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The Relationship between Restricted, Repetitive Behavior and Anxiety in Adults with Intellectual Disability

by

Casey M. Mazzola

A Thesis in

Experimental Psychology

Submitted in Partial Fulfillment of the Requirements for the Degree of
Master of Science in Experimental Psychology

December 19th, 2017

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Abstract

This study investigated the relationship between restricted, repetitive behavior (RRB) and anxiety in a sample of adults with intellectual disability (ID). Six regression analyses were conducted. Predictor variables were age, severity of autism spectrum disorder (ASD) symptoms, level of adaptive functioning, and anxiety; RRB (in general and specific subtypes) was the criterion. Together, the four predictor variables accounted for a significant proportion of the variance in total RRB, Stereotypic Behavior, Compulsive Behavior, Ritualistic/Sameness Behavior, and Restricted Interests. Self-injurious behavior (SIB) was the only subtype of RRB in which the results of the regression analysis were not significant. Anxiety was found to independently account for a significant proportion of the variance in total RRB, Compulsive Behavior, and Ritualistic/Sameness Behavior. This suggests that changes in RRB in general and in particular subtypes, specifically compulsive behavior and ritualistic/sameness behavior, may be observable indicators of anxiety in adults with ID. Overall, this study highlights the need for more research on RRB in general and on the relationship between RRB and anxiety, especially across different populations and settings.

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The Relationship between Restricted, Repetitive Behavior and Anxiety in Adults with Intellectual Disability

Intellectual disability (ID; see Appendix A for a list of abbreviations) is a developmental disorder that is characterized by deficits in both intellectual and adaptive functioning (American Psychiatric Association [APA], 2013). ID originates during the developmental period and persists throughout the lifespan (Stein, Blum, & Barbaresi, 2011). ID affects close to 1% of the general population (APA, 2013; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Approximately 40% of those with ID also have autism spectrum disorder (ASD; La Malfa, Lassi, Bertelli, Salvini, & Placidi, 2004; Matson & Shoemaker, 2009). The co-occurrence of ID and ASD (ID+ASD) is associated with poor outcomes; most people with ID+ASD will require lifelong care and support (Howlin, Goode, Hutton, & Rutter, 2004; Williamson & Perkins, 2014). Additionally, people with ID+ASD may be at a greater risk for developing psychiatric conditions, including anxiety, compared to those with ID or ASD alone (Bakken et al., 2010; Buck et al., 2014; Cervantes & Matson, 2015; La Malfa et al., 2007). Untreated psychopathology in ID is associated with greater functional impairment, a need for more support, and decreased quality of life (Alim, 2014; Allen et al., 2013; Horovitz, Shear, Mancini, & Pellerito, 2014). As such, there is a need to identify people with ID who may have an anxiety disorder, so that they can then be referred for a complete diagnostic evaluation and subsequently receive disorder-specific treatment.

Restricted, repetitive behavior (RRB) is a core symptom of ASD that is also seen in varying degrees in the ID population (Bodfish, Symons, Parker, & Lewis, 2000). Examples of RRB seen in both ID and ASD include stereotypic movements, such as body rocking and hand flapping, repetitive manipulation of objects (e.g., twirling a string), and strict adherence to

specific rituals and routines (Bodfish et al., 2000; Moss, Oliver, Arron, Burbidge, & Berg, 2009; Schopler, 1995; Turner, 1999). RRB may serve as a coping mechanism to reduce anxiety levels (Glenn, Cunningham, Nananidou, Prasher, & Glenholmes, 2015; Joosten, Bundy, & Einfeld, 2012; Uljarevic & Evans, 2016). As such, changes in RRB may be related to the presence of anxiety. This study will examine the relationship between different forms of RRB and anxiety symptoms in a sample of adults with ID, in order to evaluate the extent to which RRB may serve as an observable indicator of anxiety in this population.

