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for Transition-Aged Youth with Autism Spectrum Disorders

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14. ABSTRACT The objective of this research was to identify specific day-to-day experiences that are associated with depressive symptoms and quality of life among adolescents and young adults with ASD. To accomplish this objective, we recruited 252 families of individuals with ASD between the ages of 15 and 25 from existing research and clinical registries. Using a multi-trait (i.e. multiple aspects of psychological health and daily experiences), multi-method (e.g., self- and parent-reports; surveys, diagnostic interviews, daily reports) design, we have commenced examining relationships between depressive symptoms, quality of life, and multiple types of experiences of these youth. Initial analyses suggested that it was not the amount of time in interactions that was associated with depressive symptoms rather how they felt during the interactions that was important. Knowledge gained from this project will lay the groundwork for clinical efforts to improve psychological health in adolescents and young adults with ASD.					
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TABLE OF CONTENTS

1. INTRODUCTION	4
2. KEYWORDS	4
3. ACCOMPLISHMENTS.....	4
4. IMPACT	19
5. CHANGES.....	20
6. PRODUCTS	20
7. PARTICPANTS AND COLLABORATING ORGANIZATIONS.....	21
8. SPECIAL REPORTING REQUIREMENTS.....	23
9. APPENDICES	24

1. INTRODUCTION

Adolescents and adults with autism spectrum disorder (ASD) experience sharply elevated lifetime rates of depression relative to both typically developing individuals and those with other developmental disabilities. The objective of this research is to identify specific day-to-day experiences that are associated with depressive symptoms and quality of life among adolescents and young adults with ASD. Many aspects of social, vocational, and educational experiences are mutable, making them ideal potential targets for interventions to improve psychological health for people with ASD. The Specific Aim of this study is to test associations between depressive symptoms, quality of life, and various educational, vocational, and social experiences among individuals with ASD with average or above cognitive functioning. An additional exploratory aim is to determine whether the strength of relationships between specific experiences and depressive symptoms differ based on functional (e.g., IQ, adaptive behavior) and behavioral (e.g., core ASD symptoms) factors. To accomplish these objectives, we recruited 252 families of individuals with ASD between the ages of 15 and 25 from existing research and clinical registries. Using a multi-trait (i.e. multiple aspects of psychological health and daily experiences), multi-method (e.g., self- and parent-reports; surveys, diagnostic interviews, daily reports) design, we have commenced examining relationships between depressive symptoms, quality of life, and multiple types of experiences of these youth. Knowledge gained from this project will lay the groundwork for clinical efforts to improve psychological health in adolescents and young adults with ASD.

2. KEYWORDS:

Autism spectrum disorder, depression, quality of life, employment, education, relationships, social activities, academic

3. ACCOMPLISHMENTS:

• What were the major goals of the project?

The major goal of this project was to examine how particular educational, vocational, and social experiences are related to depressive symptoms and quality of life for adolescents and adults with ASD. The specific scope of work tasks, percent complete of each task, and data completed are presented in Table 1.

Table 1. Scope of work tasks and completion information

Tasks Proposed in Scope of Work	Project Year	% Complete	Date of completion
Task 1: Finalize study protocol and measures	1	100%	Initial protocol: Jun. 2020 Updated protocol: Oct. 2020

Task 2: Obtain Institutional Review Board approval for the proposed research	1	100%	Initial protocol: Jul. 2020 Updated protocol: Oct 2020
Task 3: Hire Research Assistants at each site to assist in tasks related to the proposed research	1	100%	Fall 2020
Task 4: Receive contact information for potential participants from the Simons Simplex Collection (SSC) registry	1	100%	Ongoing from Feb. 2021 to May 2022
Task 5: Collect data from 250 youth with ASD and their parents. Identical procedures will be utilized across project sites.	1-2	100%	Jun. 2022
Task 6. Clean the data and prepare them for data analysis	1-2	100%	Sept. 2022
Task 7. When approximately one-half of the data are collected, prepare an abstract detailing initial findings and submit it to the International Meeting for Autism Research.	2	100% (Gatlinburg conference)	Oct. 2022
Task 8. Analyze final dataset for the Specific and Exploratory Aims, and present the findings at the International Society for Autism Research Meeting (INSAR).		See below	
8a. Analyze final dataset	2	50%	In process
8b. Submit abstract to present findings at INSAR	2	100%	Oct. 2022
Task 9. Submit 1-2 manuscripts detailing these findings.	2	25%	In process

- **What was accomplished under these goals?**

Major Tasks 1-3: Preparatory Activities for Data Collection (finalize study protocol and measures, obtain Institutional Review Board approval, hire project staff)

As detailed in the scope of work, major activities for Year 1 of this grant included preparatory activities for data collection. Initial activities including finalizing the study protocol and measures and building study-specific data collection and storage platforms through REDCap. Because we were planning to begin data collection during the COVID-19 pandemic, additional care was taken to develop a protocol that would be feasible for youth and families who might be under additional distress due to the pandemic. We also considered and ultimately included some additional questions related to the COVID-19 pandemic so that we would be able to understand how mental health and day-to-day activities (the primary constructs of interest in this study) might be impacted by COVID-19.

After finalizing study protocols and measures, we submitted a Single IRB application, and received approval at the primary site (Vanderbilt University Medical Center) and at the relying sites (University of California San Francisco, Cincinnati Children's Hospital Medical Center). We also received study approval from the Department of Defense Human Research Protections Office. We hired project staff at each site to assist in data collection and other tasks related to the research protocol. We developed online data collection instruments and data entry databases, and trained research staff in administration and scoring procedures for the study measures.

Major Task 4: Receive contact information for potential participants from the Simons Simplex Collection (SSC) registry

Though we had initially expected to only recruit participants from the Simons Simplex Collection (SSC) registry, we encountered unanticipated challenges that made this registry less useful than anticipated. Though parents had initially consented for their family to be part of the registry, adults with ASD had to be reconsented once they turned 18 years of age. This resulted in fewer potential participants than we had planned for. When we proposed the project, we were anticipating that over 700 youth and adults with ASD would be eligible from the SSC registry. However, it turned out that fewer than 300 families were available for recontacting. Further, the response rate for those 300 families was lower than expected. This is likely due, at least in part, to COVID-19 and the additional stressors that autistic individuals and their families were facing. It was also due to restrictions in the methods we are able to use to contact and recruit families. Instead of using multiple methods of contact to reach out to eligible families (e.g., mailings, telephone calls), each family only received an email about the study and two follow-up reminder emails.

To trouble shoot these challenges and meet our recruitment goals, we identified other recruitment sources. On April 20, 2021 we received permission from our Program Officer to broaden the registries used for participant recruitment to include other individuals who were ascertained in a similar manner as those in the SSC registry. We recruited from a different registry run by the Simons foundation (Simons Powering Autism Research or SPARK, which is substantially larger than the SSC registry) and from research registries at our participating universities. In all these cases, adolescents/adults with autism had received a clinical diagnosis of ASD – just as in the SSC registry. Only one important piece of data was missing from some participants in the other registries – estimates of IQ. For those without existing IQ information, during the interview with the adolescent/adult with autism, we administered the online Peabody Picture Vocabulary Test, 5th Edition (PPVT-5) to provide an IQ estimate. All of these changes to our protocol were approved by our Institutional Review Board. In essence, these additional recruitment venues provided us with comparable samples to the one we had proposed in the grant. Other than delaying data collection while we were waiting for IRB approvals and additional recruitment, using these additional registries did not affect our ability to test the aims of the project in any way. It also may have resulted in a more representative sample than what was available through the SSC.

