from adolescence to adulthood have been observed (Woodman, Smith, Greenberg, & Mailick, 2015). However, little is known about social participation among adolescents and adults with fragile X. More research is needed using carefully selected comparison groups to better understand if and how social relationships and social participation may change with age for individuals with FXS.

Fragile X Syndrome

It may be particularly useful to compare individuals with FXS to individuals with autism regarding friendships and social participation (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). Both conditions can be associated with intellectual disability, and there often is a period of uncertainty prior to receiving a diagnosis. Further, social difficulties, particularly gaze aversion, are common features of FXS (Hessl, Glaser, Dyer-Friedman, & Reiss, 2006; Murphy et al., 2007) and these difficulties may be significant enough to result in a diagnosis of ASD. Despite these similarities, however, there are distinct behavioral profiles for individuals with FXS compared to idiopathic autism, with individuals with autism having higher levels of social difficulty and challenging behavior, and fewer strengths and adaptive behaviors (Smith, Barker, Seltzer, Abbeduto, & Greenberg, 2012). These behavioral differences may in turn influence QOL differently for individuals with FXS compared to those with ASD.

In addition, challenging behaviors also may have a negative impact on the family's level of social involvement. Previous research has suggested that families of individuals with autism have higher levels of stress and lower well-being compared to other groups (Smith, Seltzer, & Greenberg, 2012; Abbeduto et al., 2004). Similarly, families of individuals with fragile X have more family conflict, but not lower well-being, than other groups (Lewis et al., 2006). Questions remain, however, regarding the impact of having a son or daughter with FXS and AD on family social life, particularly later in the life course.

Present Study

The present study examined experiences of friendships and social participation of two groups of individuals with ID, comparing experiences during adolescence and during

adulthood. Specifically, we addressed three research questions. First, are there differences between individuals with FXS and individuals with autism in friendship experiences, frequency of participation in social and recreational activities, and social experiences of families? Second, are there differences between adolescents and adults in these three QOL domains? Third, are there interactions of diagnostic group and developmental stage influencing the three QOL domains?

For this study, we focused on the friendships and social participation of adolescents and adults with FXS who did not have a co-occurring diagnosis of autism, compared to adolescents and adults with autism. Past research has shown elevated levels of challenging behavior for individuals with autism relative to individuals with FXS (Smith et al., 2012); this difference in the behavioral phenotype may place individuals at risk for reduced access to social and recreational activities. Therefore, we hypothesized that those with FXS would be more likely to have a mutual friend than those with autism. Next, we anticipated that individuals with FXS would have a higher frequency of participation in social and recreational activities compared to individuals with autism. We also expected that for both groups, adolescents would have a greater frequency of participation than adults, given the organized nature of many activities and supports available through school. Consistent with prior work documenting a high level of stress and negative impact for families of individuals with autism relative to other groups (Abbeduto et al., 2004; Bishop et al., 2008; Eisenhower, Baker, & Blacher, 2005), we hypothesized that families of individuals with FXS would be less likely to report that their son or daughter had a negative impact on their social networks than families of individuals with autism. Finally, we hypothesized that families of adults would have higher social participation than families of adolescents. This is consistent with previous literature demonstrating decreases in symptoms from adolescence to adulthood for individuals with FXS (Smith et al., 2016) as well as for individuals with autism (Woodman et al., 2015).

Method

Participants

The data analyzed for this research were collected via two linked longitudinal studies, one focused on families of adolescents and adults with FXS (Greenberg et al., 2012; Seltzer et al., 2012) and the other focused on families of adolescents and adults with autism (Seltzer et al., 2003; Seltzer et al., 2011). The two studies shared many measures and similar aspects of the research design.

