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Characterizing Objective Quality of Life and Normative Outcomes in Adults with Autism Spectrum Disorder: An Exploratory Latent Class Analysis

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Abstract

This study aims to extend the definition of quality of life (QoL) for adults with autism spectrum disorder (ASD, *n*=180, ages 23-60) by: (1) characterizing the heterogeneity of normative outcomes (employment, independent living, social engagement) and objective QoL (physical health, neighborhood quality, family contact, mental health issues); and (2) identifying predictors of positive normative outcomes and good objective QoL. Findings of an exploratory latent class analysis identified three groups of adults with ASD–Greater Dependence, Good Physical and Mental Health, and Greater Independence. Findings indicate that better daily living skills, better executive function, and more maternal warmth are associated with assignment to better outcome groups. Findings have implications for interventions designed to enhance achievement of normative outcomes and objective QoL.

Keywords

heterogeneity; daily living skills; expressed emotion; maternal warmth; executive function

Introduction

The growing population of adults with autism spectrum disorder (ASD) has spurred increased interest in characterizing outcomes and quality of life (QoL) for this population. Research conducted to date generally indicates that a large majority of adults with ASD do not achieve the conventional markers of adulthood (i.e., becoming self-supporting, living

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Author contribution: Dr. Bishop-Fitzpatrick conceptualized the analytic method, conducted the statistical analyses, developed composite case studies, wrote the initial draft of the manuscript, and revised the manuscript to address reviewer comments. Drs. Hong and Smith provided guidance on the design of the study and the statistical analyses and participated in the manuscript development and revisions. Ms. Makuch helped to conceptualize the three classes and composite case studies based on her extensive knowledge of study participants. Drs. Mailick and Greenberg designed the larger study from which the data were drawn, participated in the formulation of the research questions, provided consultation on statistical analyses, and participated in the manuscript development and revisions. Dr. Mailick is the lead PI of the study.

Conflict of Interest: Dr. Bishop-Fitzpatrick, Dr. Hong, Dr. Smith, Ms. Makuch, Dr. Greenberg, and Dr. Mailick declare that they have no conflict of interest.

Informed consent: Informed consent was obtained from all individual participants included in this study.

independently, and developing a network of friends). Their normative adult outcomes have thus been characterized as poor (e.g., Howlin et al. 2004; Eaves and Ho 1996; Seltzer et al. 2004). Improvement in functioning, or "recovery" from ASD, has been noted in a very small proportion of individuals diagnosed with ASD in childhood whose autism symptoms eventually diminish to the point that they no longer meet diagnostic criteria (Anderson et al. 2014), although these individuals generally still retain impairments that interfere with completely independent functioning and thus require some ongoing supports (Farley and McMahon 2014).

Fully characterizing the complex nature of adult life for all individuals, including individuals with ASD, necessarily goes beyond normative markers such as living independently and being self-supporting to include other aspects of QoL that further refine what it means to have a good life. For example, having good physical and mental health, adequate living conditions, and supportive and fulfilling social relationships can be conceptualized as factors that define a basic quality of life (Felce and Perry 1995). In individuals with intellectual disabilities, QoL has been conceptualized as a multi-element framework, including domains of emotional well-being, interpersonal relationships, material well-being, personal development, and physical well-being (Schalock 2004). Within the ASD literature, a small body of research has focused on QoL in adults with ASD in order to characterize outcomes more holistically. For example, Ruble and Dalrymple (1996) suggest an alternate model of "good outcomes" that takes into account objective markers of QoL (e.g., working in valued jobs, participating in family and community activities, learning to make choices, generally feeling happy). The generalizability of this research on normative outcomes and QoL in adults with ASD is limited, however, by a lack of consensus on how to best measure these important facets of functioning.

Beyond expanding the conceptualization of normative outcomes and objective QoL for adults with ASD, there is a need to (1) characterize the heterogeneity of normative outcomes and objective QoL among adults with ASD and (2) identify predictors of good outcomes and QoL. Longitudinal research conducted to date indicates that intelligence quotient (IQ) and verbal communication ability in early childhood are consistent predictors of improvements in ASD symptomatology in mixed IQ groups of adults who were diagnosed with ASD as children, although the association between these factors and outcomes tends to be less strong within groups of individuals without co-occurring intellectual disabilities (e.g., Cederlund et al. 2008; Farley and McMahon 2014; Howlin et al. 2004). In adulthood, independence in daily living skills emerges as a strong and significant predictor of symptom and behavioral profiles for adults with ASD (Woodman et al. 2015). In addition, increased maternal warmth and reduced maternal criticism are associated with decreased repetitive behaviors and autism symptoms over time (Greenberg et al. 2006; Smith et al. 2008). However, more research is needed to examine whether predictors of improvements in autism symptomatology and behavior profiles identified by extant research are also associated with normative outcomes and objective QoL.

The current research aims to advance conceptualization of QoL for adults with ASD by encompassing indicators of both normative outcomes (employment, independent living, social engagement) and objective QoL (good physical and mental health, quality of

neighborhood, family contact). The first goal of this research is to characterize the heterogeneity of outcomes for adults with ASD by identifying discrete groups of adults with ASD in terms of normative outcomes and objective QoL. The second goal is to identify predictors of group membership among adults with ASD. We hypothesized that adults with ASD who did not have an intellectual disability (ID), those who had better daily living skills, and those who were exposed to higher levels of maternal warmth and lower levels of maternal criticism would have better normative outcomes and objective QoL. Composite case studies illustrate the strengths and challenges of individuals in each discrete group.

Methods

Participants

Participants were drawn from an ongoing longitudinal study, the Adolescents and Adults with Autism Study (AAA; Seltzer et al. 2011), of 406 individuals with ASD and their families living in Wisconsin (n = 202) and Massachusetts (n = 204). Participants were recruited via agencies, schools, diagnostic clinics, and media announcements using identical recruitment procedures in both Wisconsin and Massachusetts.

