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An examination of adaptive behavior and functional outcomes in adults with 22q11.2 deletion syndrome: A parental perspective

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Abstract

22q11.2 Deletion Syndrome (22q11DS) is a genetic syndrome caused by a chromosomal microdeletion. It affects approximately 1 in 850–992 pregnancies, and its clinical manifestations include congenital heart disease, gastrointestinal symptoms, and psychiatric illnesses. The study examined the relationship between adaptive behavior and functional outcomes, educational attainment, employment, and independent living, and whether age, gender, intellectual disability, presence of psychiatric disorder, and close friendships could predict levels of adaptive behavior. Parents of adults with 22q11DS (n = 101; 48 male and 54 female) completed the Waisman Activities of Daily Living Scale, demographic details, and questions elicited employment, education, and relationships status. Analysis conducted in SPSS, included descriptive statistics, measures of association, Analysis of Variance, logistic and linear regressions. Differences in levels of overall adaptive behavior were found regarding employment and living status, but not in educational attainment. Having close friendships was associated with adaptive behavior as well as the likelihood of living independently. Further research is needed, ideally using prospective designs and purposive sampling strategies. This needs to examine how social and communication deficits impact relationship building and how they are affected by the clinical manifestations of 22q11DS. It also needs to focus on how different social structures interface with levels of adaptive behavior.

KEYWORDS
22q11.2 DS, adaptive behavior, adaptive living skills, DiGeorge syndrome, Velo-cardio-facial syndrome

1 | INTRODUCTION

1.1 | Introduction to 22q11.2 deletion syndrome

22q11.2 deletion syndrome (22q11DS), also known as Velo-cardio-facial syndrome and DiGeorge syndrome is a chromosomal microdeletion syndrome that results from a deletion of contiguous genes from the q11.2 locus of chromosome 22 (Kobrynski & Sullivan, 2007). 22q11DS is the most common chromosomal microdeletion syndrome in humans (Shprintzen, 2008), with an estimated prevalence among low-risk populations of 1 in every 850–992 pregnancies (Grati et al., 2015). Phenotypic variation in 22q11DS is common, even within families. Common symptoms can include congenital heart disease, intellectual disability (ID), gastrointestinal symptoms, and psychiatric illnesses (Hallberg et al., 2010; Leader et al., 2020). Up to 41% of 22q11DS patients will develop a psychiatric illness before reaching

adulthood (Schneider et al., 2014). These clinical manifestations can have negative implications for the psychosocial and emotional wellbeing of the individuals concerned (Vo et al., 2018).

1.2 | Adaptive behavior in adults with 22q11.2 deletion syndrome

Adaptive behavior is defined as the potential for individuals to effectively respond to challenging situations, or threats in their environment, and to cope with everyday stressors (Angkustsiri et al., 2012). Individuals with 22q11DS can display moderate impairment in communication, and daily living skills (Fung et al., 2015; Schneider et al., 2014). Research involving children has demonstrated how avoidance and poor interpretation of social cues, is associated with anxiety disorders, and reduced ability of the individual to interact with their environment (Beaton & Simon, 2011). There is limited data available on the adaptive behavior of adults with 22q11DS, but Butcher et al. (2012) found that more than 75% of their adult 22q11DS sample reported deficits in adaptive behavior.

1.3 | Functional outcomes in adults with 22q11.2 deletion syndrome

Adults living with 22q11DS may strive toward independence, entering the workforce, pursuing further education, or forging relationships. However, deficits in adaptive living skills can potentially result in poorer functional outcomes. Several studies have reported suboptimal levels of employment in adults with 22q11DS (Butcher et al., 2012; McDonald-McGinn et al., 2001; Mosheva et al., 2019). McDonald-McGinn et al. (2001) found that only 35% of their adult sample were employed. A more recent study reported that 66% had engaged in employment during adulthood, but a small minority were financially independent (Butcher et al., 2012). Mosheva et al. (2019) found that 41% were unemployed, 33% were employed in open market employment, and 25% worked in assisted employment.