Fragile X Syndrome (FXS) Sample.—For the present study, 81 adolescents and adults with FXS were drawn from a larger, ongoing longitudinal study of family adaptation to FXS (n = 147; Greenberg et al., 2012; Seltzer et al., 2012). For inclusion in the larger study, mothers had to be the biological parent of a son or daughter with the full mutation of fragile X syndrome, the son/daughter be 12 years of age or older, and the son/daughter be co-residing with the mother or have at least weekly contact with the mother either in person or by phone. Mothers were required to provide documentation from an appropriate health care professional confirming that the son/daughter had the full mutation of the gene causing FXS.

ID status was determined using mother report, and confirmed through a consensus procedure based on review of educational and medical records. Families were recruited through service agencies, clinics, and FXS foundations across the United States as well as from a university-based research registry of families having a child with a disability. If a mother had more than one child with FXS, she was asked to report on the child who was co-residing with her. If there was more than one co-residing child, the mother reported on the child she assessed to be who was the most severely affected.

For the present study, 121 cases had data on variables of interest at the third wave of data collection, which was the first time all analytic variables were available. Of those, we excluded 12 cases that did not have a diagnosis of intellectual disability. We also excluded those who had a currently-valid diagnosis of autism spectrum disorder (n = 25) based on a consensus procedure, which included review of medical and educational records provided by the mother as well as reference to lifetime Social Communication Questionnaire scores . An additional 3 were dropped because there was ambiguity regarding whether a diagnosis of autism was valid, resulting in the final sample for the current study of 81 individuals with FXS and ID, who did not have an ASD diagnosis. Of these, there were 37 individuals who were 21 years of age or younger (referred to as adolescents) and 44 individuals who were 22 years of age or older (referred to as adults).

Autistic Disorder (AD) Sample.—A group 226 adolescents and adults with autistic disorder and intellectual disability was drawn from a longitudinal study of families of adolescents and adults with autism spectrum disorders (n= 406; Seltzer et al., 2003; Seltzer et al., 2011). Families of sons/daughters with autism were recruited through service agencies, schools, and clinics. For inclusion in the larger study, families had to meet three initial criteria: (a) the family had a son or daughter 10 years of age or older; (b) the child had received a diagnosis on the autism spectrum from a medical, psychological, or educational professional, as reported by parents; and (c) the child had a research-administered Autism Diagnostic Interview-Revised (Lord, Rutter, & Le Couteur, 1994) consistent with this diagnosis. Data from the second wave of data collection were used in the current study because that was the first wave in which all variables of interest were collected. Of cases with variables of interest at wave 2 (n=344), we excluded 118 from the present analysis, namely those who either did not have a diagnosis of autistic disorder (i.e., were diagnosed with Asperger's or PDD-NOS; n=16) or who did not have a diagnosis of intellectual disability (n=102). Of the resulting sample of 226 individuals with AD and ID for the present study, there were 106 individuals who were 21 years of age or younger (referred to as adolescents) and 120 individuals who were 22 years of age or older (referred to as adults).

Mothers in the FXS sample resided in 38 US states and one Canadian province. Mothers in the AD sample resided in Wisconsin and Massachusetts. Means and percentages for maternal and child demographic variables are presented in Table 1. The two groups of individuals with disabilities significantly differed ($p < .01$) in terms of residential status (those with AD were more likely to live away from the parent) and marital status of mothers (mothers of those with AD were less likely to be married), which we subsequently controlled in all analyses. There were no statistically significant differences between the diagnostic groups in age, sex, ratings of health (*0* being poor and *3* being excellent), or

number of prescription medications. Individuals with AD had significantly higher behavior problem scores than individuals with fragile X ($p<.001$).

