

Associated risk factors for depression and anxiety in adults with intellectual and developmental disabilities: Five-year follow up

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Acknowledgments

Part of this manuscript was orally presented at the 2017 International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) 4th Asia Pacific Regional Congress, Bangkok, Thailand. The contents of this paper were developed under the following grants: Grant # 90RT5020-03-00, #90AR5007 from the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and Special Olympics cooperative agreement #U01DD000302 from the U.S. Centers for Disease Control and Prevention. However, those contents do not necessarily represent the policy of the Department of Health and Human Services (DHHS) or the U.S. Centers for Disease Control and Prevention. They are solely the

responsibility of the authors and do not necessarily represent the official views of the NIDILRR.

Abstract

A better understanding of the factors associated with depression and anxiety in people with intellectual and developmental disabilities is needed to provide guidelines for service providers, clinicians, and researchers as well as improve the diagnostic process. The current study used a longitudinal dataset to explore demographic, health, and psychosocial risk factors of anxiety and depression in adults with intellectual and developmental disabilities. Women were more likely to have depression while older adults, people with autism and people with hearing impairments were more likely to have anxiety. Chronic health conditions were associated with both anxiety and depression, while changes in stressful life events were associated with an increased risk of anxiety. Clinical and research contributions are discussed.

Key Words: Depression, Anxiety, Intellectual and Developmental Disabilities, Stressful life events

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Introduction

A growing body of research has drawn attention to the prevalence of psychiatric disorders, such as depression and anxiety, among people with intellectual and developmental disabilities (IDD). Most research indicates the people with IDD are at least as likely, if not more likely, than the general population to develop depression with estimates ranging from 2.2% to 15.8% (Deb, Thomas & Bright, 2001; Cooper, Smiley, Morrison, Williamson & Allan, 2007; Cooper, McLean, Guthrie, McConnachie, Mercer, Sullivan, & Morrison, 2015; White, Chant, Edwards, Townsend & Waghorn, 2005). While there is less data on the prevalence of anxiety disorders in people with IDD, recent studies have provided estimates ranging from 3.8% to 17.4% (Reid, Smiley & Cooper, 2011). Additionally, it is likely that these prevalence rates may be underestimated due to diagnostic challenges in this population (McBrien, 2003; Perez-Achiaga, Nelson & Hassiotis, 2009).

People with IDD have health inequalities in a variety of areas compared to the general population (Krahn, Hammond & Turner, 2006). **For example, there is lack of research, service funding, community awareness and treatment accessibility on mental health disorders in people with IDD. This is further complicated by difficulties in the diagnostic process that subsequently leads to under-diagnosis and underestimated prevalence rates of mental health disorders** (Hermans & Evenhuis, 2013). While there is a growing recognition that people with IDD need access to timely and effective mental health care, barriers to accessing services are still prevalent. One barrier to accessing care is that people with IDD are unlikely to self-refer for services, which necessitates that a caregiver must recognize and facilitate the referral process. Caregivers generally do not have specialized training in mental

health issues and may miss signs and symptoms of poor mental health in people with IDD (Mileviciute & Hartley, 2015). Clinicians also struggle to recognize signs and symptoms of poor mental health in people with IDD. Clinicians lacking experience or training in this population may fall prey to diagnostic overshadowing, attributing clinical concerns to the person's disability rather than to a secondary condition (Jopp & Keys, 2001; Rush et al., 2004) or they may miss symptoms due to over reliance on verbal reporting of symptoms (Austin et al., 2018). These difficulties may be multiplied for people with more severe disabilities (Einfeld, Tonge, Chapman, Mohr, Taffe & Horstead, 2006; Scott & Havercamp, 2015).

Understanding the factors associated with depression and anxiety in people with IDD may help to provide guidelines for service providers, clinicians, and researchers and inform the diagnostic process. For the general population, many risk factors for depression, anxiety or both have been identified including: a family history of depression or anxiety, sex, age, vision or hearing impairment, health related factors, fewer social contacts and negative life events (Kendler, Hettema, Butera, Gardner, & Prescott, 2003; Beekman et al, 2000). **While there is a sizeable literature related to risk factors for psychopathology in the general population, it is less understood what factors contribute to the development and maintenance of anxiety and depression in people with IDD. It is important to understand the unique factors that contribute to depression and anxiety among people with ID because of the mental healthcare inequities they face, as well as because of the different exposure to risk factors, higher psychotropic medication use and associated diagnoses** (McGillivray & McCabe, 2007; de Kuijper et al., 2010; Paton et al., 2011).