Overview of ID

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), defines intellectual developmental disorder, or ID as it is commonly called, as a lifelong disorder characterized by deficits in intellectual and adaptive functioning (APA, 2013). Onset of intellectual and adaptive functioning deficits must have occurred during the developmental period (prior to 18 years of age; APA, 2013; Schalock et al., 2010). Intellectual functioning, which includes skills such as reasoning, problem solving, and academic learning, is typically assessed by intelligence tests (e.g., IQ tests) in conjunction with clinical judgment (APA, 2013; Tassé, Luckasson, & Schalock, 2016). Typically, an IQ score two or more standard deviations below the population mean of 100, or a score of about 70, and associated deficits in adaptive functioning are required for a diagnosis of ID (APA, 2013; McDermott, Durkin, Schupf, & Stein, 2007).

Adaptive functioning examines everyday behavior and refers to one's ability to attain independence in daily life tasks relative to age and cultural norms (APA, 2013; Tassé et al., 2016). Deficits in adaptive behavior can be observed across a variety of settings (e.g., school, work, home) and result in functional impairment within domains such as personal care,

communication, and community living skills, thus restricting the person's ability to live independently (APA, 2013; Matson, Rivett, Fodstad, Dempsey, & Boisjoli, 2009c). Adaptive functioning is assessed across three domains in the DSM-5: conceptual, social, and practical (APA, 2013). The conceptual domain encompasses a variety of practical academic skills, including language, applied quantitative concepts, and problem solving. The social domain assesses one's ability to interact with others, while the practical domain focuses on skills necessary for functioning in daily life (APA, 2013; Schalock & Luckasson, 2004). ID can be divided into four categories, mild, moderate, severe, and profound, based on the extent of adaptive functioning deficits (APA, 2013). People with more severe deficits in adaptive functioning require more support (APA, 2013; Tassé et al., 2016). For example, a person with mild ID may need some support with complex daily living skills, while a person with profound ID is dependent on others for all aspects of physical care, health, and safety (APA, 2013).

Prevalence. ID affects approximately 1% of the general population (Maulik et al., 2011), although rates vary across studies. Among those with ID, prevalence rates for mild, moderate, severe, and profound ID are 85%, 10%, 3-4%, and 1-2%, respectively (King, Toth, Hodapp, & Dykens, 2009). ID affects slightly more males than females. Evidence suggests that the sex ratio varies with severity of ID. Specifically, studies have found that the male to female ratio decreases from 1.6:1 in those with mild ID to 1.2:1 in those with severe ID (APA, 2013).

Etiology. ID has been linked to a variety of etiologies, including genetic conditions, infections during pregnancy, and brain malformation/injury (McDermott et al., 2007). However, in up to 50% of ID cases there is no identifiable cause (McDermott et al., 2007). Genetic conditions commonly associated with ID include Down syndrome, Fragile X syndrome, Williams syndrome, Prader-Willi syndrome, and Angelman syndrome (McDermott et al., 2007).

Distinctive cognitive and behavioral profiles are often observed in people with genetically-based ID (Walz & Benson, 2002). These include early-onset dementia in Down syndrome, food obsession in Prader-Willi syndrome, sociability in Williams syndrome, and ASD-like features in Fragile X syndrome (Jarvinen, Korenberg, & Bellugi, 2013; McDermott et al., 2007; Walz & Benson, 2002).

Co-occurring disorders. ID is associated with a high rate of co-occurring medical problems. These include epilepsy, sleep problems, and physiological conditions, such as cerebral palsy (Konst & Matson, 2015; McGrother et al., 2006; van de Wouw, Evenhuis, & Echteld, 2012). Additionally, people with ID are more at risk for developing psychiatric conditions, such as depression, psychosis, and anxiety, than the general population (Cervantes & Matson, 2015; Matson & Shoemaker, 2009). Challenging behavior, such as aggression and disruptive behaviors, are also common in ID (Oliver, Petty, Ruddick, & Bacarese-Hamilton, 2012; Rieske & Matson, 2014). People with ID may also engage in repetitive behaviors that are phenotypically similar to those seen in ASD (Bodfish et al., 2000; Oliver et al., 2012). It is estimated that up to 40% of those with ID also meet criteria for ASD (La Malfa et al., 2004). The prevalence of ASD appears to increase with severity of ID: an additional diagnosis of ASD is more likely to be made in individuals with severe ID relative to those with mild ID (Cervantes & Matson, 2015; Matson & Shoemaker, 2009). Stereotypic movement disorder is another common comorbid condition, affecting between 4 and 16% of individuals with ID (APA, 2013). This disorder is marked by the presence of stereotypies, repetitive motor movements that appear to serve no purpose and interfere with social, academic, and/or other activities of daily life (APA, 2013).

