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Defining Positive Outcomes in More and Less Cognitively Able Autistic Adults

James B. McCauley, Andrew Pickles, Marisela Huerta, Catherine Lord

Abstract

Identifying positive outcomes for a wide range of intellectual abilities in autism spectrum disorder (ASD) remains a challenge. Several past studies of autistic adults have used outcome definitions that do not reflect the experiences of less cognitively able adults. The aim of the current study was to (1) define three domains of outcomes: autonomy, social relationships, and purpose, and (2) examine how these outcomes relate to concurrent aspects of adult functioning. Using data from a longitudinal sample of 126 adults (85% diagnosed with ASD at some point), mean age 26, who first entered the study in early childhood, we generated distinct outcomes for less (daily living skills above an 8-year-old level, having regular activities outside the home, and social contacts outside the family) and more cognitively able adults (living independently, having paid employment, and at least one true friend). Verbal IQ, assessed in adulthood, was a significant predictor of more outcomes achieved for individuals within more and less cognitively able groups. For less cognitively able adults, having ever received a formal ASD diagnosis (in contrast to current Autism Diagnostic Observation Schedule [ADOS] CSS scores) was associated with lower odds of positive outcomes. For more cognitively able adults, living skills and happiness measures were positively associated with number of outcomes met; higher ADOS CSS, internalizing and externalizing symptoms, being racially diverse, and having caregiver education below college graduation were all negatively associated with the number of positive outcomes. Tailoring outcomes to ability levels may lead to better identification of goals and service needs.

Lay Summary

This article describes the outcomes of autistic adults who are more and less cognitively able. For less cognitively able individuals, an earlier autism diagnosis was negatively related to outcomes. Several factors that were associated with positive outcomes for more cognitively able individuals, including daily living skills, fewer mental health problems, family demographics, and subjective measures of happiness. Our study identifies several important factors for families, individuals, and service providers to consider and discuss when planning the transition to adulthood. *Autism Res 2020, 13: 1548–1560*. © 2020 International Society for Autism Research, Wiley Periodicals, Inc.

1 Introduction

There is a great need for services and supports that enhance the outcomes of adults with autism spectrum disorder (ASD). However, a more fundamental question is how we best define quality outcomes in such a heterogeneous population. Research on outcomes and interventions for autistic adults often has a heavy focus on vocational activities and independence in living, yet for the estimated 30% of autistic people estimated to have co-occurring intellectual disability [ID; Baio et al., 2018]; paid full-time employment or independent living seldom reflects their lived experience. Furthermore, a focus solely on employment or living arrangements within a group of autistic people with higher IQ's may fail to capture social experience, which serves as a universal predictor of health [Cohen, 2004] and an important determinant of objective and subjective quality of life for autistic people and people with other neurodevelopmental conditions [Kapp, 2018]. In studies of autistic adults, findings have typically demonstrated small or non-significant relations between subjective and objective measures of quality of life [Hong, Bishop-Fitzpatrick, Smith, Greenberg, & Mailick, 2016; Mason et al., 2019]. Moreover, limited outcome definitions may have led to overestimations of poor outcome [Henninger & Taylor, 2013; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011]. The goal of the current study is to define outcomes for adults with

ASD that are practical and account for the diversity that exists within the population.

1.1 *What is a Good Outcome?*

In the general population, the transition to adulthood is an important developmental milestone that spans multiple domains and has major influence on later trajectories of mental health symptoms [Schulenberg, Sameroff, & Cicchetti, 2004]. However, some of the typical adult experiences, such as finding employment, living outside of the parent home, financial autonomy, and independently establishing relationships are not appropriate benchmarks for many autistic adults. Only a minority of autistic adults live on their own, have close friends, and have employment [Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004; Roux, Shattuck, Rast, & Anderson, 2017]. Some studies have used IQ and ASD diagnosis as markers of outcomes (Fein et al., 2013], but with high rates of stability in both the diagnosis of ASD and intelligence quotients, these too can be impractical as targets for change over time, though they remain predictive factors of improvement. Other papers have only examined outcomes of individuals with an IQ above 50 [Howlin et al., 2004]. Yet, it is important to consider a range of cognitive profiles within ASD.

New attempts to define and measure adult outcomes are warranted. These attempts should reflect the priorities of self-advocates and parent caregivers of adults. One useful framework comes from the World Health Organization's (WHO) International Classification of Functioning, Disability and Health. These guidelines outlined a good outcome more broadly as living a full and decent life with dignity, self-reliance, and active participation in the community [WHO, 2001]. Similarly, autistic self-advocates stressed autonomy, community inclusion, and employment that fit the need of the individual [Autistic Self Advocacy Network, 2019]. Mothers of adults with severe ID stressed recreational activities and social contacts as important considerations for quality of life assessment [Lee McIntyre, Kraemer, Blacher, & Simmerman, 2004]. From these considerations, we operationalized three broad domains for characterizing adult outcomes: autonomy, reflecting an individual's propensity to be as self-reliant as possible; social relationships, reflecting an individual's friendships and time spent with others; and purpose, reflecting an individual's activities, motivations, and engagement with the community to live a full life. A focus on autonomy, social relationships, and purpose for defining outcomes that can be adapted according to ability level may aid the description of autistic adults.