Existing literature suggests that people with IDD may experience higher levels of depression than the general population and attributes this disparity to factors including a

biological predisposition, increased exposure to adverse psychosocial experiences, and limited cognitive ability (McGillivray & McCabe, 2007). **Some risk factors of anxiety and depression that have been explored among adults with IDD include health related factors, psychosocial factors and demographic factors. People with IDD are likely to share some risk factors for depression with the general population. For example, abusive experiences, poor social support, unemployment and social disadvantage have all been linked to increased depressive symptoms (Ailey, 2009). In terms of gender, females with IDD seem to experience higher rates of depression and anxiety compared to males with IDD, which is similar to the reported rates among people without disabilities (Chester, Chaplin, Tsakanikos, McCarthy, Bouras, & Craig, 2013; Cooper et al, 2007).**

There are also risk factors associated with anxiety and depression that may be specific to people with IDD. In terms of cognitive functioning, multiple studies have found that people with milder cognitive impairment are more likely to have a diagnosed anxiety or depressive disorder compared to those with more significant cognitive limitations, though it is unclear whether this is related to underdiagnoses or true difference (Hermans & Evenhuis, 2013; Reid, Smiley & Cooper, 2011; Stavrakaki & Lunskey, 2007). Espie et al. (2003) found that Down syndrome and epilepsy were found to be risk factors for depression whereas autism spectrum disorders, epilepsy, lack of daytime occupation and life events were associated with anxiety in young adults with IDD. A second study of older adults with IDD found that while depression and anxiety were positively associated with each other, depression was related positively to chronic diseases and negatively with activities of daily living abilities (Hermans & Evenhuis, 2013). On the other hand, the study showed that anxiety symptoms were negatively

associated with Down syndrome, epilepsy and social contacts in older adults with IDD (Hermans & Evenhuis, 2013).

In terms of psychosocial risk factors of psychopathology in people with IDD, stressful life events have been most well studied. The term “stressful life events” can be used to describe experiences or events such as death of a loved one, change in employment or change in residence. Several correlational and prospective studies have indicated that, for people with IDD, stress and amount of stressful life events are associated with increased psychopathology, especially depression (Esbensen, & Benson, 2006; Hove & Havik, 2010; Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011; Hulbert-Williams, Hastings, Owen, Burns, Day, Mulligan, & Noone, 2014; Scott & Havercamp, 2014; Owen et al., 2004). Less is known regarding anxiety specifically, or what types of stressful life events may be most likely to increase risk of developing these disorders.

Current Study

Despite the abundance of research on risk factors for people without IDD, there are few studies in adults with IDD that look at a wide variety of risk factors for psychopathology within the same population. Specifically, little is known regarding risk factors for anxiety and most previous studies have relied on cross sectional designs. Hermans & Evenhuis (2013) recommend conducting longitudinal research to examine factors associated with anxiety and depression in adults with IDD so that effective prevention and treatment policies can be developed. The current study, therefore, expands research on risk factors of anxiety and depression in people with IDD by examining multiple known risk factors simultaneously and using a longitudinal design.

Methods

Participants

Participants in the present study are those who completed data across all the four-time points (years 1, 2, 3 and year 5) on the measures from the 9-year ongoing longitudinal study “Longitudinal Health and Intellectual and Developmental Disability Study” (LHIDDS, formally as Longitudinal Health and Intellectual Disability Study, LHIDS) in the United States. While a total of 1,618 participants were followed for years 1-3 and year 5 regarding their mental/physical health, physical function and health behaviors; only 758 participants completed data across all the four-time points on the measures of the present study.

Procedure

After approval from all regulatory boards, we recruited the informants of adults with IDD, either family members or primary caregivers, at Special Olympics events, by posting recruitment information in various venues (e.g., Facebook, newsletter advisements, and recruiting materials distributed at conferences), collaborating with managed care organizations, and working with agency staff from various community service agencies. Longitudinal data were collected using a mixed-method (mail and online surveys) data collection procedure according to the informant’s preference. The University institutional review board approved the present study involving human subjects. Along with a cover letter and a subject information letter that served as informed consent for the study, the surveys were sent to the informants. A total of 2,841 surveys (2,182 paper and 659 online) were distributed, and 1,618 surveys (1,187 paper and 431 online) were completed and returned with an overall response rate of 57% at baseline. A total of 1,275 participants (79% response rate) completed the survey in year 2, followed by 1,176 (76% response rate) in year 3 and 924 (73% response rate) in year 5. The test-retest reliability of survey questions done with 15 primary caregivers and 15 direct support staff ranges from

acceptable to very high. For the categorical questions, test–retest reliability (k-statistic) ranged from 0.68 to 0.95, and for the interval questions, the test–retest reliability intraclass correlation coefficient) (Weir, 2005) ranged from 0.75 to 0.94. A detailed description of the survey development can be found in **(citation withheld for review)**.

Measures

The outcome measures in the present study are reported depression status with the use of anti-depression medication and reported anxiety status with the use of anti-anxiety medication. **Since the data is informant-reported, we included a stricter inclusion criteria for reported depression and anxiety status, for instance, those who have a diagnosis and take medication for depression and anxiety respectively, to compensate for respondent bias.** The independent variables include three factors: (1) demographic, (2) health and function-related, and (3) social-environmental factors.