In order to participate in the study, families had to meet a set of three inclusion criteria: (1) the family had a son or daughter 10 years of age or older; (2) the child had received a diagnosis on the autism spectrum from a medical, psychological, or educational professional, as reported by parents; and (3) administration of the Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994) confirmed the parental report of an ASD. Of the 406 individuals in the sample, 384 (94.6%) met all criteria for Autistic Disorder on the ADI-R (qualitative impairments in communication and language; qualitative impairments in reciprocal social interaction; repetitive, restrictive, and stereotyped behaviors; and onset of symptoms prior to 36 months). The remaining 22 individuals (5.4%) did not meet full diagnostic criteria for Autistic Disorder on the ADI-R but demonstrated a pattern of impairments on the ADI-R consistent with their parent-reported diagnosis of Asperger's disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and thus were also included in the sample.

The individuals included in the present research were 180 adults with ASD for whom outcome variable data were available from the 2011-2012 wave of data collection. Participants were between the ages of 23 and 60 (M= 33.5, SD = 7.9). The majority were male (75.0%), and more than half had been diagnosed with a co-occurring intellectual disability (52.2%).

Measures

We conceptualized QoL as reflecting three indicators of normative outcomes (social engagement, competitive employment, independent or semi-independent living) and four indicators of objective QoL (good physical health, good mental health, good quality of neighborhood, frequent contact with siblings and extended family). Each indicator was converted to a dichotomous variable where poor outcomes/QoL was coded as 0 and good outcomes/QoL was coded as 1. Normative standards were used as benchmarks to determine

"good" outcomes. These seven indicators were used to create the classes that characterize the heterogeneity of QoL in adults with ASD.

Normative Adult Outcomes

Employment: Based on the approach outlined in Taylor and Seltzer (2011), we coded employment status as competitively employed for 10 or more hours per week (1) or others (0).

Independent living: Independent living was dichotomized in order to represent those individuals who live either fully or semi-independently (1) and others (0). Our conceptualization of independent or semi-independent living included a range of living situations, from individuals who lived in their own home or apartment to individuals who lived with roommates but had regular but not full-time oversight by staff and/or family (i.e., less than 100% of the time).

Social engagement: Mothers reported the frequency of their son or daughter's socializing with friends or neighbors, and social engagement was dichotomized as individuals who socialized with friends or neighbors once per month or more often (1) and others (0).

Objective QoL

Physical health: Health status of the person with ASD was rated by the mother on a scale that has been shown to be a valid and reliable indicator of health and mortality (Idler and Benyamini 1997). Individuals who were rated as having good or very good physical health scored a 1, while all other individuals scored a 0.

Mental health: Mothers reported whether their child with ASD had a co-occurring mental health condition that was diagnosed by a medical provider. Conditions included were anxiety disorders, bipolar disorder, major depression, obsessive compulsive disorder, oppositional defiant disorder, post-traumatic stress disorder, and schizophrenia. Individuals with ASD who had a co-occurring mental health condition were given a score of 0, and individuals who did not were given a score of 1.

Quality of neighborhood: The degree of neighborhood disadvantage was scored using a method developed by Weden and colleagues (2008) with geocoding techniques based on the 2010 Census and the FFIEC Geocoding/Mapping System. This method scores neighborhood disadvantage based on indicators of neighborhood quality, including air quality, upkeep, safety, recreation, abandoned buildings, and litter. Total scores are computed on a five-point Likert scale where 1=very high neighborhood disadvantage and 5=very low neighborhood disadvantage. Individuals who were rated as living in neighborhoods with low or very low neighborhood disadvantage were assigned a score of 1, while individuals who lived in other neighborhoods were assigned a score of 0.

<u>Family contact</u>: Mothers reported the frequency of contact the adult with ASD had with siblings and extended family, excluding parents. Individuals who scored a 1 saw a sibling or extended family member weekly or more often, while all other individuals scored a 0.

Predictors of Class Membership—Intellectual disability status, age, lifetime autism symptomatology, daily living skills, executive function, maternal warmth, and maternal criticism were included as predictors of class membership for the purpose of this research. Data for the first three predictors of class membership were collected at earlier waves of the study, while the last four measures were collected concurrently with our normative outcome and objective QoL data.

Intellectual disability (ID) status: ID status was determined using a variety of sources including the Wide Range Intelligence Test (Glutting et al. 2000), the Vineland Screener (Sparrow et al. 1993), and a review of available educational records. For a full description, see Taylor and Seltzer (2010).

Age: Age was recorded based on date of birth.

Lifetime autism symptomatology: The Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994) is a standardized diagnostic interview administered to the parent, which conforms to the diagnostic criteria for Autistic Disorder in the DSM-IV (American Psychiatric Association 2000). The interviewers participated in an approved training program for the ADI-R, and all interviews were tape recorded. This study used measures of lifetime autism symptoms and behaviors collected at the beginning of the longitudinal study. Past research has established the reliability, validity, specificity, and sensitivity of the ADI-R (Hill et al. 2001; Lord et al. 1997). We reported in past research (Taylor et al. 2014) on the inter-rater reliability of the ADI-R in our larger longitudinal study. Findings indicated that inter-rater reliability between the two interviewers and two supervising doctoral-level clinical psychologists averaged 89%, mean $\kappa = .81$.

Daily living skills: The Waisman Activities of Daily Living Scale (W-ADL; Maenner et al. 2013) was used to assess daily living skills. Mothers rated the relative level of independence of the adult with ASD in 17 activities of daily living (e.g., preparing simple foods, grooming, managing finances) on a 3-point scale (0 = does not do at all, 1 = could do but does not/does with help, 2 = independent). Total scores were averaged across questions, and higher scores are indicative of better daily living skills. Reliability of the W-ADL was strong for the entire sample of adults with ASD ($\alpha = .93$), and reliability was comparable by age group (i.e., young adult, ages 23-35, vs. middle-aged adult, ages 36+) and living status (i.e., lives fully or semi-independently vs. others).