Individuals with 22q11DS probably reach adulthood having experienced great challenges during their education having required educational support (Cohen et al., 2017). Currently, 91% of children with 22q11DS report school-based learning difficulties (Cohen et al., 2017). The challenges may increase as individuals progress through education systems because children aged 5–12 are more likely to enter mainstream school than special education schools, whereas this trend reverses among adolescents.

The symptoms associated with 22q11DS can have negative consequences for the relationships maintained by the individual. Qualitative data suggest that the physical impairments experienced by adults with 22q11DS can be a barrier to communication and put a strain on their relationships with others (McNeill et al., 2020). Individuals with 22q11DS have also reported that reproductive decision-making can be problematic due to having ID and difficulties accessing reproductive understandable reproductive information (McNeill et al., 2020).

1.4 | Current study

Relatively little is known about the relationship between adaptive living skills and functional outcomes in the adult 22q11DS population. The current study builds upon the small amount of previous related research (Butcher et al., 2012; Mosheva et al., 2019). To our knowledge, the current study is the first research that focuses on levels of adaptive behavior across three key functional outcomes: education, independence, and employment. It is also the first to examine a predominantly US- and European-based sample because previous samples were from Canada, Israel, and Geneva (Butcher et al., 2012; Mosheva et al., 2019). Research involving different cultures is needed because the adaptive function of individuals and their functional outcomes will be affected by differing social systems that impact social, employment, and educational opportunities (Mosheva et al., 2019). It builds on previous work to increase nuanced understanding of factors related to adaptive behavior by examining age, gender, the presence of ID and psychiatric illness, and the existence of close friendships. This study aimed to ascertain the overall level of adaptive living skills of adults with 22q11DS and examine how this is associated with functional outcome levels. It hypothesized that levels of adaptive behavior would differ according to functional outcomes including, educational attainment, employment, and the living status achieved by adults with 22q11DS. It also examined if age, gender, presence of ID, and presence of a psychiatric disorder, and the existence of close friendships could predict levels of adaptive behavior in adults with 22q11DS. Ethical approval for this study was obtained from the National University of Ireland Galway ethical committee

2 | METHOD

2.1 | Participants

This study used a cross-sectional design and a sample of $n = 101$ adults (48 male and 54 female) with an age range of 18–60 years, ($M = 25$, $SD = 7.92$) with a diagnosis of 22q11DS, was recruited. The majority of participants (85.1%) had an ID. of participants with ID, 5% were severe, 43% moderate, and 52% had mild ID.

2.2 | Informants

Parents with an adult son/daughter with 22q11DS served as the study informants. They were mothers (92%), fathers (4%), and guardians (4%). Informants self-completed the measures described below, and guidance for completing these measures was provided to them within the online questionnaire sheet via the Limesurvey platform (https://www.limesurvey.org/).

2.3 | Procedure

Parents were recruited by placing advertisements in online 22q11DS parental support groups, on relevant websites, and through email

newsletters. The study advertisement described the aims and objectives of the study. Parents who self-selected for participation were provided with a participant information letter and a consent form. After obtaining consent, a battery of questionnaires was distributed to the parent(s) for completion at their convenience. Parents were requested to complete the questionnaires independently, without input from the child's other parent. Also, they were asked to complete them with their participant child, if possible.

2.4 | Measures

2.4.1 | Demographic information

Informants completed a demographic questionnaire designed by the researchers. The following information were collected: age, gender, country of residence, education level, age of diagnosis of 22q11DS, designation of the professional who gave the diagnosis, presence of ID, the severity of ID, presence of any other clinical feature, and the treatment received for clinical features. Regarding functional outcomes, informants were asked about their child's current job status, educational attainment status, living status, whether they had obtained a driving license, hobbies/pastimes, marital status, and if they had close friends. Finally, informants were asked whether the participants had any children of their own and whether these children had a diagnosis of 22q11DS.

