The Relationship between Age of Autism Diagnosis and Positive Life Outcomes in Adulthood

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Honors Thesis Proposal

Autism spectrum disorder is a neurodevelopmental condition that affects social communication, behavior, and sensory processing, with variations in how it manifests across individuals. Much of the research on autism concerns children; however, autism is a lifelong condition that affects adults as well. Research shows that various quality of life dimensions tend to be poorer for autistic adults than their non-autistic counterparts (Ayres et al. 2017, Kamio et al. 2012). Although autism can be reliably diagnosed in children as young as two years old (Lord et al., 2006), there is wide variability in when people receive a diagnosis, and diagnoses in adulthood have been rapidly rising in recent history (Russell et al., 2021).

Early intervention for autism is widely known to lead to enhanced cognitive and social outcomes in children. The American Academy of Pediatrics recommends screening for autism at 18 and 24 months of age, because "early intervention can and does influence outcomes" (Hyman et al., 2020). Diagnosis facilitates the receipt of necessary support and treatment, so a timely diagnosis is important: early diagnosis leads to early intervention (Okoye et al., 2023). One study found that children who were diagnosed early exhibited better outcomes, including accessing more resources available to them, demonstrating better verbal and overall cognitive outcomes, and being more likely to attend mainstream school (Clark et al., 2017).

Early diagnosis for children improves school-age outcomes, but little is known about how age of autism diagnosis relates to long-term positive adult life outcomes (e.g., quality of life, life satisfaction). Furthermore, the majority of research on timing of diagnosis/early intervention onset and outcomes is focused on childhood, so less is known about whether diagnostic timing matters after childhood. In other words, is there still a benefit to being diagnosed earlier once you are out of the most critical early childhood period?

Greater and greater numbers of people are diagnosed with autism as adults in recent years, and some research refers to them as the "lost generation" because they did not receive the

proper support needed when they were children due to a lack of diagnosis (Lai & Baron-Cohen, 2015). This "lost generation" tends to include more women, people of color, and other people who don't fit the stereotypical image of autism (Lai & Baron-Cohen, 2015). In addition to a missed opportunity for treatment, it is also possible that a later diagnosis could lead to worse adult outcomes because a person would struggle for a long time without knowing why they are "different". In qualitative work, some people who were diagnosed with autism in adulthood report having felt weird or "alien" throughout childhood, and that they are more able to be themselves since receiving their diagnosis (Kelly et al., 2024). This also may be compounded by status as a minority, according to the minority stress model (Meyer et al., 2003).

The current literature on age of diagnosis (AoD) focuses mostly on school-age outcomes. More research needs to be done to determine how the full range of ages of diagnosis relate to life outcomes in adulthood because autism is a lifelong condition and many people are not diagnosed until adolescence or adulthood. The present study aims to fill this gap in the literature by investigating the relationship between AoD and positive life outcomes in adulthood. We will accomplish this by determining demographic and clinical variables that influence positive life outcomes, then controlling for these variables while analyzing the relationship between AoD and measures of quality of life, independence, and life satisfaction.

Sociodemographic and Clinical Characteristics and Age of Diagnosis

Given the present study's interest in AoD as a predictor of positive life outcomes in adulthood, it is important to start by acknowledging potential sociodemographic and clinical characteristics that may be associated with AoD and adult life outcomes. These variables might represent confounds or moderators of the association between AoD and life outcomes. The literature about AoD focuses on children, but adults have different concerns and life experiences

than children. Ergo, relationships that may not be significant in the current literature could be significant for adults and vice versa.

The existing literature offers mixed findings regarding how sociodemographic factors are associated with AoD. Some studies suggest that demographic variables have a significant relationship with AoD. Usually, these studies find that people whose demographics do not fit the stereotype of autism (i.e. a young white boy with lots of external symptoms) tend to be diagnosed later (Lai et al., 2015). Being assigned female sex at birth (Huang et al., 2021), being Black rather than White (Mandell et al., 2002), and having a lower socioeconomic status (Loubersac et al., 2023) have been found by some studies to lead to a later average AoD. Meanwhile, other studies find no significant relationship between AoD and gender, race, socioeconomic status, and other variables. For example, a recent meta-analysis (Loubersac et al., 2023) found that zero out of the 14 studies included found a significant relationship between gender and AoD, and two out of the ten studies included found that being nonwhite increased AoD (six found no relationship and two found that being nonwhite actually decreased AoD).