Executive function: Executive function was measured using the adult version (Roth et al. 2005) of the Behavior Rating Inventory of Executive Function (BRIEF-A; Gioia et al. 2000; Gioia et al. 2002), a 75-item, informant-report (here, mother-report) scale that measures executive function in the domains of behavior regulation, emotion regulation, and metacognition. This research used the Global Executive Composite, which is a composite of two index scores, the Behavioral Regulation Index (Inhibit, Shift, Emotional Control, Self-Monitor) and the Metacognitive Index (Initiate, Working Memory, Plan/Organize, Task Monitor, Organization of Materials). Higher scores are indicative of poorer executive function. Reliability of the BRIEF-A was strong for the entire sample of adults with ASD (a = .89), and reliability was comparable by age group and living status.

Maternal criticism: The Five Minute Speech Sample was used to code maternal criticism based on the coding manual developed by Magaña and colleagues (1986). Mothers were asked to speak for five uninterrupted minutes about their child with ASD. The speech sample was tape recorded, transcribed, and independently coded for components of expressed emotion, including warmth and criticism, among others by a single rater with over 20 years of experience in coding the Five Minute Speech Sample. We reported in previous research (Greenberg et al. 2006) on the inter-rater reliability of our expressed emotion (Five Minute Speech Sample) data, including maternal warmth and maternal criticism. Findings indicated that agreement between our initial experienced rater and a second experienced rater was high, with 83.3%, $\kappa = .67$, agreement between the two raters. Number of critical remarks during the Five Minute Speech Sample were coded, with a minimum of 0 critical remarks and a maximum of 8 critical remarks.

Maternal warmth: Maternal warmth ratings were coded from the Five Minute Speech Sample. Ratings of maternal warmth were based on guidelines established by the Camberwell Family Interview (Vaughn and Leff 1976) and based on (a) tone of voice; (b) spontaneity of expression of sympathy; and (c) expression of interest in the child with ASD. Level of warmth was rated on a 5-point scale where 0 represented no warmth and 4 represented high warmth. As noted above, inter-rater reliability for our maternal warmth measure reported in previous research was high (Greenberg et al. 2006).

Additional Descriptive Variables

Although not used as predictors, we also report on additional descriptive variables in order to better characterize the groups of adults with ASD that were identified by our analyses. These measures included biological sex, age of diagnosis, primary diagnosis, family living status, and psychotropic medication use. Data for the first three descriptive variables were collected at earlier waves of the study, while the last three measures were collected concurrently with our normative outcome and objective QoL data.

Biological sex—Biological sex was recorded based on parent report.

Age of diagnosis—Age at first ASD diagnosis was reported by mothers as well as the specific diagnosis on the autism spectrum (Autistic Disorder, Asperger's disorder, or PDD-NOS), and the youngest age of diagnosis was recorded for individuals who reported an age of diagnosis for more than one category of ASD.

Primary diagnosis—Primary ASD diagnosis was reported by mothers as Autistic Disorder, Asperger's disorder, PDD-NOS, or other.

Family living status—Respondents were asked if the adult with ASD lived at home with his or her parents. Individuals who lived with their parents scored a 1, and individuals who did not live with their parents scored a 0.

Psychotropic medication use—Respondents were asked if the adult with ASD was currently taking any prescription psychotropic medications. Adults with ASD scored a 0 if

they were not taking any psychotropic medications and a 1 if they were taking one or more psychotropic medications. Experimental medications were not included.

Analytic Approach

Prior to investigating the primary analytic aims of this research, preliminary analyses were conducted to check assumptions associated with the statistical tests and inform the primary analyses about the potential effects of demographic heterogeneity. Missing data (6.1% of data on maternal warmth and maternal criticism) were imputed using the expectation-maximization algorithm, which results in less biased parameter estimates than mean or regression imputation (Dempster et al. 1977; Honaker et al. 2011; Schafer and Graham 2002; Schlomer et al. 2010).

The first objective of this research was to characterize the heterogeneity of outcomes for adults with ASD by identifying discrete groups of adults with ASD based on a combination of factors that are indicative of normative outcomes and objective QoL. Latent class analysis (LCA) was applied without a priori hypotheses about the nature of latent class categorization that might be found in order to identify and characterize classes of adults with ASD with similar normative outcome and objective QoL profiles. LCA is a type of mixture-model that characterizes classes (or groups) of similar cases within which the manifest variables used to measure class membership are statistically independent, among a set of categorical variables (Hagenaars and McCutcheon 2002; Linzer and Lewis 2011; Agresti 2002; Bandeen-Roche et al. 1997). In the current study, LCA was used in order to identify the smallest number of classes of adults with ASD required to account for the observed associations between manifest variables. Power estimates outlined by Dziak, Lanza, and Tan (2014) suggested that a sample size of 88 would be needed to detect a large effect (w=.5) for a model such as ours that included seven items. Multiple LCA models were fitted starting with a one-class model, increasing the number of classes to a 10-class model using R package poLCA (using R version 3.2.1), which is designed to handle polytomous outcome variables (Linzer and Lewis 2011) and performs well when using dichotomous outcome variables (Haughton et al. 2009). Bayesian information criteria (BIC) and Akaike information criteria (AIC) measures were compared across models, and the model that minimized both BIC and AIC was chosen as the best fitting model (Agresti 2002; Hagenaars and McCutcheon 2002; Bandeen-Roche et al. 1997). In addition, entropy values approaching one were deemed to be indicative of clear delineation of classes, which helped to confirm power estimates (Celeux & Soromenho 1996). Because poLCA does not automatically search for the best fitting model, a script was run in order to search for the best fitting LCA model among 500 iterations of two-to 10-class models (Haughton et al. 2009; Linzer and Lewis 2011).