2.4.2 | Waisman – Activities of daily living scale

The Waisman – Activities of daily living scale (ADL Scale; Maenner et al., 2013) is a 17-item assessment of activity of daily living skills in people with developmental disabilities. The ADL scale was used to ascertain the participants' ability to cope with everyday activities. Each item on the scale corresponds to an activity of daily living and respondents are asked to rate the extent to which the individual could perform these activities independently. Responses ranged from 0 (does not do at all) to 2 (independent or does on own). Higher total ADL scores indicate a greater propensity to engage in adaptive behavior. Development of the scale involved samples with a developmental disability ($n = 1014$), including Fragile-X syndrome, Down syndrome, Autism, and ID. The scale has demonstrated good reliability and criterion and construct validity (Maenner et al., 2013). Maenner et al. (2013) found that W-ADL scores correspond to levels of ID severity: Severe ID (*M* 16.1 *SD* 7.7); Moderate ID (*M* 21.8 *SD* 6.0); and Mild ID (*M* 24.9 *SD* 5.5).

2.5 | Analysis

Percentages were calculated to examine the prevalence rates of functional outcomes and a total ADL score was calculated for each participant. The relationship between the ADL total score and friendships was calculated using Pearson's Correlations, and chi-square analysis was used to determine the difference between the employment status of participants with and without ID. A one-way between groups Analysis of Variance (ANOVA) was conducted to explore the impact of the ADL score on the rates of employment.

Data on the education level of participants were divided into four groups (group one: secondary/high school; group two: further education program/certificate; group three: third level education/university degree; group four: other). A one-way ANOVA was conducted to explore the difference in adaptive behavior between participants who had achieved a primary school, secondary/high school, or a university/further education. Data on employment status were divided into six groups (group one: employed; group two: out of work and looking for work; group three: student; group four: unable to work; group five: other; group six: part-time work). It was analyzed using descriptive statistics and then a one-way between groups ANOVA was conducted to explore the impact of the ADL score on the rates of employment.

Prompted by recommendations from Butcher et al. (2012), adaptive behavior scores were compared by splitting the sample in terms of age and employing a one-way ANOVA. To obtain three discrete age groups which were comparable in size, the analysis was stratified by the following age brackets: 18–21 ($n = 39$), 22–25 ($n = 30$) and 26+ ($n = 32$). Logistic regression was conducted to examine whether gender, presence of ID, and the existence of close friendships predicted the likelihood of living status or relationship status. Finally, linear multiple regression was used to examine whether age, gender, presence of ID, and presence of a psychiatric disorder predicted levels of adaptive behavior. All statistical analyses were two-tailed, and conducted within SPSS version 26, with statistical significance defined as $p < 0.05$.

3 | RESULTS

3.1 | Participants' living status, degree of independence, and highest educational attainment

Table 1 presents demographic data that includes participants' living status, level of independence, and their highest attained educational level. This shows that a total of 73 (72.3%) participants were living with parents/guardians, and among those living independently, 15 (13.7%) received support. A total of 36 (35.6%) participants held a driving license at the time of the study. Additionally, 76 (75.2%) of parents reported that their adult son or daughter engaged in hobbies or pastimes.

3.2 | ADL in adults with 22q11DS

The total ADL scores ranged from 8 to 34. The mean ADL score was 23.81 ($SD = 6.65$), indicating that participants had a moderate level of impairment in adaptive behavior. The normality of standardized residuals for adaptive behavior was assessed using a Shapiro–Wilks test.

