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Measures of Mood: Adaptations for Adults with Developmental Disabilities and/or Severe Mental Illness

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MEASURING OF MOOD: ADAPTATIONS FOR ADULTS WITH DEVELOPMENTAL DISABILITIES AND/OR SEVERE MENTAL ILLNESS

BY

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ABSTRACT

The COVID-19 pandemic was a source of anxiety and depression for many people, and for some it exacerbated existing mood and anxiety symptoms. Measurement of symptoms of anxiety and depression can play an important role in intervention to decrease these symptoms. However, to ensure validity of these measures, one must be able to understand the language of the screeners. An adapted Patient Health Questionnaire-9 and Generalized Anxiety Disorder-7 Item Scale were created for usage with adults with developmental disability and/or severe mental illness who may have difficulty understanding the language of the original versions of these measures. A study was developed to measure the perceived benefit and ease of administration from a clinician's perspective. Results indicate that these measures may be helpful in measuring symptoms of depression and anxiety. The limitations of this study and future directions for the measures are discussed.

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Section I: Introduction

At the onset of the COVID-19 pandemic, a client, who will be identified as "Jane Doe," presented with major depressive disorder, generalized anxiety disorder, and depression-induced psychosis. Jane had been previously diagnosed with developmental disabilities that impacted her cognitive functioning. Symptoms and behaviors accelerated and decelerated at the beginning of treatment. The client had difficulty with voicing what was impacting the fluctuation in her symptoms. The original Patient Health Questionnaire-9 (PHQ-9) and the Generalized Anxiety Disorder-7 (GAD-7) item scale were administered to measure symptoms of anxiety and depression (Kroenke et al., 2001; Spitzer et al., 2006). The client's responses to the variety of symptoms on these measures were intended to be used to pinpoint different areas that could be targeted during therapy sessions.

During the first administration of the PHQ-9 and the GAD-7, Jane appeared frustrated and voiced her dislike for the two measures. Each of these measures asks the respondent to answer the questions in reference to the past two weeks. Jane seemed to have difficulty conceptualizing the two-week time frame, as well as placing severities on specific symptoms within that timeframe. Additionally, Jane had questions regarding the symptoms. For example, one question regarding sleep incorporates three components: 1) trouble falling asleep, 2) trouble staying asleep, or 3) sleeping too much. Jane appeared to have trouble with thinking about these as individual symptoms. For example, if she had no issues with falling asleep her answer would be, "not at all" regardless of whether she had trouble staying asleep or sleeping too much. These difficulties indicated that her scores would likely be an inaccurate representation of her

depression and anxiety symptoms. As severity of intellectual disability increases, a third-party report from family may provide more accurate information on one's nonverbal behaviors and mood (Costello & Bouras, 2006). However, allowing one to respond for themselves gives them a sense of autonomy that may not exist if someone else is reporting their experiences and symptoms for them. In Jane's circumstances, she became upset when others tried to discuss what the week in between sessions was like. Therefore, the clinician worked to create a questionnaire that would measure her symptoms throughout treatment, while providing her with the autonomy of reporting her own feelings.

This doctoral specialization project (DSP) will include a literature review that incorporates diagnostic criteria and prevalence of major depressive disorder, generalized anxiety disorder, developmental disabilities (e.g., autism spectrum disorder and intellectual developmental disorder), and severe mental illness (e.g., schizophrenia and bipolar disorder), as well as what comorbidity between these disorders. Additionally, information on the benefit of mental health screeners, such as the PHQ-9, and the GAD-7 will be incorporated. The final piece of the literature review will include recommended adaptations that may be necessary to incorporate in order to increase the validity of self-report measures that are used with adults with developmental disabilities and severe mental illness.

Upon completion of the literature review, the development of the adapted mood measures will be discussed in detail. The third section of this DSP will include the methodology of the ongoing research study, as well as results associated with the data that has been collected thus far. Based on the information collected from participants,

the perceived ease and benefit of the measures will be discussed. Finally, there will be a discussion on the limitations of the study, the adapted mood measures, and what the future will look like in terms of the measures and study. The overall purpose of this DSP is to examine the benefit and ease of the adapted mood measures that were created for this client so that they may potentially find utility for other individuals with developmental special needs who are receiving mental health treatment.

Section II: Literature Review

Major Depressive Disorder

Major Depressive Disorder (MDD) is a psychological disorder affecting one's mental and physical health (Lui et al., 2020). The presentation of MDD can vary between individuals as a diagnosis requires five out of nine criterial symptoms (American Psychiatric Association [APA], 2022). Symptoms of MDD include depressed mood, loss of interest or pleasure, weight change, disrupted sleep, psychomotor changes observable by others, fatigue, feeling worthless or guilty, lack of concentration or ability to think, and/or recurrent thoughts of suicide. Symptoms must be present during a 2-week period and cause significant distress or impairment. Suicidality, which encompasses suicidal ideation, a suicide plan, a suicide attempt, and/or a completed suicide, is a major concern for those diagnosed with MDD (Cai et al., 2021). Individuals with MDD are at an increased risk of suicidality compared to those without MDD.

MDD has a high prevalence rate throughout the world and can be considered disabling depending on severity (Gutiérrez-Rojas et al., 2020). Symptoms of MDD range from mild to severe, with severe symptoms being the most impactful. Cases of depression increased 49.86 percent worldwide between 1990 and 2017 (Lui et al., 2020). Results of a meta-analysis confirmed relationships between certain sociodemographic factors and MDD (Gutiérrez-Rojas et al., 2020). Female sex was more frequently associated with MDD compared to male sex. In adults, symptoms were more intense and frequent in females compared to males (Cavanagh et al., 2017). Prior to puberty, MDD symptoms are similar between boys and girls (Altemus et al., 2014).

The estimated prevalence of depression rates prior to puberty is approximately five percent. Despite the symptom intensity in females, depressed males tended to have more maladaptive coping and problem-solving skills. Socioeconomic status (SES) and education level both had an inconsistent relationship with MDD (Gutiérrez-Rojas et al., 2020). The strength of the relationship depended on the country and the population. It is also important to consider other factors that can influence SES, such as marital status and unemployment, as both may have their own relationship with MDD.

Generalized Anxiety Disorder

Generalized Anxiety Disorder (GAD) is considered a common mental health disorder that can result in impairment (Ruscio et al., 2017). To receive a GAD diagnosis, one must experience extreme anxiety or worry that occurs frequently for at least 6 months and must have trouble managing the worry (APA, 2022). Like MDD, GAD can present in a variety of ways due to the symptom criteria. One must experience at least three out of six symptoms that include restlessness, fatigue, trouble concentrating, irritability, muscle tension, and difficulties with sleep. These symptoms must cause distress in one's life.

The DSM-5 diagnosis of GAD produced an increase of new GAD cases (Ruscio et al., 2017). Cases of GAD were 37 percent to 90 percent higher than previously published estimates. Kessler et al. (2012) looked at lifetime prevalence of GAD in the United States and found that GAD had a lower lifetime prevalence rate compared to other mood and anxiety disorders at 4.3 percent. Globally, lifetime prevalence was 3.7 percent, with higher lifetime prevalence higher in high income countries (Ruscio et al., 2017). The United Stated has an approximately 8 percent lifetime prevalence. GAD has

a later age of onset with a mean of 35 years and a median of 30 years (de Lijster et al., 2017; Kessler et al., 2012). Although age of onset is higher, GAD can be diagnosed in younger ages. Approximately 5 percent of GAD cases began before the age of 13 (Ruscio et al., 2017). Females are more likely to be diagnosed with GAD, with adolescent females being twice as likely to receive the diagnosis (Ruscio et al., 2017; Burstein et al., 2014).

Developmental Disabilities

The term "developmental disabilities" represents a variety of conditions that may impact physical, learning, behavior, or language areas (Zablotsky et al., 2019). Conditions classified under developmental disabilities can include attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), blindness, cerebral palsy, hearing loss, specific learning disability, intellectual developmental disability (IDD), stuttering, and other developmental disability (Boyle et al., 2011). Though each of these disorders can affect one's life differently, we see overlap and comorbidity between disorders. To analyze the prevalence of adults with developmental disabilities, we can start by looking at the prevalence in children. Research shows that between 2006 and 2008, approximately 15 percent of children in the United States, between the ages of three and 17, were diagnosed with a developmental disability (Boyle et al., 2011). Later research shows that the prevalence of developmental disabilities between the years of 2009 and 2017 increased to 16.93 percent (Zablotsky et al., 2019). Children who were part of the older age group, ages 12 to 17, were more likely to be diagnosed with ADHD, a learning disability, or an intellectual disability, and boys had an increased risk of being diagnosed with any developmental disability

compared to girls. Although the term "developmental disability" incorporates a variety of diagnoses, this doctoral specialization project will focus on ASD and IDD.

According to the Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition, Text Revised (DSM-V-TR) intellectual developmental disorder (IDD) requires deficits in intellectual and adaptive functioning that impacts conceptual, social, and practical domains (APA, 2022). However, IDD is a recently developed term. The adaptive functioning of an individual is what classifies the severity level of the diagnosis. The original DSM used the term "mental deficiency", which classified individuals who had a defect of intelligence that occurred since birth without brain disease or prenatal causes (APA, 1952). Severity level was based off scores on an intelligence measure. The DSM-III classified IDD as "mental retardation" with criteria being subaverage general intellectual functioning that impacts adaptive behavior (APA, 1980).

Across several studies, the prevalence estimate for intellectual disability was 10.37 out of 1000 (Maulik et al., 2011). For children, adolescents, and adults, males were more likely to be diagnosed than females. Out of different age groups, adults had the lowest prevalence of intellectual disability with 4.94 out of 1000. The rates of intellectual disability were higher in low- and middle-income countries, at 16.41 and 15.94 out of 1000, respectively. More recent data shows that 11.1 out of 1000 children in the United States had a diagnosis of IDD, between the years of 2009 and 2016, which is a slightly higher estimate than the meta-analysis completed in earlier years (McGuire et al., 2019; Maulik et al., 2011). In this study, older children and boys were more likely to be diagnosed with IDD (McGuire et al., 2019). Prior to 2010, most surveys used the

term “mental retardation,” but McGuire et al. (2019) updated terminology to “intellectual disability,” which may have influenced the prevalence estimates. McConckey et al. (2019) completed a study where national census rates were compared to the national intellectual disability database (NIDD) in Ireland during the years 2011 and 2016. Census data in 2016 showed 22.2 children per 1000 had a diagnosis of IDD, which increased from 17.7 children per 1000 in 2011. The NIDD showed a decrease from 9.7 children per 1000 in 2011 to 9.4 children per 1000 in 2016. For adults, the census data showed 9.5 adults per 1000 in 2011 but increased to 10.5 adults per 1000 in 2016. Different than the children NIDD, the adult NIDD showed an increase from 5.2 adults per 1000 in 2011 to 5.3 adults per 1000 in 2016. Both census estimates were higher than data presented in Maulik et al (2011).

