Paper Title Transcending Global Borders: Lived Experiences of Students With Autism From Italy to the United States

Author(s) Jacqueline Lubin, Quinnipiac University; Alessandra Romano, University of Siena; Marsha E. Simon, Valdosta State University; Francesca Bulletti, University of Siena

Session Title Global Perspectives and Experiences of Students With Autism or Emotional and Behavioral Disabilities

Session Type Place-Based Paper

Presentation Date 4/27/2025

Presentation Location Denver, CO

Descriptors Autism, Cross-Cultural Studies, International Education/Studies

Methodology Quantitative

Unit SIG-Special and Inclusive Education Research

DOI https://doi.org/10.3102/2189847

Introduction

In this paper, we draw on findings from two global research studies on students with autism to contribute to the discussion on overcoming and reducing biases inherent in a remedial approach to research with individuals with autism. The first study conducted in Siena, Italy, with a sample of high school students with autism and neurodevelopmental disorders examined their expectations to work while the second study based in the US examined college students with autism' Quality of Life (QoL). The transition period from high school to college is of particular importance to students with ASD as some of the supports that foster their successful navigation during secondary education may not be present in higher education settings (Garcìa-Villamisa, et al., 2002). The presentation of two research studies aims to provide greater insight into the lives of students with autism and to further the discussion on reducing the remedial approach to addressing this population (Kamp-Becker, et al., 2010). While these educational settings differ, as researchers we share a common desire that our research will help to improve experiences, outcomes, and equitable opportunities for all. The rationale for the conceptual conjunction of the two studies does not pertain to statistical or conceptual comparison; rather, it is to provide two research examples that develop quantitative and qualitative tools to investigate the factors impacting the QoL of high school and university students with autism.

Aims and Epistemological Assumptions

The overarching aim of the paper is to invite researchers and educators to question the "remedy and repair" approach to examining individuals with autism. Therefore, we took on the invitation to consider how we can work across disciplinary, epistemological, and methodological orientations to forge deeper connections in our field, as an interdisciplinary, intercultural,

integrable, and interracial team of researchers. Positioning our research in the theoretical umbrella of Critical Disability Studies (Connor et al., 2016), we argue that a remedial educational approach had the effect of highlighting deficits in students with autism, instead of critically examining our institutions, social processes, politics, and policies, and our own research approaches that produce hierarchies of knowledge and legitimacy (Connor et al. 2016). Through the presentation of the two studies conducted with participants with ASD, we would engage with current and ongoing challenges of doing rigorous and robust studies to produce relevant findings for assessing perceptions of QoL and codesigning transformative actions (Romano, & Torres-Corona, 2024).

Objectives or Purpose

Research has shown that elementary and secondary children with autism often experience a low quality of life (Dijkhuis et al., 2017). Yet, there is limited research on the developmental trajectory of the quality of life as children (in K-12) transition into adulthood and college (van Heijst & Geurts, 2015). Therefore, the purpose of this paper is to share findings on high school and college students with autism on their quality of life. The following research questions guided the paper:

1. What is the QoL of high school students with autism?
2. What is the QoL of college students with autism?
3. How does the QoL of students with ASD influence perceptions of independent life, access to employment, and college life?