The second objective of this research was to identify predictors of class membership among adults with ASD. In order to accomplish this, a multinomial logistic regression model (Hosmer et al. 2013) of class membership was used to test the extent to which individual factors predict class membership. Class membership was recorded for each individual for the best fitting LCA mode. Predictors were demographic characteristics (ID status, age) and descriptive characteristics (W-ADL, lifetime ADI social, lifetime ADI behaviors, executive function, maternal criticism, maternal warmth) that were not included in the LCA model,

although descriptive statistics for variables included in the multinomial logistic regression model are reported by class. This model expresses the effect of individual predictors on the odds that an adult with ASD will belong to one class over another.

Finally, we present composite cases that best represent individuals within each class.

Results

Characteristics of Adults with ASD

In the current sample of 180 adults with ASD, only 20.0% (n = 36) were competitively employed for 10 or more hours per week, 21.1% (n = 38) lived independently or semiindependently, and 27.8% (n = 50) socialized with friends or neighbors once a month or more often, all indicators of normative adult outcomes. In total, only 2.8% (n = 5) of our sample of adults with ASD achieved all three of these good normative outcomes. Adults with ASD fared somewhat better in their objective QoL ratings. Of the current sample, 80.0% (n = 144) had good or very good physical health and an equal number lived in a good or very good neighborhood. However, only half (47.8%; n = 86) did not have a co-occurring mental health condition and fewer than half (47.2%; n = 85) spent time with their siblings and extended family once a week or more often. In total, 13.9% (n = 25) of our sample of adults with ASD achieved all four of these indicators of objective QoL. However, only two individuals (1.11%) achieved all seven markers of good normative outcomes and objective QoL.

Of the adults with ASD in our sample who had been diagnosed with a co-occurring mental health condition (n = 86), the majority (80.2%) were diagnosed with anxiety disorder or obsessive-compulsive disorder (55.8%), while a smaller proportion of those individuals had diagnoses of depression (24.4%), bipolar disorder (11.6%), posttraumatic stress disorder (5.8%), oppositional defiant disorder (3.5%), or schizophrenia (3.5%). Percentages overlap because some individuals with co-occurring mental health conditions have more than one diagnosis.

Model Selection

Combined, the fit statistics displayed in Table 1 indicated that either a one- or three-class model was most appropriate. While the BIC statistic indicated that a one-class model was most appropriate (i.e., lowest BIC), the AIC statistic indicated that a three-class model was most appropriate (i.e., lowest AIC). However, examination of the distributions of manifest variables for the one- and three-class models suggested that the three-class model more accurately distinguished a group of individuals who were neither competitively employed nor living independently and was thus more parsimonious. Consequently, a three-class model consisting of Class 1 (Greater Dependence), Class 2 (Good Physical and Mental Health), or Class 3 (Greater Independence) was selected. Names of the three latent classes were chosen by the authors.

Classification Findings

Displayed in Table 2 are the conditional item response probabilities of the manifest variables for each latent class. Table 3 displays the characteristics of individuals who were predicted to belong to the three classes.

Results indicate that Class 1 is the largest (44.44%) of the three classes. None of the adults with ASD in this group were employed in competitive jobs, nor lived independently or semiindependently, and almost none of them socialized with friends at least monthly. Overall, the Greater Dependence group had the poorest overall normative outcomes (Table 3).

Class 2 (37.22%), labeled the Good Physical and Mental Health group, is comprised of individuals who are physically and mentally healthy and who live in a low disadvantage neighborhood, indicators of objective QoL. However, fewer than 10% live independently. As noted below, most (64%) lived with family.

Class 3 (18.33%) is the smallest of the three groups and is comprised of adults with ASD who are more independent, but are less physically and mentally healthy than the other two groups. Described here as the Greater Independence group, these individuals have the best overall normative outcomes, given that a large proportion of individuals classified in this group live independently or semi-independently and are competitively employed. With respect to their objective QoL, individuals classified into the Greater Independence group have more mental health problems, live in neighborhoods with greater disadvantage, and have poorer physical health than individuals classified into the Good Physical and Mental Health group.

Demographic and Descriptive Characteristics of Three Classes

In addition to manifest variables included in the LCA model, we analyzed differences between classes on a number of pertinent demographic and descriptive variables using a series of independent samples t-tests. Table 3 displays demographic and descriptive variables that further characterize participants who were determined to be members of each of the three classes.

Members of the Greater Dependence group differed significantly from members of the other two classes on several variables (see Table 3). They were more likely to have an intellectual disability, to have a primary diagnosis of Autistic Disorder, to have poorer daily living skills, and to be more impaired with respect to ADI social behaviors. Members of the Good Physical and Mental Health group and the Greater Independence group differed from each other in several respects. Members of the Good Physical and Mental Health group were more likely to live with parents, and their mothers were rated as expressing more warmth. Members of the Greater Independence group had better executive functioning but they had poorer mental health and their mothers were rated as expressing more criticism. Of note, the three groups were composed of between one-third and two-thirds of individuals with ID, and the Good Physical and Mental Health and Greater Independence groups do not differ in their likelihood of having a co-occurring ID.

Predictors of Class Membership

After individuals were classified into discrete classes, two simultaneous multinomial logistic regression models of class membership were developed in order to better understand the relationship between demographic and descriptive characteristics of the adults with ASD in our sample and their assignment to either the Greater Dependence, Good Physical and Mental Health, or Greater Independence groups. In order to fully characterize differences between pairs of groups (i.e., Class 1 vs. Class 2, Class 1 vs. Class 3, and Class 2 vs. Class 3), Class 1 (Greater Dependence) was set as the reference group for the first model, and Class 3 (Greater Independence) was set as the reference group for the second model. Table 4 presents summary statistics of these models, which are described below. Although reported in Table 4, results of the Model 2 contrast between Classes 1 and 3 are not reported in text because they are redundant with Model 1 results.