Prognosis. ID is a lifelong disorder (APA, 2013; Williamson & Perkins, 2014). Some individuals with mild impairments in intellectual and adaptive functioning can achieve

independence. However, the majority of those with ID will require continuous care and support (Woolf, Woolf, & Oakland, 2010; Williamson & Perkins, 2014). As such, caregiver burden associated with ID is high and can result in economic strain and poor mental and physical health (Williamson & Perkins, 2014). The extent to which adults with ID can function independently depends not only on their level of functioning, but also on the early identification and treatment of comorbid conditions, such as psychiatric problems (Allen et al., 2013; Bertelli et al., 2016).

There are a variety of services and supports available to adults with ID and their families. Funded by Medicaid and the states, the goal of these programs is to support adults with ID within the community, as opposed to institutions (Friedman, 2016; Williamson & Perkins, 2014). For example, group homes, run by the states or private non-profit agencies, provide housing for individuals with disabilities within a residential community setting (Woodman, Mailick, Anderson, & Esbensen, 2014). Group homes can provide a high level of support. Direct care staff provide up to 24-hour supervision and work with residents on various skills (e.g., social, daily living, self-help, etc.), in order to increase or maintain their independence (Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008). Other living arrangements for adults with ID include supported apartments, which offer a more independent setting with less staff supervision and support, and living with family (Felce et al., 2008; Williamson & Perkins, 2014).

There are also a variety of services available during daytime hours for adults with ID. These include site based group day habilitation (Day Hab), pre-vocational programs, and supported employment. Day Hab is an alternative to employment for adults with ID. Traditional Day Hab programs support a large number of people within one central location. The focus is on teaching a variety of skills (e.g., communication, self-help, behavior management) to help adults with ID increase or maintain their independence (Friedman, 2016). Community inclusion is also

a focus of Day Hab; clients, with staff support, often attend community outings and participate in volunteer opportunities within their local community (Friedman, 2016). Pre-vocational programs are another option for adults with ID, specifically for those who want a job but lack the necessary skill set. As such, pre-vocational programs are geared towards developing specific skills needed for employment in the community (Gilson, Carter, & Biggs, 2017). Many adults with ID can be a part of the workforce, with the right supports in place. Supported employment is a service that provides variable amounts of support to assist adults with ID in finding and maintaining employment in the community (Beyer, Brown, Akandi, & Rapley, 2010).

Overview of ASD

ASD is a pervasive neurodevelopmental disorder characterized by deficits in social-communication and the presence of RRB (APA, 2013). The social-communication domain encompasses a wide variety of symptoms, including abnormal body language, lack of facial expression, and difficulty initiating, responding to, and regulating social interaction (APA, 2013). RRB refers to a class of behaviors marked by repetitiveness, invariance, and rigidity. Examples include stereotypic movements (e.g., hand flapping, spinning), inflexible adherence to routines and rituals, and atypical responses to sensory aspects of the environment (APA, 2013).

ASD is typically diagnosed in early childhood and persists throughout the lifespan (Esbensen, Seltzer, Lam, & Bodfish, 2009; Seltzer, Shattuck, Abbeduto, & Greenburg, 2004). In order to receive a diagnosis of ASD, per the DSM-5, a person must display persistent social-communication deficits across multiple contexts and engage in at least two forms of RRB (APA, 2013).

ASD is heterogeneous in nature; symptom presentation and overall severity of the disorder differs from person to person and can vary within the same person across the age range

(Lecavalier, Snow, & Norris, 2011). The presentation of ASD may be moderated by co-occurring psychiatric/mental health conditions, such as anxiety or depression (Mohiuddin, Bobak, Gih, & Ghaziuddin, 2011). For example, the onset of a psychiatric disorder in people with ASD is often accompanied by increases in core ASD symptoms, such as RRB (Lainhart, 1999; Spiker, Lyn, Van Dyke, & Wood, 2012; Sukhodolsky et al., 2008). The presence (and severity) of co-occurring ID can impact ASD symptom presentation as well (Lecavalier et al., 2011).