Major Tasks 5 and 6: Collect data from 250 youth with ASD and their parents; clean and prepare data for analysis.

Major activities for Years 1 and 2 included recruitment and data collection from 250 adolescents/adults with autism and their families. Though we had anticipated beginning data collection in month 7 of the grant (i.e., January 2021), we chose to delay commencing data collection until March 2021 because of the COVID-19 pandemic. This is because, in January 2021, the pandemic was surging in many areas across the United States. Beginning data collection at this time would have hampered our ability to test our specific aim: not only did we anticipate that individuals with ASD could be experiencing pandemic-related mental health challenges, but also these individuals' day-to-day activities were severely restricted at this time. Because youth would be less likely to be attending in-person school, working, and/or interacting socially with a range of other people (all key constructs of interest in this study), we determined it best to delay our data collection by two months to allow for the surge of COVID-19 cases to pass and the loosening of social distancing restrictions. Data collection on our first participant took place on March 1, 2021, and by the end of Year 1 we had enrolled 45 participants across project sites.

During Year 2, we enrolled the remaining participants. We exceeded our recruitment goal by consenting/assenting 252 adolescents and adults with autism (goal of 250); we consented 247 of their parents to participate in data collection. Note that we required parent consent for youth participation on all cases where youth could not provide consent for themselves – either because they were under 18 years old or because their parent was their legally authorized representative. We did not require parental participation in cases where adults with autism could consent for themselves, though nearly all parents did participate. Of the 252 adolescents/adults who consented, we collected data from 246. 244 completed the interview portion of the study, 228 completed an online survey (2 partial completion, 226 full completion), and 234 completed end-of-day surveys. Of the 247 parents who consented to participate, 232 completed a parent survey.

Within the confines of our recruitment criteria, we were able to recruit a fairly diverse sample in terms of geography, age, gender, autism symptom severity, and mental health, as seen in Table 2. Youth with autism in this sample ($n=246$) resided across 36 states, with an average age of 18.70 years old ($SD=2.55$, 51.2% below age 18). About three-quarters (74.8%) were biological male assigned at birth, 70.3% identified as male and 7.3% identified as gender-diverse. About two-thirds (62.6%) were currently in high school and 28.9% were currently working at the time of the study (see demographic details in Table 2). Our sample showed a wide range of scores on mental health symptom measures, with self-reported Beck Depression Inventory-II (BDI-II) and Depression Anxiety Stress Scales (DASS) scores covering a wide range: Mean (BDI-II) = 11.53 ($SD = 10.47$, Range: 0-46), Mean (DASS-Depression) = 8.10 ($SD = 9.51$, Range: 0-42), Mean (DASS-Anxiety) = 7.44 ($SD = 7.93$, Range: 0-38), Mean (DASS-Stress) = 10.32 ($SD = 9.0$, Range: 0-40). While we focused our recruitment on individuals with IQ over 70 to ensure their ability to complete the self-report measure, our sample still represents a wide range of adaptive functioning levels (ABAS-3 General Ability Composite Score: Mean = 70.94, $SD = 12.03$, Range: 50-120) and autism traits as indexed by the Social Responsiveness Scale-2 (SRS-2; total t-score: Mean = 68.87, $SD = 11.54$, Range: 41-107). As is the case in the registries from which we recruited, our sample was less diverse in terms of parent education and race/ethnicity, with 67.1% of parents having received a bachelor's degree or beyond, and only 14.2% identifying as Non-White and 4.9% Hispanic. However, because our sample is fairly large, we hope to be able to examine potential impacts of parent education and race/ethnicity on our relationships of interest.

Table 2. Youth and Parent Demographic Characteristics

Variable	N	% or Mean (SD)	Range
Age (years)	246	18.70 (2.55)	15.20 – 26.00
Biological sex			
Male	184	74.8%	-
Female	62	25.2%	-
Gender			
Male	173	70.3%	-
Female	49	19.9%	-
Non-binary gender or other	10	4.1%	-
Missing	14	5.7%	-
Race			
American Indian	5	2.0%	-
Asian	5	2.0%	-
Black or African American	10	4.1%	-
Native Hawaiian or Other Pacific Islander	8	3.3%	-
White	211	85.8%	-
Other	2	0.8%	-
Missing	5	2.0%	-
Ethnicity			
Not Hispanic or Latino	113	45.9%	-
Hispanic or Latino	12	4.9%	-
Missing	121	49.2%	-
High school status			
Not currently in or receiving services from high school	92	37.4%	-
Currently in or receiving services from high school	154	62.6%	-
Relationship status			
Single	208	84.5%	-
In a relationship	24	9.8%	-
Missing	14	5.7%	-
Youth education level			
Less than high school	124	50.4%	-

Received high school diploma (or equivalent)	40	16.3%	-
Attended/attending college but have not earned a degree	51	20.7%	-
Associates degree	7	2.8%	-
Bachelor's degree	2	0.8%	-
Master's degree	0	0.00%	-
PhD or professional degree	0	0.00%	-
Other	12	4.9%	-
Missing	10	4.1%	-
Youth currently working (not including Volunteering)	71	28.9%	-
Parent education level			
Less than high school	1	0.4%	-
Received high school diploma (or equivalent)	15	6.1%	-
Attended/attending college but have not earned a degree	33	13.4%	-
Associates degree	22	9.0%	-
Bachelor's degree	75	30.5%	-
Master's degree	65	26.4%	-
PhD or professional degree	22	8.9%	-
Other	3	1.2%	-
Missing	10	4.1%	-
Parent annual household income			
\$20,000 or less	10	4.1%	-
\$20,001 - \$40,000	25	10.1%	-
\$40,001 - \$60,000	20	8.1%	-
\$60,001 - \$80,000	23	9.4%	-
\$80,001 - \$100,000	23	9.4%	-
\$100,001 - \$125,000	27	11.0%	-
\$125,001 - \$150,000	29	11.7%	-
\$150,001 - \$200,000	33	13.4%	-
\$200,001 or higher	30	12.2%	-
Prefer not to answer	16	6.5%	-
Missing	10	4.1%	-

Thus, though our data collection was delayed for a number of reasons related to the COVID-19 pandemic and the administrative and regulatory tasks associated with recruiting from additional registries, we ultimately were able to complete our data collection goal (Major task 5) during the award period, resulting in a rich multi-method, multi-informant dataset on a large sample of adolescents and adults with autism, with which we can examine the impact of day-to-day activities on mental health and quality of life.

In terms of Major Task 6, ongoing data checking and cleaning occurred simultaneously with data collection. As we were collecting data until the end of the award period, final dataset cleaning, scoring, and coding occurred after the award period. That has now been completed, and data analysis on final datasets has begun.

Major Task 7. When approximately one-half of the data are collected, prepare an abstract detailing initial findings and submit it to the International Meeting for Autism Research.

We have prepared an abstract detailing initial findings around rates of depression for adolescents with autism, and have submitted that abstract to a science symposium at one of our institutions (Vanderbilt Kennedy Center Science Day) and to the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities. The Science Day poster and Gatlinburg abstract are appended to this report. The Gatlinburg Conference is the premier research conference in the U.S. on Intellectual and Developmental Disabilities. Many researchers who attend this conference are acutely interested in issues of mental health among those with disabilities, and we felt this conference was more appropriate than the International Meeting for Autism Research to present our initial findings focused on mental health. Thus, we consider this task to be fully met.

Major Task 8-9. Analyze final dataset for the Specific and Exploratory Aims, present the findings at the International Society for Autism Research Meeting (Task 8), and submit 1-2 manuscript detailing these findings (Task 9).