TABLE 1 Demographic information on adults with 22q11DS

	M	*SD*	Range	*Mdn*
Age	25	7.92	18–60	23
	n			%
Gender				
Male	48			47.5
Female	53			52.5
Intellectual disability				
Yes	86			85.1
No	15			14.9
Geographical region				
Ireland	17			16.8
United Kingdom	19			18.8
United States	51			50.5
Other	14			13.9
Living status and degree of independence				
Living with parents/guardians	73			72.3
Live independently	21			20.8
Support provided daily	7			6.9
Support provided occasionally	5			4.9
Support provided weekly	2			1.9
Sheltered/residential living	1			0.9
Held a driving license	36			35.6
Engage in any hobbies or pastimes	76			75.2
Do not engage in any hobbies or pastimes	23			22.8
Frequency and percentage of the highest educational level attained				
Secondary/high school	51			50.5
Further education program/certificate	31			30.7
Third-level education (university degree)	10			9.9
Other	9			8.9

This found that scores were not normally distributed ($W(101) = 0.94$, $p < 0.001$). However, as the sample size and degrees of freedom for the residuals were large, this violation did not pose a serious threat to the analysis.

3.2.1 | ADL and friendships

The Pearson's correlation between ADL and friendships revealed a small positive relationship where $r = 0.29$, $n = 101$, $p = 0.002$.

3.3 | Employment status in adults with 22q11DS

As demonstrated in Table 2, 24.8% of participants were employed, 24.8% were unable to work, 23.8% identified as being students, 13.9% were out of work but seeking employment, and the remainder engaged in either part-time work or an alternative arrangement not listed.

TABLE 2 Frequency and percentage of the employment status of participants

Employment status	Frequency	Percentage
Occupation status		
Employed	25	24.8%
Unable to work	25	24.8%
Student	24	23.8%
Out of work looking for work	14	13.9%
Other	8	7.9%
Part-time work	5	4.9%

3.3.1 | Gender difference in employment status

A Chi-Square test indicated that there was no statistically significant association between gender and employment status where $\chi^2(1, n = 101) = 9.9$, $p = 0.13$.

3.3.2 | Presence of an ID and employment status

Chi-square analysis showed that there was no statistical significance between the employment status of participants with and without ID (χ^2 (1, $n = 101$) =9.9, $p = 0.13$).

3.3.3 | Adaptive living skills and employment status

A one-way between-groups ANOVA was conducted to compare levels of adaptive behavior between those in employment, those unemployed, and participants who were students. Levene's test for homogeneity of variances was not significant ($F = 2.69$, $p = 0.073$). ANOVA revealed a statistically significant difference in adaptive behavior (F (2, 98) = 9.63, $p < 0.001$). A series of Tukey LSD post hoc tests were run to ascertain where the significant differences were. These found a significant difference in adaptive behavior between the employed and unemployed groups ($SE = 1.44$, 95% CI [3.13, 8.82], $p < 0.001$), and between the employed and student groups ($SE = 1.68$, 95% CI [2.30, 8.98], $p = 0.001$). There was a large effect size (Cohen's $d = 1.01$ and 1.00, respectively) observed. There was no significant difference between the unemployed and student groups ($SE = 1.54$, 95% CI [−3.39, 2.72], $p = 0.829$). As shown in Table 3, adaptive behavior was highest among those in employment ($M = 27.93$, $SD = 5.00$), and lowest among those unable to work ($M = 21.96$, $SD = 6.18$).

3.4 | Education levels in adults with 22q11DS

As shown in Tables 1, 50.5% of participants had achieved secondary/high school, 30.7% had achieved further education, and just 9.9% had achieved a university degree. A one-way between-groups ANOVA was conducted to examine differences in adaptive behavior among participants whose highest educational achievement was primary school, secondary/high school, or higher/further education. Levene's test for homogeneity of variances was not significant ($F = 0.08$, $p = 0.920$). ANOVA revealed no statistically significant differences in adaptive behavior among the three groups (F(2, 98) = 2.10, $p = 0.127$).