1.2 *Autonomy*

Autonomy in adulthood is evidenced in the propensity to make self-directed decisions and exert control over one's daily activities [Graves & Larkin, 2006]. For adults with average or above average cognitive ability, living independently is an appropriate metric of this propensity—adults who live independently have more frequent opportunities to make autonomous decisions and maintain control over their activities. However, most autistic young adults remain in the family home after transitioning out of high school [Howlin, Mawhood, & Rutter, 2000; Levy & Perry, 2011; Pickles, McCauley, Pepa, Huerta, & Lord, 2020; Taylor & Seltzer, 2011].

For individuals with ASD and ID, living with family or in residential care are the dominant living arrangements [Fujiura, 1998; Gray et al., 2014], and for some, the family home may be preferred over other options [Krauss, Seltzer, & Jacobson, 2005]. Thus, living situation may not be an appropriate metric of adult outcomes. Instead, daily living skills may be a better determinant of autonomy, adjustment, and overall functioning [Kanne et al., 2011]. Longitudinal studies demonstrate that individuals continue to gain daily living skills in adolescence and young adulthood [Bal, Kim, Cheong, & Lord, 2015; Gillespie-Lynch et al., 2012; Smith, Maenner, & Seltzer, 2012], although adults with lower IQs make more gradual gains.

1.3 *Social Relationships*

Social relationships are universal predictors of the mental and physical health of adults [Cohen, 2004; Leigh-Hunt et al., 2017]. Despite high rates of social isolation in studies of autistic adults [Bishop-Fitzpatrick, Mazefsky, & Eack, 2018; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013; Roux et al., 2017], some adults attain friendships and meaningful social experiences [Sosnowy, Silverman, Shattuck, & Garfield, 2019]. For autistic adults, friendships and social support are associated with beneficial effects on quality of life and depressive and anxiety symptoms [Bishop-Fitzpatrick et al., 2018]. However, independent friendships, when defined by frequent communication and mutual emotional support, may be less easily attained for less cognitively able autistic adults who experience persistent challenges in communication or functional skills [Orsmond et al., 2013]. Other positive relationships beyond family members such as housemates, group activities, and coworkers may be more representative of their social outcomes and their experience of inclusion.

1.4 *Purpose*

Having purpose reflects an individual's activities, motivations, and engagement with the community to live a full life. Employment is a vital component of adult life that helps imbue meaning and purpose to each day. Employment is associated with increased social engagement, increased self-regulation, and decreased symptoms of ASD and co-morbid conditions [Taylor, Smith, & Mailick, 2014]. While fulltime paid employment is not attained by all individuals, participation in substantive daily activities is quite relevant for quality of life considerations for individuals with ID [Billstedt et al., 2005; Seltzer & Krauss, 2001]. Examples include day program activities, supported employment, recreational activities, and volunteer positions.

1.5 *Ancillary Factors Associated With Adult Outcomes*

In addition to cognitive ability, past research has demonstrated that outcomes in autistic adults are associated with variegated factors, including demographics, severity of autism symptoms, co-occurring mental health symptoms, and subjective outcomes such as well-being or happiness. Independent living and employment were less likely to be achieved by adults of color or adults from more disadvantaged family backgrounds [Chan et al., 2018; Chiang, Cheung, Li, & Tsai, 2013; K. A. Anderson, Shattuck, Cooper, Roux, & Wagner, 2014]. Autism symptoms have been associated with levels of functional skills relevant to independence and the quality of social relationships [Anderson, Maye, & Lord, 2011; Shattuck, Orsmond, Wagner, & Cooper, 2011; Taylor & Seltzer, 2011]. In addition, studies showed autistic adults have high rates of co-occurring mental health symptoms, including anxiety, depression, attention deficit hyperactivity disorder, and more pertinent to less cognitively able adults, aggression [Croen et al., 2015; Stringer et al., 2020]. Both internalizing and externalizing symptoms have been found to negatively impact levels of independence and friendship in adulthood [Taylor, Adams, & Bishop, 2017; Taylor & Seltzer, 2011]. Finally, a structural network analyses found that happiness reported by autistic adults was directly influenced by satisfaction with social relationships and community contributions [Deserno, Borsboom, Begeer, & Geurts, 2017]. Therefore, adults with positive outcomes should have more positive subjective feelings, although measures of subjective experience in samples of autistic individuals can be limited [Ikeda, Hinckson, & Krägeloh, 2014].

1.6 *Current Study*

The current study aims to describe the outcomes of adults with higher and lower IQs in the domains of autonomy, social relationships, and purpose. We first constructed ordinal outcome variables that were comprised of each domain and were specific to more and less cognitively able adults. We then examined the how these outcomes are associated with additional aspects of adult's lives, including demographic variables, autism severity, cognitive ability, symptoms of co-occurring mental health problems, and measures of subjective happiness. For more cognitively able adults, we hypothesized that higher levels of autism severity, internalizing, and externalizing symptoms and diverse race would be negatively associated with positive outcomes, due to past research outlining some of the barriers adults experience in gaining employment, living independently, and gaining friendships. For less cognitively able adults, we expected autism symptoms and externalizing symptoms to be negatively associated with positive outcomes, as these symptoms would be most likely to restrict access to opportunities for social interaction and independence. While studies finding associations between these domains and subjective measures are sparse, we also included aspects of subjective happiness, including quality of life, positive affect, and well-being to examine their relations to variations in positive outcomes in both more and less cognitively able adults.