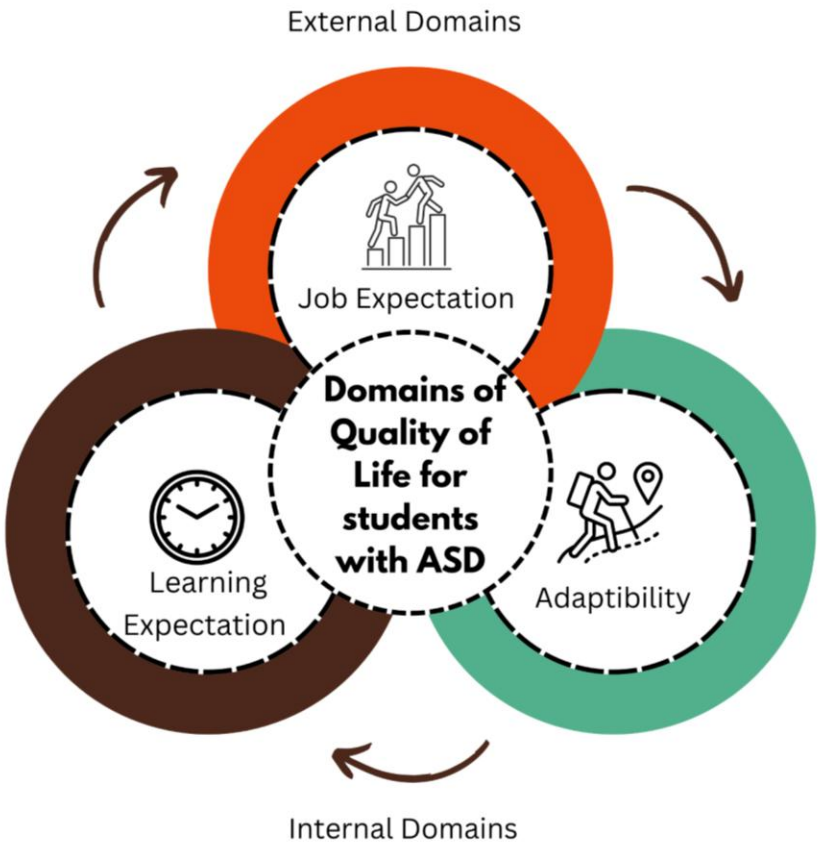
Perspective(s) or Theoretical Framework

Several frameworks were used in these studies. In the project with high school students with ASD, the researchers adopt an analytic framework based on the integrated framework of the

QoL for people with ASD (Chiang & Wineman, 2014), which includes perspective for future and job expectations as key elements of the QoL (Billstedt et al., 2011; Ostasiewicz, & Zawadzki, 2024). The QoL of people with ASD is usually correlated with psychological well-being and social support (Chiang, & Wineman, 2014). In this paper, we define the quality of life for people with ASD as a multifaceted concept that includes both internal and external domains, such as job expectations, adaptability to the environment, and job safety (García-Villamisar, Wehman, & Navarro, 2002; Chiang, & Wineman, 2014; Kamp-Becker, et al., 2010; Cottini, 2024). The conceptual model underlying these measures is represented in Figure 1.