3.5 | Independent living in adults with 22q11DS

An independent-samples t-test was conducted to examine whether participants who were living independently and participants who were not living independently had differing levels of adaptive behavior. Levene's test for homogeneity of variances was not significant ($F = 2.22$, $p = 0.139$). The results revealed a statistically significant difference between the two groups (t(99) = 3.81, 95% CI [2.79, 8.87], $p < 0.001$). Participants who were living independently had higher adaptive behavior ($M = 28.43$, $SD = 5.33$) than participants who were not living independently ($M = 22.60$, $SD = 6.45$), with a large effect size observed (Cohen's $d = 1.09$).

TABLE 3 Adaptive living scores stratified by employment status

	M	*SD*
Total scores	23.81	6.65
In employment	27.93	5.00
Unemployed	21.96	6.75
Students	22.29	6.18

3.5.1 | Predictors of living status

The logistic regression that examined if gender, presence of ID, and the existence of close friendships predicted independent living, used living status (independently/not living independently as the dichotomous criterion variable. All three predictors were entered into the regression model as dichotomous predictors (with the existence of close friendships coded as 'no close friendships/at least one close friendship').

The logistical regression model was statistically significant (χ^2(3) = 7.85, $p = 0.049$). The model explained 12% (Nagelkerke R^2) of the variance in living status, and correctly classified 79.2% of participants. Results of the regression are presented in Table 4. Examination of Wald statistics indicated that the existence of close friendships (Wald = 4.43, $p = 0.035$) significantly added to the model. The existence of close friendships ($\beta = 2.22$) increased the likelihood of living independently by an odds ratio of 9.21.

3.6 | Adaptive behavior across age cohorts

To determine whether adaptive behavior varied across age cohorts in the present sample, a one-way between-groups ANOVA was conducted. Levene's test for homogeneity of variances indicated that the assumption of homogeneity of variance was violated ($F = 5.06$, $p = 0.008$), but because the variance ratio was 2.00, the data was still considered parametric (Dean & Voss, 1999; Kirk, 2013). ANOVA revealed there were no significant differences between age groups with respect to levels of adaptive behavior (F(2) = 2.53, $p = 0.085$). Means and *SD*s are presented below in Table 5.

3.7 | Predictors of adaptive behavior

The linear multiple regression to explore whether key demographic and psychiatric illness contributed to the variance in adaptive

TABLE 4 Logistic regression for predicting likelihood of living status based on gender, presence of ID, and existence of close friendships

	B	*SE*	Wald	*df*	*p*	OR
Gender	−0.10	0.51	0.04	1	0.843	0.90
Presence of ID	−0.07	0.73	0.01	1	0.921	0.93
Friendships	2.22	1.10	4.43	1	0.035	9.21

TABLE 5 Mean and standard deviation adaptive functioning scores across age brackets

	18–21 ($n = 39$)		22–25 ($n = 30$)		26+ ($n = 32$)			Total ($N = 101$)	
	M	*SD*	*M*	*SD*	*M*	*SD*	*p*	*M*	*SD*
Adaptive functioning score	22.08	5.93	24.23	8.02	25.53	5.69	0.085	23.81	6.65

TABLE 6 Pearson's correlation statistics for predictor and criterion variables

	1	2	3	4
1. Total adaptive functioning score				
2. Age	0.23*			
3. Gender	0.14	−0.02		
4. Presence of ID	−0.04	−0.11	−0.01	
5. Presence of psychiatric disorder	−0.03	−0.17*	−0.19*	−0.10

*$p < 0.05$.
**$p < 0.01$.

TABLE 7 Summary of linear multiple regression model

Variable	β	R^2	Adjusted R^2	*F* change
Age	0.24*	0.08	0.04	1.97
Gender	0.15			
Presence of ID	−0.01			
Presence of psychiatric disorder	0.04			

*$p < 0.05$.
**$p < 0.01$.

behavior used total adaptive behavior scores as the criterion variable. The predictor variables of age, gender, presence of ID, and presence of a psychiatric disorder were entered into the regression model using the enter method.