Measures

Friendships.—Friendships were measured using current rating of friendship from the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994). For the ADI-R, individual items originally were scored on an ordinal scale, with a code of 0 signifying the *absence* of a given symptom and codes of 1, 2, and 3 indicating the *presence* of increasing levels of impairment characteristic of autism. For the peer relationship or "friendship" item, four criteria have to be met for a relationship to qualify as a ''friendship'': the relationship has to be with someone in approximately the same age group, the activities that they do together have to be varied, the activities that they do together have to take place outside of prearranged groups, and there has to be reciprocity and mutual responsiveness in the relationship. A code of '0' is given when all four criteria are met. Consistent with the general coding conventions of the ADI-R, A code of '1' is given when the individual has a relationship that involves some shared activities outside a prearranged setting, but not all four criteria are met; a code of '2' is given when there are peer relationships but only in group settings; and a code of '3' is given when there is an absence of peer relationships. For this study, we recoded the ADI-R item to reflect either absence of impairment (coded 1, corresponding to an original ADI-R code of 0) or presence of impairment (coded 0, corresponding to an original ADI-R code of 1, 2, or 3). This dichotomous coding strategy for the ADI-R has been used in previous studies (Fecteau et al., 2003; Seltzer et al., 2003; Shattuck et al., 2007; Smith et al., 2012). In our analysis, we referred to codes of '1' as "having a mutual friendship" and codes of '0' as "not having a mutual friendship."

Social and Recreational Activities.—Participation in social and recreational activities was measured using a modified version of questions from the National Survey of Families and Households (Bumpass & Sweet, 1987) which has been successfully used in past research with individuals with intellectual disability (e.g., Orsmond et al., 2004). Mothers rated the frequency of participation of the son or daughter in specific activities as 0 (less than yearly or never), 1 (about 1 to 10 times per year), 2 (about once per month), 3 (about once per week), and 4 (several times a week). Activities included: spending time with relatives; spending time with coworkers; spending time with friends and neighbors; attending religious services; attending social events with a religious group; participating in recreational activities; participating in hobby; taking overnight trips or travel; playing sports; and taking a walk or getting exercise. Consistent with previous research utilizing sociability behavior data from the National Survey of Families and Households (Trent & Spitze, 2011), we recoded scores to approximate the number of times per year that the individual engaged in each activity. Specifically, scores of "never" were recoded to 0, "1 to 10 times per year" to 4, "once per month" to 12, "once per week" to 52, and "several times a week" to 208.

Family Social Impact.—Family social impact was measured in two ways. First, four questions drawn from the Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) were used to assess social impact. Mothers indicated their agreement on a 3 point Likert scale (ranging from "*not at all*" to "*extremely*") with the following items: "I feel that my

son/daughter currently affects my relationships with other family members and friends in a negative way," "I feel that my social life has suffered because of my involvement with my son/daughter," "I feel embarrassed over son/daughter's behavior," and "I feel uncomfortable when I have friends over." These items were averaged to create total negative social impact score (alpha = .73). Second, mothers responded to the question "To what extent is your family socially isolated because of your son/daughter?" on a 4 point scale ranging from "*not at all isolated" to "extremely isolated."*

Procedures

For both FXS and AD samples, mothers provided data through self-administered, mail-back questionnaires. Of the 344 participants in the larger autism sample who were sent the questionnaire, there were only 12 questionnaires that were not returned (3.49% unreturned). Similarly, of the 121 participants who were sent the questionnaire for the larger FXS study, only 6 were not returned (4.95% unreturned). Mothers in the FXS study additionally participated in a telephone interview that typically lasted one hour whereas mothers in the autism study participated in a 2- to 3-hour in-home interview. All data collectors were master's level professionals, participated in multi-day training sessions, and received ongoing reliability checks every 5th interview to ensure consistency of administration across studies and over time. Call backs were conducted when questionnaires were not returned, when questions were skipped, and when coding was ambiguous.

Results

The goal of the current study was to examine QOL in the domains of friendships and social participation for individuals with FXS and individuals with AD during adolescence and adulthood. To this end, we conducted three sets of analyses comparing adolescents and adults with FXS to adolescents and adults with AD. In all analyses, we controlled for residential placement and maternal marital status First, we compared friendship experiences using a logistic regression model; diagnostic group (FXS vs AD), age category (adolescent vs adult) and the interaction (diagnostic group X age category) were entered as predictors of the dichotomous ADI-R rating of current friendship (mutual friendship vs no mutual friendship). Second, we compared participation in social and recreational activities using two (FXS vs AD) by two (adolescent vs adult) ANCOVA to determine the specific differences between the groups. Third, we compared family social impacts using a two (FXS vs AD) by two (adolescent vs adult) ANCOVA.