Good Physical and Mental Health vs. Greater Dependence (see Table 4, Model

1)—In Model 1, the likelihood of membership to the Good Physical and Mental Health group over membership to the Greater Dependence group increased by a factor of 1.106 for each additional point on the W-ADL (signifying greater independence in daily living skills), B = .101, $\chi^2(1) = 12.297$, p < .001, exp(B) = 1.107. In addition, the likelihood of membership to the Good Physical and Mental Health group over the Greater Dependence group decreased by a factor of .966 for each additional unit on the BRIEF-A (signifying fewer executive functioning limitations), B = ..035, $\chi^2(1) = 5.753$, p = .016, exp(B) = .966. There was no significant association between class membership and ID status, age, lifetime ADI social, lifetime ADI behaviors, or maternal criticism.

Greater Independence vs. Greater Dependence (see Table 4, Model 1)-

Similarly, the likelihood of membership to the Greater Independence group over membership to the Greater Dependence group increased by a factor of 1.189 for each additional point on the W-ADL, B = .173, $\chi^2(1) = 18.329$, p < .001, exp(B) = 1.189. In addition, the likelihood of membership to the Greater Independence group over membership to the Greater Dependence group decreased by a factor of .530 for each additional unit of maternal warmth, B = -.635, $\chi^2(1) = 5.256$, p = .022, exp(B) = .530. There was no significant association between class membership and ID status, age, lifetime ADI social, lifetime ADI behaviors, or maternal criticism.

Good Physical and Mental Health vs. Greater Independence (see Table 4,

Model 2)—The likelihood of membership to the Good Physical and Mental Health group over the Greater Independence group increased by a factor of 1.857 for each additional unit of maternal warmth, B = .619, $\chi^2(1) = 5.209$, p = .022, exp(B) = 1.857. There was no significant association between class membership and ID status, age, lifetime ADI social, lifetime ADI behaviors, or maternal criticism.

Overall, findings of multinomial logistic regression models related to predictors of class membership indicated that better daily living skills predicted membership to either the Good Physical and Mental Health or Greater Independence groups over the Greater Dependence group. Better executive function predicted membership to the Good Physical and Mental

Health group over the Greater Dependence group. Finally, more maternal warmth predicted membership to the Good Physical and Mental Health group over the Greater Independence group. Age, ID status, and autism symptomatology did not predict class membership.

Post-Hoc Analyses

Given the broad age range of participants in this study (i.e., 23 through 60), we performed a series of post-hoc analyses in order to assess the impact of age on our findings. These analyses divided participants into two age groups, young adult (n = 130, ages 23-35) and middle-aged adult (n = 50, ages 36+). Descriptively, the two groups differed in several respects. Middle-aged adults were more likely than young adults to have a co-occurring intellectual disability, $\chi^2 = 6.91$, p = .01, live outside of the family home, $\chi^2 = 14.12$, p < . 001, have been diagnosed with ASD later in childhood, t = -2.194, p = .03, and have a primary diagnosis of autism, $\chi^2 = 6.85$, p = .009. Middle-aged adults also had significantly poorer daily living skills, t = 2.81, p = .005, and greater impairments in social skills, t = -3.48, p = .001. These cohort differences motivated the examination of the major study analyses to determine if the patterns regarding adult outcomes held across cohorts.

We examined age effects with respect to (1) the extent to which the individuals in the two age groups differed in their achievement of normative outcomes and objective QoL, (2) the extent to which there were differences in the proportion of individuals in the two age groups who were classified into each of the three latent classes, and (3) whether age group (rather than a continuous measure of age) predicted class membership when the multinomial logistic regression analyses (Table 4) were repeated. We conducted these post-hoc analyses to best account for the potential differences between the two age groups in both the contexts that they experience and the likely cohort effects related to changing diagnostic and intervention practices for individuals with ASD during the past 20 years.

Findings of these post-hoc analyses revealed first that young adults and middle-aged adults fared similarly as a group in terms of their normative outcomes and objective QoL, except that a significantly larger proportion of young adults than middle-aged adults were engaged in competitive employment, t = 8.48, p = .004. Second, the proportion of individuals classified into each of the three latent classes did not differ by age group, $\chi^2 = 3.76$, p = .15. Finally, results of the two multinomial logistic regression models were equivalent when continuous age was replaced with age group.

Case Examples

The following cases, which represent anonymized composite cases, provide examples of individuals classified into each of the three groups.

Greater Dependence—Jacob, age 44, was diagnosed with an intellectual disability at two years, but was given an autism diagnosis at age six. He is able to respond to questions with one-word answers and point to things that he wants, although his parents describe him as being more aware of the world than he is able to verbalize. Jacob is very interested in watches and has a difficult time focusing on the world around him when someone in the room is wearing a watch that he has not examined before. He enjoys participating in

recreational activities with other individuals with disabilities several times per week. Jacob also attends church services and sees his sister and extended family several times per month. He currently participates in an adult day program and a sheltered workshop, and he lives with his parents. Jacob's parents have expressed concerns about what will happen to him following their death.

Good Physical and Mental Health—Alex, age 23, was diagnosed with autism at the age of five, although her parents first noticed that something was different around 18 months. She has an average IQ score. Alex's parents are well-educated: her father has a high-level professional job and her mother stayed home in order to help manage her care. Alex was very involved in school as a child and adolescent, and even served as the manager for the basketball team during high school, largely because of the high-quality special education services in her local school district. After graduating from high school, Alex matriculated to the local community college where she is studying graphic design, and she spends her weekends working at a local bead store owned by a family friend. She lives with her parents, who help her eat healthy meals and get to and from work and school. Alex's parents are hopeful that she will be able to matriculate to a four-year college after finishing her associate's degree this year, and have plans to purchase an apartment for her close to school that she can live in with a roommate.