Major Task 8 has been completed (see below) and Major Task 9 is currently in process. Delays to data collection due to reasons discussed above resulted in delays in data analysis and manuscript preparation. However, we have three manuscripts currently in process, which we detail below.

The first manuscript carefully considers rates of depression diagnosis and elevated depressive symptoms among adolescents and young adults with autism. Though primarily descriptive, this is a critically important paper as it can shed light on rates of depression in this group and how well measures and reporters correspond when assessing depression in research studies. Many studies have found very high rates of depression in this group, but often times those studies involve clinical samples and thus the rates of depression might be elevated. In contrast, our sample is a community sample and thus provides an alternate look at depression in the autism population. Information from our depression measures is found in Table 3. Among the youth in this sample, 29% reported that they had ever been diagnosed with depression. In terms of current depressive symptoms, of those who completed standardized measures 22.2% met cut-off for moderate or severe depression on the BDI-II (self-report)

Table 3. Those with a depression diagnosis and meeting cut-offs based on youth-report and MINI interview

Variable	N	%
Youth self-report lifetime depression diagnosis		
No lifetime diagnosis	169	68.7%
Lifetime diagnosis	72	29.3%
Missing	5	2.0%
Major Depressive Disorder ever (MINI)	90	36.6%
Major Depressive Disorder current (MINI)	18	7.3%
Major Depressive Disorder past (MINI)	89	36.2%
Major Depressive Disorder recurrent (MINI)	38	15.5%
BDI-II Depression Classification		
Minimal	152	61.8%
Mild	27	11.0%
Moderate	35	14.2%
Severe	16	6.5%
Missing	16	6.5%
DASS Depression Classification		
Normal	155	63.0%
Mild	23	9.3%
Moderate	27	11.0%
Severe	9	3.7%
Extremely severe	16	6.5%
Missing	16	6.5%
ABCL/CBCL DSM Depression		
Normal range	131	53.3%
Borderline clinical range	36	14.6%
Clinical range	53	21.5%
Missing	26	10.6%

and 22.6% met cut-offs for moderate or severe depression on the DASS (self-report). In terms of parent-reported depressive symptoms, 21.5% had scores on the Adult Behavior Checklist/Child Behavior Checklist (ABCL/CBCL) in the clinical range and an additional 14.6% had scores in the borderline clinical range. Just over 20% (21.4%) of cisgender males reported having received a depression diagnosis, compared to 42.2% of cisgender females and 55.6% of those who were gender non-congruent.

Additional analyses focused on those who were under 18, as we have data on self-report of depression diagnosis and parent-report of depression diagnosis in this younger group. Parents were more likely than youth to report that their son/daughter had received a depression diagnosis, which suggests that youth with autism may not always be aware when they receive a

depression diagnosis. Finally, we compared parent reports of depressive symptoms and diagnosis for youth under 18 to a comparable sample of youth with autism and lower IQs. Though rates of borderline and clinical depressive symptoms on standardized instruments were similar across the two samples, the current sample of youth with IQ over 70 were three times as likely to have received a depression diagnosis as those with lower IQs. These findings suggest that depression might be particularly under-diagnosed among those with autism and lower IQ. A poster presenting these findings is being presented at an internal science symposium and an abstract detailing these findings has been submitted to the Gatlinburg conference (see attached).

The second manuscript presents findings from our specific aim, examining the role of day-to-day activities in depression and quality of life. These analyses utilize our survey and interview data, as well as the end-of-day report (EOD) from youth. The youth completed the EOD for seven days in a row at 9PM each night where they reported about social activities that occurred during 5 periods across the day. During each period, they reported on what specific activities they were engaged in, who they were with (alone vs interacting with others) and how they felt during each instance. On average 43.7% (SD = .23) of instances over the week were spent alone, while 25.2% (SD = .18) of instances were spent in interactions. Multiple regressions tested associations between the average ratings of how youth felt during instances spent alone and instances during interactions for 10 different feelings, other predictors related to school, work, and social activities, and depressive symptoms (measured by self-report and parent report), and quality of life while controlling for demographic measures (see Table 4). As seen in Table 4, feelings of being rejected, lonely, and sad while alone, and feelings of stress, being mad, and frustrated while interacting with others were associated with self-reports of depressive symptoms on the BDI-II. Additionally, self-reports of general loneliness, ostracism, and peer victimization were associated with self-reports of higher depressive symptoms, whereas liking school, and school engagement were associated with self-reports of lower depressive symptoms on the BDI-II. In terms of parent report of depressive symptoms (i.e., CBCL/ABCL), feelings of being mad, frustrated, and sad while alone was associated with depressive symptoms, as well as parent-reported school and vocational avoidance. For quality of life (i.e., ASQOL), feelings of being lonely while being alone and feelings of being happy, excited, stressed, mad, and frustrated while interacting were associated with quality of life. The amount of time spent alone or interacting was not associated with any of the outcomes. An abstract detailing these initial findings has been submitted for consideration to the International Meeting for Autism Research, and is appended to this report.

These findings provide initial insights relevant to treating depression and enhancing quality of life in this group. Specifically, it was not the amount of time in interactions that was associated with depressive symptoms rather how they felt during the interactions that was important. These findings suggest future studies may want to focus less on changing the number of interactions and instead on improving the quality of interactions. Studies may also want to focus on which social cognitions are associated with these specific feelings when alone and when interacting, and what aspects of school and work make them more enjoyable and less likely to avoid to identify possible targets for future interventions.

The third manuscript will present findings from our exploratory aim, examining whether characteristics of the youth influence the associations between day-to-day activities and depression or quality of life. Though we will ultimately examine a number of different potential moderators, we have so far examined the potential role of youth gender and whether or not the youth is in high school. Utilizing multiple regression moderator analyses, we have not observed moderating effects for those two variables (all $\Delta R^2 < .007$, non-significant), suggesting that the impact of day-to-day activities on depression or quality of life is not dependent on the youth's current gender nor on his/her high school exit status. We will continue to examine relevant moderators, resulting in at least one manuscript to be submitted for publication.

Table 4. Regression analyses

Variable	β	t-value	SE	ΔR^2
Outcome measure: BDI-II total score				
Control variables				
Youth age	0.029	0.386	0.262	0.034
Gender/sex (1=Female, 2=Male)	-0.160	-2.145	1.694	
Parent education status (0=Less than bachelors, 1=Bachelors or higher)	0.057	0.057	1.466	
Race/Ethnicity (0=Non-White, 1=White)	0.044	0.044	2.167	
Predictor variables				
EOD mean time alone	0.188	2.117	1.422	0.024
EOD mean time interacting with others	-0.090	-1.034	1.407	
EOD feeling happy when alone	-0.206	-2.193	1.493	0.075*
EOD feeling happy when interacting with others	-0.098	-1.039	1.719	
EOD feeling rejected when alone	0.092	2.548	6.610	0.107*
EOD feeling rejected when interacting with others	0.092	0.907	4.996	
EOD feeling lonely when alone	0.408*	5.179	2.063	0.271*
EOD feeling lonely when interacting with others	0.166	2.091	2.771	
EOD feeling stressed when alone	0.084	0.960	2.617	0.176*
EOD feeling stressed when interacting with others	0.365*	4.181	1.966	
EOD feeling satisfied when alone	-0.094	-1.035	1.453	0.037
EOD feeling satisfied when interacting with others	-0.127	-1.411	1.499	
EOD feeling mad when alone	0.104	1.316	6.051	0.200*
EOD feeling mad when interacting with others	0.383	4.857	3.375	
EOD feeling bored when alone	0.206	2.516	2.253	0.101*
EOD feeling bored when interacting with others	0.182	2.332	1.742	