2 Methods

2.1 *Participants*

The current study draws participants from a longitudinal study involving three recruitment sites. In total, 213 children under age 3 years (192 were referred for possible autism to two tertiary autism programs and 21 children of the same age with non-ASD developmental delays) were recruited in North Carolina and Chicago. Three quarters of the original participants received ASD diagnoses at age 2. All children and parents who could be reached were seen for face-to-face assessments around age 2, 3 (ASD referrals only), 5 (North Carolina only), 9, 19, and 26, with lengthy phone interviews at 14 and some young adults seen for an additional assessment at 21. In addition, 40 children from Michigan referred for possible autism at early ages who joined the study at approximately age 13 were followed for an average of 16 years at the same intervals as the initial recruits. The average ages for joining the study varied for the initial sample (*M* = 2.5 years, *SD* = 0.43) and the new recruits (*M* = 13.3 years, *SD* = 2.49). In recent analyses of the current subjects, we have empirically derived latent classes of adult outcomes [Pickles et al., 2020], and we have described differences in adulthood between individuals who ever received an ASD diagnosis to those who never have in the course of the study while also considering IQ [Lord, McCauley, Pepa, Huerta, & Pickles, 2020]. The goals of the current analyses build on these papers by attempting to provide ways of conceptualizing practical outcomes.

Of the original 213 participants recruited at age 2, attrition occurred due to geographical relocation and unreachable status with 24 refusing ongoing participation by adulthood. In previous studies, attrition has been higher in African-American families and families with less education, with no effects of gender, earlier diagnoses, site, or IQ on attrition at any point [see Anderson, Liang, & Lord, 2014; Lord et al., 2006]. In the current sample, attrition was similarly associated with lower parent education (p = .008) and being racially diverse (p = .002), but not with gender, IQ, site, nor diagnosis at baseline. The current analyses included 126 young adults (17% female) from the longitudinal study with a mean age of 26 (*SD* = 1.57) at the most recent assessment who had adequate data from adult in-person assessments, at least one of which was between age 18 and 27, and questionnaires that were completed throughout adulthood. In total, 83% of the participants were white, 15% were Black or African American, with the remaining 2% being Asian or of mixed background. Participants from diverse racial backgrounds were combined into a single group for statistical analyses. In total, 19 of the participants in the current study have never been diagnosed with ASD, although they have had repeated diagnostic assessments. We retain individuals without ASD diagnoses in the current study because this is a prospective cohort study and the groups share many similarities across development and in outcomes as shown below [See also, Lord et al., 2020].

2.2 *Procedure*

Data collection consisted of in-person visits, telephone interviews, and batteries of questionnaires sent out to families and participants throughout adolescence and young adult years. During in-person visits, a battery of diagnostic and psychometric instruments was administered at home, school, work or a nearby clinic selected by the participant. Clinicians administered test batteries blind to results from previous assessments, including diagnosis. A team of one PhD level psychologist, an advanced graduate student, and/or one or two post-baccalaureate research assistants who had achieved research reliability on measures carried out in-person assessments. Families and participants received questionnaire packets, which consisted of standardized questionnaires to be filled out by caregivers and participants (when able) in adulthood. For the current study, we analyzed questionnaire data from their latest questionnaires (*M* age = 25.65). Informed consent was obtained from all participating families and individuals themselves whenever possible. This research was approved by IRBs at the University of North Carolina at Chapel Hill, the University of Chicago, the University of Michigan, Cornell University, and the University of California, Los Angeles.

2.3 *Measures*

2.3.1 ***Diagnostic measures***

At each in-person visit, participants were administered the Autism Diagnostic Observation Schedule [ADOS-2; Lord et al., 2012]. Caregivers were also administered the Autism Diagnostic Interview–Revised [ADI-R; Lord, Rutter, & Le Couteur, 1994], a standard investigator-based interview at age 19. At each time point (2, 5, 9, 19, 26), each participant was assigned an overall current best estimate consensus diagnosis of ASD, other nonspectrum disability or disorders (which could overlap or not with ASD), or typical development was made by the team based on all available information. These diagnoses were reviewed with the researchers on the team (CL at each age and MH for adult visits) after each visit, including observation of videotapes and consideration of raw data if necessary.

2.3.2 *Cognitive measures*

Cognitive skills were assessed during the first adult visit (age 19 or older) using the following hierarchy of tests from most to least difficult to complete: Wechsler Abbreviated Scale of Intelligence [Wechsler, 1999], Differential Ability Scales [DAS-II; Elliott, 2007] and the Mullen Scales of Early Learning [Mullen, 1995], with ratio IQs calculated from age equivalences when raw scores fell outside deviation score ranges. Adults were first administered the test with the greatest difficulty corresponding to their ability level, estimated by past performances, verbal abilities, and adaptive skill levels assessed via parent interviews. If basal or ceiling scores were not achieved, the participant was administered the next more or less difficult measure [see also Anderson, Liang, & Lord, 2014].

We created two groups: more cognitively able and less cognitively able individuals. More cognitively able describes individuals with a verbal IQ of 70 or above, and less cognitively able describes individuals with a verbal IQ below 70 at the most recent assessment. These two groups have non-overlapping distributions of IQ; with means slightly above 100 for the more cognitively able and in the severe to profound range for less cognitively able adults [Pickles et al., 2020].