Autism spectrum disorder incorporates social communication and interaction deficits and restricted or repetitive behaviors, interests, or activities (APA, 2022). Difficulties with social-emotional reciprocity, nonverbal communication, and interpersonal skills make up the social deficits, while stereotyped behaviors or speech, rigidity, intense interests, and sensory seeking or sensory aversion behaviors fall under the restricted and repetitive behaviors. Dietz et al. (2020) reviewed unpublished ASD data in combination with published ASD mortality rates to estimate the prevalence of ASD in adults. The estimated prevalence of adults, between the ages of 18 and 84, with ASD in the United States was 2.21 percent, or approximately 5, 437, 988 individuals in 2020 (Dietz et al.). In this estimate, males were more likely to be diagnosed with ASD compared to females.

Severe Mental Illness

Schizophrenia, bipolar disorder, and severe depression have been classified under severe mental illness (SMI) (Uher, 2014). Genetics and the environment have a part in the development of SMI. There are a several environmental factors that can play a role, such as perinatal complications, maternal stress while in utero, childhood maltreatment, bullying, traumatic events, and more. To better understand SMI, it is beneficial to look at each disorder individually.

Schizophrenia is a mental disorder depicted by a variety of symptoms including delusions, hallucinations, disorganized dialogue, disorganized or rigid behavior, and negative symptoms, such as blunted affect, which must be present for a significant amount of time within a one-month period (Saha et al., 2005; APA, 2022). These symptoms require impairment in functioning in at least one life area, like work or self-care, and the disturbance of symptoms continues for at least 6 months (APA, 2022). Prevalence can be broken down between lifetime prevalence, which is the number of individuals who have had a disorder and are alive, and lifetime morbid risk, which attempts to include both living and deceased individuals of a birth cohort (Saha et al., 2005). Estimates from 46 countries found that lifetime prevalence was approximately 4.0 out of 1000 people, whereas the lifetime morbid risk was 7.2 per 1000 people. In addition to the public, prisoners have a high prevalence of psychotic symptoms (Fazel and Seewald, 2022). Prisoners in low- and middle-income countries had higher rates of psychosis compared to prisoners in high-income countries.

Though there were no statistically significant differences in the number of males and females, data from developing countries showed that females had a higher

schizophrenia prevalence than males (Saha et al., 2005). Similarly, there were no significant differences between rates of psychosis in the prisoner population (Fazel and Seewald, 2022). There are a variety of risk factors associated with schizophrenia. Some research shows that migrant populations are at a higher risk for the development of schizophrenia compared to native population, though this information may not be completely accurate due to biases (Saha et al., 2005). Overall, risk factors of schizophrenia vary based on sex and location in the world.

Bipolar 1 disorder is a mental health disorder that requires at least one manic episode (APA, 2022). A manic episode may have a variety of symptoms, such as grandiosity, less need for sleep, increased talking, flight of ideas, easily distracted, increased goal-activity behavior, and involvement in things that may have potential consequences. At least three of the previous mentioned symptoms must be present for a weeklong period. Bipolar 1 disorder can also include a hypomanic episode, which is like mania, but lasts between 4 and 7 days.

Individuals with bipolar are likely to have increased suicidality, negative health, and overall impairment in functioning (Clemente et al., 2015). Bipolar has previously been one of the top 20 causes of disability, in addition to being one out of five causes of mental disorder and substance use disorder (Ferrari et al., 2016). In 1990 there were approximately 32.7 million individuals with bipolar disorder. There was an approximate 49.1 percent increase by 2013, with approximately 48.8 million individuals with bipolar. Within bipolar disorder prevalence, females have a higher prevalence than males (Dell'Osso et al., 2021).

Comorbidity

Depression and Developmental Disabilities

Though some data shows that there are lower rates of depression in the IDD population, the consensus is that individuals with IDD are at a higher risk for psychopathology (Poindexter, 2006). More specifically, research has shown that people with IDD have a higher risk of developing depression than those without. However, depressed mood may appear different than what is considered "normal" depressive symptoms. For example, sad facial expressions, withdrawing from peers, somatic complaints, and aggressive symptoms or behavioral regression can all be signs of depressed mood in individuals with IDD. Outside of these symptoms, hopelessness, guilt, and suicidal ideation, were identified as central symptoms of depression in individuals with IDD (Charlot, 1997). However, severity level of IDD influenced the presence of these symptoms. Those with mild IDD experienced the core symptoms at an increased rate compared to those with severe to profound IDD. Other depressive symptoms that may be prevalent within IDD can include changes in mood, difficulties with sleep, appetite changes, and alterations in psychomotor behaviors. Regardless of symptom presentation, depression can be difficult to identify, and as a result, may go undetected or unreported in those diagnosed with IDD (Poindexter, 2006).

Like IDD, depression within ASD may be impacted by cognitive functioning (Sterling et al., 2008). In a sample of autistic adults, those that had increased symptoms of depression typically had higher cognitive abilities and fewer social impairments. As depression becomes more severe, suicidality may rise as well. Adults with autism have a higher chance of experiencing suicidality compared to their neurotypical peers

(Cassidy et al., 2018). Indeed, an autism diagnosis or autistic traits may explain variance within suicidality that goes past the breadth of known risk factors, which suggests a diagnosis or traits may be unique suicidality risk markers. Other research by McDermott et al. (2005) shows that in an adult disabilities population, autism had the lowest rates of depression symptoms, while traumatic brain injury, cerebral palsy without intellectual developmental disability, and stroke had the highest rates of depression symptoms. Despite the lower prevalence rate in this population, those with mild developmental disabilities were more likely to be depressed compared to those with moderate to severe developmental disabilities.

Individuals with autism, specifically females, tend to engage in masking, which can be defined as hiding characteristics of oneself (Cassidy et al., 2018). Masking may be used as a coping or protective mechanism or in some situations, simultaneously, to meet the needs of the situation they are in. In this population, masking may contribute to suicidality, as individuals hide traits of themselves. Masking suggests that a person has insight into their personal challenges, how others view them, and wishes to change their behavior to meet societal expectations. Similar to results of Sterling et al. (2008), masking requires insight that may be consistent with higher cognitive functioning (Cassidy et al., 2018). Regardless of level of functioning, the wish for interpersonal relationships, mixed with social impairments, can result in failed social interactions. These failed social interactions may lead to symptoms of depression in an individual, as they lack insight of complex social dynamics (Sterling et al., 2008).

Anxiety and Developmental Disabilities

As a clinician, it may be harder to identify symptoms of anxiety disorders in individuals with developmental disabilities (Davis et al., 2008). Symptoms that are related to a developmental disability diagnosis may overpower the symptoms that stem from an anxiety disorder. Additionally, the client must be able to accurately identify the symptoms they are experiencing. If they are unable to adequately describe their symptoms or do not have the communication skills to correctly define their symptoms, it may become more difficult to identify and diagnose an anxiety disorder. A therapist may place more of an emphasis on a diagnosis such as ASD or IDD compared to generalized anxiety disorder, as those symptoms may be easier to identify, leading to diagnostic overshadowing (Blair, 2017). However, it is important to ensure we can accurately assess for symptoms of other disorders within this population, so we can create a comprehensive treatment plan.

In the past, there has been limited research regarding severe and profound intellectual disabilities and the comorbidity with anxiety (Matson et al., 1997). Most research has surrounded mild to moderate intellectual disabilities, and as a result, there has been little information regarding symptoms within severe and profound intellectual disabilities. Most symptom screeners require an individual to be able to identify their symptoms that align with what is being assessed. This may prove to be more difficult in clients with severe and profound IDD. When assessing anxiety in this population, one may have to depend on observable symptoms, such as trembling or shortness of breath to determine the presence of anxiety. Outside of severity level, there is a deficit of research in older adults with IDD compared to younger adults (Hermans & Evenhuis,

2013). In older adults, anxiety was negatively correlated with severity level of the cognitive deficits. Research indicated that anxiety was associated with borderline or mild IDD, compared to more severe levels of IDD.

In addition to IDD, anxiety is prevalent in individuals with ASD. A wide variety of anxiety sources were identified when following young adults with ASD (Trembath et al., 2012). Though there were approximately 20 different sources identified, researchers were able to group them together, which resulted in five subgroupings of anxiety. These included: 1) the environment, 2) interactions with others, 3) concern for others, 4) fearful anticipation of an event or outcome, 5) disappointment. Most individuals tend to experience anxiety because of multiple sources, instead of just one. One's anxiety may stem from the environment (e.g., crowds) and interactions with others (e.g., communication with other people). Comorbidity of anxiety and ASD varies depending on the type of anxiety. Results of a meta-analysis showed social anxiety and obsessive-compulsive disorder (OCD) as having the highest comorbidity with autism (Hollocks et al., 2018). Generalized anxiety disorder had the third highest current estimated prevalence at 18 percent and the fourth highest pooled lifetime prevalence at 26 percent in autistic adults. Overall anxiety, as measured by a diagnosis of any anxiety disorder, had a lifetime prevalence of 42 percent, and an estimated current prevalence of 27 percent.