There is general consensus about how some clinical variables influence AoD. Specifically, most studies find that higher symptom severity/higher level of impairment is associated with an earlier AoD and that having co-occurring mental health conditions is associated with a later AoD. The same recent meta-analysis (Loubersac et al., 2023) found that three of five studies analyzed found that low language level relates to an earlier AoD, and seven out of ten studies that investigated IQ found that a lower IQ (<=70) relates to an earlier AoD. Meanwhile, most studies find that co-occurring psychiatric conditions are related to later AoD, including but not limited to anxiety disorders, OCD, ODD (Jadav et al., 2022), and depression (Huang et al., 2021; Jadav et al., 2022).

Importantly, many of these same sociodemographic and clinical variables have been found to be associated with adult outcomes as well. Female sex assigned at birth tends to relate to a lower quality of life in most studies on autistic adults. (Kamio et al., 2013; Mason et al., 2018). Adults with more "severe" autism or more intense autistic traits tend to have a lower quality of life as well (Mason et al., 2018; Huang et al., 2017). Co-occurring psychiatric conditions also were related to a lower quality of life (Mason et al., 2018; Kamio et al., 2013). Studies found mixed results about whether age relates to quality of life in autistic adults: some found that older age relates to lower quality of life (Mason et al., 2018) while others found no such relationship (Kamio et al., 2013; Van Heijst & Geurts, 2014; Huang et al., 2017). Notably, the literature reviewed did not attempt to find a relationship between race or socioeconomic status and quality of life.

Taken together, it is clear that certain sociodemographic and clinical characteristics are likely to be associated with both AoD and positive adult life outcomes and thus need to be considered when attempting to understand the association between these two variables. Research about AoD and adult outcomes should keep demographic characteristics in mind because people from all diverse backgrounds have autism and because diversity impacts peoples' life experiences, including their experience with autism.

Age of Diagnosis and Positive Life Outcomes in Adulthood

There have only been a handful of studies, mostly published in the last five years, that have examined the association between AoD and positive life outcomes in adulthood, and results from these studies have been mixed. I have identified five key papers that are most relevant to this topic: three of them were written within the last three years and primarily focus on the relationship between AoD and quality of life (Atherton et al. 2022; Oredipe et al. 2023; and Leung et al. 2024); while the other two (Kamio et al. 2013; Mason et al. 2018) are slightly older

and have a more broad focus on factors that may be related to quality of life in autistic adults, examining AoD alongside other key predictors.

Three of these five studies found that a later AoD was associated with worse adult life outcomes (Atherton et al., 2022; Oredipe et al., 2022; Kamio et al., 2012). Atherton and colleagues (2022) used a sample of 210 British autistic adults with a mean age of 29 and an almost even gender distribution. The median AoD for men was 15 years, while the median for women was 21 years. The study used a composite measure of quality of life, combining dimensions of loneliness, social anxiety, social avoidance, social support, and life satisfaction. Adults who were diagnosed earlier in life had a higher quality of life score, specifically in the domains of social anxiety, social avoidance, and social support. This was a simple correlation and no other variables were controlled for. Finally, the study found that autistic women had higher levels of autistic traits and were diagnosed later than autistic men but did not have a significantly different quality of life. The study suggests that this may be due to the increased tendency to "mask," i.e. to adjust one's behavior consciously or unconsciously to hide autistic traits and blend in with neurotypical people, in women. While the study did not test whether gender moderated the relationship between AoD and quality of life, this pattern of findings suggests that this may be a possibility.

Oredipe et al. (2022) used a sample of 78 mostly American university students with a male-leaning gender distribution and a mean age of 24 (although most of the sample was of a "typical" university age of 18-25). The mean age that participants learned they were autistic was 14.71 years old, with a standard deviation of 8.83. They measured quality of life using the AS-QoL (autism-specific quality of life), the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS), and the single question from the World Health Organization Quality of Life scale (WHOQOL) "How would you rate your quality of life?". Oredipe et al. (2022) found that a

younger age of learning one is autistic, an older current age, and lower scores on a self-report measure of autistic traits were associated with a higher quality of life, while gender had no relationship with quality of life. Despite the poorer quality of life, people who were diagnosed at a later age reported feeling better about being autistic. This might indicate the importance of a diagnosis to one's identity, even when received later in life.