2.3.3 *Affective, behavioral, and happiness measures*

Participants' caregivers reported on their adult son or daughter's affect, behavior, and happiness. We also asked more cognitively able participants to report on their own affect and happiness. Affective symptoms were assessed using the Adult Behavior Checklist [ABCL; Achenbach & Rescorla, 2003], the Adult Manifest Anxiety Scale [AMAS; Reynolds, Richmond, & Lowe, 2003] and the Beck Depression Inventory [BDI-II; Beck, Steer, & Brown, 1996] completed by caregivers. The current study uses internalizing and externalizing scales from the ABCL, the total score from the AMAS, and the total score from the BDI-II. Irritability and hyperactivity symptoms were assessed using subscales from the Aberrant Behavior Checklist [ABC; Aman, Singh, Stewart, & Field, 1985]. Happiness was assessed using the positive and negative totals from Positive and Negative Affect Scale [PANAS; Watson, Clark, & Tellegen, 1988], the total score from the Well-Being Questionnaire [WBQ; Ryff, 1989] and the total score from the Quality of Life Questionnaire [QLQ; Schalock & Keith, 1993]. When possible, individuals also reported themselves on the AMAS, BDI-II, PANAS, WBQ, and QLQ. In this study, all scores represent concurrent levels of functioning in adulthood.

To reduce the number of outcomes we tested, we conducted an exploratory factor analysis on the parent-report versions of the affective, behavioral, and happiness measures. Principal components factor analysis was applied to the above scales. Examination of the scree plot led us to retain three factors for parent report data for the full sample (explaining 70.6% of the total variance). Varimax rotation was used to produce orthogonal factors. Factor loadings above 0.5 were used in the interpretation of the factor output. We label the three factors as internalizing symptoms, externalizing symptoms, and happiness (Table 1). Scores within each factor were scaled and averaged to produce three composites.

Table 1. Factor Loadings on Affective, Behavioral, and Happiness Measures

Parent report measures	**Factor 1: Internalizing**	**Factor 2: Happiness**	**Factor 3: Externalizing**
AMAS total	0.86		
ABCL internalizing	0.80		
BDI total	0.75		
PANAS negative	0.67		
PANAS positive		0.87	
WBQ total		0.78	
QLQ total		0.72	
ABC irritability			0.81
ABC hyperactivity			0.80
ABCL externalizing			0.63

Self-report measures	**Factor 1: Internalizing – SR**	**Factor 2: Happiness − SR**
AMAS total	0.94	
BDI total	0.87	
PANAS negative	0.83	
PANAS positive		0.71
WBQ total		0.82
QLQ total		0.96

Note. Extraction method: Principal component analyses with varimax rotation. All subjects included in factor analyses on parent reported measures, only more cognitively able subjects included on factor analyses for self-reported measures.

We also applied principal components factoring to the self-report scales (available for 41 of the more cognitively able participants) and we retained two factors (explaining 83.5% of the total variance). Varimax rotation was used to produce orthogonal factors. We identified the two factors as internalizing symptoms, and happiness (Table 1). Scores were then scaled and averaged to produce two composites.

2.3.4 *Primary adult outcome measures*

Caregivers and participants, if verbally fluent, were interviewed at the age 25 in-person assessment using an updated version of the Social Emotional Functioning

Interview [SEF-S & SEF-I; Rutter et al., 1988]. The interview consists of a series of open-ended questions about living status, routines, social contacts, and interests that has been previously employed on samples of autistic adults [Howlin et al., 2000]. Work and residential living status were assessed with direct questions to participants and caregivers about where they had ever lived and how they spent the day (e.g., employment). Caregivers and participants regularly updated information about work and living status in questionnaires up through age 26. Adaptive skills were assessed using the Vineland Adaptive Behavior Scales [Vineland-II; Sparrow, Cicchetti, & Balla, 2005].

For more cognitively able individuals, we defined three outcomes: (1) having regular employment or undertaking age-appropriate education, (2) having at least one friend, and (3) living independently. For less cognitively able individuals, we defined three outcomes: (1) having either supported, non-supported, or voluntary work activities outside the home, (2) having any social contact outside of family members; that is, friends, peers, or acquaintances, and (3) having an average age equivalent score above 8 years on the personal and domestic subscales from the Vineland-II. An 8-year-old age-equivalence was selected because skills at this level included self-care (toileting, dressing oneself, basic hygiene) and the ability to complete some household chores. This age equivalence also fell near the median of the less cognitively able individuals.

2.4 *Data Analysis*

Inverse probability scores were calculated from a logistic model predicting attrition from race and parent education and were then applied to all analyses to account for selective attrition. Relations between adult outcome counts as defined above and characteristics of the adults were tested using ordinal regression models. Models were run separately for more and less cognitively able groups. Due to sample size and collinearity concerns, we first present models with single predictors. We then used a multivariate approach to test the effect of each individual characteristic (ADOS-CSS, daily living skills, happiness, and comorbid symptoms) while including the covariates of demographics, ASD diagnosis, and

Verbal IQ in each model. We did not test daily living skills in the models for the less cognitive able outcomes because they were part of the outcome count. All analyses for the current study were conducted in SPSS Version 25, or the MASS package in R version 3.5.1 [R Core Team, 2018].

3 Results

3.1 *What Outcomes are Adults Achieving?*

Of the 57 more cognitively able adults with adequate data, 39 (68%) had regular employment, 7 (12%) were still in education, 2 (4%) had employment with supports, 1 (2%) was in a day program, 1 (2%) had voluntary work, and 7 (12%) had no occupation or daily activity. For living arrangements, 22 (38%) were living independently, 1 (2%) was in a group home, and 34 (60%) were living at home with parents. For friends, 30 (53%) adults had one or more friends, 15 (26%) had peers through shared activities but only had limited interactions, 7 (12%) only reported having acquaintances, and 5 (9%) had no current friends.