First, Table 2 shows the results of the logistic regression model predicting currently having a mutual friendship. Consistent with our hypothesis, the FXS group was significantly more likely than the AD group to currently have a mutual friend (B=2.46, Exp(B)=11.69, $p<.05$, 95% CI [2.16, 63.21]). The odds ratio was 11.69, suggesting that individuals in the FXS group were almost 12 times more likely to have a mutual friend than were individuals in the AD group. There was no statistically significant main effect of age category and the interaction was also not statistically significant, *p*s>.05. Notably, although the proportion of individuals in the FXS group who currently had a friend was higher than for those with AD, the presence of mutual friendships was low for all four subgroups, ranging from 2% (teens

with AD) to 17% (teens with FXS). Maternal marital status was a significant covariate (B=1.14, Exp(B)=3.12, p<.05, 95% CI [1.20, 8.10]), with married mothers having children who were significantly less likely to have a mutual friend. Residential placement was not a statistically significant covariate.

Next, we compared the frequency of participation in social and recreational activities (spending time with relatives; spending time with coworkers; spending time with friends and neighbors; attending religious services; attending social events with a religious group; participating in recreational activities; participating in hobby; taking overnight trips or travel; playing sports; and taking a walk or getting exercise) by diagnostic group and age category, controlling for residential placement and maternal marital status, using ANCOVA (see Table 3). We anticipated that individuals with FXS would have a higher frequency of social and recreational participation than individuals with an autism diagnosis, and that adolescents would have a higher level of participation than adults. These hypotheses were partially supported. When appropriate, we have reported partial eta squared effect sizes, where a value of .01 represents a small effect, .06 represents a medium effect, and .14 represents a large effect (Cohen, 1969).

Individuals with FXS were significantly more likely to engage in a hobby (F=18.71, p<.001, $\eta^2_{partial}$=.06) and to spend time with friends and neighbors (F=8.91, p<.01, $\eta^2_{partial}$=.03) than those with AD. Regarding main effect differences between adolescents and adults, across diagnostic groups, adolescents were significantly less likely to spend time with relatives (F=4.81, p=.03, $\eta^2_{partial}$=.02) and with friends and neighbors (F=7.26, p=.01, $\eta^2_{partial}$=.02) than adults, but significantly more likely to take walks or exercise (F=6.48, p=.01, $\eta^2_{partial}$=.02). There were significant group by age interactions for participating in recreational activities (F=4.37, p=.04, $\eta^2_{partial}$=.01) and playing sports (F=4.27, p=.04, $\eta^2_{partial}$=.01), such that there were no differences between diagnostic groups among adolescents, but among adults, individuals with FXS were more engaged than individuals with AD. There were no statistically significant main effects for group, main effects for age, or interaction terms for time with coworkers, participation in religious services, social events in religious group, or travel.

Residential placement was a statistically significant covariate in several analyses, although the pattern of association was different depending on the type of activity. Specifically, living away from the parent was significantly associated with more frequent social time with coworkers (F=27.36, p<.001, $\eta^2_{partial}$=.08), engaging in recreational activities (F=8.57, p<.01, $\eta^2_{partial}$=.03), and going on walks. In contrast, living away from the parent was significantly associated with *less frequent* attendance at religious services (F=5.25, p=.02, $\eta^2_{partial}$=.02) and participation in hobbies (F=6.98, p=.01, $\eta^2_{partial}$=02). Maternal marital status was not a statistically significant covariate in any of the analyses.