Figure 1

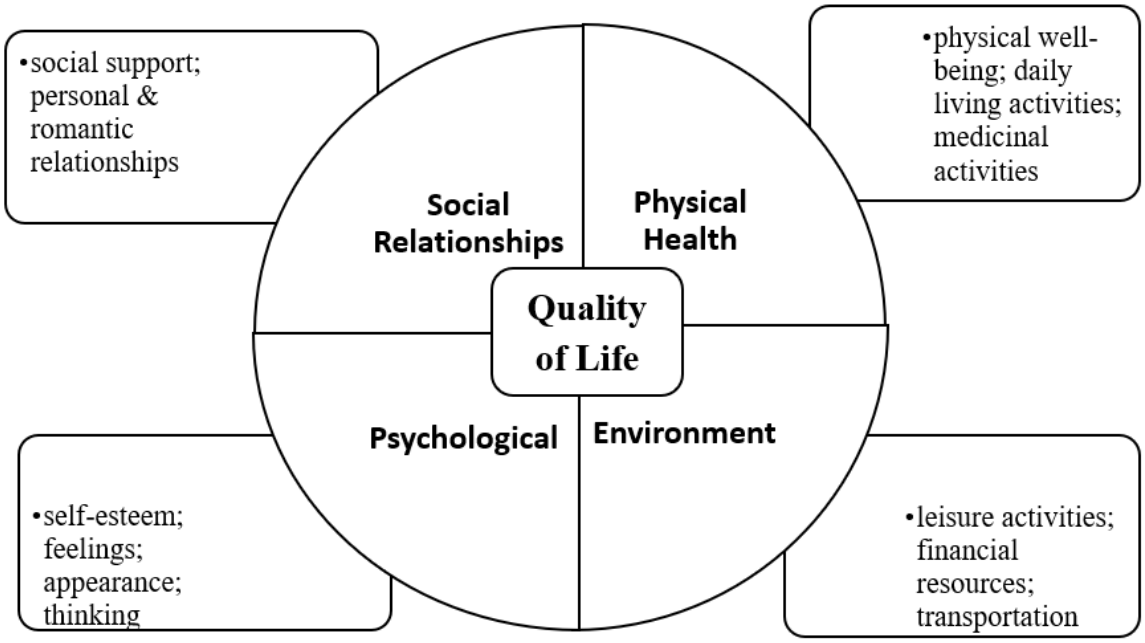
Integrated Framework: Quality of Life



The World Health Organization (WHO) framework guided the study on college students with ASD. The WHO framework entails four domains: Physical Health, Social Relationships, Psychological, and Environment (Chao, 2018; Dijkhuis et al., 2017; WHO, 1995) (see Figure 2).

Figure 2

WHO Quality of Life Domains



The Physical Health domain involves an individual's physical well-being, health knowledge, and ability to maintain a school-life balance. This includes one's ability to manage college daily living activities, medical needs, mobility on campus, and academic tasks (Accardo, 2017; Balbin et al., 2022; Chao, 2018; Dijkhuis et al., 2017; WHOQOL, 1995). The Psychological domain evaluates an individual's perception of their body image, feelings, self-esteem, beliefs, spirituality, metacognition, and learning capacity during postsecondary years (Chao, 2018; Dijkhuis et al., 2017; Hull et al., 2021; Nasamran et al., 2017; WHOQOL, 1995). The Social Relationships domain examines an individual's personal relationships, social support, and

romantic relationships while at college (Balbin et al., 2022; Chao, 2018; Dijkhuis et al., 2017; WHOQOL, 1995). The Environment domain delves into an individual's financial resources, freedom, physical safety, accessibility, opportunities for acquiring new information and skills, recreation/leisure activities, physical environment, and access to services while on campus (Chao, 2018; Dijkhuis et al., 2017; WHOQOL, 1995).

Methods, Techniques, or Modes of Inquiry

The study with high school students in Italy, entitled "ALL Inclusive", employed quantitative research with groups of students (Hirose & Crewswell, 2022). Quantitative data were collected through a self-administered survey. The relationship between QoL and adaptivity was investigated by examining scores through: Adaptability Scale, Orientation to Work Individual Plan Expectations Scale (Job Expectation), Job Safety Scale, Difficulty Expectations Scale, Satisfaction Scale and Learning Expectation Scale (García-Villamisar, Wehman, & Navarro, 2002; Kamp-Becker, et al., 2010). Our research purpose was to explore how the four internal and external domains assessed by the scale correlate and moderate the self-determination and QoL of students with ASD. Items are measured on a 5-point Likert scale where 1= strongly disagree, and 5= strongly agree. Of the 160 questionnaires collected, 18 were incomplete. The 142 remaining questionnaires were analyzed using IBM SPSS (Version 23).

Respondents were young female and male white and BIPOC disabled students of secondary schools located in three school districts of the Tuscany Region in the Center of Italy (N= 142), including 63% men (N=89) and 37% women (N=53). Their average age was 17 years old ($\bar{X}$= 17,5; SD= 0,9126). Due to the infeasibility of conducting the survey administration on the entire school population through randomization of participants, a purposive nonprobability sampling procedure was adopted. Criteria for the sample selection related to their autistic and neurodivergent characteristics. In addition, the contact process was facilitated by the respondents' teachers, who belonged to a group of classes participating in the ALL Inclusive project. Students possess multiple identities, which shape their experiences and compound the levels of systemic oppression, racism, and ableism present in their social and educational contexts. The totality of respondents has been diagnosed with autism and neurodivergent learning styles, and

approximately half are of a migratory background. A small number of respondents exhibit characteristics that are intertwined with non-binary gender identities. The internal consistency of the survey was moderately high (Cronbach's α= 0.892). Descriptive statistics were calculated to determine the reported levels on each scale.