EOD feeling sad when alone	0.493*	6.208	3.027	0.333*
EOD feeling sad when interacting with others	0.128	1.598	2.924	
EOD feeling frustrated when alone	0.096	1.233	3.409	0.236*
EOD feeling frustrated when interacting with others	0.426*	5.450	2.244	
EOD feeling excited when alone	-0.133	-1.297	1.519	0.012
EOD feeling excited when interacting with others	0.034	0.332	1.428	
Loneliness in context total score	0.525*	8.900	0.070	0.267*
Ostracism total score	0.326*	5.085	0.057	0.206*
Victimization total score	0.248*	3.834	0.652	
School engagement (youth report)	-0.329*	-3.686	0.061	0.141*
School engagement (parent report)	-0.102	-1.125	0.055	
School liking (youth report)	-0.366*	-3.580	0.199	0.169*
School liking (parent report)	-0.034	-0.350	0.178	
School avoidance (youth report)	-0.101	-1.107	0.312	
School avoidance (parent report)	-0.125	1.266	0.196	
Vocational liking (youth report)	-0.155	-0.933	0.355	0.142
Vocational liking (parent report)	-0.335	-1.957	0.344	
Vocational avoidance (youth report)	-0.035	-0.232	0.522	
Vocational avoidance (parent report)	-0.196	-1.339	0.470	

Outcome measure: CBCL/ABCL anxious/depressed t-score				
Variable	β	t-value	SE	ΔR^2
Control variables				
Youth age	0.119	1.654	.289	0.100*
Gender/sex (1=Female, 2=Male)	-0.212	-2.941	1.844	
Parent education status (0=Less than bachelors, 1=Bachelors or higher)	-0.142	-1.973	1.573	
Race/Ethnicity (0=Non-White, 1=White)	0.105	1.452	2.331	

Predictor variables				
EOD mean time alone	-0.003	-.029	1.542	0.038
EOD mean time interacting with others	-0.183	-2.150	1.525	
EOD feeling happy when alone	-0.008	-0.088	1.685	0.006
EOD feeling happy when interacting with others	-0.076	-0.794	1.932	
EOD feeling rejected when alone	0.192	1.955	7.731	0.020
EOD feeling rejected when interacting with others	-0.103	-1.050	5.816	
EOD feeling lonely when alone	0.091	1.020	2.607	0.024
EOD feeling lonely when interacting with others	0.085	0.947	3.789	
EOD feeling stressed when alone	0.180	1.938	3.053	0.050
EOD feeling stressed when interacting with others	0.063	0.675	2.295	
EOD feeling satisfied when alone	-0.129	-1.449	1.600	0.028
EOD feeling satisfied when interacting with others	-0.059	-0.664	1.632	
EOD feeling mad when alone	0.152	1.847	7.269	0.029
EOD feeling mad when interacting with others	0.035	0.424	4.094	
EOD feeling bored when alone	0.043	0.518	2.569	0.001
EOD feeling bored when interacting with others	-0.016	-0.196	1.977	
EOD feeling sad when alone	0.267	2.924	3.925	0.043
EOD feeling sad when interacting with others	-0.137	-1.497	3.875	
EOD feeling frustrated when alone	0.201	2.424	4.111	0.060*
EOD feeling frustrated when interacting with others	0.069	0.829	2.690	
EOD feeling excited when alone	0.080	0.790	1.676	0.003
EOD feeling excited when interacting with others	-0.049	-0.492	1.550	
Loneliness in context total score	0.160	2.352	0.086	0.025
Ostracism total score	0.014	0.199	0.070	0.019

Victimization total score	0.139	1.928	0.778	
School engagement (youth report)	-0.049	-0.528	0.073	0.029
School engagement (parent report)	-0.147	-1.566	0.066	
School liking (youth report)	-0.132	-1.328	0.220	0.182*
School liking (parent report)	-0.131	-1.377	0.195	
School avoidance (youth report)	-0.200	-2.242	0.342	
School avoidance (parent report)	0.308*	3.188	0.215	
Vocational liking (youth report)	0.028	0.185	0.387	0.185
Vocational liking (parent report)	-0.170	-1.066	0.376	
Vocational avoidance (youth report)	-0.082	-0.582	0.589	
Vocational avoidance (parent report)	0.356	2.589	0.524	
Outcome measure: ASQOL mean score				
Variable	β	t-value	SE	ΔR²
Control variables				
Youth age	-0.168	-2.298	0.017	0.057
Gender/sex (1=Female, 2=Male)	0.105	1.433	0.108	
Parent education status (0=Less than bachelors, 1=Bachelors or higher)	-0.001	-0.012	0.093	
Race/Ethnicity (0=Non-White, 1=White)	-.101	-1.367	0.138	
Predictor variables				
EOD mean time alone	0.065	0.737	0.091	0.004
EOD mean time interacting with others	0.005	0.055	0.091	
EOD feeling happy when alone	-0.073	-0.808	0.092	0.128*
EOD feeling happy when interacting with others	0.408*	4.524	0.106	
EOD feeling rejected when alone	-0.085	-0.847	0.425	0.090*
EOD feeling rejected when interacting with others	-0.235	-2.331	0.321	
EOD feeling lonely when alone	-0.263*	-3.135	0.142	0.153*

EOD feeling lonely when interacting with others	-0.175	-2.067	0.190	
EOD feeling stressed when alone	0.048	0.529	0.174	0.102*
EOD feeling stressed when interacting with others	-0.350*	-3.883	0.131	
EOD feeling satisfied when alone	0.021	0.234	0.091	0.058
EOD feeling satisfied when interacting with others	0.232	2.640	0.094	
EOD feeling mad when alone	0.072	0.874	0.406	0.114*
EOD feeling mad when interacting with others	-0.372*	-4.533	0.226	
EOD feeling bored when alone	-0.153	-1.868	0.145	0.076*
EOD feeling bored when interacting with others	-0.180	-2.305	0.112	
EOD feeling sad when alone	-0.208	-2.297	0.222	0.120*
EOD feeling sad when interacting with others	-0.179	-1.965	0.215	
EOD feeling frustrated when alone	0.008	0.093	0.232	0.130*
EOD feeling frustrated when interacting with others	-0.366*	-4.436	0.153	
EOD feeling excited when alone	-0.132	-1.338	0.094	0.061*
EOD feeling excited when interacting with others	0.322*	3.282	0.089	
Loneliness in context total score	-0.425*	-6.866	0.005	0.175*
Ostracism total score	-0.389*	-6.004	0.004	0.170*
Victimization total score	-0.080	-1.229	0.043	
School engagement (youth report)	-0.313*	3.414	0.004	0.099*
School engagement (parent report)	-0.024	0.256	0.004	
School liking (youth report)	0.283	2.646	0.013	0.093
School liking (parent report)	0.124	1.202	0.012	
School avoidance (youth report)	0.175	1.823	0.020	
School avoidance (parent report)	0.003	0.024	0.013	
Vocational liking (youth report)	-0.035	-0.197	0.025	0.085
Vocational liking (parent report)	0.344	1.871	0.024	

Vocational avoidance (youth report)	-0.015	-0.093	0.037
Vocational avoidance (parent report)	0.093	0.592	0.033

Summary and Conclusion

Despite facing a number of challenges – primarily due to COVID-19 – we were nonetheless able to complete nearly all of the major tasks outlined in the original Scope of Work. We completed all preparatory activities for data collection on the general timeline proposed in the Scope of Work. Perhaps most importantly, though challenges due to COVID and using the SSC registry led to delays in our data collection timeline affecting our quarterly enrollment, we were ultimately able to surpass our recruitment goal of 250 adolescents/adults with autism during the project period. We have begun to disseminate our findings via conference proposals and presentations, and we will continue that work after the award has ended. Preliminary analyses are uncovering important associations that shed light on how day-to-day activities are related to depression and quality of life among adolescents and adults with autism.