Depression. Depression is defined as having a reported diagnosis of depression and taking antidepressant medication. We asked the informants, “Does he/she have depression based on a diagnosis from a doctor?” The variable was defined as 1 (yes) for depression and 0 (no) for no depression. If the participant had depression, we asked if he/she was taking medication for depression. The variable for medication was defined as 1 (yes) for taking medication and 0 (no) for not taking medication.

Anxiety. Anxiety is defined as having a reported diagnosis of anxiety and taking medication for it. We asked the informants, “Does he/she have anxiety based on a diagnosis from a doctor?” The variable was defined as 1 (yes) for anxiety and 0 (no) for no anxiety. If the participant had anxiety, we asked if he/she was taking medication for anxiety. The variable for medication was defined as 1 (yes) for taking medication and 0 (no) for not taking medication.

Demographic/characteristic factors. Demographic information included age, sex, intellectual disability related conditions (IDD only and other conditions, autism spectrum disorder, cerebral palsy and Down syndrome), and employment status.

Health and function-related factors. *Informant rated health status.* Informant rated health status ranged from 1 “fair or poor”, 2 “good” and 3 “excellent or very good”. *Mobility limitation.* Using any walking aids (i.e., a cane, crutches, a walker, or a wheelchair) was coded as having a mobility limitation (1) Yes or (0) No. *Obesity.* Informant-reported body weight and height were used to calculate Body Mass Index (BMI) by using the formula $(\text{Weight in Pounds} / (\text{Height in inches})^2) \times 703$. Based on the Centers for Disease Control and Prevention criteria, obesity was defined as $\text{BMI} \geq 30.0 \text{ kg/m}^2$. *Hearing impairment.* Whether the person with ID has a diagnosis of hearing impairment was coded as (1) Yes or (0) No. *Vision impairment.* Whether the person with ID has a diagnosis of vision impairment (not including corrective lenses) was coded as (1) Yes or (0) No. *Number of chronic health conditions.* Informants were asked to check whether the person with IDD had a list of 36 health conditions. The number of chronic health conditions is the total number of 27 physical health conditions (**arthritis, osteoporosis, heart condition, high blood cholesterol, high blood pressure, low blood pressure, stroke, diabetes Type 1 or Type 2, thyroid disorder, asthma, chronic bronchitis/emphysema, sleep disorder, back pain, constipation, foot pain, gastrointestinal pain or discomfort, headaches, hip/knee pain, neck/shoulder pain, dizziness/vertigo, hearing impairment, vision impairment, cancer, chronic fatigue, epilepsy/seizure disorder, heartburn/acid reflux, and urinary incontinence**) and 7 mental health conditions (**alcohol or substance abuse, attention deficit disorder, bipolar disorder, dementia/Alzheimer’s disease, eating disorder, obsessive-compulsive disorder, and Schizophrenia**) excluding depression and anxiety. **Literature has**

shown that summed chronic health condition scales are important correlates to psychosocial indices (Piazza, Charles & Almeida, 2007; Lichtenstein, Harris, Pedersen, & McClearn, 1993). The total number of chronic health conditions was grouped into four categories: (1) None, (2) 1, (3) 2, and (4) 3 and more chronic health conditions.

Health risk behavior. Smoking. Smoking was defined as 1 (yes) for a current smoker and 0 (no) for a non-current smoker.

Social-environmental factors. Number of Special Olympics events participated. Informants were asked to check whether the person with IDD participated in Special Olympics events. The total number of events was grouped into three categories: (1) None, (2) 1-3, (3) 4 or more events. *Number of stressful life events. Stressful life events-change* experienced in the past 12 months include: moved to a new residence, changed jobs, changed caregiver/primary caregiver, changed service provider, changed schools, change at work, stopped work **or day program**, any change, and transition. Number of stressful life events-change was grouped into four categories: (1) None, (2) 1, (3) 2, (4) 3 or more events. *Stressful life events-loss* experienced in the past 12 months include: death of an immediate family member, changed roommate, death of a friend, death of relatives, death of others, change of **direct care staff due to staff turnover**, divorce or break up, loss, and **loss of job**. Number of stressful life events-loss was grouped into three categories: (1) None, (2) 1, (3) 2 or more events. The *total number of stressful life events* experienced in the past 12 months is the sum of the number of stressful life events in change, loss, and illness. The total number of stressful life events was grouped into four categories: (1) None, (2) 1, (3) 2, (4) 3 or more events.