Prevalence. ASD is currently thought to affect 1 in 68 individuals in the United States, with a rate of occurrence four times higher in males than in females (Centers for Disease Control and Prevention [CDC], 2014). There is some evidence to suggest that the sex ratio of ASD varies with intellectual level. Some studies have reported a more even sex ratio (i.e., closer to 1:1) in those with deficits in intellectual functioning (CDC, 2014; Giarelli et al., 2010). For example, Yeargin-Allsopp et al. (2003) examined the sex ratio of ASD in children with ID+ASD and found that the male-to-female ratio decreased from 4.4 in children with mild IQ deficits (IQ between 50 and 70) to 1.3 in children with profound intellectual impairment (IQ below 20).

The diagnostic rate of ASD has increased dramatically since it was first described in 1943 (Kanner, 1943; Matson & Kozlowski, 2011; Rutter, 2005). The current rate of 1 in 68 represents a rise in cases from 1 in 88 in 2008 and from 1 in 150 in 2000 (CDC, 2014). Comparatively, the first epidemiological study of ASD, conducted in England in 1966, found a diagnostic rate of only 4 in 1000 (Lotter, 1966). This increase is likely attributable to changes in the diagnostic criteria and increased recognition of the disorder, especially among those with mild symptoms and average to above average intelligence (CDC, 2016).

Etiology. There is no known single cause of ASD. It is likely that both genetics and the environment play a role (Gillberg, 2007). Research suggests that multiple genes are involved;

over 30 different genes have been linked to the development of the disorder (Gillberg, 2007). Further evidence for the role of genetics in ASD comes from twin studies, which have consistently found higher concordance rates in monozygotic compared to dizygotic twins (Hallmayer et al., 2011; Rosenberg et al., 2009). Estimates of heritability vary across studies, with concordance rates for monozygotic twins ranging from 36% to over 90% (Rosenberg et al., 2009). Environmental risk factors for ASD that have been identified include low birth weight (Lampi et al., 2012), older parental age (Durkin et al., 2008), and perinatal or prenatal brain damage (Gillberg, 2007). Prenatal exposure to teratogens, such as prescription medications, can increase the risk of ASD (Dufour-Rainfray et al., 2011). For example, taking the anti-convulsant drug Valproate during pregnancy is associated with a 4.4% increased risk of ASD (Christensen et al., 2013).

Co-occurring disorders. ASD disproportionately co-occurs with a variety of other disorders, including ID, epilepsy, gastrointestinal problems, and psychiatric conditions such as anxiety and depression (Bakken et al., 2010; Buck et al., 2014; Ibrahim, Voigt, Katusic, Weaver, & Barbaresi, 2009; Leyfer et al., 2006; Neymotin & Nemzer, 2016). ASD also occurs in the context of known genetic conditions, including Fragile X syndrome, Prader-Willi syndrome, Down syndrome, and Rett syndrome (DiGuseppi et al., 2010; Dykens, Lee, & Roof, 2011; Gillberg & Coleman, 1996). Prevalence rates for comorbid diagnoses vary across the literature (Buck et al., 2014; La Malfa et al., 2007; Mattila et al., 2010). However, the presence of an additional diagnosis has consistently been associated with poorer outcomes (Cervantes & Matson, 2015; Levy & Perry, 2011; Matson & Shoemaker, 2009).

Prognosis. The prognosis for adults with ASD varies. Long-term outcomes can range from difficulties in finding and maintaining employment to a complete inability to function

independently. Many adults with ASD live in group homes or other assisted living settings and attend specialized work programs (Gray et al., 2014; Howlin et al., 2004). Caregivers may experience financial strain, chronic stress, and poor mental and physical health (Khanna et al., 2011). As such, caregiver burden associated with ASD is high, especially when ASD symptoms are severe (Stuart & McGrew, 2009).

IQ and ASD severity are two best predictors of outcome for people with ASD. Those who do not have comorbid ID or who have only mild impairments in intellectual functioning tend to have better outcomes relative to those with more severe ID (Seltzer et al., 2004). Long term outcomes are also impacted by the severity of core ASD symptoms. Specifically, the presence of severe social-communication impairments and high rates of RRB have been associated with greater IQ deficits, increased functional impairment, and a need for more support (Levy & Perry, 2011; Mahan & Kozlowski, 2011; Troyb et al., 2016).