An ordinal count variable was created to describe the number of outcomes each more cognitively able individual met. In total, 19 (33%) individuals met all three outcomes, 12 (21%) met two out of three outcomes, 14 (25%) met one out of three outcomes, and 12 (21%) met none of the three outcomes. There were no significant differences in the outcomes of individuals who had ever received a diagnosis of ASD and those who had never received a diagnosis: $\chi_2(3) = 4.22$, $p = .23$.

Of the 69 less cognitively able adults with adequate data, 35 (51%) had social contacts outside of the family, and 34 (49%) had no social contacts other than with family members. For activities, 13 (19%) had either supported or non-supported employment, 8 (12%) had voluntary work, 9 (13%) were in day programs, and 39 (57%) had very limited activities outside the home. For daily living skills, 28 (41%) were at or above an 8-year-old level, and 41 (59%) were below an 8-year-old level.

An ordinal count variable was created to describe the number of positive outcomes met by less cognitively able individuals. In total, 12 (17%) individuals were identified as meeting all three of these criteria, 18 (26%) met two out of three of these criteria, 20 (29%) met only one of these criteria, and 19 (27%) did not meet any of the criteria. There was a significant difference in the number of individuals who ever had an ASD diagnosis compared to the number who never received a diagnosis on outcome count: $\chi 2(3) = 15.85$, $p = .001$. Less cognitively able individuals with an ASD diagnosis were more evenly spread across the number of outcomes met, except for at the maximum of 3 (0: $n = 19$; 1: $n = 20$, 2: $n = 14$, 3: $n = 7$), individuals who never had an ASD diagnosis all met either 2 ($n = 4$) or all 3 positive outcomes ($n = 5$). Figure 1 displays the outcome counts and the distributions of the criteria for both more and less cognitively able individuals.

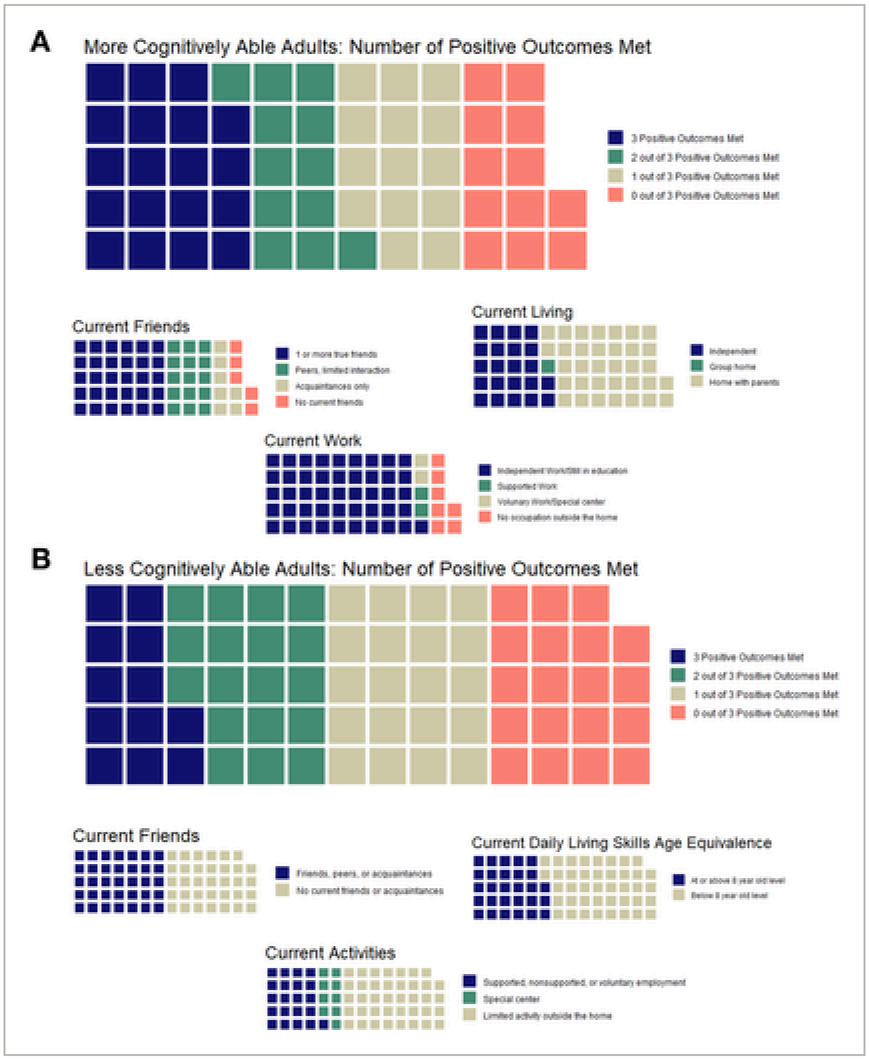

Figure 1

Outcomes met for more cognitively able (A) and less cognitively able (B) participants. For each criterion, blue indicates the positive outcome

3.2 *How do Outcomes Relate to Demographic and Adult Characteristics?*

3.2.1 ***More cognitively able participants***

Table 2 contains the summaries of the univariate and multivariate ordinal logistic regression models predicting positive outcome counts for more cognitively able individuals. Univariate models indicated that higher verbal IQ, higher daily living skills, and higher happiness measured in adulthood were significantly associated with increased odds of moving up in the number of positive outcomes met (from 0 to 3). Being racially diverse, having caregiver education below college completion, higher CSS, and higher internalizing and externalizing symptoms were all significantly associated with decreased odds of moving up in the number of positive outcomes. Neither gender nor ASD diagnosis (ever) were associated with achieving more outcomes. These associations were similar when examining each outcome separately with binary logistic regressions, with the exception of race and internalizing symptoms being associated only with employment, and caregiver education and happiness being significantly associated only with living independently (Table S1).