Data Analysis

Descriptive statistics were used to summarize the data. Prevalence of depression and anxiety over time for the participants who completed the surveys at all time points were calculated. We first identified variables from the literature review of studies relating to both the general population and people with IDD. Generalized Estimating Equations analysis (GEE) was carried out to conduct the longitudinal analysis. GEE is a type of regression analysis that considers the correlation of the repeated measures within a person and also includes subjects regardless of the missing values (Liang & Zeger, 1993). The GEE method is an estimation of the correlation parameters using all available data over time, and the method is robust with regard to the choice of correlation structure. For GEE, the long data structure is used when each subject has multiple data records, as these are measurements over time. The outcome and predictor variables, therefore, were measured as a diagnosis at any time point of data collection. We used univariate GEE to identify potential variables. Using a traditional p value of 0.05 may fail to identify variables of known importance; therefore, to identify potential covariates and confounders, any independent variables in a univariate regression model with a cut-off point of $p < 0.20$ were included (Bendel & Afifi, 1977; Mickey & Greenland, 1989). All of the independent variables that met the cut-off criteria in the univariate analysis were included in the final multiple GEE model. Variation Inflation Factors (VIFs) statistics were employed to assess collinearity, and all the VIF values were less than 2, suggesting non-collinearity of the variables. Although age did not meet the inclusion criteria ($p < 0.02$) in the univariate analysis, it was included based on the literature review. A significance level at a p value of 0.05 was used for all analyses. **Cochran-Armitage test and Linear-by-Linear Association test were used to examine for trend on informant rated health, percentages of depression and anxiety, and**

number of chronic health conditions (Agresti, 2002). All the data analyses were conducted using SPSS 24 (IBM Corp, 2016).

Results

Descriptive of Study Participants

Table 1 summarizes the demographic characteristics of the participants at baseline. A total of 758 adults with IDD at baseline were included in the analysis. Fifty-seven percent of participants were male. Almost two-thirds of participants were in the age group of 18-44 years (64.6%), and the mean age was 35.96 years (SD = 13.61, range = 18 – 77). More than a quarter of participants (25.6%) had Down syndrome, 13.0% had autism, 13.0% had cerebral palsy, and 48.5% had ID only or other conditions. While 6.8% of adults with ID were reported to be in poor or fair health, 35.7% reported good health and 57.5% were reported having very good or excellent health. More than 60% were employed (62.4%), 12.9% of participants had mobility limitation, and more than two-fifths of participants (41.2%) had 3 or more chronic conditions. Almost forty percent of the participants were obese (38.1%), 11.2% had hearing impairment and 10.2% had vision impairment. Only 2.7% of participants smoked. More than half (51.4%) of the participants participated in at least one Special Olympics event. More than a third of the participants (35.1%) experienced at least one negative life event in the past 12 months, with a quarter experiencing at least one negative change and more than a tenth (12.5%) experiencing at least one loss. The percentage of participants with depression and anxiety at baseline were 10.8% and 12.3% respectively. Social factors remained stable, but overall the health of participants changed significantly over time. The percentage of informants who reported a fair or poor health status increased from 6.8% in Year 1 to 11.8% in Year 5, and the percentage of informants who reported very a good or excellent health status declined from 57.5% in Year 1 to

50.9% in Year 5. **Linear-by-linear association (LLA) test showed that the percentages of the health status, changed significantly over time (LLA statistic = 9.479, df = 1, p = 0.002).** The percentage of participants who reported three or more health conditions increased from 41.2% in Year 1 to 52.4% in Year 5. **Linear-by-linear association test showed that the percentage of reported three or more health conditions significantly increased over time (LLA statistic = 15.416, df = 1, p = 0.000)**

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Table 1
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Depression and anxiety across time

Figure 1 shows the frequency of depression and anxiety across the four time points. The percentage of participants who had depression in Year 1, Year 2, Year 3 and Year 5 were 10.8%, 11.5%, 12.3% and 12.1% respectively. Furthermore, the percentage of participants who had anxiety in Year 1, Year 2, Year 3 and Year 5 were 12.3%, 13.3%, 14.2% and 15.0% respectively.

Results of the Cochran-Armitage trend test indicated that the percentages of depression (p=0.0437) and anxiety (p=0.0303) significantly increased over time.

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Figure 1
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Univariate GEE for depression and anxiety outcomes

Accounting for the longitudinal analysis using univariate GEE models (Table 2), the variables that were significantly associated ($p < 0.20$) with depression included older age (≥ 45 years: OR= 1.51, $p = 0.049$), being female (OR= 1.64, $p = 0.009$), having a hearing impairment (OR= 1.40, $p = 0.088$), having a greater number of chronic health conditions (1: OR = 1.33, $p =$

0.061; 2: OR= 1.89, $p < 0.001$; ≥ 3 : OR= 2.25, $p < 0.001$), smoking (OR= 2.25, $p = 0.015$), and reporting 3 or more stressful life events (OR= 1.60, $p = 0.148$). The factors associated with less depression included IDD related conditions (autism: OR= 0.72, $p = 0.140$; cerebral palsy: OR= 0.66, $p = 0.095$; Down syndrome: OR= 0.50, $p = 0.002$), and informant-rated health (good: OR= 0.66, $p = 0.032$; very good/excellent: OR= 0.45, $p < 0.001$), and 4 or more Special Olympics events (OR= 0.72, $p = 0.105$). While obesity (OR= 1.15, $p = 0.341$) and number of stressful life events—change (1: OR = 1.33, $p = 0.061$; 2: OR= 1.89, $p < 0.001$; ≥ 3 : OR= 2.25, $p < 0.001$) did not achieve statistical significance, they were included in the multivariate analysis because other studies have shown they are potential factors.