Severe Mental Illness and Developmental Disabilities

Psychotic disorders frequently occur in individuals with IDD (Cooper et al., 2007). Like anxiety and depression, severity level of IDD can play a role in severe mental illness symptom presentation. When looking at psychotic symptoms, adults with

mild IDD were more likely to experience hallucinations and delusions compared to their peers with severe to profound IDD (Charlot, 1997). In addition to these two core symptoms, other schizophrenia spectrum symptoms, such as odd behaviors, flat or inappropriate affect, incoherent speech, and deterioration in adaptive functioning and interpersonal relationships, were reported. Like hallucinations and delusions, more individuals with mild IDD experienced these symptoms compared to those with severe to profound IDD. Additional research corroborated Charlot (1997) results, which showed that those with a dual diagnosis, which is an intellectual disability and a psychiatric illness, were more likely to have an intelligence quotient (IQ) that is within the borderline to mild range (Morgan et al., 2008). Schizophrenia appeared to be more common in persons with intellectual disability, compared to bipolar disorder. However, bipolar disorder was within the general population estimates.

Overall, there is a heightened risk of major mental disorders, such as schizophrenia and bipolar, within ASD (Stahlberg et al., 2004; Selten et al., 2015). Prior to ASD being a childhood onset disorder, it was believed to be a variant of schizophrenia (Stahlberg et al., 2004). Autistic individuals may show bizarre ideas, odd behaviors, disorganized speech, or mood swings. However, positive psychotic symptoms, like hallucinations or delusions, are not a component of the diagnostic criteria for these childhood onset disorders. Therefore, a psychotic disorder diagnosis may be merited. As a clinician, it is important to look at the clients wholly, compared to individual components. Though some behaviors overlap, you should work to tease apart whether there is comorbidity, or a single diagnosis. Regardless of this overlap, autistic individuals were more likely to develop a non-affective psychotic disorder (NAPD),

bipolar disorder, and schizophrenia (Selten et al., 2015). When comparing ASD and ADHD, a bipolar diagnosis in both groups appeared equally common, but schizophrenia appeared to be more common in the ASD group than in the ADHD group (Stahlberg et al., 2004). Outside of those meeting diagnostic criteria, a larger group of individuals experienced psychotic symptoms or fluctuations in mood when in a stressful situation. A specifier in ASD is "with or without accompanying intellectual impairments" (APA, 2022). The chance of NAPD, bipolar disorder, and schizophrenia was higher in the ASD population that did not have an accompanying intellectual impairment.

Mental Health Screening

Diagnosis of some mental health disorders, such as depression and anxiety, are largely based on self-report. Accurately measuring and diagnosing GAD and MDD may be a vital component of treatment, as symptom presentation can influence treatment planning for a clinician. There are a variety of measures that may be used to screen for depression and anxiety symptoms, including the Patient Health Questionnaire-9 and the Generalized Anxiety Disorder-7 items scale, which are beneficial because they can be used in different settings to screen depression and anxiety symptoms. These measures have become popular in primary care settings to screen for symptoms in adults (Thase, 2016). Both measures are relatively short and allow the client to complete them on their own. It can be helpful to look at sensitivity and specificity of measures to assist in deciding whether the measure is useful. According to the New York State Department of Health (1999), sensitivity is defined as, "a test's ability to designate an individual with disease as positive" while specificity is defined as, "ability to designate an individual who does not have a disease as negative."

The Patient Health Questionnaire-9 (PHQ-9)

The Patient Health Questionnaire-9, which may be viewed in Appendix A, is a common measure used to screen depression symptoms. The PHQ-9 was developed in 1999 and is a nine question self-report measure that focuses on symptoms of depression, such as lack of interest in things, depressed mood, difficulty with concentration, and more (Kroenke et al., 2001). It is derived from the original patient health questionnaire, which was a three page questionnaire that patients would complete on their own. The PHQ-9 takes a time-oriented approach, focusing specifically on symptoms present in the past 2 weeks. Additionally, there is a time component in the responses as well, such as "not at all," several days," "more than half the days," and "nearly every day."

Based on past research, there is clear evidence for the validity of the PHQ-9 as a screener for depression. Additionally, the PHQ-9 was able to accurately diagnose major depression with high sensitivity and exclude major depression with high certainty (Gilbody et al., 2007). The PHQ-9 showed the maximum sensitivity and specificity at a cut-off score of 10 (Levis et al., 2019; Volker et al., 2016). A study comparing the PHQ-9 to the Hamilton Rating Scale for Depression (HAMD-17), showed that the dimensions of the PHQ-9 were better at classifying depression severity compared to the HAMD-17 (Ma et al., 2021). Therefore, the PHQ-9 may be a beneficial measure to use when assessing depression of severity. The brevity and simple scoring associated with the PHQ-9 are likely a reason this measure is utilized in clinical settings, as it is simple to administer and simple to score (Kroenke et al., 2001). Higher PHQ-9 scores indicate more severe depression.

Within a psychiatric setting, the PHQ-9 can be used to assess depression severity, but it may also be used to monitor symptoms throughout therapy (Sun et al., 2020). Symptom monitoring in therapy can be beneficial because it allows the clinician and the patient to see changes in their individual symptoms each week compared to where they were at baseline. Decreasing scores may provide the client with hope and reflect an appropriate treatment intervention. If depression scores are increasing, it may suggest the treatment plan should be adjusted so goals can be met. Overall, symptom monitoring can prove beneficial throughout treatment and may aid in termination when a client is resistant.

The Generalized Anxiety Disorder-7 (GAD-7) Item Scale

The generalized anxiety disorder-7 (GAD-7) item scale (Appendix C) is a measure used to screen for anxiety symptoms. The GAD-7 was developed in 2006 and is a seven question self-report that incorporates symptoms of generalized anxiety, such as feeling nervous, anxious, worrying about too many things, and more (Spitzer et al., 2006). Prior to the finalization of seven items, there were nine items that were based off diagnostic criteria for generalized anxiety disorder. Resembling the PHQ-9, the GAD-7 requires the individual responding to reflect on symptoms in the previous 2 weeks and respond in the same manner. Most individuals with GAD had a GAD-7 score of 10 or higher, while those without GAD had a score below 10. Similar to the PHQ-9, higher scores on the GAD-7 indicate more severe anxiety, whereas lower scores reflect less anxiety. A cut point of 10 indicates optimal sensitivity and specificity, with little difference between men and women.

The GAD-7 has proven useful in screening potential symptoms of anxiety in individuals within the general population and in primary care settings (Löwe et al., 2008; Spitzer et al., 2006). In low- to middle-income countries, the GAD-7 showed good sensitivity and specificity when taking the population of the countries into consideration (Mughal et al., 2020). When looking at the usage of the GAD-7 with patients in a partial hospitalization program, the GAD-7 showed good internal consistency, convergent validity, and good sensitivity (Kertz et al., 2013). However, good specificity was not confirmed, as higher scores on the measure impacted the ability to differentiate those who did meet criteria of GAD compared to those who did not. Though the psychiatric hospital data suggests that though the GAD-7 may be beneficial in measuring overall anxiety and worry, it appeared to be not useful in this population. Despite this, a strength of the GAD-7 is the ability to measure symptom improvement over a short period of time. Similar to the PHQ-9, the GAD-7 may prove useful in a therapeutic setting when measuring symptoms throughout treatment. Research on the GAD-7, developmental disabilities, and severe mental illness appears to be limited.

Adaptations for Intellectual Developmental Disability and Severe Mental Illness

Diagnosis of mental disorders, like anxiety and depression, can prove more difficult if an individual has impaired verbal communication, as well as limited conceptualization and expression of emotions (McBrien, 2003; Costello & Bouras, 2006). Any impairment places these individuals at a disadvantage on assessments involving emotions (Costello & Bouras, 2006). Furthermore, some disorders have more complex symptoms, which may cause comprehension difficulties if the individual must

read them on a self-report measure. When responding to self-report measures, individuals must read and comprehend the instructions and the questions on the measure (Emerson et al., 2013). In addition, they must recall information, such as how they have felt in the previous week and report their feelings either verbally or through written response. Recommendations for self-report design and development for developmental disabilities and severe mental illness have arisen as the field of psychology has matured.

Finlay and Lyons (2001) comprised several years of research to provide recommendations for several different components of self-report measures. When creating measures with adaptations, it can be beneficial to use minimal words and avoid phrases that are complex or vague. Under this umbrella, there is also negatively worded questions, which incorporates "no" or "not" into positively worded phrases. This combination of positive and negative wording can increase complications in responding. It may also lead someone to respond to the question as if the phrasing was positive. Time components may also result in challenges with responding, so a visual aid is typically provided as well to help with judgements. The visual time component may be a shaded bar graph that represents each component of time.

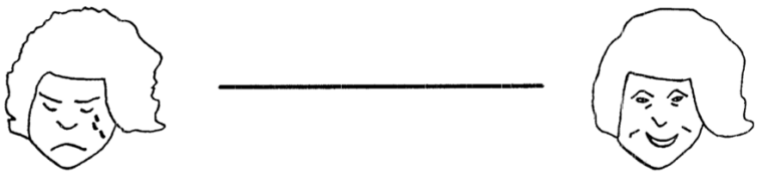
When reflecting on the original PHQ-9 and the GAD-7, there are no visual aids with the responses, only numbers (Kroenke et al., 2001; Spitzer et al., 2006). Additionally, the PHQ-9 and GAD-7 use double or triple barrel questions, such as "feeling down, depressed, or hopeless." This could be confusing as there are three different options in the question, and if one indicates they experience this, there is no way to know which they are experiencing. Additionally, they may respond in a way that indicates they do not experience any of those because they did not experience one of

them. It would be beneficial to ask about each one individually to ensure appropriate answers are recorded. Other concern areas include yes or no questions as they may result in some responding without really understanding what the question is asking. Yes or no questions can cause "yea-saying" or "nay-saying" (Finlay and Lyons, 2001). To combat that, it may be beneficial to include an "I don't know" or "maybe" component, so they have a place to respond appropriately.

In a study where an analogue scale was used to measure how one felt, most individuals were able to use this format (Dagnan & Ruddick, 1995). There were a variety of analogue scales that had two images with a line in between each image. When focusing on mood, images were a happy and sad face (see Figure 1). Other images included an ear and an ear with an "x" through it to represent being listened to and not listened to. These images originated from Makaton Vocabulary, which are symbols based on signing language that is used with individuals who have learning disabilities. When responding to the questions, individuals pointed to a spot on the line to represent where they were located on the line between the two opposite images. The line in between images were split into half-inch segments, and they were measured on a scale of one to 10. In this individual study, researchers assessed reliability by flipping images and having individuals respond again.