Finally, we examined differences in family social networks (i.e., negative social impact and family social isolation) by diagnostic group and age category using ANCOVA, controlling for residential placement and maternal marital status (see Table 4). We expected that families of individuals with FXS would report lower levels of negative impact on family social participation than families of individuals with autism. We also anticipated that families of

adolescents would report higher negative impact than families of adults. As expected, mothers of individuals with FXS were significantly less likely to report that the family was socially isolated than mothers of individuals with AD (F=18.69, p<.001, $\eta^2_{partial}$=.06). Also consistent with our hypothesis, mothers of adolescents reported significantly higher isolation than mothers of adults (F=5.43, p=.02, $\eta^2_{partial}$=.02). The interaction term of group by age was not statistically significant. Mothers of individuals with FXS also were significantly less likely to report that the son/daughter negatively affected her social relationships compared to mothers of individuals with AD (F=9.46, p<.01, $\eta^2_{partial}$=.03). Mothers of adolescents reported significantly more negative social impact than mothers of adults (F=5.65, p=.02, $\eta^2_{partial}$=.02). Again, the group by age interaction term was not statistically significant for negative social impact.

We note that residential status was a statistically significant covariate for family social isolation and negative social impact. Living away from the parent was related to less family social isolation (F=10.04, p<.01, $\eta^2_{partial}$=.03) and lower levels of negative social impact (F=12.13, p<.001, $\eta^2_{partial}$=.04). Maternal marital status was not a significant covariate.

Follow Up Analyses

Given group differences in the behavior problem phenotype (i.e., higher levels of behavior problems for individuals with AD compared to individuals with FXS), we conducted follow up analyses with the same aforementioned models but with the addition of behavior problems as a covariate. For the logistic regression analyzing likelihood of having a mutual friend, behavior problems were significantly associated with a lower likelihood of having a friend, (B=−.10, p=.02) and the association of diagnostic group (FXS vs AD) became nonsignificant (B=.52, p=.43). This suggests that differences in behavior problem phenotypes may account for differences in the likelihood to have a mutual friend.

Regarding social and recreational activities, the level of behavior problems was not a statistically significant covariate for any participation in social and recreational activities we examined. When considering family social impact, the level of behavior problems was a significant covariate for both family social isolation (F=53.72, p<.001, $\eta^2_{partial}$=.15) and negative social impact (F=58.35, p<.001, $\eta^2_{partial}$=.16). With behavior problems entered into the model, the original significant diagnostic group effect remained significant for social isolation (F=7.93, p<.01, $\eta^2_{partial}$=.03) but not for negative impact (F=2.13, p=.15).

Discussion

Friendships and social participation are key aspects of quality of life for individuals with ID (Murphy, 2009; Schalock, 2004). Even though past research has documented that social difficulties are common to both children with FXS and children with autism (Hessl et al., 2006; Solish et al., 2010), less is known about how the social experiences for these individuals differ during adolescence and adulthood or how QOL may vary by type of developmental disability. To address this gap, the present study explored the QOL domains of friendships and social participation for two distinct diagnostic groups of adolescents and adults with ID, individuals with FXS and individuals with AD, and compared reports of friendships and social participation in adolescence and adulthood.

One of the most striking findings from the present study pertained to the paucity of friendships for adolescents and adults with ID, particularly those with AD. Almost none (only 4%) of the individuals with AD currently had a mutual friend. Although still very concerning, significantly more individuals with FXS than AD had a mutual friend. These group differences are consistent with past work documenting that individuals with FXS are considerably less impaired in reciprocal social interactions than individuals with idiopathic autism (Budimirovic et al., 2006; Hernandez et al., 2009; Kau et al., 2004; Smith et al., 2012). However, previous studies have focused primarily on children and have not included frequency of participation in specific social activities. These effects held regardless of developmental stage, demonstrating that individuals with FXS are more likely to have a mutual friend than those with are AD, across adolescence and adulthood. In addition, elevated levels of challenging behavior in AD (Smith et al., 2012) may limit reciprocal social interactions for individuals with AD compared to those with FXS. We explored this possibility and found that indeed, behavior problems were significantly associated with lower likelihood of having a mutual friendship. Behavioral interventions for individuals with FXS and those with ASD, such as positive behavior support (Kincaid et al., 2016), may be helpful across the lifespan to increase opportunities for friendships.