For the second study on college students with ASD, the WHOQOL-BREF (1997) survey was used to measure the quality of life of university students in the US. The participants were recruited using convenience sampling. Fifty-six college students with autism from four-year universities in the USA responded to the surveys, including 27% were women, 66% were men, and 7% identified as non-binary. The sample was fairly homogenous in race/ethnicity as most identified as White (71%), with 14% Hispanic, 9% African American/Black, and 5% Asian. Data were analyzed using the IBM SPSS (Version 27). Descriptive statistics were calculated to determine the reported levels on each WHOQOL-BREF domain. Data analysis was informed by the domains of quality of life.

Results and/or Substantiated Conclusions or warrants for arguments/point of view

Quality of Life of High School Students with Autism

For the study of high school students, we used Cronbach's Alpha coefficient to check the reliability of the scales. Good internal consistency was found with an adequate level of reliability for the Adaptability Scale (α = 0.89), Orientation to Work Individual Plan Expectations Scale (α = 0.79), Learning Expectations Scale (α = 0.84), Difficulty Expectations Scale (α = 0.73), Satisfaction Expectations Scale (α = 0.86), Job Safety Scale (α = 0.80).

For the scales examined, we conducted a multivariate cluster analysis (Rencher, 2002). Indices were calculated by comparing the sum of the values assigned for each variable on a scale from 0 to 1 (1 represents the highest value obtained while 0 corresponds to the lowest value). The indices found were categorized into four classes with a value range of 0.25. For the adaptability index, values were found that can be categorized into three classes: low adaptability,

adaptability, high adaptability. For the Orientation to Work Individual Plan Expectations index, classes corresponding to: no expectations, low expectations, expectations, high expectations were found. Finally, for the Learning Expectations index, the classes were found to be: no competence, low competences, competences, high competences.

Once the indices were defined, the associations between the indices of Adaptability, Orientation to Work Individual Plan Expectations, and Learning Expectations with gender and age were analyzed by means of multivariate correspondence analysis. The analysis obtained the following proximity matrix:

Figure 3

Proximity Matrix One

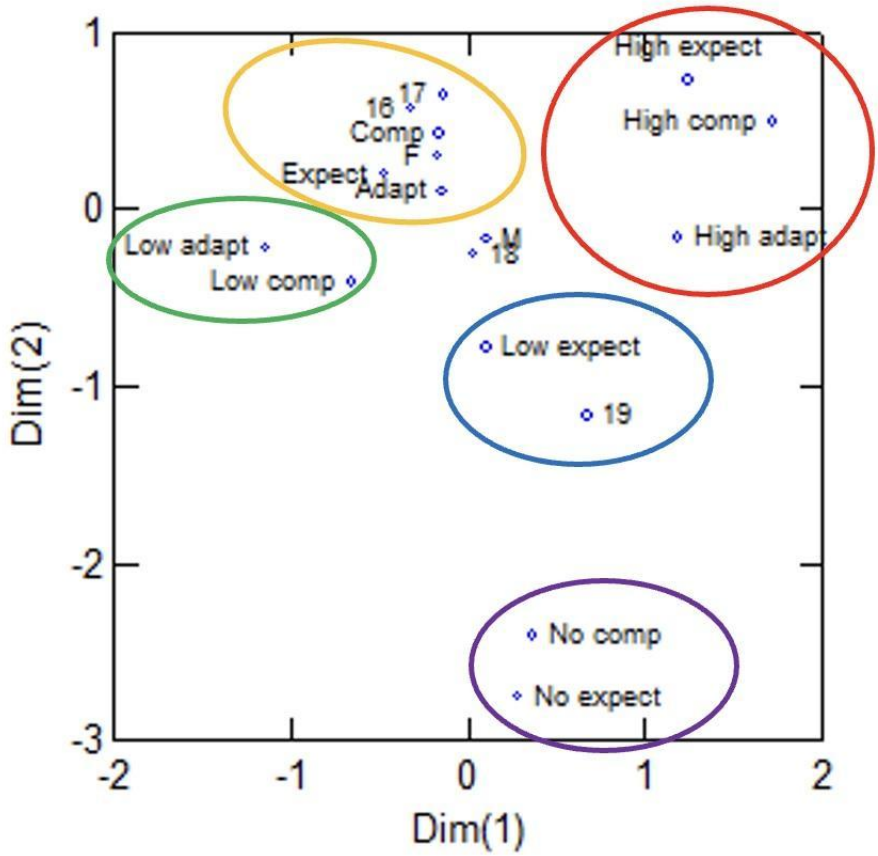
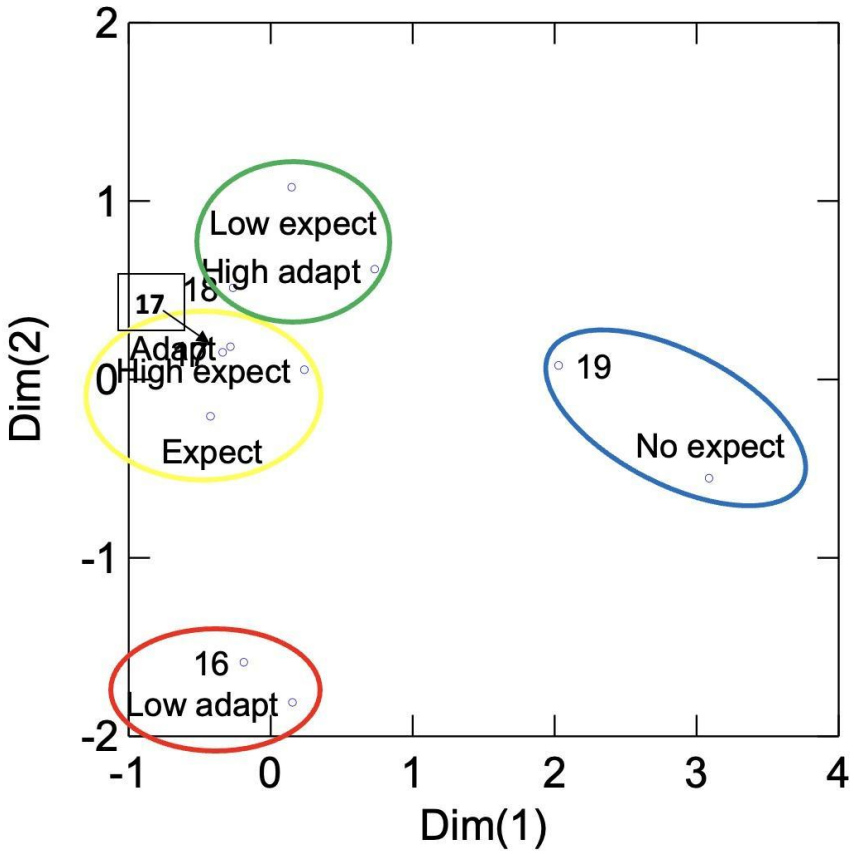


Figure 3 illustrates how the domains of adaptability, Orientation to Work (or Job Expectations), and Learning Expectations relate to each other and to gender and age variables. Learning expectations play a crucial role in the perceived QoL of students with ASD. The 16- and 17-year-old girls perceive themselves as adaptable and have medium expectations of successful work performance as well as a good perception of acquiring more skills in the training experience. Students with ASD who have a high perception of their own competencies and perceive themselves as highly adaptable also have high expectations of successful completion of the work experience. Those who have a very low perception of adaptability also have low perceptions of acquiring new skills and consequently low perceptions of QoL. Finally, most 19-year-old students have low expectations of a successful career path with negative effects on their QoL. The investigation revealed a direct proportional relationship between the internal and external domains. Specifically, the correlation between adaptability, learning expectations and job expectations was found to be positive. The findings revealed no correlation between gender and age with higher job expectations or self-perceived adaptability and learning abilities.