Figure 1

Analogue Scale (Dagnan & Ruddick, 1995)



Individuals with mild to moderate ID were able to comprehend a self-stigma scale that was in a simple format, had large font, used images to illustrate symptoms, and kept a simple yes or no response style (Ali et al., 2008). Use of images in place of questions or in combination to enhance questions may be a beneficial adaptation when thinking of self-report measures.

Section III: Screener Development

Adapted Mood Measure Creation

As previously stated, the measures created within this DSP are derived from the PHQ-9 and the GAD-7 (Kroenke et al., 2001; Spitzer et al., 2006). To alter these measures, the first step involved simplifying the questions. When adapting measures, using minimal wording, and avoiding complex or vague statements can be beneficial (Finlay and Lyons, 2001). The statements on the PHQ-9 have multiple components or contradict each other (Kroenke et al., 2001). An example of a multiple component statement is, "feeling down, depressed, or hopeless." An example of a contradictory statement would be "poor appetite or overeating." The GAD-7 is like the PHQ-9 in that it has multiple components or contradictory responses (Spitzer et al., 2006). For example, "feeling nervous, anxious, or on edge" may be viewed as different components, while "becoming easily annoyed or irritable" may be viewed as contradictory. Examples of the adapted statements compared to the original can be viewed in Table 1. The statements on the adapted mood measures were simplified or separated to aid in understanding the questions. The adapted depression measure and generalized anxiety measure can be viewed in Appendix B and D, respectively.

Table 1

Adaptation Examples

Original Statement	**Adapted Statement**
PHQ-9:	**Adapted depression measure:** • "Like falling asleep is hard"

• "Trouble falling or staying asleep, or sleeping too much"	• "Like you wake up a lot" • "Like you sleep way too much" • "Tired"
PHQ-9: • "Feeling down, depressed, or hopeless"	**Adapted depression measure:** • "Unhappy or very sad"
GAD-7: • "Feeling nervous, anxious or on edge"	**Adapted anxiety measure:** • "Like you have been very worried or nervous"
GAD-7: • "Like you are annoyed or irritable"	**Adapted anxiety measure:** • "Like you are easily annoyed" • "Like you are easily angry"

The time components that are included in the PHQ-9 and the GAD-7 include reflecting on the previous two weeks and the prevalence of symptoms during that period (Kroenke et al., 2001; Spitzer et al., 2006). When using a time component, it can be beneficial to use a visual time component, such as a bar graph (Finlay and Lyons, 2001). Given the difficulties Jane had with the time component, it was removed on the adapted measures. The statements "Over the last 2 weeks, how often have you been bothered by any of the following problems?" that are used were replaced with "Do you feel:" to simplify the instructions (Kroenke et al., 2001; Spitzer et al., 2006). The responses, "not at all," "several days," "more than half the days," and "nearly every

day," were replaced with "yes," "no," and "sometimes." "Sometimes" was added to the response options to avoid "yea-saying" and "nay-saying" (Finlay and Lyons, 2001). The goal of adding this was to provide the client an appropriate response if a simple yes-no response was not appropriate for them.

Previous research showed that adding images in place of questions or in combination with questions and responses has been beneficial (Ali et al., 2008). During the adaptations, images were added to the responses. For example, "no" would indicate one has not experienced that symptom since their last session. A smiling face represents a positive mood. A "yes" would indicate experiencing that symptom since their last session. A frown represents an upset mood.

Figure 2:

"No" response

Figure 3:

"Sometimes" response

Figure 4:

"Yes" response

Adapted Mood Measure Information

The creator of these adapted measures contacted Dr. Janet Williams, co-creator of the PHQ-9 and the GAD-7 regarding the use of adapted mood measures for this DSP. Dr. Williams indicated the PHQ-9, and the GAD-7, are no longer under copyright and may be used, and adapted, without permission. It is important to note there is no scoring component to these adapted measures like there is with the PHQ-9 and the GAD-7. These measures should not be used to diagnose major depressive disorder or generalized anxiety disorder. Additionally, these measures will not aid in specifying a severity level for either disorder. These measures should be used in treatment to monitor symptoms as the client progresses.

These measures are intended to be used with individuals who have been diagnosed with a developmental disability (e.g., autism spectrum disorder, intellectual developmental disorder, etc.) that may be experiencing symptoms of depression, anxiety, or psychosis. Persons should have a chronological age of eighteen years or older to be administered this measure, but there is no set mental age limit. However,

usage of these measures should be up to the clinician's discretion. Clinicians should ensure clients are able to understand what is being asked before using it in a treatment setting.

Section IV: Usage of Adapted Mood Measures: A Clinician's Perspective

Method

A component of this doctoral specialization project is evaluating the ease of administration and the perceived benefit of using these measures to assess depression and anxiety symptoms of the specified population. The clinicians chosen to participate in this study must have a client who is over the age of 18. The client must have a diagnosis of a developmental disability (e.g., ASD or IDD) and/or symptoms of a severe mental illness (e.g., hallucinations or delusions). Clinicians were asked to administer the adapted mood measures to their clients, or they requested to use the adapted mood measures. Clinicians who requested using the adapted measures indicated that they needed a way to measure their client's symptoms, or they had previously administered the PHQ-9 or the GAD-7 and the clients had difficulty understanding.

The current sample includes five student clinicians from the Eastern Kentucky University (EKU) psychology clinic with clients meeting the above mentioned criteria. Information on the individual clients who responded to the adapted mood measures was not collected due to the protections surrounding this population. Once student clinicians administered the adapted mood measures, they notified the creator of the mood measures. Clinicians were then sent a link to a google form that had the questionnaire on it. To evaluate ease and benefit, clinicians completed a questionnaire, which can be viewed in appendix E. The first question asks clinicians why they chose to give the adapted measure compared to the standard PHQ-9 and GAD-7. Clinicians were to report whether they completed the standard measures before administering the adapted measures. To evaluate the differences between standard measures and adapted

measures, clinicians were to report behavioral differences that they noticed in their client as they were responding to the adapted measures. On this questionnaire, behaviors could mean a variety of things, such as refusal to complete the measure, apparent frustration, and more. The reported behaviors are based off clinician perception. Clinicians reported whether they feel their clients were able to understand the adapted questions and how their clients indicated they understood. The clinicians were asked to voice their likes and dislikes of the measures, so adaptations could be made as needed. Clinicians were asked a variety of open ended questions, so they could provide as much detail as they could. In addition to open ended questions, clinician answered questions on the likelihood of using the measure again, the ease, perceived enjoyment of the client, and perceived effectiveness of the adapted mood measures. Responses are on a five point Likert scale, with one being strongly disagree and five being strongly agree.

Results

Five clinicians have completed the questionnaire that is evaluating perceived ease of administration and benefit. Clinicians responded to a question regarding why the adapted measures were administered. Raw data from the clinicians may be viewed in appendix F. Clinicians noted that their client had difficulty understanding the time component of the PHQ-9 and GAD-7. For example, one clinician stated, “I tried the PHQ-9 and the GAD-7 first. My client had a difficult time processing the ‘not at all,’ ‘several days,’ ‘more than half the days,’ and ‘nearly every day’ parts.” Additionally, two clinicians mentioned clients had difficult using the traditional Likert scale version. The other main reason clinicians chose to use the adapted measure is because their

clients had difficulty with the wording of the original measures. Clinicians noted that client's spent significant time trying to interpret the questions, which typically resulted in confusion.

Four clinicians who responded to the questionnaire administered the PHQ-9 and the GAD-7 prior to the administration of the adapted mood measures. Clinicians compared client behaviors during the PHQ-9 and the GAD-7 administration to the behaviors during the adapted mood measure administration. When analyzing qualitative data, three clinicians reported that their clients appeared less agitated or frustrated while completing the adapted measures. Additionally, two clinicians' responses indicated that their clients were able to complete the measures on their own without assistance. It was noted that when completing the PHQ-9 and the GAD-7, clients had a difficult time going through the questions and required a clinician's help interpreting the questions. Another significant behavior difference indicated that clients spent less time making a decision about their answer.

Clinicians reported whether they felt as though their client was able to understand the questions that had been adapted. All five clinicians felt their clients were able to understand the adapted questions. One clinician reported the client stated, "I like this one way better." The other clinicians noticed either a change in their client's behavior or their clients reported they were able to understand the measures, which made it easier for them to respond.

Finally, clinicians reported aspects they liked and disliked about the measure. This question takes into consideration the clinician's thoughts and feelings toward the adapted measures. Simplicity appeared to be the most favorable aspect about the

measures. Another component clinicians favored about the adapted measures was because their clients had an easier time understanding the questions and responses. The visual aid of the responses was the final piece that clinicians liked about the measures. The visual component seemed to make it easier for their client to understand. There were no dislikes reported by the clinicians. In this sample, only one clinician customized the images with their client.

As previously noted, clinicians responded to five questions on a Likert scale (appendix G). All clinicians reported they were likely to use this measure again with other clients who meet criteria (M = 5, SD = 0). Overall, clinicians felt this measure was easy to use with their client (M = 4.8, SD = 0.4). Client's perceived enjoyment of the mood measures was evaluated. Eighty percent of clinicians felt their client enjoyed the mood measures, while twenty percent of the clinicians was unable to identify whether their client appeared to enjoy the measure or not (M = 4, SD = 0.9). All respondents felt the measure was easy to administer and that they were effective in measuring their client's mood (M = 5, SD = 0). Clinicians felt these adapted measures were effective in measuring their client's mood (M = 4.8, SD = 0.4).

Screener Evaluation

The results of the clinician questionnaire indicate that the adapted measures are easy to administer to their clients. The simplicity of the wording and the responses appears to be beneficial, as it allows the clients to complete the measures without clinicians needing to provide significant assistance. If clients can complete the measures on their own, it may help foster independence, which could be beneficial in rapport building. Based on clinician report, the adapted measures appeared to adequately

measure their client's symptoms. Although these measures will not assist in diagnosing generalized anxiety disorder or major depressive disorder, they can be beneficial in helping clinician's monitor client's symptoms throughout treatment. Clinicians would also be able to use their client's responses on the adapted mood measures to guide treatment. One response indicated that they used the responses on the adapted mood measures to target symptoms the client was experiencing. Overall data indicates that these adapted mood measures are beneficial in monitoring anxiety and depression symptoms in adult clients with developmental disabilities and/or severe mental illness.