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 Table 2
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The variables that were significantly associated ($p < 0.20$) with anxiety in univariate GEE analysis included older age (≥ 45 years: OR= 1.55, $p = 0.012$), being female (OR= 1.39, $p = 0.066$), autism (OR = 2.00, $p < 0.001$), obesity (OR= 1.18, $p = 0.162$), hearing impairment (OR= 1.37, $p = 0.021$), a greater number of chronic health conditions (1: OR = 1.77, $p = 0.001$; 2: OR= 1.73, $p = 0.010$; ≥ 3 : OR= 2.82, $p < 0.001$), smoking (OR= 1.57, $p = 0.015$), 3 or more stressful life events (OR= 1.48, $p = 0.063$), 2 stressful life events-change (OR= 1.43, $p = 0.026$), and 1 stressful life event-loss (OR= 1.15, $p = 0.166$). The factors associated with less anxiety included ID related conditions (Down syndrome: OR= 0.62, $p = 0.041$), employment (OR= 0.71, $p = 0.016$) and informant-rated health (good: OR= 0.62, $p = 0.002$; very good/excellent: OR= 0.53, $p < 0.001$).

Multivariate GEE for depression and anxiety outcomes

Table 3 presents the adjusted odds ratios (AOR) from the results of Model I of the multivariate GEE for depression (N=2,527) and anxiety (N=2,516) with number of stressful life events included, whereas Table 4 presents the adjusted odds ratios (AOR) from the results of the multivariate GEE for depression (N=2,527) and anxiety (N=2,516) with number of stressful life events-change included.

The significant associated factors in model I for depression where the number of stressful life events was included were as follows: female (AOR = 1.62, p = 0.014); Down syndrome (AOR = 0.55, p = 0.013); very good or excellent informant rated health status (AOR = 0.56, p = 0.005); 1 chronic condition (AOR = 1.71, p = 0.004), 2 chronic conditions (AOR = 2.70, p < 0.001), and 3 or more chronic conditions (AOR = 3.82, p < 0.001); and smoking (AOR = 2.61, p = 0.001). In model I for anxiety where the number of stressful life events was included, the significant associated factors were: being 45 years or older (AOR = 1.51, p = 0.048); autism (AOR = 2.39, p < 0.001); very good or excellent informant rated health status (AOR = 0.68, p = 0.027); hearing impairment (AOR = 1.39, p = 0.048); and 1 chronic condition (AOR = 1.44, p = 0.029), and 3 or more chronic conditions (AOR = 1.96, p = 0.002).

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In model II (Table 4) for depression where the number of stressful life events-change was included the significant associated factors were as follows: female (AOR = 1.63, p = 0.014); very good or excellent informant rated health status (AOR = 0.55, p = 0.004); 1 chronic condition (AOR = 1.68, p = 0.005), 2 chronic conditions (AOR = 2.70, p < 0.001), and 3 or more chronic conditions (AOR = 3.85, p < 0.001); and smoking (AOR = 2.79, p < 0.001). In the model II for

anxiety where the number of stressful life events-change was included the significant associated factors were: being 45 years or older (AOR = 1.51, p = 0.047); autism (AOR = 2.45, p < 0.001); very good or excellent informant rated health status (AOR = 0.67, p = 0.022); hearing impairment (AOR = 1.40, p =0.049); 1 chronic condition (AOR = 1.45, p = 0.024) and 3 or more chronic conditions (AOR = 1.98, p = 0.002); and 2 stressful life events-change (AOR = 1.44, p = 0.032).

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Discussion

Four models were tested to explore demographic, health and psychosocial factors related to anxiety and depression in adults with IDD. In terms of demographic variables, women were more likely to have depression while older adults, people with autism and people with hearing impairments were more likely to have anxiety. **Some of these results are consistent with previous studies, for example the finding that women are more likely to have depression, and the indications that people with autism are at an increased risk for having anxiety** (Bryant, Jackson, & Ames, 2008; Nolen-Hoeksema, 2001; van Steensel, Bögels, & Perrin, 2011). **This study also found that older age and having a hearing impairment, two demographic variables that have received little research attention in the IDD population, were risk factors for anxiety. Understanding what demographic factors are associated with psychopathology can help guide screening techniques, and inform research.** For example, a consistent finding from this and other studies is that people with Autism Spectrum Disorders are likely to be at an increased risk of anxiety related disorders. This knowledge can be translated to

better secondary prevention efforts as well as providing rationale for additional research services and supports to better understand how best to treat anxiety in this population.