• **What opportunities for training and professional development has the project provided?**

This award has provided numerous opportunities for trainees at different levels to participate in every step of the scientific process. Research assistants who assisted with data collection are now trained on how to administer standardized measures, including the MINI interview, preparing them for future research and clinical activities involving this population. Incidentally, the two research assistants who conducted most of the direct data collection with participants are in the process of applying to graduate school for clinical psychology so that they can continue their work with individuals with autism. These research assistants, together with our post-doctoral fellow and pediatric fellow, are also working on data cleaning, as well as collaborating on the data analyses described above. Moreover, our post-doctoral fellow was recently awarded a K99/R00 using pilot data from this project. The trainees are working on preparing abstract submissions for upcoming conferences, which will allow them to gain experience presenting this work to a larger audience.

• **How were the results disseminated to communities of interest?**

We have submitted two abstracts to national/international scientific conferences that are taking place in Spring 2023 (see attached abstracts), and will continue to submit abstracts detailing study findings to scientific conferences over the upcoming year. In terms of other communities of interest, the PIs regularly deliver talks to parents and family members of individuals with autism, self-advocates, and other members of the clinical community. Last year, Dr. Bishop gave a talk for a foundation (the Alan Hu Foundation) to a group of several hundred parents, which was focused on mental health in adults with autism. As soon as results from the current study are available, these will be shared through the PIs' ongoing community engagement work.

• **What do you plan to do during the next reporting period to accomplish the goals?**

Nothing to report.

4. IMPACT

- **What was the impact on the development of the principal discipline(s) of the project?**

There are two primary ways we envision the project findings having significant impacts on the current state of research and clinical care in this area. The exploration of life circumstance variables, including daily interactions and experiences, and their impact on mental health in individuals with ASD is highly novel. It has the potential to transform clinical care of individuals with ASD with depression by identifying novel treatment targets. Whereas currently available treatments focus on addressing the depressive symptoms themselves (e.g., through modified CBT techniques), this work aims to identify experiences that can be modified to promote well-being. For example, our initial findings underscore the need for interventions to focus on improving interaction quality experienced by individuals with autism when targeting social experiences to promote psychological health. Such information will help inform recently launched efforts to apply behavioral activation techniques to depressed individuals with ASD. The research team has already used findings from this data as preliminary studies to support an R01 to identify targets for interventions for depression, and an Institute of Educational Studies exploration grant to identify social experiences to target to improve academic outcomes in adolescents with ASD that are mainstreamed.

Another broad area of impact relates to measurement of depressive symptoms in individuals with ASD, which has implications for screening, diagnosis, and measuring treatment response. Our multi-method, multi-reporter data collection strategy yielded a large amount of data that will allow us to critically evaluate best practices for measurement of depressive symptoms and other relevant constructs in this population.

Finally, this project was novel in its use of methods (especially EOD reports) that are commonly used in typically developing groups but have not yet been widely applied to individuals with ASD. The field of ASD research stands to benefit greatly from methodologies developed in other disciplines. Thus, showing the feasibility of a method that is new to ASD research represents a significant impact. To this end, our research team has used findings from this data as preliminary studies to support an R21 to further test the EOD as a measure of social functioning.

- **What was the impact on other disciplines?**

Nothing to report.

- **What was the impact on technology transfer?**

Nothing to report.

- **What was the impact on society beyond science and technology?**

Nothing to Report.

5. CHANGES/PROBLEMS:

All changes described below were reported in the interim report and approved by our Program Officer.

To address delays in data collection due to COVID-19, we received permission from our Program Officer as well as IRB approval to recruit from additional research and clinical registries. Broadening our recruitment venues did not result in changes to the aims of the project, and only minimal changes to the research protocol and research activities.

Delays in recruitment, data collection, and subject participation significantly impacted our expenditures. We spent less funds than we had budgeted during Year 1 of this project. By carrying these funds forward to Year 2, we had sufficient funds for personnel and subject participation to collect data from the remaining 205 families, thus meeting our recruitment goal of 250 families.

6. PRODUCTS:

• Publications, conference papers, and presentations

Journal publications.

Nothing to report.

Books or other non-periodical, one-time publications.

Nothing to report

Other publications, conference papers and presentations.

The following conference presentations and abstracts are appended to this report:

1. Sullivan, V., Bellan, J., Durrani, E., Bishop, S., Adams, R., & Taylor, J.L. (Nov. 2022). Depression in transition- aged youth on the autism spectrum who have a low IQ. Poster to be presented at Vanderbilt Kennedy Center Science Day, Nashville, TN.
2. Sullivan, V., Zheng, S., Bishop, S., Adams, R., & Taylor, J.L. (Submitted Oct. 2022, Conference Apr, 2023). Comparing depressive diagnosis and symptoms and transition-aged autistic youth with and without low IQ. Poster abstract submitted to the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Kansas City, MO.
3. Adams, R.A., Lampinen, L., Zheng, S., Bishop, S., Taylor, J. (Submitted Oct. 2022, Conference May 2023). Web-Based Measure of Social Functioning and Daily Life of Autistic Adolescents and Young Adults. Submitted as part of a symposium to the annual meeting of the International Society for Autism Research, Stockholm, Sweden.

• Website(s) or other Internet site(s)

Nothing to report

- **Technologies or techniques**

Nothing to report

- **Inventions, patent applications, and/or licenses**

Nothing to report

- **Other Products**

As specified in the terms of the grant award, all data will be shared to the National Database for Autism Research (NDAR). We are currently in the process of uploading data to NDAR.

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

Name:	<i>Taylor, Julie, PhD</i>
Project Role:	<i>PI/PD, Vanderbilt University Medical Center</i>
Researcher Identifier (e.g. ORCID ID):	0000-0002-3904-3476
Nearest person month worked:	2.4 Person Months
Contribution to Project:	Dr. Julie Taylor has provided expertise in measures of adult outcomes. She has overseen all aspects of the day-to-day management of the study at VUMC, supervising VUMC study staff on recruitment of participants, data collection, and data entry and implementation of the project design.
Funding Support:	<i>N/A</i>
Name:	<i>Adams, Ryan, PhD</i>
Project Role:	Co-Investigator, Cincinnati Children's Hospital Medical Center
Researcher Identifier (e.g. ORCID ID):	0000-0002-5716-4335

Nearest person month worked:	2.4 Person Months
Contribution to Project:	Managed all aspects of the day-to-day management and the start-up of the study at CCHMC, supervised CCHMC study staff on recruitment of participants, data collection, and entry at the CCHMC site.
Funding Support:	N/A
Name:	<i>Durrani, Eman</i>
Project Role:	Research Assistant, Vanderbilt University Medical Center
Researcher Identifier (e.g. ORCID ID):	
Nearest person month worked:	1.2 Person Months
Contribution to Project:	Ms. Durrani has provided administrative support to the project, assisting in the development of databases, study documents, and data cleaning. She is also trained to administer the study protocol.
Funding Support:	N/A
Name:	<i>Sullivan, Virginia</i>
Project Role:	Research Assistant, Vanderbilt University Medical Center
Researcher Identifier (e.g. ORCID ID):	
Nearest person month worked:	4.0 Person Months
Contribution to Project:	Ms. Sullivan has led the development of data entry databases for all sites, as well as study-related documents. She oversees IRB submissions/approvals and collects data from study participants.
Funding Support:	N/A

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Changes:

Julie L. Taylor, PhD

Ended: FAR Fund

New, VUMC94207(R34MH123584(Burke)

Ryan Adams, PhD

Ended: Ended: Proctor & Gamble (Parent Guide to Bullying)

New, previously pending: Proctor & Gamble Fund (Teacher Guide to Bullying)

What other organizations were involved as partners?