We also explored differences between diagnostic groups in the QOL domain of social participation, as measured by participation in social and recreational activities. We found that spending time with friends and neighbors, and participating in a hobby were significantly more frequent among individuals with FXS compared to individuals with AD. The lower frequency of engagement in a hobby for individuals with AD is interesting given that restricted interests are a core feature of autism. It may be that mothers of adolescents and adults with AD did not consider their son or daughter’s restricted interest (which they might have viewed as a symptom) to be a hobby (which they may have interpreted to be a preference).

We also note that social participation by both groups was generally lower than what might be expected in the general population. Trent and Spitze (2011) found that adults in the National Survey of Families and Households (NSFH) spent time with friends and neighbors over 60 times a year, whereas in our study, spending time with friends and neighbors occurred approximately two-thirds this rate in our FXS group and only one-third in our AD group. Similarly, adults from the NSFH on average attended social events at a church or synagogue 20 times per year compared to less than 5 times per year for both groups of individuals with ID. However, time with coworkers appeared to be higher among individuals with ID (just over 30 times per year for both FXS and AD groups) compared to the NSFH sample (less than 20 times per year). It may be that adult service models which integrate work and community activities enable individuals with ID to more easily spend social time with individuals with whom they work. However, these social activities might not reflect individual preferences, but rather agency social programming. Overall, these findings indicate a strong need for more opportunities for adolescents and adults with ID to engage in social and recreational pursuits.

Our findings demonstrated that there were differences between individuals with FXS and AD in the frequency they engaged in recreational activities and sports depending on

developmental stage. Specifically, there were no differences between the two groups in adolescence, but in adulthood those with FXS were more likely to participate in recreational activities and sports than were those with ASD. This may reflect differences in opportunities to participate in organized activities across the lifespan. During adolescence, recreational activities and sports may be structured for individuals in both diagnostic groups in school and other organizations. In adulthood, structured activities may be less easily accessed for the same individuals, depending on the level of support needed. Interestingly, behavior problems were not associated with frequency of engagement in social and recreational activities, demonstrating that factors beyond the level of challenging behavior measured in the current study may account for group differences in social participation.

Regarding family social networks, we hypothesized that families of individuals with autism would report a higher level of negative impact on their social participation than families of individuals with FXS. Numerous studies have shown that parents of children with autism have higher levels of caregiving stress relative to other groups (Abbeduto et al., 2004; Eisenhower, Baker, & Blacher, 2005) and we anticipated that having a child with autism likewise would have an observable impact on family social networks. Mothers of individuals with FXS reported significantly lower levels of family social isolation than mothers of individuals with autism. Mothers in the FXS group also reported significantly lower levels of negative impact on their relationships compared to mothers of individuals with AD. Also, mothers of adolescents reported more social isolation than mothers of adults. Taken together our findings suggest that similar to their adolescent and adult children, parents of individuals with AD may be particularly vulnerable to social isolation and the level of child behavior problems may contribute to these difficulties (e.g., the effect sizes for the impact of behavior problems on social impact variables were the largest that we observed in this study). As such, family psychoeducational interventions and supports may need to be extended and modified to better serve the needs of these parents and their adult children. To this end, additional research is needed to explore what role the broader autism phenotype may play in family social isolation, both independent of and in combination with the possible isolating effects of children's behavior problems, as these potential mechanisms would lead to different implications for intervention.