Section V: Limitations and Future Directions

Limitations

Though results point to the mood measures being easy to administer and beneficial in monitoring symptoms, the current sample size is small. The current sample is limited to Eastern Kentucky University doctoral level trainees who have adult clients with a developmental disability or symptoms of severe mental illness. Therefore, results of the clinician questionnaire may not be generalizable to the general population. Additionally, not all clients administered the PHQ-9 and the GAD-7 before administering the adapted mood measures. Therefore, it is difficult to say that the adapted mood measures are as effective or beneficial in measuring symptoms and severity level of depression and anxiety.

Future Directions

A goal of the future of this study is to collect more data from clinicians about their thoughts and opinions on the adapted measures. The adapted mood measures and the study are in the process of being reviewed by the Human Resource Committee (HRC) at the Oakwood Clinic in Somerset, Kentucky. If approved, clinicians will administer the adapted mood measures to their clients. It would be up to clinician's discretion on whether their clients could accurately complete the measures. Once the measures have been administered, the clinicians will complete the questionnaire so data can be collected outside of Eastern Kentucky University clinicians. The data collected from Oakwood clinicians can be used to make changes to the measures as needed.

To expand on the study of this doctoral specialization project, it would be beneficial to submit an updated institutional review board application to be able to

collect demographic information on the clients who are completed the adapted mood measures. If chronological age and cognitive functioning of the clients were measured in the clinician questionnaire, we would be able to see a minimum mental age that this can be used with. To measure mental age, one must divide the individual's score on an intelligence measure by the average of the score for individuals the same age (i.e., 100), and then multiple by the age of the individual (American Psychological Association, n.d.). As of now, an individual's chronological age must be at least 18 years old to complete the measure. However, a chronological age of 18 years does not mean one can accurately respond to the measures. If one inaccurately rates their symptoms, it will be difficult for the clinician to monitor what the client is feeling and may impact treatment. The information on one's mental age would give us a better understanding of who these measures can be used on, outside of an adult with a developmental disability or severe mental illness. To measure this, one would need to calculate the mental age and then compare mental ages to the clinician's responses on the questionnaire. This information would be beneficial, as it would make administration of the questionnaire more standardized.

Outside of this study, additional research may be completed to evaluate the effectiveness of the adapted mood measures. One study could examine the construct validity of the adapted measures. It would be beneficial to look at whether the scores on the measures correspond with clinician and caregiver judgement of anxiety and depression. For example, clinician or caregiver report of anxiety and depression would indicate that symptoms of depression and anxiety would be indicated on the adapted measures. This study could also look at the reliability of the measure. Beyond construct

validity and reliability, it may be beneficial for future research to look at whether the images in the adapted measures are confusing to any clients. If any client finds the images confusing, would it be beneficial to have them pick their own images to represent whether they are experiencing a symptom or not.

References

Ali, A., Strydom, A., Hassiotis, A., Williams, R. & King, M. (2008). A measure of perceived stigma in people with intellectual disability. *The British Journal of Psychiatry, 193*, 410-415. 10.1192/bjp.bp.107.045823

Altemus, M., Sarvaiya, N., & Neill Epperson, C. (2014). Sex differences in anxiety and depression clinical perspectives. *Frontiers in Neuroendocrinology*, *35*(3), 320–330. https://doi.org/10.1016/j.yfrne.2014.05.004

American Psychiatric Association (1952). *Diagnostic and statistical manual of mental disorders* (1st ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association (1980), *Diagnostic and statistical manual of mental disorders* (3rd ed.). Arlington, VA: American Psychiatric Association

American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders, fifth edition, text revision.

American Psychological Association (n.d.). *APA Dictionary of Psychology.* American Psychological Association. Retrieved February 7, 2023 https://dictionary.apa.org/mental-age https://doiorg.libproxy.eku.edu/10.1176/appi.books.9780890425787

Blair, J. (2017 January). *Diagnostic overshadowing: See beyond the diagnosis.* University of Hertfordshire: Intellectual Disability and Health. http://www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis#:~:text=Diagnostic%20overshadowing%20can%20occur%20during,any%20possible%20underlying%20health%20cause.

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., Visser, S., & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, *127*(6), 1034–1042. https://doi.org/10.1542/peds.2010-2989

Burstein, M., Beesdo-Baum, K., He, J.-P., & Merikangas, K. R. (2014). Threshold and subthreshold generalized anxiety disorder among US adolescents: Prevalence, sociodemographic, and clinical characteristics. *Psychological Medicine*, *44*(11), 2351–2362. https://doi.org/10.1017/S0033291713002997

Cai, H., Xie, XM., Zhang, Q., Cui, X., Lin, JX., Sim, K., Ungvari, G. S., Zhang, L., & Xiang, YT. (2021). Prevalence of suicidality in major depressive disorder: A systematic review and meta-analysis of comparative studies. *Frontiers in Psychology*, *12*(690130). https://doi.org/10.3389/fpsyt.2021.690130

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism, 9*(42). https://doi.org/10.1186/s13229-018-0226-4

Cavanagh, A., Wilson, C. J., Kavanagh, D. J., & Caputi, P. (2017). Differences in the expression of symptoms in men versus women with depression: A systematic review and meta-analysis. *Harvard Review of Psychiatry*, *25*(1), 29–38. https://doi.org/10.1097/HRP.0000000000000128

Charlot, L. R. (1997). Irritability, aggression, and depression in adults with mental retardation: A developmental perspective. *Nursing & Allied Health Premium, 27*(3), 190-197. https://doi.org/10.1080/09638280400007380

Clemente, A. S., Diniz, B. S., Nicolato, R., Kapczinski, F. P., Soares, J. C., Firmo, J. O., & Castro-Costa, É. (2015). Bipolar disorder prevalence: A systematic review and meta-analysis of the literature. *Revista Brasileira de Psiquiatria*, *37*(2), 155–161. https://doi.org/10.1590/1516-4446-2012-1693

Cooper, SA., Smiley, E., Morrison, J., Allan, L., Williamson, A., Finlayson, J., Jackson, A., & Mantry, D. (2007). Psychosis and adults with intellectual disabilities: Prevalence, incidence, and related factors. *Social Psychiatry and Psychiatric Epidemiology*, *42*(7), 530-536. https://doi.org/10.1007/s00127-007-0197-9

Costello, H. & Bouras, N. (2006). Assessment of mental health problems in people with intellectual disabilities. *Israel Journal of Psychiatry and Related Sciences, 43*(4), 241-251.

Dagnan, D. & Ruddick, L. (1995). The use of analogue scales and personal questionnaires for interviewing people with learning disabilities. *Clinical Psychology Forum*, 21-24. https://doi.org/10.53841/bpscpf.1995.1.79.21

Davis, E., Saeed, S. A., & Antonacci, D. J. (2008). Anxiety disorders in persons with developmental disabilities: Empirically informed diagnosis and treatment: reviews literature on anxiety disorders in DD population with practical take-home messages for the clinician. *Psychiatric Quarterly*, *79*(3), 249–263. https://doi.org/10.1007/s11126-008-9081-3

de Lijster, J. M., Dierckx, B., Utens, E. M. W. J., Verhulst, F. C., Zieldorff, C., Dieleman, G. C., & Legerstee, J. S. (2017). The age of onset of anxiety disorders: A meta-analysis. *The Canadian Journal of Psychiatry*, *62*(4), 237-246. https://doi.org/10.1177/0706743716640757

Dell'Osso, B., Cafaro, R., & Ketter, T. A. (2021). Has Bipolar Disorder become a predominantly female gender related condition? Analysis of recently published large sample studies. *International Journal of Bipolar Disorders*, *9*(1), 3. https://doi.org/10.1186/s40345-020-00207-z

Dietz, P. M., Rose, C. E., McArthur, D., & Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*, 4258-4266. https://doi.org/10.1007/s10803-020-04494-4

Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities, 51*(5), 333-349. 10.1352/1934-9556-51.5.333

Fazel, S. & Seewald, K. (2012). Severe mental illness in 33,588 prisoners worldwide: A systematic review and meta-regression analysis. *The British Journal of Psychiatry, 200*, 364-373. https://doi.org/10.1192/bjp.bp.111.096370

Ferrari, A. J., Stockings, E., Khoo, J.-P., Erskine, H. E., Degenhardt, L., Vos, T., & Whiteford, H. A. (2016). The prevalence and burden of bipolar disorder: Findings from the global burden of disease study 2013. *Bipolar Disorders*, *18*(5), 440–450. https://doi.org/10.1111/bdi.12423

Finlay, W. M. & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*(3), 319-335. https://doi.org/10.1037/1040-3590.13.3.319

Gilbody, S., Richards, D., Brealey, S., & Hewitt, C. (2007). Screening for depression in

medical settings with patient health questionnaire (PHQ): A diagnostic meta-analysis. *Journal of General Internal Medicine, 22*(11), 1596-1602. 10.1007/s11606-007-0333-y.

Gutiérrez-Rojas, L., Porras-Segovia, A., Dunne, H., Andrade-González, N., & Cervilla, J. A. (2020). Prevalence and correlates of major depressive disorder: A systematic review. *Brazilian Journal of Psychiatry, 42*(6), 657-672. https://doi.org/10.1590/1516-4446-2020-0650

Hermans, H. & Evenhuis, H. M. (2013). Factors associated with depression and anxiety in older adults with intellectual disabilities: Results of the healthy ageing and intellectual disabilities study. *International Journal of Geriatric Psychiatry, 28*, 691-699. https://doi.org/10.1002/gps.3872

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2018). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine, 49*, 559-572. https://doi.org/10.1017/ S0033291718002283

Kertz, S. Bigda-Peyton, J., & Bjorgvinsson, T. (2013). Validity of the generalized anxiety disorder-7 in an acute psychiatric sample. *Clinical Psychology & Psychotherapy, 20*, 456-464. https://doi.org/10.1002/cpp.1802

Kessler, R. C., Petukhova, M., Sampson, N. A., Zaslavsky, A. M., & Wittchen, H-U. (2012). Twelve-month and lifetime prevalence and lifetime morbid risk of anxiety and mood disorders in the United States. *International Journal of Methods in Psychiatric Research, 21*(3), 169-184. https://doi.org/10.1002/mpr.1359

Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*(9), 606-613. 10.1046/j.1525-1497.2001.016009606.x

Levis, B., Benedetti, A., & Thombs, B. D. (2019). Accuracy of patient health questionnaire-9 (PHQ-9) for screening to detect major depression: In individual participant data meta-analysis. *BMJ, 365*(1476). http://dx.doi.org/10.1136/bmj.l1476

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the generalized anxiety disorder screener (GAD-7) in the general population. *Medical Care, 46*(3), 266-274.