Multicollinearity was not present in the data. Pearson's Correlation statistics for predictor variables were less 0.7 (see Table 6). The variance inflation factor scores were less than 10 (range = 1.03–1.09) and tolerance scores were greater than 0.1 (range 0.92–0.97). The results of the multiple regression analysis (see Table 7) show that the overall model was not significant ($F(4, 96) = 1.97$, $p = 0.106$, $R^2 = 0.08$, adjusted $R^2 = 0.04$). Examination of standardized beta coefficients revealed that age was the only significant contributor to the model ($\beta = 0.24$, $p = 0.018$).

4 | DISCUSSION

This study built upon previous research by examining factors that may moderate the relationship between adaptive behavior and its relationship to ecologically valid outcomes, including living status, employment, and educational attainments. As noted in a recent systematic review, the use of data solely derived from psychological tests has limited associations with real-world outcomes (Jhawar et al., 2021). It found that a quarter of participants engaged in employment, half had attained second-level education, and only 9.9% had obtained a third-level education. Statistically significant differences in levels of adaptive behavior, and employed participants reported higher adaptive behavior than unemployed participants, and participants living independently reported higher adaptive behavior than those not living independently. No statistically significant differences in adaptive behavior were observed among participants with various levels of educational attainment. In addition, adaptive behavior shared a small positive correlation with friendships, and the existence of close friendships increased the likelihood of living independently.

A quarter of participants were employed at the time of the study and these individuals had higher adaptive behavior levels than their unemployed counterparts. The percentage of employment found in this study is consistent with findings from Mosheva et al. (2019) but it contrasts with data from Butcher et al. (2012), who found that the majority of their sample had maintained employment more often than not. However, it is difficult to draw conclusions about comparisons between these findings due to the subtle, but important difference in the way in which data on employment were collected in this study and in Butcher et al. (2012). While it is not necessarily surprising that employed participants in this study reported higher levels of adaptive behavior than those not in employment, this finding highlights the need to assist individuals with 22q11DS to engage in employment, as the higher levels of adaptive behavior observed are likely to have transferable benefits in their everyday lives.

Living status also emerged as a factor that is related to adaptive behavior. Participants living independently had greater adaptive behavior than those not living independently. It was encouraging to

see that a fifth of adults with 22q11DS (20.8% in the present study) lived independently. This finding is comparable with data from Butcher et al. (2012). It is also noteworthy that the existence of close friendships increased the likelihood of living independently. This suggests that close friendships play a key role in supporting individuals with 22q11DS to live independently, and by extension, in developing the everyday living skills of individuals. However, it is difficult to discern entirely from this data the precise pathways through which maintaining close friendships and independent living impact adaptive behavior. But it is plausible that close friendships moderate the association between living status and adaptive behavior. However, further work is needed to fully understand the role played by close friendships.

It is somewhat surprising that age did not predict levels of adaptive behavior because cognitive ability declines with age in 22q11DS (Green et al., 2009). However, this finding was probably impacted because the age of the sample being was relatively young ($M = 25$ years). The findings might have been different if older participants were better represented in the sample, who had more time and life opportunities. The need for future research to better represent older adults with 22q11DS is compounded because previous studies also recruited relatively younger samples (Butcher et al., 2012; Mosheva et al., 2019). Therefore, future studies would benefit from using purposive sampling strategies to ensure a normal distribution of age in their sample.

The finding that greater levels of adaptive behavior are associated with greater levels of employment and independent living suggests that supports and interventions to improve the adaptive behavior of adults with 22q11DS should be promoted. In addition, because this study emphasizes that close friendships are related to adaptive behavior and independent living, emphasis should be placed on supporting the development of communication skills and those aiming to facilitate relationship-building. These supports should be personalized and tailored to the individual to address their unique presentation of 22q11DS symptoms based on an assessment of need. Furthermore, supports are also likely to benefit individuals if they are promoted during childhood and adolescence and if they also involve family members.