Kamio et al. (2012) used a sample of 154 Japanese adults with "high functioning" autism, primarily male (n = 123) and the rest female (n = 31). This sample had a mean participant age of 27.6 years and had a much lower proportion of adult-diagnosed adults than the previously mentioned studies (mean AoD of 10.25 years). The study used the WHOQOL-BREF (a shortened, 26-item version of the WHOQOL) to measure quality of life. Kamio and colleagues found that being assigned male at birth and an AoD under four years old (the only two groups for AoD included "under 4" and "above 4") predicted a higher quality of life, while aggressive behavior and late speech (commonly associated with higher autism severity) as well as co-occurring psychiatric conditions predicted a lower quality of life.

Other studies found no relationship between AoD and adult quality of life when relevant variables were controlled for (Leung et al., 2024; Mason et al., 2018). Leung et al. (2024) attempted to replicate findings from Oredipe et al. (2022), but did not find a significant association between AoD and quality of life. Leung et al. (2024) recruited a sample of 300 adults from the United Kingdom, 171 of whom were female, with a mean age of 31.54 years. Like Oredipe et al. (2022), Leung et al. (2023) used the ASQoL to assess quality of life and the WEMWBS to assess mental wellbeing; Leung et al. (2024) also added the WHOQOL as a quality-of-life measure and combined it with the ASQoL to create a composite quality of life score. A higher age at autism diagnosis was correlated with a worse QoL before regression analyses but was not found to be a relevant predictor of QoL when other variables (i.e., autistic

traits, age, sex, ethnicity, relationship status, living status, education level, employment status, adjusted income, and co-occurring mental health conditions) were controlled for. On the other hand, being assigned female at birth predicted a better quality of life, while having more autistic traits (the strongest relationship) and having co-occurring conditions predicted a worse quality of life.

Mason et al. (2018) used a sample of 370 autistic people from the United Kingdom with a mean age of 41.61 years. The study was heavily comprised of recently diagnosed, adult-diagnosed adults: the mean AoD was 36.89 years old. It used WHOQOL-BREF to measure quality of life and the Social Responsiveness Scale (SRS) to measure autistic traits. It found that AoD neared significance but did not reach it for prediction of quality of life after controlling for other variables (relationship status, living status, employment status, co-occurring mental health conditions, physical health conditions, financial support, education level, SRS score); although it did reach significance when only considering participants with a formal diagnosis. Instead, significant factors for predicting a lower quality of life included being assigned female at birth, having higher autistic traits, and having a co-occurring mental health diagnosis. It should be noted that while this study did not see AoD reaching significance as a predictor of quality of life, the inclusion of co-occurring mental health conditions (which is associated with a later AoD) as a predictor of quality of life may have been confounding. It is not clear whether co-occurring mental health conditions should be considered a predictor of QoL in this case, or an outcome.

There are key patterns to note when examining the differences between the papers that find a relationship between AoD and adult quality of life and those that do not. Notably, those papers that find a relationship between AoD and QOL tend to have participants that were diagnosed earlier and who are currently younger than the participants in the studies that found no relationship. The mean age of the participants in the Atherton et al. (2022), Oredipe et al. (2023,

and Kamio et al., (2013) studies were 24, 24, and 27.5 years respectively, and their average AoD was 18, 15, and 10 years old respectively. Meanwhile, Leung et al. (2024), and Mason et al. (2018) has a mean age of participants of 31.5 and 41.5 years, respectively, and their mean ages of diagnosis were 21.5 and 37 years old, with few participants in these studies being diagnosed in early childhood. This brings into question whether there is some "tipping point" after which differences in age of autism diagnosis no longer incrementally improve positive adult life outcomes. Perhaps the difference between being diagnosed in early childhood rather than adolescence is significant, while the difference between being diagnosed in young adulthood rather than middle age is not. Additionally, the ages of diagnosis in the samples tended to cluster to the mean in all studies, meaning that we do not have a clear picture of how a broad range of ages of diagnosis might impact positive adult outcomes.