One of the most consistent findings of this study was the relationship between physical health and mental health. Having chronic health conditions was associated with both anxiety and depression, while being in very good or excellent health was negatively correlated with both depression and anxiety. These findings lend strong support to previous research on people both with and without IDD that have shown the interconnected nature of physical and mental health. This is likely a bidirectional relationship with physical health influencing mental health and vice versa. Chronic health conditions may lead to isolation and decreased activity while poor mental health may lead to a decrease in self-care or a lack of follow through with health provider advice (DiMatteo, Lepper, & Croghan, 2000; Stein, Cox, Afifi, Belik, & Sareen, 2006). Higher incidences of mental disorders are correlated with a variety of chronic health conditions, and self-reported health, as well as objective measures of health, are risk factors for the development of a variety of mental health concerns (Egede & Zheng, 2003; McWilliams, Cox, & Enns, 2003; Prince, Patel, Saxena, Maj, Maseko, Phillips, & Rahman, 2007; Wells, Golding, & Burnam, 1989). These findings show that, for people with IDD, poor physical health should be considered a risk factor for declining mental health. People who have chronic conditions or who are experiencing a physical health crisis would likely benefit from additional supports as well as increased monitoring of their mental health status. Both service providers and health professionals need to be aware of and be sensitive to the increased risk that people experiencing poor health may have for developing depression and/or anxiety. These results may also inform treatment, for example treatment modalities primarily considered related to physical health such

as diet, may be an avenue towards treatment of mental health concerns (Lopresti, Hood & Drummond, 2013).

While neither stressful life events nor change in stressful life events was associated with depression, change in stressful life events was associated with an increased risk of anxiety. While previous studies (Esbensen & Benson, 2006; McGillivray and McCabe, 2007) have highlighted stress as associated with depression in people with IDD, the current study did not find an increased risk of depression associated with either stressful life events or a change in life events. We did find that a change (increase) in number of stressful life events over time was associated with an increased risk for anxiety, falling in line with previous research that has indicated that stressful life events are associated with psychopathology (Hove & Havik, 2010; Hulbert-Williams et al., 2011; Hulbert-Williams et al., 2014; Scott & Haverkamp, 2014; Owen et al., 2004). It is possible that the types of stressors captured in this study (changes and losses) were simply more related to anxiety than depression. Some research has suggested that interpersonal conflict may be a significant source of stress for people with IDD and this was not captured in the current study. Additional research is needed to understand this discrepant finding and to fully capture the variety of experiences that one can consider stressful. These and previous findings support the idea that stress should be considered a risk factor for poor mental health outcomes. This is particularly important given that the existing research suggests that people with IDD may experience unique stressors and have less support available to cope with these stressors (Hastings, Haton, Taylor, & Maddison, 2004; Lunskey & Benson, 2001). Recognizing the impact of stress, taking steps to improve interpersonal stressors, which people with IDD often report, and providing additional support in times of unavoidable stress may all be tangible ways in which to **prevent anxiety attacks and** indirectly improve health outcomes.

Research into how treatments that focus on stress reduction or developing coping strategies in advance of stress may provide another avenue for addressing anxiety and depression in people with IDD.

This study was limited by several factors. First, due to our recruitment strategy, it is unlikely that people with IDD not connected to the developmental disability service system were included in this sample. This may limit the generalizability of results. In addition, this study relied solely on report of information from an informant **and we were unable to independently confirm diagnostic information.** However, we used two **criteria** (reported diagnosis and on medication) to identify depression and anxiety, which may have improved the validity of those variables. **It should be noted however, that people with IDD experience mental health inequities and may not receive appropriate mental health diagnoses and treatment; therefore, it is likely that these results apply only to those people who have received mental health care and may not generalize to those who may have undiagnosed concerns.** Despite these limitations, this study contributes important information about risk factors for anxiety and depression in adults with IDD using a longitudinal design and robust sample.

Conclusions and Future Directions

This study explored demographic, health, and psychosocial factors contributing to depression and anxiety in a longitudinal sample of adults with IDD. Demographic factors such as age and co-occurring diagnoses, stress, and poor health were all associated with increased risk of psychopathology. As this study and others have shown that anxiety and depression are common concerns for people with IDD, it is important to consider what treatment modalities may be effective for this population. While there has been some research focused on treatment interventions such as cognitive-behavioral therapy and mindfulness-based therapy, this line of

research is still developing and randomized studies are needed. This study showed that stress and health are important factors in understanding psychopathology. Future research should focus on better understanding that relationship, for example, some research has suggested that people who are aging with chronic conditions may experience more stressful life events (Hermans, & Evenhuis, 2013). Future research may want to explore stress, health and psychopathology in different age cohorts to better understand how these factors interplay. Lastly, while this study and others have contributed important information through the use of proxy reporters, future research is needed to explore how people with IDD themselves report on symptoms of anxiety and depression as well as contributing factors such as health and psychosocial wellness.