Table 2. Ordinal Regression Summaries Predicting Number of Outcomes in More Cognitively Able Adults

Predictor (*N*)	**Univariate B (SE)**	**Multivariate B (SE)**	**Univariate odds ratio (95th CI)**	**Multivariate odds ratio (95th CI)**

Gender (female; *N* = 57)	−0.85 (0.58)	0.66 (0.66)	0.43 (0.14–1.32)	1.97 (0.54–7.17)
Race (racially diverse; *N* = 57)	−1.53 (0.23)**	−1.11 (0.57)	0.22 (0.09–0.53)	0.32 (0.11–1.01)
Caregiver education (<college degree; *N* = 57)	−1.71 (0.46)***	−1.23 (0.50)*	0.18 (0.07–0.45)	0.29 (0.11–0.79)
ASD diagnosis ever (*N* = 57)	0.64 (0.38)	−0.07 (0.45)	1.89 (0.89–4.00)	0.93 (0.38–2.28)
Most recent VIQ (*N* = 57)	0.04 (0.01)***	0.04 (0.01) ***	1.04 (1.03–1.07)	1.04 (1.02–1.06)
Most recent CSS (*N* = 57)	−0.36 (0.07)***	−0.28 (0.09)**	0.70 (0.61–0.80)	0.75 (0.63–0.90)
Daily living skills (*N* = 56)	0.06 (0.01)***	0.07 (0.01)***	1.07 (1.06–1.09)	1.07 (1.04–1.11)
Internalizing composite (*N* = 54)	−0.62 (0.16)***	−0.50 (0.17)**	0.54 (0.40–0.73)	0.61 (0.44–0.85)

Internalizing – SR Composite (*N* = 42)	−0.79 (0.36)*	−1.41 (0.26)***	0.45 (0.23–0.91)	0.24 (0.15–0.40)
Externalizing composite (*N* = 52)	−1.14 (0.26)***	−0.98 (0.26)***	0.32 (0.19–0.53)	0.37 (0.23–0.62)
Happiness composite (*N* = 48)	1.55 (0.25)***	2.28 (0.34)***	4.71 (2.91–7.64)	9.78 (5.02–19.04)
Happiness – SR composite (*N* = 41)	1.26 (0.41)***	1.27 (0.27)***	3.53 (1.58–7.89)	3.51 (2.08–5.94)

Note. Multivariate statistics represent each individual predictor while accounting for covariates (Gender, Race, Caregiver Education, ASD Diagnosis, and VIQ). Multivariate statistics presented for covariates do not include any additional main predictors in multivariate models. "—SR" indicates self-report, otherwise internalizing, externalizing, and happiness composites are caregiver report. *$p < .05$, **$p < .01$, ***$p < .001$.

In the multivariate ordinal regression models that adjusted for gender, race, caregiver education, VIQ, and ASD diagnosis, each individual characteristic, including CSS, daily living skills, internalizing symptoms, externalizing symptoms, and happiness significantly predicted outcomes. The internalizing and happiness composites from self-reported measures were also significant predictors of outcomes. Figure 2a is a summary of confidence intervals attained from univariate models with notations identifying significance at the multivariate step for the more cognitively able group.

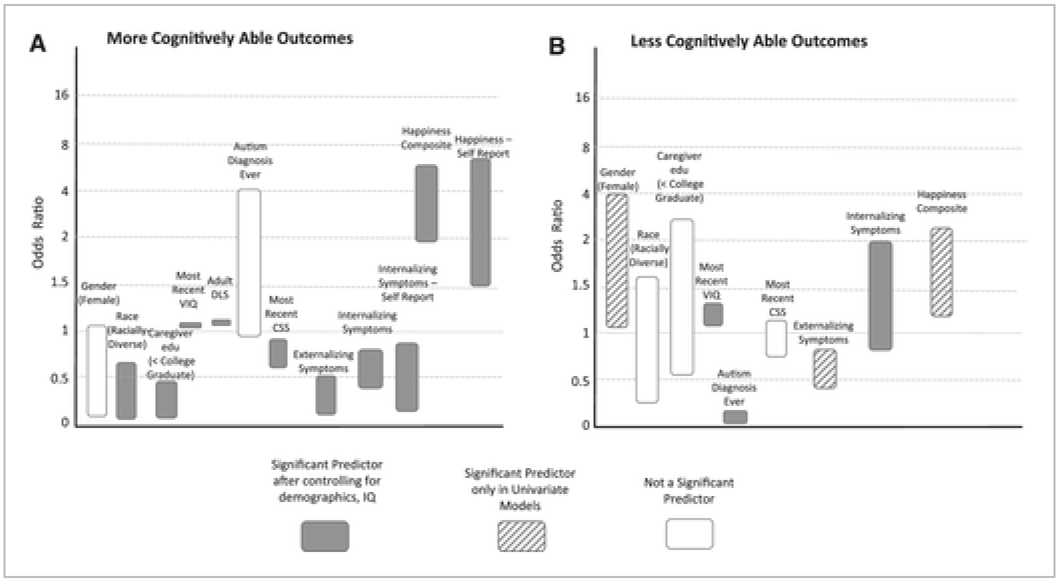

Figure 2

Confidence intervals predicting number of outcomes achieved. Presented confidence intervals are derived from univariate models, with significance indicated from multivariate models that covaried for demographics, IQ, and ever receiving ASD diagnosis