As can be seen from Figure 4, in our sample focusing on the domains of Adaptability and Job Expectations in relation to the age of the students, we observe that expectation values were inversely proportional to age, decreasing with increasing age.

Figure 4

Proximity Matrix Two



In contrast, for students entering the world of work for the first time, expectations were very high. For the adaptability domain, on the other hand, the relationship was directly proportional: as age increases, so does the students' perception of adaptability. It is plausible that the work orientation experiences that students have during their last three years of high school may influence their perception of their own sense of adaptability and job expectations.

The results obtained from older students who expressed low job expectations underscored the significance of planning an Orientation to Work Individual Plan for students with ASD. This plan necessitates inter-institutional collaboration among school actors, school leaders, healthcare professionals, and parents to create training pathways for students with ASD based on work-related learning. These findings are in line with the results of Garcia-Villamisar et al.'s (2002)

study, which reported a positive relationship between participation in supported employment and the QoL of adults with ASD.

Quality of Life of College Students with Autism

Overall, students' total quality of life scores ranged between 100 to 350, with the average total score indicating that most students' QoL was slightly above the central point ($\bar{X}$ = 205.61; *SD* = 53.70). Specifically, z-score analysis revealed that 66% of participants reported average QoL scores, 12% were above average, 18% were below average, and 4% were significantly below average. Mean ratings across individual domains fell between 46 and 60. On average, three of the four domains—Physical Health ($\bar{X}$= 46.94; *SD*= 14.98), Psychological ($\bar{X}$= 49.26; *SD*= 19.86), and Social Relationships ($\bar{X}$= 49.33; *SD*= 22.36)—were rated below the midpoint, while the Environment ($\bar{X}$= 60.08; *SD*= 22.51) domain was the only one rated above the midpoint. Analysis of z-scores across QoL domains indicated that all participants reported an average level of Physical Health, Psychological, Social Relationships, and Environment. These findings suggest that while the majority of participants perceived their overall QoL as slightly above the midpoint, their ratings for three of the four individual domains remained below this threshold. Notably, the higher rating of the Environment domain aligns with Dijkhuis et al. (2017), who found that college students with ASD rated their living arrangements the highest.

Regarding sex/gender, men (*M* = 218.54; *SD* = 55.37) rated their overall QoL above the midpoint, whereas participants who identified as women (*M* = 181.00; *SD* = 35.34) and non-binary (*M* = 187.86; *SD* = 47.35) reported below midpoint values. In terms of individual QoL domains, men rated three of the four domains—Physical Health, Psychological, and

Environment—above the midpoint, while non-binary participants rated these same domains below the midpoint (see Table 1).

< insert Table 1>

Women rated all QoL domains below the midpoint. A multivariate analysis revealed significant differences in Environment, $F(2, 53) = 5.18$, $p < .01$, and Physical Health, $F(2, 53) = 4.972$, $p = .01$, scores based on sex/gender. A Tukey post hoc test identified a significant difference in Environment scores between men ($M = 66.43$) and women ($M = 49.26$) as well as a significant difference in Physical Health scores between men ($M = 52.76$) and non-binary ($M = 33$) participants.

Based on race/ethnicity, participants who identified as White ($M = 220.52$; $SD = 44.09$) reported the highest QoL ratings, followed by Black/African American ($M = 187.00$; $SD = 87.66$), while Hispanic/Latino ($M = 158.87$; $SD = 46.94$) participants reported the lowest QoL ratings. A clear pattern emerged where White participants rated all QoL domains above the midpoint, whereas Hispanic/Latino respondents rated all domains below the midpoint. A multivariate analysis revealed significant differences in Environment, $F(3, 52) = 3.05$, $p < .05$, Physical Health,$F(3, 23) = 4.86$, $p = .01$, and Total QoL, $F(3, 52) = 3.71$, $p < .05$, scores. A Tukey post hoc test confirmed significant differences between White and Hispanic/Latino participants across these domains, with White participants reporting higher QoL. These findings align with de Vries and Geurts (2015), who noted that sociocultural factors and ethnicity may influence QoL in individuals with ASD. Given the limited literature on this topic, further research is warranted.