The Present Study

Little research exists so far on the relationship between AoD and positive adult life outcomes. The existing literature has key limitations, especially with sample diversity and size. Most notably, all existing studies lacked sufficient variability in AoD and sufficiently large sample size to provide a full understanding of how AoD relates to adult outcomes. Additionally, while prior research has examined how certain sociodemographic and clinical characteristics contribute to positive adult outcomes alongside AoD, there is no existing research about possible moderating effects between demographic/clinical variables and AoD predicting positive adult outcomes. The present study will use a large community sample with sufficient variability in ages at diagnosis, aiming to fill key gaps in the literature on this topic. The three aims of the present research are as follows:

Aim 1: First, we will describe the relationship between key demographic (i.e., age, sex assigned at birth, gender, sexual orientation and race/ethnicity) and clinical variables (i.e., autism

traits as measured by the SRS-2 and the presence of an intellectual disability) and age of diagnosis. We predict that our findings will corroborate the findings of previous studies that female sex assigned at birth and being a woman or gender diverse predict a later autism diagnosis. We also predict that our results will corroborate the findings of previous studies that more severe autistic traits predict an earlier diagnosis. Since our key papers do not look at race/ethnicity, we have no hypothesis about its relationship with AoD. This analysis will inform covariates and potential moderators included in aims 2 and 3.

Aim 2: We aim to determine whether there is a significant association between AoD and positive life outcomes in adulthood (Relationships, Employment, Autonomy, and Life Satisfaction scale (REALS), WHOQOL, and Adapted Flourishing Scale (AFS) when accounting for relevant demographic and clinical variables (decided following aim 1 analyses). We predict that an earlier AoD will predict more positive life outcomes in adulthood, with this relationship decreasing in strength as the AoD increases. In other words, we predict that the difference between being diagnosed in early childhood versus middle childhood will be greater than the difference between being diagnosed in adolescence versus adulthood.

Exploratory Aim 3: In a final exploratory aim, we will examine whether the sociodemographic and clinical variables identified as significant predictors of AoD in aim 1 moderate the association between AoD and positive adult life outcomes. While there has been no prior work in this area, based on the pattern of results by Atherton et al. (2022; described above) we hypothesize that the association between AoD and positive adult outcomes may be weaker in individuals assigned female sex at birth compared to those assigned male sex at birth.

Methods

Participants

The data used in this study come from a completed study from the REAACT program which aimed to develop a measure of relationships, employment, autonomy, and life satisfaction (the REALS measure) in autistic adults. Data were collected online via the Simons Powering Autism Research (SPARK) registry and via local recruitment. The study recruited a total of 910 participants between 18-78 years old. For this project, we will use only the autistic participants (N=818). Since AoD is central to our study, only participants that provide their AoD will be included in the study, leaving us with a total of 769 participants (M(SD) age = 35.19[12.57] years). Participant demographics and clinical characteristics are reported in Table 1.

Table 1. Participant demographic information and characteristics

Variable	N (total)	Whole Sample N=769 n (%) /M(SD)
Current age	768	35.24 (12.51)
Sex at birth	764	
Male		317 (41.49%)
Female		445 (58.27%)
Intersex		2 (0.26%)
Gender Identity	767	
Man		303 (39.50%)
Woman		365 (47.59%)
Other		94 (12.26%)
Gender Diverse (i.e. not cisgender)	761	119 (15.64%)
Sexual Orientation (% straight)	749	441 (58.88%)
Race*	765	
White		699 (91.37%)
Black		47 (6.14%)
Native American		43 (5.62%)
Asian		22 (2.88%)
Native Hawaiian		3 (0.39%)
Other		25 (3.27%)
Ethnicity (% Hispanic)	757	63 (8.32%)
Intellectual Disability	769	48 (6.24%)
Level of Autistic Traits (Mean SRS-2 Score)	716	70.28 (10.16)

*Numbers in the "race" column add up to more than 100% because participants were counted for every race they identified as (i.e. a person who is both black and white counts once for "black" and once for "white").

Procedure

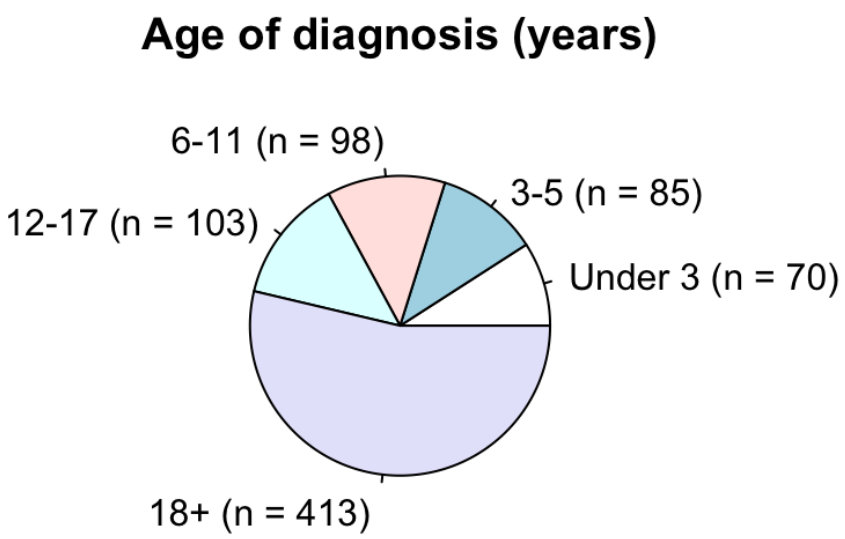
Data were collected from July 2022 to August 2023. Most of our data (611 participants) was collected online via the Simons Powering Autism Research (SPARK) registry. The remaining 158 participants took the same survey in-person in our lab.