Greater Independence—Rich, age 31, was diagnosed with Asperger's disorder at the age of seven after struggling with behavioral control and social interaction for much of his early childhood. He also has co-occurring anxiety and depression. While Rich has an IQ over 130, graduated from college, and completed a Ph.D. in Medieval Studies, he moved back home after finishing his education and was unable to find a job for a year. He now lives on his own in a studio apartment close to downtown and works full-time at a bank as a data management specialist, making slightly above minimum wage. Although Rich was able to establish some friendships with individuals living in his dorm in college, he was unable to maintain those friendships after moving out of the dorm. In his free time, Rich travels to gaming conventions and is trying to find a girlfriend who shares his interests in role-playing games (specifically, Dungeons and Dragons).

Discussion

This study sought to describe normative outcomes and objective QoL in adults with ASD, characterize the heterogeneity of normative outcomes and objective QoL, and identify predictors of QoL in this population. Findings from the current study align with a growing body of research that characterizes outcomes and QoL for adults with ASD as relatively poor (e.g., Levy and Perry 2011; Howlin et al. 2004; Seltzer et al. 2004; Anderson et al. 2014). Overall, only two individuals in our study achieved all seven markers of normative outcomes and objective QoL, a finding that further supports this characterization. In terms of normative outcomes, the great majority of adults with ASD in our sample were unemployed, did not live independently or semi-independently, and did not socialize with friends even monthly. Their objective QoL was somewhat better: most of the adults with ASD in our sample were physically healthy and lived in good neighborhoods. However, only about half

saw their siblings and extended family frequently and nearly half had a co-occurring mental health condition.

Our analyses classified adults with ASD into three groups with distinct patterns of normative outcome and objective QoL. The first group was the largest and was comprised of individuals who experienced "Greater Dependence." These individuals generally did not live independently or semi-independently, work in a competitive job, or spend time with friends. They also tended to have poorer daily living skills, which limited their level of overall independence. The Greater Dependence group had the worst overall normative outcomes and objective QoL. The case of Jacob illustrated the Greater Dependence group well as he is an individual who has very limited independence, but who experiences a degree of satisfaction from the supported social and vocational experiences that he has on a regular basis. However, like many parents, Jacob's parents are concerned about his future QoL after their death.

The second group was the "Good Physical and Mental Health" group and was comprised of individuals who are physically and mentally healthy and live in good neighborhoods. The individuals classified into the Good Physical and Mental Health group experienced better normative outcomes than individuals in the Greater Dependence group. Individuals classified into the Good Physical and Mental Health group are distinguished from individuals in the Greater Independence group by greater maternal warmth and continued co-residence with parents. The case of Alex describes a woman who has succeeded in school despite her many challenges and who has parents who have helped her immensely to find a place for herself in which she can contribute and find a degree of stability.

Finally, the third group is the "Greater Independence" group. These individuals tended to be employed in competitive jobs and live independently. However, their lives are not without challenges. Interestingly, individuals in the Greater Independence group experienced objective QoL that did not differ markedly from that of individuals in the Greater Dependence group, although their normative outcomes were better. Rich illustrated the Greater Independence group well in that he was able to complete college and obtain an advanced degree, but he did not find work in his field and struggled to maintain his independence and social relationships despite his many successes.

This research additionally sought to identify predictors of membership to these three classes. Findings indicated that better daily living skills predicted membership in either the Good Physical and Mental Health or Greater Independence classes over the Greater Dependence class. Additionally, better executive function predicted membership to the Good Physical and Mental Health class over the Greater Dependence class. Findings also indicated that more maternal warmth and better executive function predicted membership to the Good Physical and Mental Health class over the Greater Independence class. Notably, age, ID status, and autism symptomatology did not predict class membership.

Our post-hoc analyses examined the impact of age group (i.e., young adults versus middleaged adults) on class membership in order to assess potential cohort effects related to changing diagnostic and early intervention practices. Interestingly, results of these analyses

did not reveal any statistically significant differences in the proportion of young adults or middle-aged adults assigned to each of the three classes. With the exception of our finding that a significantly greater proportion of young adults than middle-aged adults were competitively employed, these two age groups did not differ significantly in their normative outcomes or objective QoL. This finding is unexpected because of hypothesized cohort effects, yet suggests that factors unrelated to early diagnosis and intervention may lead to differing patterns of normative outcomes and objective QoL for all adults regardless of age.

Although limited in scope, there is some evidence in the literature that indicates that there may be a small number of individuals with ASD who experience relatively good outcomes, and subsequently few challenges, in adulthood (Anderson et al. 2014; Cederlund et al. 2008; Eaves and Ho 1996; Farley and McMahon 2014; Howlin et al. 2004). Our results reveal that, indeed, there may be a number of individuals with ASD who experience greater independence in adulthood, an outcome that many might classify as a "good outcome." However, independence does not come without a number of challenges and greater potential for instability and, in turn, poorer QoL, for the adults with ASD classified into the Greater Independence group. It is important to note that individuals with better normative outcomes in our sample largely experienced poorer overall objective QoL. This finding that good normative outcomes do not necessarily lead to good objective QoL in adults with ASD indicates that the bigger picture of outcomes and QoL for adults with ASD is more nuanced than expected. It is possible that the Greater Independence group, with their high rates of cooccurring mental health diagnoses, may have an increased likelihood of having strained relationships with family.