Lui, Q., He. H., Yang, J., Feng, X., Zhao, F., & Lyu, J. (2020). Changes in the global burden of depression from 1990 to 2017: Findings from the global burden of disease study. *Journal of Psychiatric Research, 126*, 134-140. https://doi.org/10.1016/j.jpsychires.2019.08.002

Ma, S., Yang, J., Yang, B., Kang, L., Wang, P., Zhang, N., Wang, W., Zong, X., Wang, Y., Bai, H., Guo, Q., Yao, L., Fang, L., & Zhongchun, L. (2021). The patient health questionnaire-9 vs. the hamiltion rating scale for depression in assessing major depressive disorder. *Frontiers in Psychiatry, 12.* https://doi.org/10.3389/fpsyt.2021.747139

Matson, J. L., Smiroldo, B. B., Hamilton, M., & Baglio, C. S. (1997). Do anxiety disorders exist in persons with severe and profound mental retardation? *Research in Developmental Disabilities*, *18*(1), 39–44. https://doi.org/10.1016/S0891-4222(96)00036-4

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities, 32*(2), 419–436. https://doi.org/10.1016/j.ridd.2010.12.018

McBrien, J. A. (2003). Assessment and diagnosis of depression in people with intellectual disability. *Journal of Intellectual Disability Research, 47*,1-13.

McConkey, R., Craig, S., & Kelly, C. (2019). The prevalence of intellectual disability. A comparison of national census and register records. *Research in Developmental Disabilities, 89*, 69-75. https://doi.org/10.1016/j.ridd.2019.03.009

McDermott, S., Moran, R., Platt T., Issac, T., Wood, H., & Dasari, S. (2005). Depression in adults with disabilities, in primary care. *Disability and Research, 27*(3), 117-123. https://doi.org/10.1080/09638280400007380

McGuire, D. O., Tian, L. H., Yeargin-Allsopp, M., Dowling, N. F., & Christensen D. L (2019). Prevalence of cerebral palsy, intellectual disability, hearing loss, and blindness, national health interview survey, 2009-2016. *Disability and Health Journal, 12*(3), 443-451. 10.1016/j.dhjo.2019.01.005

Morgan, V. A., Leonard, H., Bourke, J., & Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: Population-based study. *The British Journal of Psychiatry, 193*, 364-372. https://doi.org/10.1192/bjp.bp.107.044461

Mughal, A. Y., Devadas, J., Ardman, E., Levis, B., Go, V. F., Gaynes, B. N. (2020). A

systematic review of validated screening tools for anxiety disorders and PTSD in low to middle income countries. *BMC Psychiatry, 20*(338). https://doi.org/10.1186/s12888-020-02753-3

New York State Department of Health (1999, April). *Disease screening – statistics teaching tools*. https://www.health.ny.gov/diseases/chronic/discreen.htm

Poindexter, A. R. (2006). Diagnosis of depression in people with developmental disabilities: Progress and problems. *International Review of Research in Mental Retardation, 32,* 261-281. https://doi.org/10.1016/S0074-7750(06)32009-5

Ruscio, A. M., Hallion, L. S., Lim, C. C. W., Aguilar-Gaxiola, S., Al-Hamzawi, A., Alonso, J., Andrade, L. H., Borges, G., Bromet, E. J., Bunting, B., Caldas de Almeida, J. M., Demyttenaere, K., Florescu, S., de Girolamo, G., Gureje, O., Haro, J. M., He, Y., Hinkov, H., Hu, C., … Scott, K. M. (2017). Cross-sectional comparison of the epidemiology of *DSM-5* generalized anxiety disorder across the globe. *JAMA Psychiatry, 74*(5), 465. https://doi.org/10.1001/jamapsychiatry.2017.0056

Saha, S., Chant, D., Welham, J., & McGrath, J. (2005). A systematic review of the prevalence of schizophrenia. *PLoS Medicine, 2*(5), 0413-0433. https://doi.org/10.1371/journal.pmed.0020141

Selten, JP., Lundberg, M., Rai, D., & Magnusson, C. (2015). Risk for nonaffective psychotic disorder and bipolar disorder in young people with autism spectrum disorder: A population-based study. *JAMA Psychiatry, 72*(5), 483-489. https://doi.org/10.1001/jamapsychiatry.2014.3059

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Lowe, B. (2006). A brief measure for

assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine, 166*(10), 1092-1097. 10.1001/archinte.166.10.1092

Stahlberg, O., Soderstrom, H., Rastam, M., & Gillberg, C. (2004). Bipolar disorder, schizophrenia, and other psychotic disorders in adults with childhood onset AD/HD and/or autism spectrum disorders. *Journal of Neural Transmissions, 111*(7), 891-901. https://doi.org/10.1007/s00702-004-0115-1

Sterling L., Dawson, G., Estes, A., & Greenson, J. (2008). Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 38,* 1011-1018. https://doi.org/10.1007/s10803-007-0477-y

Sun, Y., Fu, Z., Bo, Q., Mao, Z. Ma, X., & Wang, C. (2020). The reliability and validity of the PHQ-9 in patients with major depressive disorder in psychiatric hospital. *BMC Psychiatry, 20*(474). https://doi.org/10.1186/s12888-020-02885-6

Thase, M. E. (2016). Recommendations for screening for depression in adults. *JAMA, 315*(4), 349. https://doi.org/10.1001/jama.2015.18406

Trembath, D., Germano, C., Johanson, G., & Dissanayake, C. (2012). The experience of anxiety in young adults with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 27*(4), 213-224. https://doi.org/10.1177/1088357612454916

Uher, R. (2014). Gene-environment interactions in severe mental illness. *Frontiers in Psychiatry, 5(48)*. https://doi.org/10.3389/fpsyt.2014.00048

Volker D., Zijlstra-Vlasveld, M. C., Brouwers, E. P. M., Homans, W. A., Emons, W. H.

M., & van der Feltz-Cornelis, C. M. (2016). Validation of the patient health questionnaire-9 for major depressive disorder in the occupational health setting. *Journal of Occupational Rehabilitation, 26,* 237-244. https://doi.org/10.1007/s10926-015-9607-0

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*, *144*(4). https://doi.org/10.1542/peds.2019-0811

Appendix A

Patient Health Questionnaire-9 (Kroenke et al., 2001)

Figure A.1

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING 0 + _____ + _____ + _____

=Total Score: _____

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
☐	☐	☐	☐

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Appendix B

Adapted Depression Measure

Figure B.1

Client Name:

Do you feel:	**No**	**Sometimes**	**Yes**
1. Little or no interest in things you like to do (like watching a movie)			
2. Unhappy or very sad			
3. Like falling asleep is hard			
4. Like you wake up a lot			
5. Like you sleep way too much			
6. Tired			
7. Like your appetite is different			
8. Like you have problems paying attention			
9. Like you are moving slower			
10. Like you are moving more than normal			
11. Like you want to hurt yourself			
12. Like you would be better off dead			
If you answered yes or sometimes: Have these problems made things hard (like taking care of yourself, doing things you want)?			

***Tell your therapist what you want to talk about**

Appendix C

Generalized Anxiety Disorder-7 Item Scale (Spitzer et al., 2006)

Figure C.1

GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

(For office coding: Total Score T____ = ____ + ____ + ____)

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Appendix D

Adapted Anxiety Measure

Figure D.1

Client Name:

Do you feel:	**No**	**Sometimes**	**Yes**
1. Like you have been very worried or nervous			
2. Like controlling your worry is hard			
3. Like you are worrying about a lot of things at the same time			
4. Like relaxing is hard			
5. Like you are restless and have trouble sitting still			
6. Like you are easily annoyed			
7. Like you are easily angry			
8. Afraid, like something bad might happen			
If you answered yes or sometimes: Have these problems made things hard (like taking care of yourself, doing things you want)?			
***Tell your therapist what you want to talk about**			

Appendix E

Questionnaire for Clinicians

Table E.1

Instructions: Please respond to the following questions. *There are no right or wrong answers.*
1. Why did you choose to give this adapted measure rather than the standard PHQ-9 and GAD-7?
2. Did you try the standard PHQ-9 and GAD-7 first? **Yes or No**
3. Do you think your examinee understood the adapted questions or not? How do you know?
4. If you tried the standard measures first, how did behavior differ between standard and adapted measure response?
5. What aspects of the adapted mood measures did you like?
6. What aspects of the adapted mood measures did you dislike?
7. Did you customize images when using it with your client? **Yes or No**

Table E.2

INSTRUCTIONS: Use the scale below that ranges from 1 (*Strongly Disagree*) to 5 (*Strongly Agree*) to respond to the statements. Please use the scale to indicate how much you disagree or agree with each statement by selecting the number under each statement that best reflects your opinion. *There are no right or wrong answers.*

1. I am likely to use this instrument again with a client.				
1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
2. It was easy to use this measure with my client.				
1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
3. My client appeared to enjoy the measures.				
1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
4. This measure was easy to administer.				
1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree
5. This measure appeared effective in measuring my client's mood.				
1 Strongly Disagree	2 Disagree	3 Neither Agree nor Disagree	4 Agree	5 Strongly Agree

Appendix F

Clinician Raw Qualitative Data

Table F.1

Why did you choose to give this adapted measure rather than the standard PHQ-9 and GAD-7?
I felt it was something my client could relate to more.
I tried the PHQ-9 and the GAD-7 first. My client had a difficult time processing the "not at all" "several days" "more than half the days" "nearly every day" parts. When the adapted measure was offered, I decided to try it. It made it easier for my client to understand what was being asked. It simplified it.
My client was unable to understand the wording and the time component of the standard PHQ-9 and GAD-7.
My client has ASD and often spends a lot of time during struggling to pick between the traditional Likert style, he often becomes distracted and needs reminders to stay on task with the standard PHQ-9 and GAD-7. With this measure I felt that the options would be more limited, and it would allow me to use a measure to target his current symptoms without taking up too much time or frustrating him.
My client often had difficulty in differentiating between numerical rating scales and this scale appeared more approachable.