3.2.2 *Less cognitively able participants*

Table 3 contains the summaries of the univariate and multivariate models for less cognitively able individuals. Female gender, higher verbal IQ, and higher happiness scores were significantly associated with achieving more positive outcomes. More externalizing symptoms and ever having an ASD diagnosis were associated with achieving fewer positive outcomes. There were no associations between outcome counts and internalizing symptoms, current autism severity, or race. These associations were consistent when examining singular outcomes in binary logistic regressions, with the exception that externalizing and happiness were uniquely related to having a daily living skills age equivalence over 8 years old (Table S2).

Table 3. Ordinal Regression Summaries Predicting Number of Outcomes in Less Cognitively Able Adults

Predictor (*N*)	**Univariate B (SE)**	**Multivariate B (SE)**	**Univariate odds ratio (95th CI)**	**Multivariate odds ratio (95th CI)**
Gender (female; *N* = 69)	−0.75 (0.34)*	−0.53 (0.40)	2.12 (1.09–4.14)	0.59 (0.27–1.29)
Race (racially diverse; *N* = 69)	−0.35 (0.41)	0.42 (0.46)	0.71 (0.32–1.57)	1.52 (0.62–3.74)
Caregiver education (<college degree; *N* = 69)	0.41 (0.46)	−0.05 (0.49)	1.51 (0.61–3.69)	0.95 (0.36–2.48)
ASD diagnosis ever (*N* = 69)	2.89 (0.47)***	−2.51 (0.56)***	0.05 (0.02–0.22)	0.08 (0.03–0.24)
Most recent VIQ (*N* = 69)	0.07 (0.01)***	0.06 (0.01) ***	1.08 (1.06–1.10)	1.07 (1.05–1.09)
Most recent CSS (*N* = 69)	0.01 (0.06)	−0.01 (0.06)	1.01 (0.91–1.13)	0.99 (0.88–1.11)
Internalizing composite (*N* = 66)	0.23 (0.23)	0.51 (0.25)*	1.26 (0.80–1.99)	1.67 (1.01–2.75)

Externalizing composite (*N* = 66)	−0.46 (0.17)**	0.18 (0.21)	0.63 (0.45–0.89)	1.19 (0.79–1.81)
Happiness composite (*N* = 63)	0.63 (0.18)***	0.19 (0.20)	1.87 (1.32–2.66)	1.21 (0.82–1.80)

Note. Multivariate statistics represent each individual predictor while accounting for covariates (gender, race, caregiver education, ASD diagnosis, and VIQ). Multivariate statistics presented for covariates do not include any additional main predictors in multivariate models.
*$p < .05$, **$p < .01$, ***$p < .001$.

Multivariate ordinal regression models demonstrated that having received a formal ASD diagnosis in the past (in contrast to current ADOS CSS scores) was associated with fewer positive outcomes, and higher verbal IQ is consistently associated with more positive outcomes. Higher internalizing symptoms were associated with more positive outcomes when covariates were in the model. Associations between externalizing symptoms and happiness were no longer significant once covariates were included in the models, perhaps suggesting the effects of VIQ and/or diagnosis accounted for these relations. Figure 2b contains confidence intervals from univariate models with significance adjusted from multivariate findings for the less cognitively able group.

4 Discussion

We attempted to define outcomes that were specific to ability level that were attainable, and informative about the functioning of autistic adults. In more and less cognitively able individuals, we emphasized autonomy, social relationships, and purpose as primary to the definition of our outcomes. We considered IQ and ASD symptoms, not as outcomes, but as two of several features that could be related to positive functioning. For participants at both cognitive levels, the number of outcomes met was associated with verbal IQ (within IQ-defined levels although at a small effect size), aligning with previous analyses on the same sample [Pickles et al., 2020] and past work describing the pervasive associations between verbal IQ and adaptive functioning across development [Bal et al., 2015; Liss et al., 2001], even though they are different constructs.

Past research has struggled to resolve discrepancies between measures of objective and subjective quality of life in ASD [Hong et al., 2016; Mason et al., 2019]. Our happiness composite reflected a combination of quality of life, well-being, and positive affect about oneself (or described by caregivers), and therefore represent more subjective outcomes. We found that outcome count was associated with caregiver reports of happiness for both more and less cognitively able autistic participants in univariate models, though not consistently in multivariate analyses. Self-reported measures, including affective symptoms and indices of happiness, were also associated with the number of different positive outcome in individual more cognitively able people. In examining each outcome criterion separately, we found that the subjective happiness composite was associated with independent living in more cognitively able adults and adaptive skills in less cognitively able adults, which were both conceptualized to assess autonomy Establishing these associations is an important step in describing adult outcomes more holistically.