In the present study we also found residential status to be important covariate of specific social and recreational activities and family social connections. Consistent with previous research showing that individuals living in staffed housing participate in more community activities than individuals living in the family home (Felce et al., 2011), we found that living away from the family home was associated with spending more time with coworkers and more time in recreational activities and exercise. However, living away from the family home was associated with *less time* in religious services, hobbies, and travel. Having a child live away from the parent's home also was associated with lower levels of negative family impact and perceived social isolation, although it was not significantly related to the son or daughter having a mutual friendship. Taken together, these findings suggest that while the pattern of social and recreational participation for adolescents and adults with ID may differ depending on the residential arrangement, the overall level of social and recreational activities is low and mutual friendships are extremely limited.

Limitations

We also note the limitations of the present study. First, although the relatively large sample size is a strength of the current study, the ethnic diversity of the sample was limited, particularly for the FXS groups. Second, although our study explored the frequency in which individuals in our study participated in a wide variety of social and recreational activities, we did not assess the quality of the interactions with others during social and recreational activities or the level of engagement of the individuals in these activities. Past work has shown that the involvement in recreational and work activities does not necessarily translate into friendships (Lippold & Burns, 2009). It may be that environmental factors such as active support from staff (Emerson & McVilly, 2004; Mansell, Beadle-Brown, Macdonald, & Ashman, 2003) or family members (Orsmond, Krauss, & Seltzer, 2004) can scaffold recreational activities in a way that promotes the emergence of friendships. In the current study we also did not assess the number or type of social skills interventions individuals may have been receiving which could similarly shape social participation. It will be valuable for future research to explore these hypotheses. Third, we did not assess the level of intellectual disability within each group. Although all individuals in the study had an intellectual disability, there may have been differences in level of IQ between the groups which could potentially explain some of group differences. Fourth, the current study did not collect data from typically-developing adolescents and adults to serve as a comparison. Finally, given the design of the present study, we cannot disentangle if the low level of social and recreational participation for individuals with AD compared to FXS was due to lack of opportunity, personal preference or a combination of individual and environmental factors over time. We also did not conduct direct observations of social interactions and activities. Instead, data was obtained from the mother. Longitudinal studies as well as qualitative studies specifically investigating QOL are needed for understanding how these diagnostic group differences in friendships and social inclusion emerge across the life course. Additionally, studies obtaining data from the individuals with ID would allow for the examination of whether conceptualizations of friendships differ from those without ID.

Conclusions

Contemporary conceptualizations of QOL for individuals with disabilities assert that a high quality of life involves participating in community life and having access to support networks (Murphy, 2009; Schalock, 2004). In the present study we compared outcomes in these QOL domains between two groups of adolescents and adults with ID. Notably, our findings indicated that both groups of individuals with ID have very few reciprocal friendships and significantly reduced social and recreational activities. Those with ASD had particularly low levels and their mothers reported high levels of social isolation. These substantial differences in QOL are a cause for concern and indicate a clear call for future work in understanding how to promote a high QOL for all individuals with disabilities. Research and clinical efforts are needed regarding intervention strategies, such as social skills interventions and family psychoeducation interventions, which will support social participation for individuals with FXS and autism and their families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Background Variables for Mothers and Children

	FXS		AD	
	Teen n=37	**Adult n=44**	**Teen n=106**	**Adult n=120**
Child Variables				
Mean age (*SD*)	18.66 (1.93)	29.71 (5.67)	16.46 (2.26)	32.20 (8.65)
% living with family	94.6%	75.0%	73.6%	36.2%
% living in public or private institution	2.7%	18.2%	18.8%	4.2%
% living in a community residence	0%	0%	6.6%	52.9%
% living semi-independently or independently	2.7%	6.8%	0.9%	6.7%
Sex (% female)	21.6%	11.4%	25.51%	26.7%
Health (*SD*)	2.32(.81)	2.47(.59)	2.33 (.60)	2.20(.66)
# of medications (*SD*)	2.06(2.32)	2.09(2.46)	1.81(1.65)	2.43(1.71)
Behavior problems (*SD*)	109.22(6.93)	107.30(7.34)	116.48(9.97)	110.83(8.77)
Maternal Variables				
Mean age (*SD*)	49.27 (4.62)	58.78 (5.61)	46.14 (5.71)	60.88 (9.91)
Race (% White)	94.6%	93.2%	89.6%	95.8%
% Married or cohabiting	82.3%	90.7%	73.6%	65.3%
% Divorced or separated	14.7%	9.3%	23.6%	19.4%
% Widowed	0%	0%	0.9%	14.4%
% Never married	2.9%	0%	1.9%	0.8%

Table 2.