Scientific or scholarly significance of the study or work

The QoL of high school and college students with ASD has received relatively little attention (Nadig et al., 2018). Over the past decades, research has delved into understanding the quality of life of students with ASD in the K-12 settings (Newman et al., 2015); however, little has been done to understand the QoL in the secondary school or at the college level (Elias et al., 2019; Gelbar et al., 2020; Getzel, 2014). The limited research is mostly based on professional expert knowledge and experience working with students and not necessarily the lived experiences of college students with autism. Therefore, findings add to the body of research on the life of college students with autism. It also informs practitioners on areas of consideration when working with high school and college students with ASD.

Conclusions and discussions

The findings of these investigations have practical implications for services, practices, and policies on the perceived quality of life of students with autism. They confirm that individual adaptivity, Physical Health, Environment support, and Job Expectation are intertwined constructs, and multiple measures are needed to understand the QoL of individuals with autism holistically.

The two assessment measures that were the focus of the investigation can be useful in creating multilevel and multidimensional assessment tools that provide guidance on how to support the internal and external dimensions of the quality of life of students with autism, without a remedial approach that differentiates people with ASD from the general population (Simões, et al., 2016). Moving the educational system from a defect/disability/pathology remedial orientation to the incorporation of an integrated, multifaceted QoL framework should be a priority of the educational agenda.

Reference

Accardo, A. L. (2017). College-bound young adults with ASD: Self-reported factors promoting and inhibiting success. *Division of Autism and Developmental Disorder (DADD) Online Journal*, 4, 36-46.

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*, 15(1), 7-20.

Chao, P. (2016, July). *Investigation of the self-determination skills and learning adjustment of Taiwanese college students with disabilities.* Paper presented at the International Conference on Social Science, Hokkaido, Japan.

Chao, P. (2018). Using self-determination of senior college students with disabilities to predict their quality of life one year after graduation. *European Journal of Educational Research, 7*(1), 1- 8.

Chiang, H.-M., & Wineman, I. (2014). Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders*, 8 (8), 974 - 986. https://doi.org/10.1016/j.rasd.2014.05.003.

Connor, D.J., Ferri, B.A., Annamma, A.S. (2016). *DisCrit. Disability Studies and Critical Race Theory in Education.* New York: Teachers College Press.

Cottini, L. (2024). *L'autismo in età adulta.* Roma: Carocci Editore.

Dijkhuis, R. R., Ziemans, T. B., Van Rijn, S., Staal, W. G., & Swaab, H. (2017). Self-regulation and quality of life in high-functioning young adults with autism. *Autism, 21*(7), 896-906. https://doi.org/10.1177/1362361316655525

Elias, R., Muskett, A. E., & White, S. W. (2019). Educator perspectives on the postsecondary transition difficulties of students with autism. *Autism: The International Journal of*

Research and Practice, *23*(1), 260–264.

Embregts, P. J. C. M., Taminiau-Bloem, E. F., Heerkens, G. C. J., Schippers, A., & van Hove, G. (2018). Collaboration in inclusive research: Competencies considered important for people with and without intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(3), 193-201. https://doi.org/10.1111/jppi.12248

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G* Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, *41*(4), 1149-1160.

Field, S. (2016). *Developing thoughtful learners: Supporting self-determination in postsecondary education*. In S. Field &D. R. Parker (Eds.) Becoming self-determined: Creating thoughtful learners in a standards-driven, admissions-frenzied culture (pp. 9–42). The Association on Higher Education and Disability.