However, there are limitations to the current study which should be noted. Firstly, when comparing levels of adaptive behavior in levels of educational attainment, the group sizes were not equal. The majority of participants' highest educational achievement to date was high school/secondary education, and only 10 participants had obtained a third-level education. This made establishing the differences in adaptive behavior difficult, and as such the findings of this analysis should be interpreted with caution. Secondly, the study relied on parental reporting to provide proxy information, rather than obtaining data directly from individuals with 22q11.2 deletion or clinicians. This may have reduced the accuracy of the data. However, it can be noted that parental reporting has been found to closely align with clinical evaluation (Gorrindo et al., 2012), and parents can be expected to have detailed relevant knowledge about the adaptive behavior of their children. Thirdly, bias may have been created through not determining the criteria used to diagnose ID, and because the evidence that participants had genetically confirmed deletions, was not obtained. Fourthly, the sample examined had a relatively high proportion of the participants with mild, moderate, and severe ID, who lived with parents/guardians. Typically among populations of individuals with 22q11DS, there are approximately 50% with ID and approximately 33% have normal IQ (Swillen & McDonald-McGinn, 2015), therefore the sample was not representative of the typical 22q11DS population. Consequently, the study's results may underestimate the adaptive behavior of the wider population of individuals with 22q11DS.

Informants were recruited to the study in three different ways, as described above, however, with the reliance on parental reporting and self-selection there was a high probability of ascertainment bias. We cannot know with certainty, for the large sample ascertained, but it is possible that due to the sampling strategies and method of data collection, it was less likely that individuals with 22q11DS and their parents, who were living independently, and without ID, would be made aware of the study.

The study findings suggest that further research is needed in several key domains. Firstly, a more nuanced understanding of the relationship between factors is required and prospective longitudinal studies could ascertain whether the factors associated with adaptive behavior are unidirectional or bidirectional. Secondly, this study emphasizes the importance of close friendships, and a growing body of evidence suggests that symptoms of 22q11DS can impact the quality of the relationships maintained by the individual (Vo et al., 2018), less is known about which symptoms are most problematic for relationship building. Future investigations should seek a deeper understanding of these symptoms to inform service provision and interventions that aim to address deficits in social communication in 22q11DS, and thereby improve the psychosocial well-being of the individual. Thirdly, it is known that anxiety can negatively impact everyday living skills, and that anxiety is negatively correlated with adaptive behavior (Angkustsiri et al., 2012). However, there has been little research dedicated to this subject that involves adult populations.

The study examined the relationships between adaptive behavior and important functional outcomes in adults with 22q11DS. Marked differences in levels of overall adaptive behavior were found in the areas of employment and living status, but not in educational attainment. The existence of close friendships was identified as a factor associated with adaptive behavior, as well as the likelihood of living independently. Considerable future research is needed, ideally using prospective designs, and purposive sampling strategies, to further understand the clinical manifestations of 22q11DS, the social and communication deficits that can be experienced by this population, and how different social structures interface with levels of adaptive behavior. If done successfully, the functional outcomes and psychosocial well-being of this population can be enhanced through the development of tailored interventions and supports to aid adults with 22q11DS to maximize their potential to flourish in their everyday lives.

CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

AUTHOR CONTRIBUTIONS

Authors made the following contributions to this paper: Conceptualization - Andrea Curtin, Arlene Mannion, Geraldine Leader, Robert Shprintzen. Methodology - Andrea Curtin, Arlene Mannion, Geraldine Leader, Robert Shprintzen. Formal analysis - Andrea Curtin, Rory Coyne. Writing—original draft preparation - Andrea Curtin, Robert Shprintzen, Geraldine Leader, Arlene Mannion. Writing—review and editing - Sally Whelan, Arlene Mannion, Rory Coyne. Supervision - Arlene Mannion, Geraldine Leader. Project administration - Andrea Curtin, Arlene Mannion, Geraldine Leader.

DATA AVAILABILITY STATEMENT

N/A.

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