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Table 1. Participants characteristics at baseline (N=758)

| Characteristics | N | % |
|--|-----|------|
| Outcome measures | | |
| Depression | | |
| Yes | 82 | 10.8 |
| No | 676 | 89.2 |
| Missing | - | - |
| Anxiety | | |
| Yes | 93 | 12.3 |
| No | 661 | 87.7 |
| Missing | 4 | 0.5 |
| Independent variables | | |
| <i>Health and function-related factors</i> | | |
| Informant-rated health ^b | | |
| Poor/fair | 51 | 6.7 |
| Good | 268 | 35.4 |
| Very good/excellent | 432 | 57.0 |
| Missing | 7 | 0.9 |
| Mobility limitation | | |
| Yes | 96 | 12.7 |
| No | 651 | 85.9 |
| Missing | 11 | 1.5 |
| Obesity | | |
| Yes | 276 | 36.4 |
| No | 449 | 59.2 |
| Missing | 33 | 4.4 |
| Hearing impairment | | |
| Yes | 85 | 11.2 |
| No | 673 | 88.8 |
| Missing | - | - |
| Vision impairment | | |
| Yes | 77 | 10.2 |
| No | 681 | 89.8 |
| Missing | - | - |
| Number of chronic conditions ^{ab} | | |
| 0 | 131 | 17.3 |
| 1 | 164 | 21.6 |
| 2 | 151 | 19.9 |
| 3 or more | 312 | 41.2 |
| Missing | - | - |
| <i>Health risk behavior</i> | | |
| Smoking | | |
| Yes | 20 | 2.6 |

| | | |
|--|-----|------|
| No | 733 | 96.7 |
| Missing | 5 | 0.7 |
| <i>Social-environmental factors</i> | | |
| Number of Special Olympics events participated | | |
| 0 | 361 | 47.6 |
| 1-3 | 129 | 17.0 |
| 4 or more | 254 | 33.5 |
| Missing | 14 | 1.8 |
| Number of stressful life events | | |
| 0 | 492 | 64.9 |
| 1 | 183 | 24.1 |
| 2 | 58 | 7.7 |
| 3 or more | 25 | 3.3 |
| Missing | - | - |
| Number of stressful events-change | | |
| 0 | 576 | 76.0 |
| 1 | 124 | 16.4 |
| 2 | 44 | 5.8 |
| 3 or more | 14 | 1.8 |
| Missing | - | - |
| Number of stressful life events-loss | | |
| 0 | 663 | 87.5 |
| 1 | 92 | 12.1 |
| 2 or more | 3 | 0.4 |
| Missing | - | - |

Note. ^aExcluding depression, anxiety and obesity

^bSignificant across four time points

Table 2. Univariate GEE for depression and anxiety

| Variables | Depression | | Anxiety | |
|--|------------|---------|---------|---------|
| | OR | P value | OR | P value |
| Demographic/characteristic factors | | | | |
| Age | | | | |
| 18 – 44 (ref) | | | | |
| ≥ 45 | 1.51 | 0.049 | 1.55 | 0.012 |
| Gender (Female) | 1.64 | 0.009 | 1.39 | 0.066 |
| ID-related conditions | | | | |
| ID only and others (ref) | | | | |
| Autism | 0.72 | 0.140 | 2.00 | 0.000 |
| Cerebral palsy | 0.66 | 0.095 | 0.90 | 0.704 |
| Down syndrome | 0.50 | 0.002 | 0.62 | 0.041 |
| Employment (Yes) | 0.96 | 0.786 | 0.71 | 0.016 |
| Health and function-related factors | | | | |
| Informant-rated health | | | | |
| Poor/fair (ref) | | | | |
| Good | 0.66 | 0.032 | 0.62 | 0.002 |
| Very good/excellent | 0.45 | 0.000 | 0.53 | 0.000 |
| Mobility limitation | 1.17 | 0.468 | 1.09 | 0.622 |
| Obesity | 1.15 | 0.341 | 1.18 | 0.162 |
| Hearing impairment | 1.40 | 0.088 | 1.37 | 0.021 |
| Vision impairment | 0.78 | 0.224 | 1.05 | 0.715 |
| Number of chronic conditions | | | | |
| 0 (ref) | | | | |
| 1 | 1.33 | 0.061 | 1.77 | 0.001 |
| 2 | 1.89 | 0.000 | 1.73 | 0.010 |
| 3 or more | 2.91 | 0.000 | 2.82 | 0.000 |
| Health risk behavior | | | | |
| Smoking (Yes) | 2.25 | 0.015 | 1.57 | 0.015 |
| Social-environmental factors | | | | |
| Number of Special Olympics events participated | | | | |
| 0 (ref) | | | | |
| 1-3 | 0.84 | 0.344 | 0.89 | 0.414 |
| 4 or more | 0.72 | 0.105 | 0.93 | 0.613 |
| Number of stressful life events | | | | |
| 0 (ref) | | | | |
| 1 | 1.07 | 0.511 | 1.10 | 0.256 |
| 2 | 0.98 | 0.904 | 1.09 | 0.519 |
| 3 or more | 1.60 | 0.148 | 1.48 | 0.063 |
| Number of stressful life events-change | | | | |
| 0 (ref) | | | | |

| | | | | |
|--------------------------------------|------|-------|------|-------|
| 1 | 1.07 | 0.591 | 0.98 | 0.809 |
| 2 | 1.19 | 0.546 | 1.43 | 0.026 |
| 3 or more | 1.51 | 0.367 | 1.23 | 0.484 |
| Number of stressful life events-loss | | | | |
| 0 (ref) | | | | |
| 1 | 1.12 | 0.389 | 1.07 | 0.562 |
| 2 or more | 0.71 | 0.588 | 1.05 | 0.945 |