Measures

Age of Diagnosis

Participants were asked, “How old were you when first diagnosed with ASD?”. There were five age brackets participants could choose from: under 3 years old, 3-5 years old, 6-11 years old, 12-17 years old, and 18+ years old. We will refer to these brackets, respectively, as “very early childhood”, “early childhood”, “school age”, “adolescence”, and “adulthood”. Our largest bracket of participants were people diagnosed in adulthood, with slightly more than half falling into this category. The other four brackets were roughly evenly distributed, with between 69 and 102 participants in each bracket. Figure 1 serves as an illustration of how many participants fell into each bracket.

Figure 1. Pie chart of age of diagnosis in sample



Sociodemographic Measures

Age. Participants were asked their date of birth. This was translated to an age in months at time of survey.

Sex/Gender. Sex at birth and gender were determined by asking participants to choose from a list of options ("Male", "Female", and "Intersex", for the former; "Male", "Female", "Nonbinary/Gender Fluid", "Agender/No Gender", "Unsure/Questioning", and "Other" for the latter). We used this information to create categories for gender diverse identity: participants whose sex at birth aligned with their gender were put into "cisgender man" or "cisgender woman" categories, while everyone else (including transgender men, transgender women, and people who did not identify as men or women) was labeled as "gender diverse".

Sexual orientation. The survey asked, "What is your sexual orientation?" and gave 10 possible answer choices. Six of them corresponded to sexual minority identities ("Lesbian", "Gay", "Bisexual", "Pansexual", "Queer", "Asexual/Aromantic"); one was "Straight/Heterosexual"; two were "Unsure/Questioning" and "Other"; and one was "Prefer not to answer". Because some buckets were small, we created two categories for "straight" and "sexual minority", with the "sexual minority" category including everyone except for people who selected "Straight/Heterosexual" and those who declined to answer.

Race/Ethnicity. Participants were able to check one or multiple boxes pertaining to their race, including "Native American", "Asian", "Black", "Native Hawaiian", "White", and "other". The survey also asked about Hispanic ethnicity, allowing participants to say "yes" or "no". For analysis, we will use a deterministic bridging method to assign multi-racial participants to the single race they identified with that had the highest prevalence in the sample other than White (thus prioritizing their minoritized racial identity). This will result in racial categories of Asian

American and Pacific Islander, Black or African American, Hispanic/Latine, Native American, White, or Another Race.

Clinical Characteristics

Intellectual disability. Participants self-identified history of an intellectual disability with a question that asked, "Have you ever been diagnosed with an intellectual disability?"

Social Responsiveness Scale, 2nd Edition (SRS-2). The SRS-2 will be used as a measure of autism traits. This self-report measure assesses the communication, social, and interaction difficulties that are associated with autism. It measures five key domains: Social Awareness, Social Cognition, Social Communication, Social Motivation, and Restricted Interests and Repetitive Behavior. This scale is commonly used to screen for autism. Reliability and internal consistency are excellent (alpha = 0.95) (Constantino, 2021).

Outcome Measures

To assess positive adult outcomes, we used the satisfaction domains of the REALS scale, the Adapted Flourishing Scale, and the WHOQOL-BREF scale. Average participant scores for each outcome measure are reported in table 2.