The conceptualization of normative outcomes and objective QoL reported herein may set the bar too high for adults with ASD. For example, many individuals without ASD do not see siblings or extended family on a weekly basis. However, literature on the perspectives of individuals with ASD (e.g., Sperry and Mesibov 2005) and their parents (e.g., Cooney 2002) indicates that there is a great desire for full social inclusion in adulthood that necessarily incorporates the development and maintenance of interpersonal relationships, involvement in competitive and stimulating work environments, and maintenance of good physical and mental health. Thus, we argue that while our conceptualization of good normative outcomes and objective QoL may be a high bar relative to the current realities for individuals in contemporary society, this conceptualization represents the desires of many adults with ASD and their families. It must be noted, however, that while a very small proportion of adults with ASD in our sample achieve fully "good" normative outcomes and objective QoL as it is conceptualized herein, there are many ways in which adults with ASD can have a good life, with objective QoL being good for most in the sample. For example, in the case of Alex, although she was not living independently, she had good health, was employed in a fulfilling job, and had good QoL with her family's support. This finding aligns with the developmental psychopathology concept of equifinality, which posits that the same outcome (i.e., having a good life) can be reached via a number of different developmental pathways (Cicchetti and Rogosch 1996).

This study is not without limitations. One limitation is that the included individuals had been participating in research for almost 15 years at the time of data collection, and thus may not

be representative of all adults with ASD whose families are not accustomed to participating in research. In addition, the individuals in the current sample are primarily of European American descent and come from relatively highly-educated families, thus limiting the generalizability of findings to individuals from different racial, ethnic, and/or socioeconomic groups. Finally, our sample had a higher proportion of individuals with ID (52.2%) than would be expected in the general population of individuals with ASD based on the most recent estimates from the Centers for Disease Control and Prevention (CDC) of 31% with a co-occurring ID (CDC, 2014), which potentially limits the generalizability of our findings.

Despite these limitations, a number of conclusions and implications for practice and future research can be drawn from our findings. This research proposed a broad conceptualization of normative outcomes (employment, independent living, social engagement) and objective QoL (physical and mental health, quality of neighborhood, family contact) that takes into account many facets of life, is long-term in nature, and may be variable over time. Interestingly, our findings indicate that normative outcomes and objective QoL for adults with ASD may be quite nuanced; having good normative adult outcomes may not necessarily be accompanied by good objective QoL, and vice versa. This finding has important implications for research and practice in the development of treatments and interventions designed to improve outcomes for adults with ASD. These interventions should include activities of daily living interventions for individuals with ASD of all ages and family support to promote warmth. A continued need for mental health services for adults with ASD is evident in the results of this research. It is additionally important for clinicians, researchers, and policymakers to note that an individual who appears to be doing well in terms of their normative outcomes may, in fact, have QoL that is quite poor in other respects. Thus, future research should take care to both classify observed outcomes and individuals' satisfaction with life when evaluating the impact of interventions and services.

Notably, there appears to be a relatively strong association between better daily living skills and membership to a group with better normative outcomes and objective QoL. In addition, greater maternal warmth also seems to predict membership to a group with better normative outcomes and objective QoL. These predictors of normative outcomes and objective QoL are likely modifiable and could thus be targeted by interventions in the future. The development of an intervention that targets daily living skills among adults with ASD is a logical next step, especially considering the lack of available and effective psychosocial interventions for adults with ASD (Bishop-Fitzpatrick et al. 2013; Smith, Greenberg, & Mailick 2012).

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Table 1

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Fit Statistics for Latent Class Model (N = 180)

# of Classes	df	BIC	AIC	G2	χ^2	Relative Entropy
1	120	1473.20	1450.85	152.21	217.33	-
2	112	1483.12	1435.22	120.59	210.54	.716
3	104	1490.65	1417.22	86.58	136.31	.700
4	96	1520.79	1421.80	75.17	71.38	.694
5	88	1551.84	1427.31	64.68	60.96	.688
9	80	1582.73	1432.66	54.02	52.62	.683
7	72	1616.22	1440.60	45.97	48.33	.678
8	64	1651.07	1449.92	39.28	38.11	.674
6	56	1686.28	1459.58	32.94	35.99	.670
10	48	1721.42	1469.18	26.54	28.81	.668

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((Class 1 Gre	ater Dependence (N=80)	<u>Class 2</u> Good Ph	Class 1 Greater Dependence (N=80) Class 2 Good Physical & Mental Health (N=67) Class 3 Greater Independence (N=33)	Class 3 Great	ter Independence (N=33)
Variable	pr(1)	pr(2)	pr(1)	pr(2)	pr(1)	pr(2)
Competitively employed $(N = 36)$	1.000	0.000	.6873	.3127	.5987	.4013
Lives Independently $(N = 38)$	1.000	0.000	.8450	.1550	.2428	.7572
Sees friends at least monthly $(N = 50)$.9254	.0746	.5453	.4547	.6367	.3633
Has good physical health $(N = 143)$.2597	.7403	0.000	1.000	.4568	.5432
Has good mental health $(N = 86)$.5754	.4246	.2640	.7360	.9036	.0964
Lives in a good neighborhood ($N = 143$)	.3523	.6477	.0138	.9862	.2379	.7621
Sees family weekly or more often $(N = 84)$.4258	.5742	.6762	.3238	.4571	.5429
Predicted class population shares		44.44%		37.22%		18.33%

Note. The N for each column refers to the number of participants classified into each latent class; pr(1) is the probability of a poor outcome (e.g., not being employed; pr(2) probability of a good outcome (e.g., being employed). The N for each row refers to the number of participants who met criteria for a "good outcome" (i.e., score of 1) for each marker of normative outcomes and objective QoL.