According to a recent meta-analysis of studies conducted between 1967 and 2013, approximately 20% of adults with ASD have good outcomes (are independent), while close to half have poor outcomes and require substantial support (Steinhausen, Jensen, & Lauritsen, 2016). The vast majority of those who are able to achieve independence have mild ASD and average to above average intelligence (Gray et al., 2014). The actual percentage of adults with ASD who have good outcomes is likely higher than what is reflected in the literature currently, as the modern population has a greater proportion of individuals with mild ASD and less with severe symptoms and/or comorbid ID (Henninger & Taylor, 2013).

Co-Occurrence of ID and ASD

ID+ASD has been associated with a wide range of impairments above and beyond those experienced by those with ID or ASD alone (Matson & Shoemaker, 2009). Specifically, ID+ASD

in adults has been associated with greater social and communication deficits (Matson, Dempsey, & LoVullo, 2009b), increased severity of RRB (Bodfish et al., 2000, Cervantes & Matson, 2015; La Malfa et al., 2004), the presence of more severe challenging behaviors (McCarthy et al., 2010), greater deficits in adaptive functioning (Matson, Dempsey, & Fodstad, 2009a; Matson et al., 2009c), and increased rates of comorbid psychiatric conditions (Bakken et al., 2010; Cervantes & Matson, 2015; La Malfa et al., 2004). As early intervention is associated with better outcomes, timely identification and treatment of co-occurring conditions, such as psychiatric problems, is imperative (Mohiuddin et al., 2011).

Restricted and Repetitive Behavior

RRB can be conceptualized as an umbrella term; it refers to a variety of behaviors (e.g., hand flapping, flicking light switches, preoccupation with a certain item or topic) that are similar in terms of their repetitive nature, rigidity, invariance, and inappropriateness to the place and context (Turner, 1999). There is debate as to whether there should be an overarching definition of RRB or if it is best viewed as a multidimensional construct consisting of a number of distinct but related categories. Additionally, there is no agreed upon terminology or classification system within the RRB literature (Honey, Rodgers, & McConachie, 2012; Leekam, Prior, & Uljarevic, 2011).

There is also no clear consensus as to what dimension of RRB best represents severity. The frequency RRB is engaged in, number of topographies or forms, intensity of the behavior, degree of interference in everyday life, and distress that results from interrupting the behavior have all been employed as definitions of severity. Although it is likely that all of these features are important, the dimension(s) which best represent severity depends on the behavior and the context in which the behavior is occurring (Honey et al., 2012). For example, the severity of

hand flapping may be best measured in terms of frequency, whereas intensity may be a better description of severity for repetitive head banging.

Conceptually-based classification of RRB. One commonly employed method of conceptualizing RRB involves breaking it down into conceptually-derived subcategories based on expert consensus. For example, in the diagnostic criteria for ASD in the DSM-5, RRB is divided into four categories: a) stereotyped and repetitive motor movements; b) insistence on sameness, inflexible routines, ritualized behavior; c) restricted, fixated interests; and d) hyper or hypo-reactivity to sensory input, unusual interests in sensory aspects of the environment (APA, 2013). However, boundaries between subcategories are not always clean cut; a certain behavior may fall into any number of categories (Leekam et al., 2011).

Stereotypies. Stereotyped and repetitive motor movements, also referred to as stereotypies or self-stimulatory behaviors, are typically described in the literature as repetitive motions that are invariant and developmentally inappropriate (Chebli, Martin, & Lanovaz, 2016; Cunningham & Schreibman, 2008; Turner, 1999). Stereotypies are often excessive in rate, frequency, and/or amplitude and may appear to lack an obvious goal or function (Turner, 1999). Stereotypies can be broken down into categories based on form. Categories include: 1) whole body stereotypies (e.g., body rocking), 2) repetitive movements of specific body parts (e.g., head nodding, hand flapping), 3) locomotion (e.g., twirling, jumping), 4) repetitive manipulation of objects (e.g., twirling a string), 5) sensory (e.g., sniffing objects, unusual interest in sensory aspects of the environment), and 6) vocal stereotypy (e.g., repeating words or phrases; Chebli et al., 2016).