Table F.2

Do you think your examinee understood the adapted questions or not? How do you know?
Yes. I asked after they had completed the questions if they understood the content.
Yes, she understood it. She expressed her difficulty with the PHQ-9 and GAD-7. She said the adapted measure was much easier to understand because it allowed her to make a decision easier.
I think they understood it better. I could see a difference in their scores, and they appeared less agitated when responding to it.
Yes, he stated that he found it much easier than standard measures. (Ex. during administration of these adapted measures he said, "I like this one way better.")
My client stated that these questions were much easier to understand and thus easier for them to answer.

Table F.3

If you tried the standard measure first, how did behavior differ between standard and adapted measure responses?
I didn't.
Less visible frustration, less amount of time spent trying to make a decision.
They were less agitated and quicker to respond.
With the standard measure my client would often become frustrated when trying to pick if his symptoms fit with the question because they would often be more complex. He would begin explaining exactly why he was confused or would ask many clarifying questions that would interfere with administration. With the adapted measure he was able to complete that measure with no assistance, which led to use being able to reference his responses and guide the therapy session to topics that targeted his symptoms.
When given the standard measures my client would frequently ask questions about my interpretation of the questions so that they could gain a better understanding of the questions that were more faceted or complex. With this measure the straightforward style of the questions was very helpful and allowed my client to answer the questions completely on their own. The visual rating scale also made them more comfortable and confident when answering the questions.

Table F.4

What aspects of the mood measure did you like?
I liked that it was simple and easier for my client to understand.
The simplicity.
The ease of it with the client since they could understand it better, the picture component
I like the simplicity of the questions and the visual aids for the responses
I love the visual aspect of it and the simplified questions.

Table F.5

What aspects of the adapted mood measure did you dislike?
I didn't dislike any part of it.
None
None
Nothing
Nothing!

Appendix G

Likert Scale Responses

Figure G.1

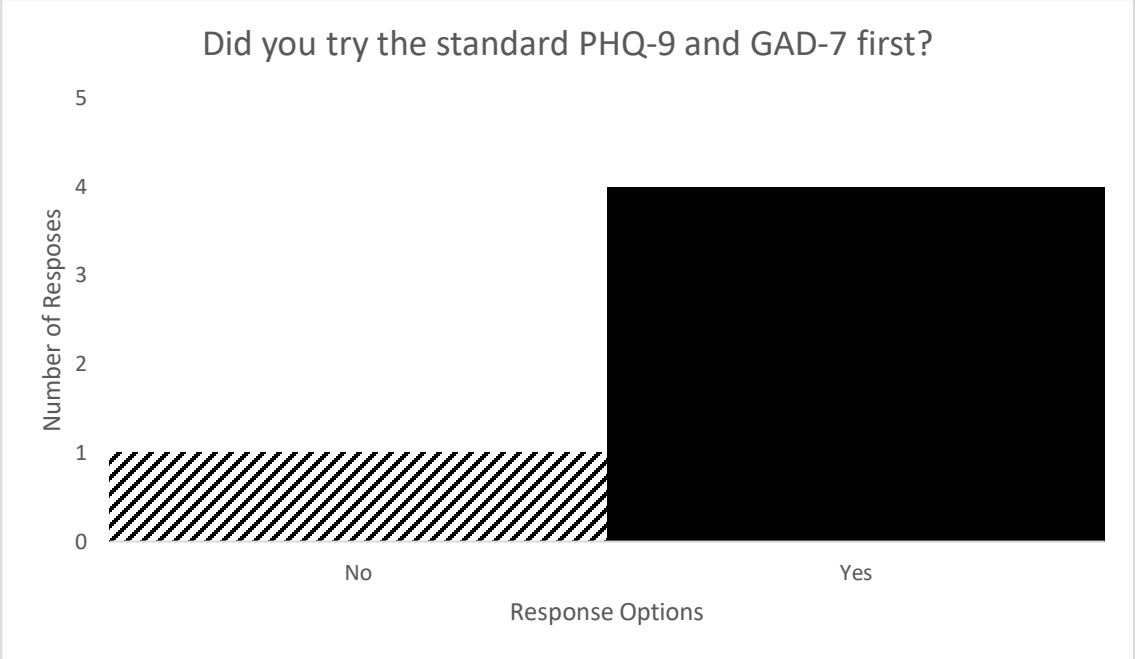


Figure G.2

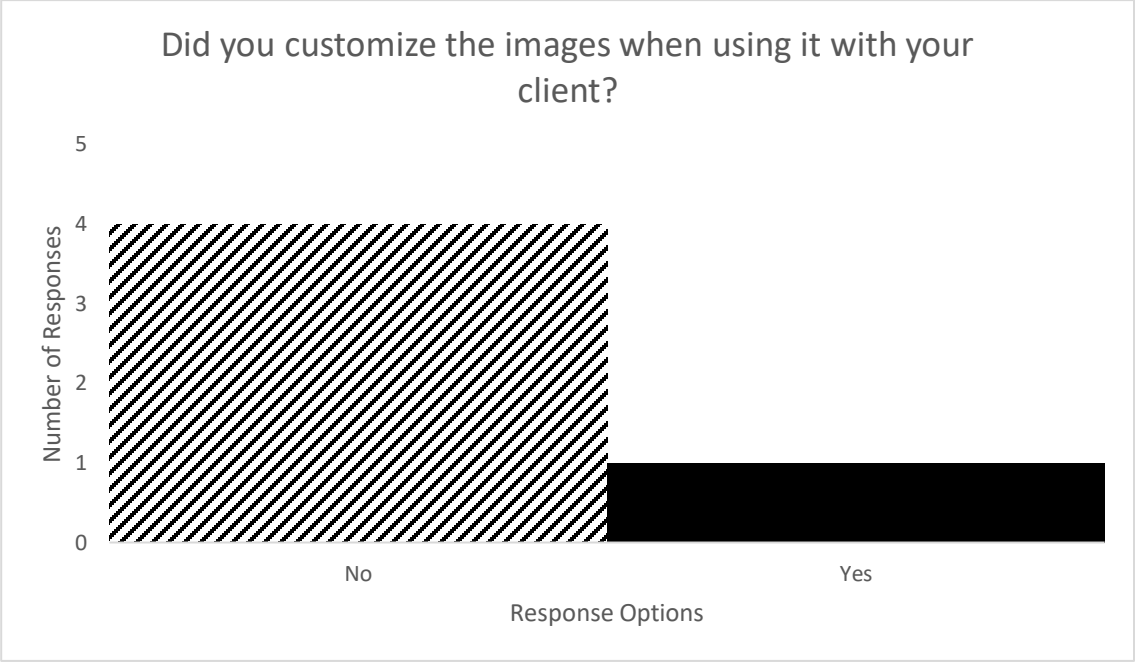

Did you customize the images when using it with your client?
5
4
3
2
1
0
Number of Responses
No
Yes
Response Options

Figure G.3

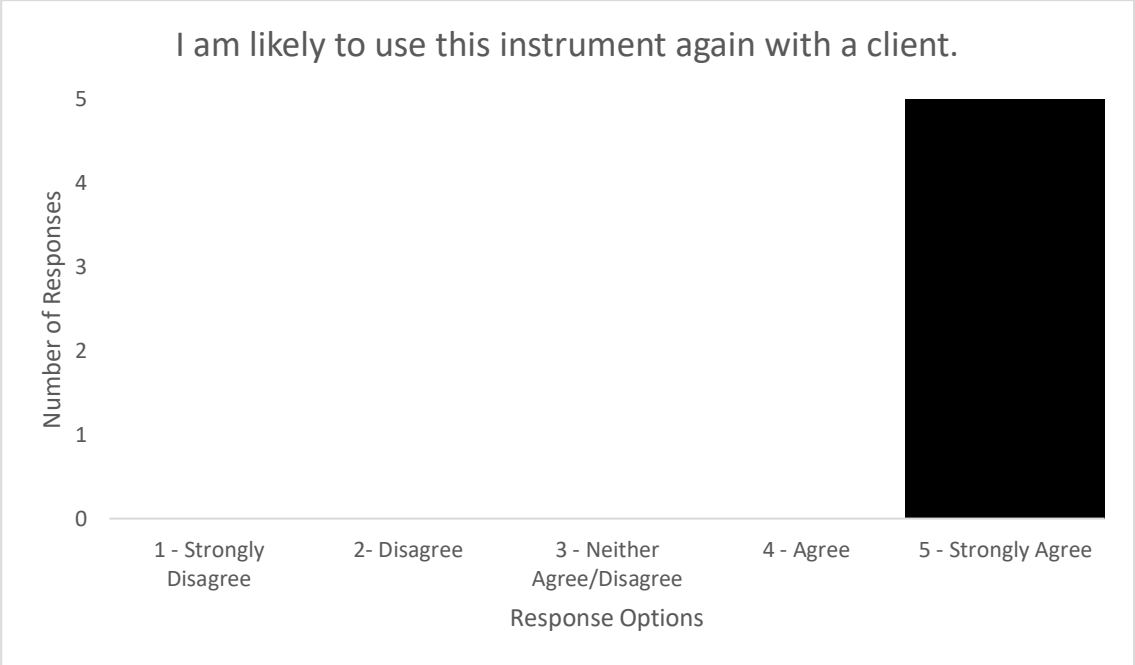

I am likely to use this instrument again with a client.
Number of Responses
5
4
3
2
1
0
1 - Strongly Disagree
2- Disagree
3 - Neither Agree/Disagree
4 - Agree
5 - Strongly Agree
Response Options