Table 3. Multivariate GEE for depression and anxiety (Model I)

| Variables | Depression (N=2,527) | | Anxiety (N=2,516) | |
|--|----------------------|---------|-------------------|---------|
| | AOR | P value | AOR | P value |
| Demographic/characteristic factors | | | | |
| Age | | | | |
| 18 – 44 (ref) | | | | |
| ≥ 45 | 1.27 | 0.302 | 1.51 | 0.048 |
| Gender (Female) | 1.62 | 0.014 | 1.32 | 0.151 |
| ID-related conditions | | | | |
| ID only and others (ref) | | | | |
| Autism | 0.85 | 0.543 | 2.39 | 0.000 |
| Cerebral palsy | 0.60 | 0.065 | 0.86 | 0.569 |
| Down syndrome | 0.55 | 0.013 | 0.65 | 0.095 |
| Employment (Yes) | - | - | 0.78 | 0.093 |
| Health and function-related factors | | | | |
| Informant-rated health | | | | |
| Poor/fair (ref) | | | | |
| Good | 0.71 | 0.073 | 0.74 | 0.065 |
| Very good/excellent | 0.56 | 0.005 | 0.68 | 0.027 |
| Mobility limitation | - | - | - | - |
| Obesity | 1.28 | 0.127 | 1.14 | 0.344 |
| Hearing impairment | 0.94 | 0.769 | 1.39 | 0.048 |
| Vision impairment | - | - | - | - |
| Number of chronic conditions | | | | |
| None (ref) | | | | |
| 1 | 1.71 | 0.004 | 1.44 | 0.029 |
| 2 | 2.70 | 0.000 | 1.33 | 0.222 |
| 3 or more | 3.82 | 0.000 | 1.96 | 0.002 |
| Health risk behavior | | | | |
| Smoking (Yes) | 2.61 | 0.001 | 1.48 | 0.109 |
| Social-environmental factors | | | | |
| Number of Special Olympics events participated | | | | |
| 0 (ref) | | | | |
| 1-3 | 1.01 | 0.945 | - | - |
| 4 or more | 0.75 | 0.249 | - | - |
| Total number of stressful life events (change, loss & illness) | | | | |
| 0 (ref) | | | | |
| 1 | 1.12 | 0.340 | 1.05 | 0.603 |
| 2 | 0.95 | 0.832 | 1.07 | 0.642 |
| 3 or more | 1.46 | 0.284 | 1.37 | 0.137 |

Table 4. Multivariate GEE for depression and anxiety (Model II)

| Variables | Depression (N=2,527) | | Anxiety (N=2,516) | |
|--|----------------------|---------|-------------------|---------|
| | AOR | P value | AOR | P value |
| Demographic/characteristic factors | | | | |
| Age | | | | |
| 18 – 44 (ref) | | | | |
| ≥ 45 | 1.27 | 0.297 | 1.51 | 0.047 |
| Gender (Female) | 1.63 | 0.014 | 1.32 | 0.151 |
| ID-related conditions | | | | |
| ID only and others (ref) | | | | |
| Autism | 0.84 | 0.509 | 2.45 | 0.000 |
| Cerebral palsy | 0.61 | 0.074 | 0.85 | 0.545 |
| Down syndrome | 0.55 | 0.509 | 0.66 | 0.103 |
| Employment (Yes) | - | - | 0.79 | 0.112 |
| Health and function-related factors | | | | |
| Informant-rated health | | | | |
| Poor/fair (ref) | | | | |
| Good | 0.70 | 0.057 | 0.73 | 0.053 |
| Very good/excellent | 0.55 | 0.004 | 0.67 | 0.022 |
| Mobility limitation | - | - | - | - |
| Obesity | 1.26 | 0.144 | 1.12 | 0.404 |
| Hearing impairment | 0.94 | 0.773 | 1.40 | 0.049 |
| Vision impairment | - | - | - | - |
| Number of chronic conditions | | | | |
| None (ref) | | | | |
| 1 | 1.68 | 0.005 | 1.45 | 0.024 |
| 2 | 2.70 | 0.000 | 1.34 | 0.206 |
| 3 or more | 3.85 | 0.000 | 1.98 | 0.002 |
| Health risk behavior | | | | |
| Smoking (Yes) | 2.79 | 0.000 | 1.59 | 0.053 |
| Social-environmental factors | | | | |
| Number of Special Olympics events participated | | | | |
| 0 (ref) | | | | |
| 1-3 | 1.03 | 0.896 | - | - |
| 4 or more | 0.76 | 0.282 | - | - |
| Number of stressful life events-change | | | | |
| 0 (ref) | | | | |
| 1 | 1.11 | 0.486 | 0.93 | 0.566 |
| 2 | 1.16 | 0.636 | 1.44 | 0.032 |
| 3 or more | 1.43 | 0.457 | 1.24 | 0.314 |