Stereotypies may serve several purposes. One hypothesis suggests that these behaviors occur due to automatic reinforcement, where the behavior is maintained by the consequences it

inherently produces (see Lovaas, Newsom, & Hickman, 1987). For example, an individual may wave fingers in front of his or her face because of the visual stimulation it produces (Healy & Leader, 2011). Stereotypies can be highly reinforcing to the individual and may engage their complete attention (Charlop-Christy & Haymes, 1996). As such, an individual may engage in stereotypic behavior as opposed to pursuing more productive alternative behaviors, such as academic learning or social interaction with others (Cunningham & Schreibman, 2008; Lanovaz & Sladeczek, 2012). Stereotypies may also serve communicative functions. For example, repetitive language may be an individual's attempt to express an emotional state, such as anxiety or frustration (Gal, 2011). Stereotypies may also be related to self-regulation. Specifically, an individual may engage in stereotypic behavior to increase stimulation when under-aroused and/or to decrease stimulation when over-aroused (Leekam et al., 2011).

Although stereotypies are often associated with an ASD diagnosis, they are not unique to ASD; people with ID demonstrate high rates of stereotypic behavior as well. Up to 60% of adults with ID engage in at least one form of stereotypy (Bodfish, et al., 1995; Bodfish et al., 2000; Chebli et al., 2016). When stereotypies interfere with an individual's ability to function in daily life, an additional diagnosis of stereotypic movement disorder may be made (APA, 2013). Stereotypies seen in stereotypic movement disorder are topographically similar to those seen in ASD and include both non-self-injurious and self-injurious behaviors (APA, 2013; Schopler, 1995). Examples include body rocking, self-biting, hand flapping, and waving fingers in front of the face (APA, 2013). A co-occurring diagnosis of stereotypic movement disorder can be made in those with ASD if the stereotypies are severe enough to be a focus of treatment or if they result in injury (APA, 2013).

Self-injurious behavior. Repetitive self-injurious behavior (SIB) refers to any number of

behaviors that are performed in a repetitive and rhythmic manner where an individual causes damage to their body (Matson et al., 1997a). Topographies of SIB included under the diagnostic criteria for stereotypic movement disorder include head banging, self-biting, and hitting one's own body. SIB can result in significant physical injury (Minshawi et al., 2014) and has been associated with psychopathology in both ID and ASD (Marston, Perry, & Roy, 1997; Turygin, Matson, MacMillan, & Konst, 2013). There is debate as to whether SIB should be considered a form of RRB or as another subcategory of challenging behavior, along with aggressive/destructive behavior and noncompliance (Matson & Nebel-Schwalm, 2007; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). As such, SIB is excluded in some definitions of RRB, such as in the DSM-5 definition of RRB in ASD (APA, 2013; Leekam et al., 2007; Lewis & Bodfish, 1998).

Compulsions and ritualistic/sameness behavior. The insistence on sameness, inflexible routines, and ritualistic behavior category can be further broken down into compulsive and ritualistic/sameness behaviors (Lam & Aman, 2007). Compulsions are repetitive behaviors similar to those seen in obsessive-compulsive disorder (OCD). These behaviors are repeated according to some "rule" and often involve things being done "just so" (Bodfish et al., 2000). Compulsive behaviors seen in ID include hoarding, need for completeness (e.g., doors must be open or closed), arranging/ordering, repeating routine events, checking, counting, and cleaning (Bodfish et al., 2000). Prior research suggests that up to 40% of adults with ID display compulsive behaviors (Bodfish et al., 1995). Rate and presentation of compulsions may be related to the etiology of ID. Certain genetic syndromes and neurodevelopmental conditions have been associated with high levels and/or specific topographies of compulsive behaviors (Matson & Dempsey, 2009). For example, a high rate of obsessive-compulsive behavior is characteristic