- **Organization Name:** Cincinnati Children's Hospital Medical Center, Ryan Adams
- **Location of Organization:** Cincinnati, Ohio
- **Partner's contribution to the project - Collaboration:** In addition to expertise in social development and developing measures, Dr. Adams lead the project staff to recruit and collect and manage data for the participants assigned to the CCHMC site.
- **Organization Name:** Simons Foundation
- **Location of Organization:** New York, New York
- **Partner's contribution to the project - Other.** The Simons Foundation provides support to all researchers to make use of research registries that are managed and funded by the foundation. For the present study, we worked with Simons staff to recruit study participants from two of their research registries: the Simons Simplex Collection registry and the SPARK registry.

8. SPECIAL REPORTING REQUIREMENTS

• **COLLABORATIVE AWARDS:**

Award Number: W81XWH2010473

Log Number: AR190086P3

Recipient: The Regents of the University of California, San Francisco

Principal Investigator: Dr. Somer Bishop

This is a collaborative, multiple-PI award. The other PI, Dr. Somer Bishop from the University of California, San Francisco, will be submitting a separate report.

- **QUAD CHART:** Attached

9. APPENDICES: Attached



PI: Julie L. Taylor, PhD Org: Vanderbilt University Medical Center Award Amount: \$425,106

Study/Product Aim(s)

- The Specific Aim of this study is to test associations between depressive symptoms, quality of life, and various educational, vocational, and social experiences among individuals with ASD with average or above cognitive functioning.
- An additional exploratory aim is to determine whether the strength of relationships between specific experiences and depressive symptoms differ based on functional and behavioral factors.

Approach

We will recruit 250 families of individuals with ASD between the ages of 15 and 25 from existing research and clinical registries. We will use a multi-trait, multi-method (e.g., self- and parent-reports; surveys, diagnostic interviews, daily reports) design to examine relationships between depressive symptoms, quality of life, and multiple types of experiences of these youth.

Transitions Lab



Improving the quality of life for autistic youth as they transition to adulthood

Accomplishment: We completed all preparatory activities for data collection including hiring and training staff, finalizing protocols, developing data entry databases, and getting IRB approvals. Data collection began in Year1 and is ongoing in Year 2

Goals/Milestones (Example)

CY20/21 Goals– Study preparatory activities

- ☒ Finalize protocol, hire and train staff
- ☒ Receive IRB approval
- ☒ Gain access to research registry

CY21/22 Goals – Collect data from 250 participants

- ☐ Recruit 250 participants
- ☐ Collect data from all participants and clean data for analysis

CY21/22 Goal – Data analysis and manuscript preparation

- ☐ Submit abstract to professional meeting
- ☐ Submit two manuscripts for publication

Comments/Challenges/Issues/Concerns

- COVID-19 has delayed our data collection timeline..
- To meet our recruitment goals, we will be recruiting from additional research registries (approved by program officer)

Budget Expenditure to Date

Projected Expenditure: \$425,106
 Actual Expenditure: \$421,380

24

Timeline and Cost

Activities	CY	20/21	21/22
Preparatory activities (e.g., finalize protocol/measures, hire/train staff, IRB approval)			
Recruit and collect data from 250 participants			
Clean and prepare data for analysis			
Analyze data, prepare manuscripts and conference abstracts			
Estimated Budget (\$K)		\$289,320	\$132,060

Updated: (10/2022)

INTRODUCTION

- Young adults with an autism experience higher rates of depression than typically developing peers (Hudson et al., 2019; Muskett et al., 2019)
- Much of the extant research on depression in this group only includes those youth who can self-report on their own depressive symptoms. Far less is known about rates of depression diagnosis and elevated depressive symptoms among youth with autism who are minimally verbal or are otherwise unable to self-report on their symptoms.
- This study examines the frequency of depression diagnosis and elevated depressive symptoms in a sample of youth with autism who were unable to report on their own depressive symptoms (all with IQ < 70).

METHODS

Participants
Data for this study were taken from a cross-sectional survey investigating contributors to mental health for transition-aged youth with autism who are unable to self-report. Participants included 287 caregivers of youth with autism ages 15-25 and an IQ lower than 70. Participants were primarily recruited through Simons Foundation databases (SSC, SPARK). The mean age of caregivers was 50.2 years, ranging from 31.4 to 81.9. Caregivers identified primarily as female (n = 249, 93.3%). Mean age of youth was 19.3 years. Youth primarily identified as male (n=214, 80.1%).

To better contextualize the findings, follow-up analyses compared a subset of this sample to a comparable sample of youth with IQ higher than 70. Only youth younger than 18 were included in these analyses. The sample with IQ < 70 included 143 caregivers and the sample with IQ > 70 included 122 caregivers. All other inclusion criteria and measures were the same.

Procedures
All measures in this analysis were completed via online REDCap survey. Youth depression was measured via caregiver-report.

- Measures**
- **Questions about Depression:** We asked parents to report on youth diagnosis of depression and beliefs about whether the youth was depressed at the time of survey completion.
 - **Youth Depression:** The Adult Behavior Checklist (over 18) and Child Behavior Checklist (under 18) (ABCL; CBCL; Achenbach & Rescorla, 2003); is a parent-report measure that examines several aspects of adaptive and maladaptive behavior. For this study, the DSM-oriented depression subscale was used.

Analyses
Crosstabulation analyses were conducted using Pearson's Chi-Square. All crosstabulation values have an asymptotic significance of $p < .001$.

RESULTS

Rates of Depression in Sample with IQ < 70

- 13.8% (n = 37) had a reported diagnosis of depression.
- 16.4% (n = 44) of youth with autism and a low IQ met clinical criteria for depression on the DSM-oriented depression subscale, and an additional 11.5% (n = 31) fell within the borderline range.

Caregiver Beliefs about Youth Depression in Sample with IQ < 70

- Of those youth whose depression scores met the clinical cut-off, 25.0% of caregivers reported that they did not believe the youth was depressed, 45.5% reported that they believed the youth was depressed, and 29.5% reported that they did not know whether their youth was depressed.
- Of those who fell within the borderline range, 74.2% of caregivers reported that they did not believe the youth was depressed, and 22.6% reported that they did not know.

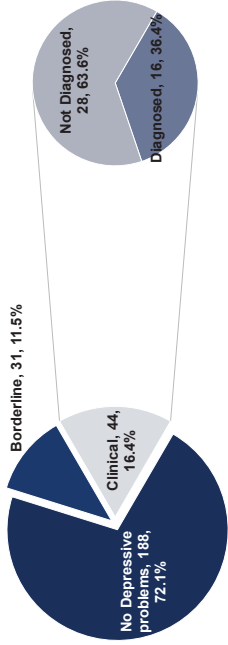


Figure 1. CBCL Depression Problems Scores in the sample with low IQ and the rates of diagnosis in those who fell within the clinical range.