Table 2. Outcome measures

Measure	N (total)	Whole Sample (N=769) M (SD) Range
REALS Work/School Satisfaction (theta)	696	-0.041 (0.928) -1.873 to 1.438
REALS Social Activity Satisfaction (theta)	705	-0.067 (0.928) -1.897 to 1.855
REALS Autonomy Satisfaction (theta)	695	-0.100 (0.906) -2.896 to 2.278
Adapted Flourishing Scale (mean item score)	704	4.930 (1.347)

		1.000 to 7.000
WHOQOL-BREF (mean item score transformed to 0-100 scale)	703	85.49 (17.19) 18.42 to 100.00

Relationships, Employment, Autonomy, and Life Satisfaction Scale (REALS). There are 108 REALS self-report items, including 20 questions about social relationships, 13 measures about employment and school, 41 items about autonomy, and 33 items about satisfaction in each of the previously mentioned domains. For the present study, we will be using the satisfactions scales, which are derived from the 33 satisfaction items. These items were rated on a four-point satisfaction scale (not at all, a little bit, quite a bit, completely), with higher scores indicating more satisfaction. These items load onto the 3 subscales: work/school satisfaction; social activity satisfaction; and autonomy satisfaction. Previous work using the whole REALS sample has demonstrated excellent internal consistency in the satisfaction scales (Cronbach's alphas = 0.90-0.92; (Conner et al., 2024 [in progress])

World Health Organization Quality of Life-BREF (WHOQOL-BREF). The WHOQOL-BREF is a shortened, 26-item version of the original 100-item WHOQOL, a survey from the World Health Organization that is meant to determine quality of life across diverse populations. The WHOQOL-BREF evaluates four broad domains: physical health, psychological health, social relationships, and environment. Each item is scored on a self-report scale of 1 to 5. We will be using the mean item score across all domains. This is a widely used scale with good internal consistency (Cronbach's alpha for whole scale = 0.92) (The WHOQOL group, 1998).

Adapted Flourishing Scale (AFS). The AFS is an adapted version of Diener's Satisfaction with Life Scale (Diener et al., 1985; Beck, et al., 2024) for autistic adults. The scale is part of the AutProm toolbox, a set of measures designed for and by autistic adults to measure outcomes for autistic adults. The Flourishing Scale includes 8 self-reported items, with items

related to life satisfaction, meaning, and other measures of flourishing on a 7-point Likert scale of 1 (strongly disagree) to 7 (strongly agree). This scale is in development, and no norms exist, so the 8 items on the scale will be summed to yield a total score. Internal consistency for this scale in the REALS sample was good (Cronbach's alpha =.92; Conner et al., 2024 [in progress])

Data Analytic Plan

Aim 1

Our first aim is to explore the associations between sociodemographic (i.e., age, sex at birth, gender, orientation, race, ethnicity) and clinical (i.e., autism traits, intellectual disability) variables and AoD. We will accomplish this by analyzing the bivariate associations between AoD and each variable of interest. Because AoD will be treated as a categorical variable, we will use chi-squared tests to examine associations with other categorical variables (e.g., race, sex, sexuality) and ANOVAs for continuous variables (e.g., age, autism traits). Due to the large number of analyses in this aim, we will apply a Bonferroni correction to reduce the likelihood of Type 1 errors when interpreting these results.

Aim 2

Our next aim is to determine whether AoD predicts scores on our five life outcome measures (i.e., WHOQOL-BREF, AFS, 3 satisfaction REALS subscales) above and beyond the effects of sociodemographic and clinical variables. We will accomplish this by performing five multiple regressions predicting each of our outcome variables of interest with AoD and any sociodemographic/clinical variables from aim 1 that had a significant association with AoD. AoD will be entered as a factor variable with diagnosis in adulthood (18+) as the reference group. In determining which sociodemographic/clinical variables to include, we will include any variable that reaches a significance level of <0.05 (rather than the stricter Bonferroni corrected alpha) in aim 1.

Aim 3

Our third aim will be exploratory. We aim to determine whether relevant sociodemographic and clinical variables moderate the relationship between AoD and adult outcome variables. We will add interaction terms between the sociodemographic/clinical variables included in aim 2 analyses and AoD to each regression explored in aim 2. For any significant interaction terms identified in the regression analyses, follow-up analyses will be conducted to clarify the nature of the interactions. Specifically, for interactions between AoD and another categorical variable, we will perform post hoc pairwise comparisons between the groups defined by the interaction, using adjustments for multiple testing where appropriate. For interactions between AoD and a continuous variable, we will conduct simple slopes analyses to examine the association between the continuous predictor and the outcome at each level of AoD. Interaction effects will also be visualized using plots to illustrate group differences or patterns, aiding interpretation and reporting.

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