García-Villamisar, D., Wehman, P., & Navarro, M. D. (2002). Changes in the quality of autistic people's life that work in supported and sheltered employment. A 5-year follow-up study. *Journal of Vocational Rehabilitation*, *17*(4), 309-312.

Gelbar, N., Madaus, J. W., Dukes, L., Fagella-Luby, M., Volk, D., & Monahan, J. (2020). Self-determination and college students with disabilities: Research trends and construct measurement. *Journal of Student Affairs Research and Practice*, *57*(2), 163–181.

Kamp-Becker, I., Schröder, J., Remschmidt, H., & Bachmann, C. J. (2010). Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *Psycho-social medicine*, *7*, Doc03. https://doi.org/10.3205/psm000065

Nadig, A., Flanagan, T., White, K., & Bhatnagar, S. (2018). Results of a RCT on transition support program for adults with ASD: Effects on self-determination and quality of life.

Autism Research, 11(12), 1712-1728. https://doi.org/10.1002/aur.2027

Nasamran, A., Witmer, S. E., & Los, J. E. (2017). Exploring predictors of postsecondary outcomes for students with autism spectrum disorder. *Education and Training in Autism and Developmental Disabilities, 52*(4), 343-356.

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school. *A report from the National Longitudinal Transition Study-2 (NLTS2*). SRI International. https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf

Newman, L. A., & Madaus, J. W. (2015). Reported accommodations and supports provided to secondary and postsecondary students with disabilities: National perspective. *Career Development and Transition for Exceptional Individuals, 38*(3), 173–181.

Ostasiewicz, K., & Zawadzki, A. (2024). Students' expectations about future jobs as a factor influencing their quality of life. Prace Naukowe Uniwersytetu Ekonomicznego We Wrocławiu, Wydawnictwo Uniwersytetu Ekonomicznego we Wrocławiu, 435, 2016, 98-111. http://dx.doi.org/10.15611/pn.2016.435.06

Rencher, A.C. (2002). *Methods of Multivariate Analysis*. Second edition. Wiley.

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Watner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with autism spectrum disorder. *Pediatrics, 129*(6). 1042-1049. https://doi.org/10.1542/peds.2011-2864

The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28,* 551-558.

White, S. W., Elias, R., Salinas, C. E., Capriola, N., Conner, C. M., Asselin, S. B., Miyazaki, Y., Mazefsky, C. A., Howlin, P., & Getzel, E. E. (2016). Students with autism spectrum

disorder in college: Results from a preliminary mixed method needs analysis. *Research in Developmental Disabilities, 2*5, 29- 40. https://doi.org//10.1016/j.ridd.2016.05.010

World Health Organization Quality of Life Assessment Group (WHOQOL) (1995) The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine 41*(10), 1403–1409.

Table 1

Means and Standard Deviations of Quality-of-Life Domains Per Demographic Area

Demographic	Physical Health		Psychological		Social Relationships		Environment		Total	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Gender/Sex										
Men	52.76	15.02	51.37	22.11	47.97	18.71	66.43	20.98	218.54	55.37
Women	43.80	11.73	46.80	14.18	48.00	29.03	49.26	19.66	187.86	47.35
Non-binary	33.00	10.73	39.00	13.83	67.00	24.16	42.00	26.15	181.00	35.34
Race/Ethnicity										
White	52.70	13.23	51.45	19.78	51.37	20.27	65.00	19.15	220.52	44.09
Black/African American	45.20	16.49	50.20	10.82	36.40	28.15	55.20	35.81	187.00	87.66
Hispanic/ Latino	32.87	11.84	36.00	21.70	49.25	29.20	40.75	17.91	158.87	46.94
Asian	48.00	19.31	54.00	22.06	44.00	25.00	54.33	31.72	200.33	65.85
Disabilities										
ASD Only	47.08	14.00	50.33	21.81	50.04	22.21	61.66	24.45	209.12	59.19
ASD +	50.34	15.75	48.46	18.56	48.81	22.81	58.90	21.26	206.53	50.14