Comparing to a Similar Sample with High IQ (Under 18 only)

- Rates of depression diagnosis are more disparate than would be suggested by scores of depressive problems.

	IQ > 70		IQ < 70		
	n	%	n	%	
Has [youth] ever been diagnosed with depression?					
	No	75	61.5	117	81.8
	Yes	45	36.9	18	12.6
	Don't know	2	1.6	8	5.6
Age at first diagnosis					
	5-7	5	11.4	3	17.6
	8-10	13	29.5	5	29.4
	11-13	13	29.5	2	11.8
	14-16	13	29.5	5	29.4
17-19	0	0	2	11.8	
Do you believe that [youth] is currently depressed?					
	No	75	61.5	99	69.2
	Yes	24	19.7	14	9.8
	Not sure	23	18.9	30	30
CBCL Scores					
	No depressive problems	70	57.4	89	62.2
	Borderline	22	18.0	20	14.0
	Clinical	30	24.6	34	23.8

Table 1. Diagnostic information and CBCL scores for a sample with IQ > 70 and a sample with IQ < 70. All youth are below age 18.

RESULTS CONTINUED

Comparing to a Similar Sample with High IQ (Under 18 only)

- For those with IQ < 70 the CBCL aligns with parental beliefs about youth depression. However, this is less true for those with IQ > 70.

IQ < 70		CBCL Depressive Problems Score				
		No depressive problems		Borderline	Clinical	Total
Do you believe that [youth] is currently depressed?	No	n	73	16	10	99
		%	73.7%	16.2%	10.1%	100.0%
	Yes	n	1	0	13	14
		%	7.1%	0.0%	92.9%	100.0%
	Not sure	n	15	4	11	30
		%	50.0%	13.3%	36.7%	100.0%

IQ > 70		CBCL Depressive Problems Score				
		No depressive problems		Borderline	Clinical	Total
Do you believe that [youth] is currently depressed?	No	n	55	12	8	75
		%	73.3%	16.0%	10.7%	100.0%
Yes	n	6	1	17	24	
		%	25.0%	4.2%	70.8%	100.0%
Not sure	n	9	9	5	23	
		%	39.1%	39.1%	21.7%	100.0%

Figure 3. Crosstabulations between parent beliefs about youth current depression and depressive problem scores.

DISCUSSION

- Among those with and without ID, about 40% of youth had borderline or clinical depressive symptoms. Clinicians should be mindful of the potential rates of depression in these groups.
- In the extant literature, it is unclear whether lower rates of depression diagnoses in those with autism and ID (compared to those without ID) are due to less depression or less recognition of depression. Our findings suggest that, despite similar levels of depressive symptoms to those without ID, those with autism and ID are less likely to get a depression diagnosis.

- For those with autism and ID, parent belief that youth was depressed corresponded well with depressive symptoms scores on the standardized measure, suggesting that parents can provide important information about their youth's mood - particularly when the youth cannot self-report.

REFERENCES



ACKNOWLEDGEMENTS

This research was supported by the FAR Fund (4049546135, PI: Taylor) and the Department of Defense (W81XWH-PI: Taylor).

Title: Comparing Depressive Diagnosis and Symptoms in Transition-Aged Autistic Youth with and without Low IQ

Authors: Virginia Sullivan¹, Shuting Zheng², Somer Bishop², Ryan Adams³, Julie Lounds Taylor¹

Introduction: Young adults with autism experience higher rates of depression than typically developing peers (Hudson et al., 2019; Muskett et al., 2019). However, much of the extant research on depression in this group only includes those youth who can self-report on their own depressive symptoms. Far less is known about rates of depression diagnosis and elevated depressive symptoms among youth with autism who are minimally verbal or are otherwise unable to self-report on their symptoms. The present study examined the frequency of depression diagnosis and elevated depressive symptoms among youth with autism who were unable to report on their own depressive symptoms ($IQ < 70$), and compared them to a similar sample of youth with autism with IQ above 70.

Method: Data for this study were taken from a cross-sectional survey investigating contributors to mental health for transition-aged youth with autism. Participants included 265 caregivers of youth with an autism diagnosis ages 15-18 who were living at home: 143 (54.0%) of the youth had an IQ below 70 (i.e., Lower IQ group) and 122 (46.0%) had an IQ above 70 (i.e., Higher IQ group). Participants were primarily recruited through Simons Foundation databases (SSC, SPARK). The mean age of youth in the Lower IQ group was 16.5 and 16.8 in the Higher IQ group. Youth primarily identified as male ($n=201$, 75.8%). Youth depression was measured via caregiver-report using t-scores from the DSM-oriented depression subscale of the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001); using well-established cut-offs, t-scores were categorized into no depressive problems, borderline depressive problems, and clinically-relevant depressive problems. Caregivers were also asked to report on whether their son/daughter had received a depression diagnosis, age of diagnosis, and whether they believed the youth was depressed at the time of survey completion.

Results: Caregivers reported that 12.6% ($n = 18$) of youth in the Lower IQ group had received a diagnosis of depression, compared to 36.9% ($n = 45$) of youth in the Higher IQ group. Rates of depression diagnoses were more disparate than would be suggested by scores on current depressive problems using the CBCL. Though less than 15% had received a depression diagnosis, one-quarter (24.6%, $n = 30$) of youth in the Lower IQ group had t-scores indicating clinically-relevant depressive symptoms and an additional 18% ($n = 22$) had scores in the borderline range. The distribution of t-scores was similar to the Higher IQ group: 23.8% ($n = 34$) had scores that fell in the clinically-relevant range and 14.0% ($n = 20$) had scores in the borderline range. Among those in the Lower IQ group, in all cases but one, parents' beliefs that their son or daughter was currently depressed was reflected in elevated depressive symptoms scores on the CBCL. This correspondence was weaker among parents in the Higher IQ group.

Discussion: Among both those with higher and lower IQ scores, about 40% of autistic youth had borderline or clinical depressive symptoms on the CBCL. Clinicians should be mindful of the potential rates of depression in these groups. Previous research suggests that youth with intellectual disability have more difficulty expressing feelings to caregivers and clinicians due to limited social and cognitive skills (Mayes et al., 2011; Turygin et al., 2013), and this might make it

more difficult to identify (and diagnose) depression in this group. This is consistent with our findings: despite similar levels of depressive symptoms to those with higher IQs, those with lower IQs are less likely to get a depression diagnosis. For those with autism and lower IQ, parents' beliefs that their youth was depressed corresponded well with depressive symptoms scores on the standardized measure, suggesting that parents can provide important information about their youth's mood - particularly when the youth cannot self-report.

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1

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Title: Web-Based Measure of Social Functioning and Daily Life of Autistic Adolescents and Young Adults

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Background: Adolescents and young adults with autism face significant challenges related to social isolation, ostracism, and connection. In turn, the social world has been seen as a possible target for intervention to improve quality of life and to possibly address high rates of depression in this group. However, studies have not yet been able to isolate which, of the many types of social experiences, are most impactful for quality of life and psychological health. Current available measures of social functioning and daily life are problematic because they do not measure a broad range of social activities. They also often do not measure how reporters feel about their interactions, which is critical given the evidence that certain social connections *increase* distress among this group.

Objective: The objective of the current study is to provide evidence of feasibility and validity of a new measures of social functioning/daily life of autistic youth that address the measurement concerns mentioned above.