Figure G.4

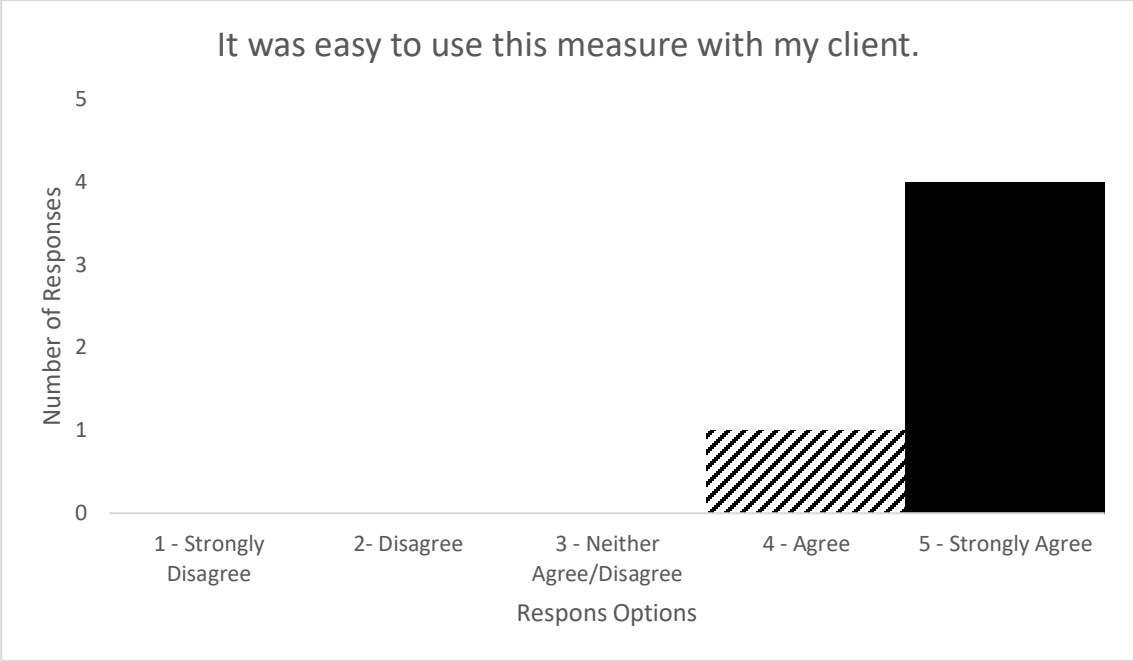

It was easy to use this measure with my client.
Number of Responses
5
4
3
2
1
0
1 - Strongly Disagree
2- Disagree
3 - Neither Agree/Disagree
4 - Agree
5 - Strongly Agree
Respons Options

Figure G.5

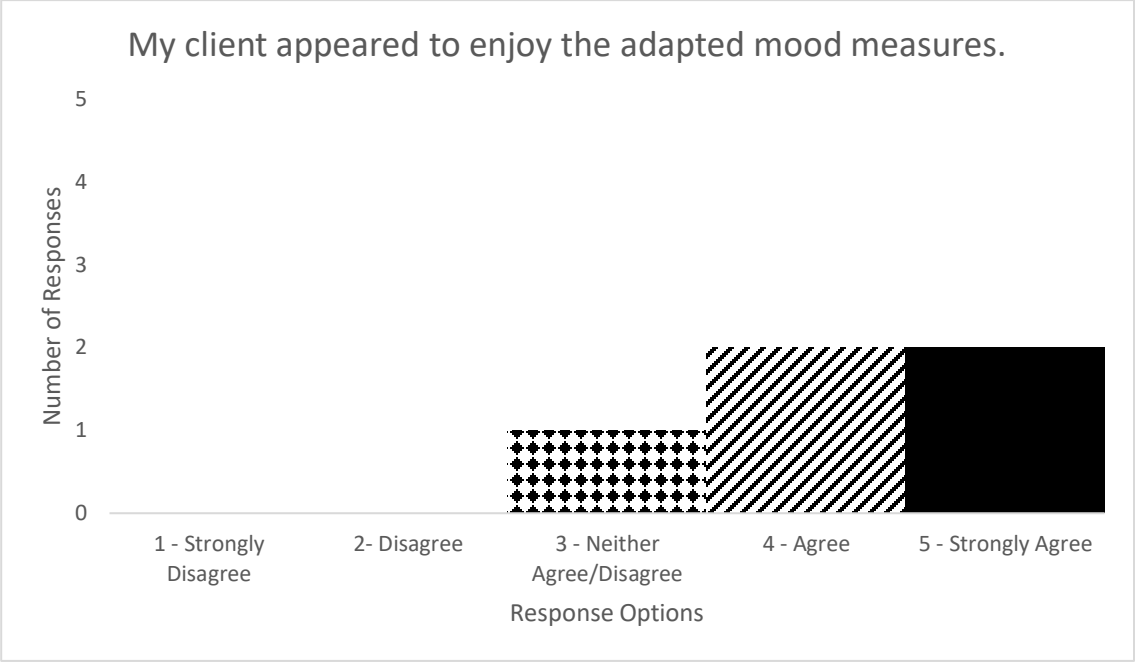

My client appeared to enjoy the adapted mood measures.
Number of Responses
5
4
3
2
1
0
1 - Strongly Disagree
2- Disagree
3 - Neither Agree/Disagree
4 - Agree
5 - Strongly Agree
Response Options

Figure G.6

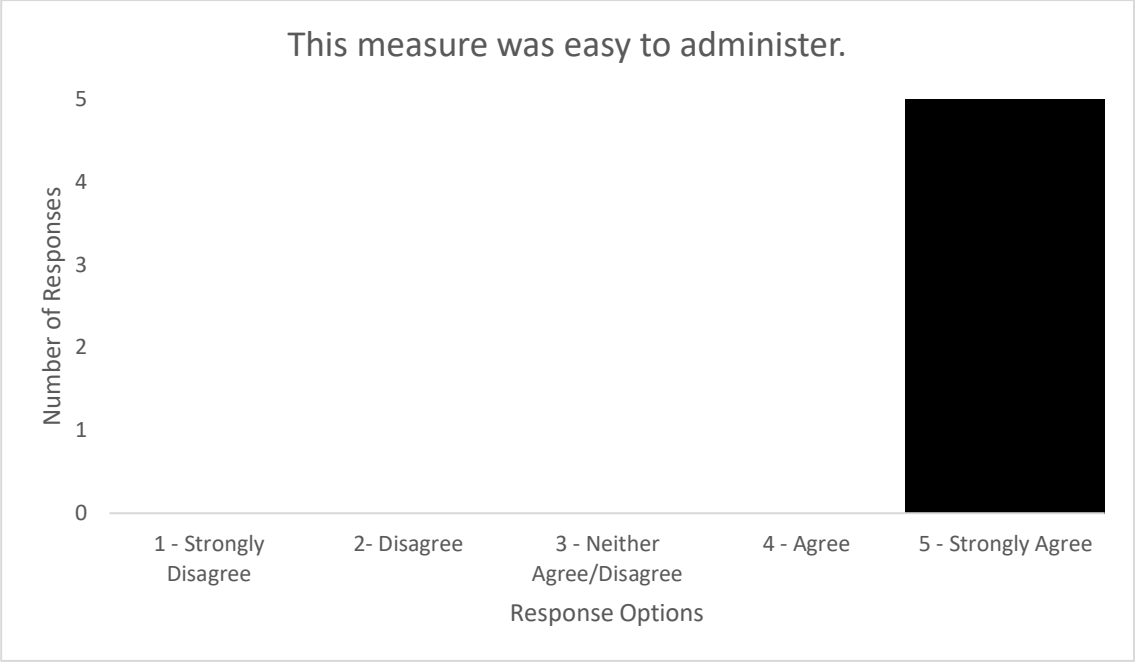
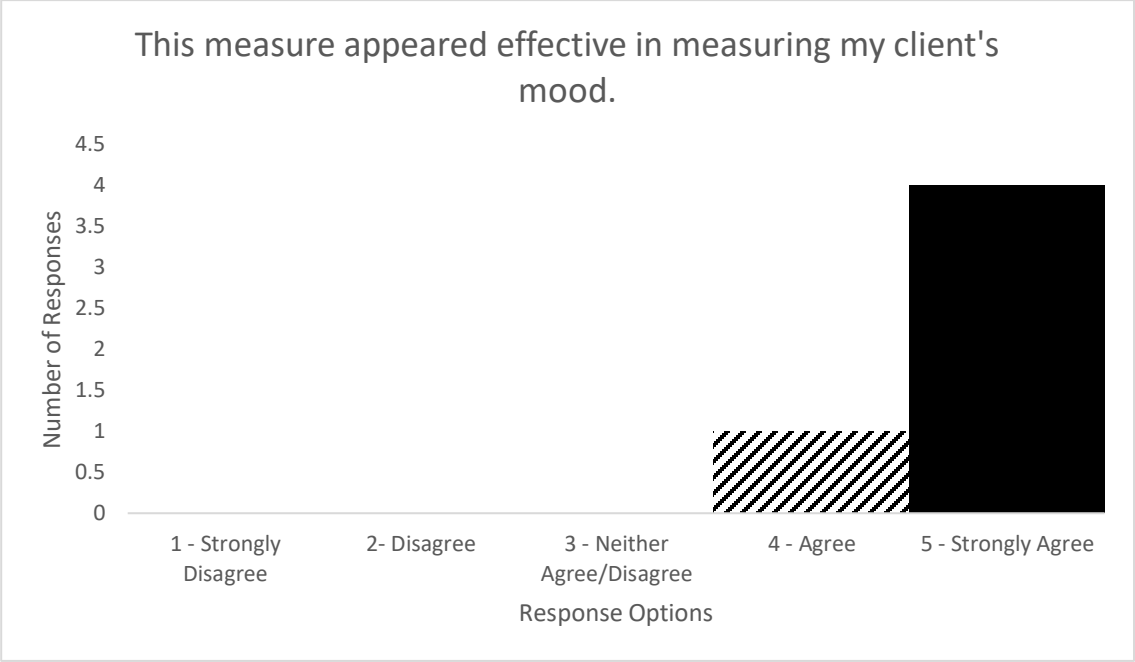

This measure was easy to administer.
Number of Responses
5
4
3
2
1
0
1 - Strongly Disagree
2- Disagree
3 - Neither Agree/Disagree
4 - Agree
5 - Strongly Agree
Response Options

Figure G.7


This measure appeared effective in measuring my client's mood.
Number of Responses
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
1 - Strongly Disagree
2- Disagree
3 - Neither Agree/Disagree
4 - Agree
5 - Strongly Agree
Response Options