Logistic Regression Comparisons of Mutual Friendship Controlling for Residential Status and Marital Status

	FXS		AD						
Variable	***Teen***	***Adult***	***Teen***	***Adult***	***Group B***	***Age Category B***	***Group by Age B***	***Residential Status B***	***Marital Status B***
Mutual friend	.17 (.04)	.13 (.04)	.02 (.03)	.07 (.03)	**2.46** **	1.35	−1.65	.02	**1.14** *

Note. Adjusted means (standard errors) are reported.

* $p < .05$

** $p < .01$

*** $p < .001$

Table 3.

ANCOVA Comparisons of Activities Controlling for Residential Status and Marital Status

Variable	FXS		AD						
	Teen n=37	*Adult n=44*	*Teen n=106*	*Adult n=120*	*Group F*	*Age Category F*	*Group by Age F*	*Residential Status F*	*Marital Status F*
Time with relatives	28.39 (11.00)	52.40 (9.86)	33.39 (6.35)	47.80 (6.33)	.00	**4.81** *	.32	2.7	.84
Time with coworkers	34.15 (11.16)	34.33 (10.01)	35.95 (6.45)	30.27 (6.42)	.02	.10	.12	**27.36** ***	.06
Time with friends/ neighbors	25.90 (9.26)	57.93 (8.31)	15.82 (5.35)	23.54 (5.34)	**8.91** **	**7.26** **	2.92	.96	2.19
Religious service	30.07 (6.55)	22.86 (5.87)	13.50 (3.78)	19.42 (3.77)	3.61	.02	1.71	**5.25** *	.26
Social event-religious group	4.70 (1.54)	3.70 (1.38)	3.08 (.89)	3.27 (.89)	.69	.11	.25	2.70	.39
Recreational activities	38.04 (11.24)	61.75 (10.08)	45.46 (6.49)	33.10 (6.43)	1.38	.40	**4.37** *	**8.57** **	.49
Hobby	112.07 (15.53)	123.16 (13.93)	73.17 (8.97)	53.99 (8.93)	**18.71** ***	.11	1.61	**6.98** **	.72
Travel	4.10 (1.42)	4.58 (1.27)	4.36 (.82)	5.41 (.82)	.23	.46	.07	1.76	3.03
Play sports	32.57 (10.12)	49.41 (9.07)	30.28 (5.84)	15.06 (5.82)	**5.07** *	.01	**4.27** *	.51	.48
Walk/Exercise	160.14 (14.90)	132.07 (13.36)	149.75 (8.60)	117.42 (5.57)	1.09	**6.48** *	.04	**9.00** **	.03

Note. Adjusted means (standard errors) are reported reflecting the number of times per year for each activity.

* $p < .05$

** $p < .01$

*** $p < .001$

Table 4.

ANCOVA Comparisons of Family Social Impacts Controlling for Residential Status and Marital Status

Variable	FXS		*AD*						
	Teen	*Adult*	*Teen*	*Adult*	*Group F*	*Age Category F*	*Group by Age F*	*Residential Status F*	*Marital Status F*
Family is socially isolated	.76 (.16)	.53 (.14)	1.38 (.09)	1.02 (.09)	**18.69** ***	**5.43** *	.23	**10.04** **	.07
Negative social impact	.50 (.07)	.39 (.07)	.71 (.04)	.55 (.04)	**9.46** **	**5.65** *	.28	**12.13** *	.05

Note. Adjusted means (standard errors) are reported.

* $p < .05$

** $p < .01$

*** $p < .001$