Method: 248 adolescents and young adults with autism diagnoses who could self-report (M age = 18.7, SD = 2.5, range 15.2-26.0; 67.6 % male; 84.8% white) were recruited from two national registries and completed the end of day report (EOD) as well as the Beck Depression Inventory (BDI) and an autism quality of life measure (AQOL). Youth completed the (EOD) for seven days in a row at 9PM each night, where they reported about social activities that occurred during 5 periods across the day (See Figure).

Results: Overall, only 3.6% ($n=9$) did not completed the EOD and those who did start had an average completion rate across all 35 instances across the week of 87.6 % (SD = 8.9). Multiple regressions tested associations between the time across the week spent alone and interacting, as well as average rates across the week of how youth felt during instances spent alone and instances during interactions with others for 10 different feelings and the BDI and the AQOL, while controlling for demographic measures (see Table 1). As seen in Table 1, feelings of being rejected, lonely, and sad while being alone and feelings of stress, being mad, and frustrated while interacting were associated with BDI scores. Additionally, feelings of being lonely while being alone and feelings of being happy, excited, stressed, mad, and frustrated while interacting were associated with the AQOL. The amount of time spent alone and interacting was not associated with the BDI or AQOL.

Conclusion: The findings provide initial evidence of feasibility and validity of this new measure of social functioning/daily life of autistic youth. Specifically, the completion rates suggest the measures is feasible for the targeted population and the multiple regression findings provided evidence of concurrent validity. It was not the amount of time in interactions that was associated with the outcomes rather it was how one felt during the interactions that was important. This suggests that it may be more impactful to attempt to improve the quality of interactions than increase the length of interactions.

Figure 1. The Schema of the End of Day Report Questions for One Reporting Period.

Choose all activities/events you were doing before 9am. Select all that apply.

☐ Resting
☐ Sleeping
☐ Reading
☐ Using the internet to find information or read
☐ Using the internet for communicating with others
☐ Playing video games/gaming
☐ Listening to music
☐ Watching a movie or TV (on TV or internet)
☐ Personal care (bathing, dressing, etc.)
☐ Educational activity (in class, ...)

Continued

From before 9am, choose the one activity/event that lasted the longest.

☐ Resting
☐ Sleeping
☐ Reading
☐ Using the internet to find information or read
☐ Using the internet for communicating with others
☐ Playing video games/gaming
☐ Listening to music
☐ Watching a movie or TV (on TV or internet)
☐ Personal care (bathing, dressing, etc.)
☐ Educational activity (in class, ...)

You listed Resting. Where did this happen?

☐ My Home
☐ Another Person's Home
☐ Public Place
☐ Work
☐ School
☐ Traveling
☐ Other

You listed Resting. How long did this activity/event last?

☐ Less than 5 minutes
☐ 5-15 minutes
☐ 15-30 minutes
☐ 30-60 minutes
☐ 1-2 hours
☐ More than 2 hours

You listed Resting. Were you...

☐ Alone
☐ With other people but not interacting with them
☐ With other people and interacting with them

How well do each of these words describe how you felt during the longest activity: Resting.

Not at all		Some		A Lot	
Rejected	☐	☐	☐	☐	☐
Happy	☐	☐	☐	☐	☐
Lonely	☐	☐	☐	☐	☐
Stressed	☐	☐	☐	☐	☐
Satisfied	☐	☐	☐	☐	☐
Mild	☐	☐	☐	☐	☐
Anxious	☐	☐	☐	☐	☐
Bored	☐	☐	☐	☐	☐
Sad	☐	☐	☐	☐	☐
Frustrated	☐	☐	☐	☐	☐
Excited	☐	☐	☐	☐	☐

How well do each of these words describe this interaction with this person/people?

Not at all		Some		A Lot	
Angry	☐	☐	☐	☐	☐
Cooperated	☐	☐	☐	☐	☐
Fun	☐	☐	☐	☐	☐
Stressful	☐	☐	☐	☐	☐
Pleasant	☐	☐	☐	☐	☐

During the interaction, the other person/others was/were _____ to me.

Not at all		Some		A Lot	
Nice to me	☐	☐	☐	☐	☐
Mean to me	☐	☐	☐	☐	☐
Ignored me	☐	☐	☐	☐	☐
Supportive	☐	☐	☐	☐	☐

Table 1. Regression analyses

Variable	β	t-value	SE	R ² Δ
Outcome measure: BDI-II total score				
EOD mean time alone	0.188	2.117	1.422	0.024
EOD mean time interacting with others	-0.090	-1.034	1.407	
EOD feeling happy when alone	-0.206	-2.193	1.493	0.075*
EOD feeling happy when interacting with others	-0.098	-1.039	1.719	
EOD feeling rejected when alone	0.092	2.548	6.610	0.107*
EOD feeling rejected when interacting with others	0.092	0.907	4.996	
EOD feeling lonely when alone	0.408*	5.179	2.063	0.271*
EOD feeling lonely when interacting with others	0.166	2.091	2.771	
EOD feeling stressed when alone	0.084	0.960	2.617	0.176*
EOD feeling stressed when interacting with others	0.365*	4.181	1.966	
EOD feeling satisfied when alone	-0.094	-1.035	1.453	0.037
EOD feeling satisfied when interacting with others	-0.127	-1.411	1.499	
EOD feeling mad when alone	0.104	1.316	6.051	0.200*
EOD feeling mad when interacting with others	0.383	4.857	3.375	
EOD feeling bored when alone	0.206	2.516	2.253	0.101*
EOD feeling bored when interacting with others	0.182	2.332	1.742	
EOD feeling sad when alone	0.493*	6.208	3.027	0.333*
EOD feeling sad when interacting with others	0.128	1.598	2.924	
EOD feeling frustrated when alone	0.096	1.233	3.409	0.236*
EOD feeling frustrated when interacting with others	0.426*	5.450	2.244	
EOD feeling excited when alone	-0.133	-1.297	1.519	0.012
EOD feeling excited when interacting with others	0.034	0.332	1.428	
Outcome measure: ASQOL mean score				
EOD mean time alone	0.065	0.737	0.091	0.004
EOD mean time interacting with others	0.005	0.055	0.091	
EOD feeling happy when alone	-0.073	-0.808	0.092	0.128*
EOD feeling happy when interacting with others	0.408*	4.524	0.106	
EOD feeling rejected when alone	-0.085	-0.847	0.425	0.090*
EOD feeling rejected when interacting with others	-0.235	-2.331	0.321	
EOD feeling lonely when alone	-0.263*	-3.135	0.142	0.153*
EOD feeling lonely when interacting with others	-0.175	-2.067	0.190	
EOD feeling stressed when alone	0.048	0.529	0.174	0.102*
EOD feeling stressed when interacting with others	-0.350*	-3.883	0.131	
EOD feeling satisfied when alone	0.021	0.234	0.091	0.058
EOD feeling satisfied when interacting with others	0.232	2.640	0.094	
EOD feeling mad when alone	0.072	0.874	0.406	0.114*
EOD feeling mad when interacting with others	-0.372*	-4.533	0.226	
EOD feeling bored when alone	-0.153	-1.868	0.145	0.076*
EOD feeling bored when interacting with others	-0.180	-2.305	0.112	
EOD feeling sad when alone	-0.208	-2.297	0.222	0.120*
EOD feeling sad when interacting with others	-0.179	-1.965	0.215	
EOD feeling frustrated when alone	0.008	0.093	0.232	0.130*
EOD feeling frustrated when interacting with others	-0.366*	-4.436	0.153	
EOD feeling excited when alone	-0.132	-1.338	0.094	0.061*
EOD feeling excited when interacting with others	0.322*	3.282	0.089	