For more cognitively able individuals, contemporaneous internalizing and externalizing symptoms were associated with less positive outcomes. Anxiety, depression, and attention problems are common in adults with ASD [Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2019], and may present challenges for entering the workforce, independent living, or establishing social relationships. There have been many recent calls for adaptations and better access to interventions that incorporate cognitive behavioral techniques to reduce these symptoms for autistic adults in vocational and social contexts [Eack et al., 2013; Oswald et al., 2018; Pallathra, Cordero, Wong, & Brodkin, 2019]. In less cognitively able individuals, the internalizing association was in the reverse direction (predicting more positive outcomes), but only after accounting for verbal IQ and diagnosis. Internalizing may be difficult to measure through caregiver reports for adults who are minimally verbal [Fok & Bal, 2019; Lerner et al., 2018]; it is also possible that having some anxiety is a function of either greater demands or greater opportunities available for less cognitively able adults with ASD in social, self-care, and daytime activities.

ASD diagnosis had a greater negative association with outcomes for less cognitively able individuals but not for more cognitively able individuals, perhaps in part because of the similar challenges experienced by the participants with a history of non-spectrum neurodevelopmental disabilities and higher IQs [Lord et al., 2020]. Another previous study found trajectories of adaptive skills in adults with ASD and co-morbid ID slowing in the 20s and beginning to decline in the 30s, in contrast to continuously increasing skill trajectories in adults with Down syndrome [Smith et al., 2012]. Our study indicates a divergence in outcomes associated with never or ever receiving a diagnosis of ASD for less cognitively able people—in that individuals without a diagnosis of ASD tended to have more positive outcomes even with a similar IQ range. Adaptive skills at least at an 8-year-old level were one criterion we used to construct positive outcomes for less cognitively able adults, and represents a modifiable goal that can be directly targeted by families and programs for adults with ASD.

For the first time in our analyses of this sample, being racially diverse as well as having caregiver education below college completion were negatively associated with overall number of positive outcomes for more cognitively abled adults. In other ASD samples, attaining post-secondary employment has been related to parental education and income [Chiang et al., 2013], and sustained employment was associated with family income [Chan et al., 2018]. Living situation was also associated with family income and race, with African-American autistic adults more likely to remain in the family home [K. A. Anderson, Shattuck, et al., 2014]. Perhaps, families with higher levels of education and income can access a wider social network of employment opportunities or are better able to find resources that support a transition to independent living. Special attention is needed to understand barriers and access to treatment that may particularly affect people of color with ASD from attaining work, friendship, and independence [Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015].

While there were some similarities in the results between more and less cognitively able adults (e.g., VIQ, a consistent predictor of achieving outcomes at a small effect size; subjective happiness associated with indices of autonomy), one of the key differences was that we found a higher number significant predictors of outcomes for more cognitively able adults. Given that our outcome definitions for more cognitively able adults reflect commonly used metrics in studies of autistic adults, our ability to predict them more readily is not wholly surprising. In addition, it is important to consider that the mechanisms that allow for more cognitively able adults to achieve more positive outcomes, such as alleviating symptoms of co-occurring conditions or addressing racial and economic disparities in opportunities, could be distinct from less cognitively able adults or perhaps are not well characterized by available measurement tools. It is critical to continue to uncover the experiences and services that increase autonomy, community inclusion, and feelings of purpose in less cognitively able adults.

4.1 *Limitations and Future Directions*

Well-being and quality of life measures currently in use do not adequately capture the subjective experience of individuals with severe ID or language impairments. The current study gathered information from caregivers as surrogate reporters, but these reports may be biased by the well-being of the caregiver or other factors. A more holistic approach, as suggested by McVilly and Rawlinson (1998] would be to use multiple reporters, have an observational component, and reflect the motivations of the adult. We also do not describe family relationships in adulthood. It will be important to consider how support from caregivers and siblings contributes to wellbeing in adults with ASD [Seltzer & Krauss, 2001].

The current sample is limited due to attrition and the socio-cultural context of these our participants who were primarily very young referrals for possible autism or developmental delays in the early 1990s. We corrected our analyses for attrition with the use of probability weights, though findings were very similar when we restricted our analyses to individuals with complete data. We made decisions of how to define positive outcomes (e.g., considering only non-relative relationships as criterion, treating living or working outside the home as indicators of independence), but clearly one could define different criteria that might be more relevant to some individuals. Furthermore, our relatively small sample size limited our ability to look more closely at gender differences or to account for each predictor concurrently and therefore to draw more generalizable conclusions with confidence.

5 Conclusions

In many previous studies on adult outcomes, investigators have struggled to describe positive outcomes across cognitive profiles within ASD samples, and hence, primarily reported on limitations of the population. Our outcome definitions, focused on goals of autonomy, social relationships, and purpose adapted to cognitive level. Our results suggest that definitions of positive outcomes can be tailored to the cognitive level, and in doing so, we can perhaps better describe the needs of different autistic individuals. Using these and similar existing data, outcome variables can be created that better reflect the lived experience of autistic adults, particularly for less cognitively able people. In this study, we considered adaptive skills, social contact, and activities to be indicative of positive outcomes of less cognitively able adults. For more able adults, we operationalized outcomes similarly to existing studies of autistic adults, but condensed information into a single ordinal variable and were able to address the relation between objective and subjective measures. These approaches are feasible and warrant replication in other longitudinal and treatment studies. Going forward, new measures are needed to capture the qualities of daily experiences, skills, and social experiences of all autistic adults so that we may have dynamic and practical descriptions of optimal outcomes.

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