			Characterist	Characteristics of Classes				Contrasts	
Variable	Class 1 Greater Dependence (N=80)	lence	<u>Class 2</u> Good Physical & Mental Health (N=67)	ysical & Mental (N=67)	<u>Class 3</u> Greate (N	<u>Class 3</u> Greater Independence (N=33)	1v2	1v3	2v3
	No Yé	Yes	No	Yes	No	Yes			
Competitively employed	80 0		44	23	20	13	1<2 ***	1<3 ***	
Lives Independently	80 0		58	6	4	29	1<2 ***	1<3 ***	2<3 ***
Sees friends at least monthly	78 2		32	35	20	13	1<2	1<3 ***	
Has good physical health	20 60	0	0	67	16	17	1<2	1>3 *	2>3 ***
Has good mental health	48 32	2	15	52	31	2	1>2 ***	1>3 ***	2>3 ***
Lives in a good neighborhood	28 52	2	0	67	8	25	1<2 ***		2>3 ***
Sees family weekly or more often	30 50	0	51	17	15	18	1>2 ^{***}		2<3 **
Demographic and Descriptive Variables (Not Included in LCA) Has intelloctual dissibility N(%)	luded in LCA) 55(68 75)		27(40.30)	30)	6)61	12(36 36)	* * -		
				(0.00		(2000	4/1		
Male, <i>N(%)</i>	55(68.75)		55(82.08)	.08)	25(7	25(75.76)	$1{<}2^{\acute{\tau}}$		
Age, mean(SD)	34.74(8.65)		32.39(7.38)	7.38)	32.88	32.88(6.91)	$_{1>2}\dot{\tau}$		
Does not use psychotropic medications, $N(\%)$	19(23.75)		19(28.36)	:36)	7(2	7(21.21)			3>2**
Lives with family, $N(\%)$	33(41.25)		43(64.18)	.18)	4(1)	4(12.12)	1<2 **	1>3 **	2>3 **
Age of first ASD diagnosis, <i>mean(SD)</i>	5.46(3.95)		6.44(4.58)	1.58)	6.73	6.73(3.93)			
Primary diagnosis of autism, $N(\%)^{a}$	66(82.5)		36(53.73)	:73)	15(4	15(45.45)	1>2 ***	1>3 ***	
Primary diagnosis of Asperger's, $N(\%)^{a}$	3(3.75)		14(20.90)	(06)	8(2	8(24.24)	1<2 **	1>3 **	
Primary diagnosis of PDD-NOS, $N(\%)^{d}$	7(8.75)		10(12.5)	2.5)	7(2	7(21.21)		$1>3$ $\dot{\tau}$	
W-ADL, mean(SD)	17.56(6.41)		23.59(7.96)	7.96)	25.36	25.36(6.13)	1<2 ***	1<3 ***	
Lifetime ADI Social, mean(SD)	25.75(3.02)		24.31(3.97)	3.97)	24.12	24.12(4.09)	$1{>}2^{*}$	1 > 3 *	
Lifetime ADI Behaviors, mean(SD)	7.01(2.42)		6.96(2.56)	2.56)	7.67	7.67(2.46)			
Executive Function (BRIEF), mean(SD)	61.75(14.58)		53.81(11.38)	11.38)	58.64	58.64(13.87)	$1 > 2^{***}$		$2{<}3^{\dagger}$

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Table 3

Characteristics of Three Classes

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			Characterist	Characteristics of Classes				Contrasts	
Variable	<u>Class 1</u> Greater Dependence (N=80)	er Dependence 80)	<u>Class 2</u> Good Physical & Mental Health (N=67)	ysical & Mental (N=67)	<u>Class 3</u> Greater Independence (N=33)	Independence 3)	1v2	1v3	2v3
	No	Yes	No	Yes	No	Yes			
Maternal Warmth, mean(SD)	3.00(1.09)	1.09)	3.28(.97)	(27)	2.72(.83)	83)			2>3 **
Maternal Criticism, mean(SD)	.60(1	.60(1.40)	.19(.55)	.55)	.41(.75)	⁷ 5)	$_{1>2}^{\circ}$		$2 < 3 t^{\dagger}$
$\dot{\tau}^{\dagger}_{p}$ < .10,									
* p <.05,									
$\substack{**\\p<.01,}$									
$^{***}_{P < .001;}$									
a Does not equal 100% because some mothers reported non-ASD primary diagnoses	ported non-ASD print	tary diagnoses							

Table 4	
Multinomial Logistic Regression Predicting Class Membership	

		В	SE	O.R.
Iodel 1				
Class 1: Greater Dependence		Refere	nce Gro	up
Class 2: Good Physical and Mental Health	ID Status	316	.397	.729
	Age	036	.024	.965
	W-ADL	.101	.029	1.106**
	Lifetime ADI Social	025	.058	.975
	Lifetime ADI Behaviors	061	.083	.941
	Executive Function	035	.014	.966*
	Maternal Criticism	556	.303	.573 <i>†</i>
	Maternal Warmth	016	.233	.984
Class 3: Greater Independence	ID Status	.201	.501	1.222
	Age	025	.031	.976
	W-ADL	.173	.040	1.189**
	Lifetime ADI Social	016	.072	.984
	Lifetime ADI Behaviors	.002	.100	1.002
	Executive Function	005	.020	.995
	Maternal Criticism	494	.283	.610†
	Maternal Warmth	635	.277	.530*
Aodel 2				
Class 1: Greater Dependence ^a	ID Status	201	.501	.818
	Age	.025	.031	1.025
	W-ADL	173	.040	.841 ***
	Lifetime ADI Social	.016	.072	1.016
	Lifetime ADI Behaviors	002	.100	.998
	Executive Function	.005	.020	1.005
	Maternal Criticism	.494	.283	$1.639^{ t\! t}$
	Maternal Warmth	.635	.277	1.888*
Class 2: Good Physical and Mental Health	ID Status	517	.495	.597
	Age	011	.032	.989
	W-ADL	072	.039	.930 [†]
	Lifetime ADI Social	009	.066	.991
	Lifetime ADI Behaviors	063	.094	.939
	Executive Function	030	.019	.971
	Executive Function	050	.017	.,,1

		В	SE	O.R.
	Maternal Warmth	.619	.271	1.857*
Class 3: Greater Independence		R	eference	Group
† p < .10,				

* p < .05,

** p <.01,

*** p < .001, Nagelkerke R² = .318

^aResults of the contrast between Class 1 and Class 3 in Model 2 mirror results of the Model 1 contrast between Class 1 and Class 3.

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