for individuals with Prader-Willi syndrome. Examples of OCD-like behavior seen in Prader-Willi syndrome include food obsessions and related compulsive eating, as well as hoarding, ordering, arranging, and skin picking (Wigren & Hansen, 2003). Down syndrome has been associated with a particular form of obsessive-compulsive behavior: obsessional slowness. Obsessional slowness involves performing everyday activities, such as eating and dressing, in an extremely slow manner (Charlot, Fox, & Friedlander, 2002). Compulsions are also a prominent feature of ASD. Autism-related obsessive-compulsive behavior differs from that seen in OCD (Neil & Sturmey, 2014). OCD is most often times characterized by the presence of obsessions and associated compulsions. Obsessions are intrusive thoughts, impulses, or images that cause distress and anxiety. People with OCD perform compulsions (specific repetitive behaviors) to reduce the anxiety caused by their obsessions (Lewin, Wood, Gunderson, Murphy, & Storch, 2011). Autism-related obsessive-compulsive behavior is topographically similar to that seen in OCD. However, research suggests that individuals with ASD may not experience the distress related to the performance of compulsive behaviors that is characteristic of OCD (Neil & Sturmey, 2014).

Ritualistic/sameness behavior encompasses resistance to change, performance of rituals/routines, and an insistence on sameness (Bodfish et al., 2000). Examples include eating/drinking items in a set order, insisting on taking particular routes/paths, and difficulty with transitions. Interruption of ritualistic/sameness behavior can result in distress, anxiety, and challenging behavior, such as temper outbursts and aggression (Bull, Oliver, & Woodcock, 2017). Relative to typically developing children, higher levels of ritualistic/sameness behavior have been found in a variety of developmental disabilities, including ASD, Prader-Willi syndrome, Fragile X syndrome, and Down syndrome (Moss et al., 2009; Uljarevic & Evans,

2016; Wigren & Hansen, 2003). Children with ASD show a higher level of ritualistic/sameness behavior compared to children with Down syndrome (Uljarevic & Evans, 2016), while ritualistic/sameness behavior in Prader-Willi syndrome appears to occur at a rate similar to that seen in ASD (Greaves, Prince, Evans, & Charman, 2006). Ritualistic/sameness behavior may be related to deficits in behavioral flexibility, the ability to adjust behavior in relation to changes in the environment. Studies using the Behavior Flexibility Rating Scale (Green et al., 2006), a measure which assesses distress associated with particular situations involving change in routine, have found that insistence on sameness/behavioral inflexibility is present in ASD, Down syndrome, and ID. However, ASD is associated with the highest rates of behavioral inflexibility (Green et al., 2006; Peters-Scheffer, Didden, Sigafos, Green, & Korzilius, 2013).

Restricted behavior. Restricted, fixated interests fall under the category of restricted behavior. Restricted behaviors are defined by a limited range of focus, interest, or activity (Bodfish et al., 2000). Restricted behavior may manifest as an intense preoccupation with a specific topic, or as an unusually strong attachment to certain objects (Lam, Bodfish, & Piven, 2008). Restricted behaviors, including restricted interests, are observed in people with ASD alone and in those with co-occurring ID (Lam et al., 2008). Restricted interests can be age appropriate or may be unusual in focus (Leekam et al., 2011). Examples include insects, the weather, serial numbers on electric fans, washing machines, and Japanese cartoons (Mercier, Mottron, & Belleville, 2000; Schopler, 1995; Spiker et al., 2012). These interests tend to be pursued to the exclusion of more appropriate behaviors, which may impact academic or vocational success (Attwood, 2003). In those with adequate verbal skills, the interest may be talked about for extended periods of time, with little conversational reciprocity (back and forth conversation). However, restricted interests can have positive effects, especially in people with

ASD sans ID. For example, incorporating restricted interests into learning activities can improve an individual's performance in school (Mancil & Pearl, 2008). Additionally, restricted interests can lead to a rewarding career, such as for Temple Grandin, who turned her interest in cows into a successful career as an animal science professor and researcher (see Grandin & Scariano, 1986). Restricted behavior is not specific to ASD. For example, attachment to objects is a part of the behavioral phenotype of Cri-du-Chat syndrome, a genetic condition associated with ID (Moss et al., 2009).

Sensory abnormalities. Hyper or hypo-reactivity to sensory input and unusual interests in sensory aspects of the environment are thought to reflect abnormalities in sensory processing. Examples include preoccupation with visual aspects of the environment, such as lights or spinning objects, adverse reactions to specific sounds or textures, and excessive smelling or touching of objects (APA, 2013). Sensory abnormalities can occur in all senses and present a variety of challenges to the individual and those around them. For example, a person may seek out items (e.g., colored lights), avoid particular things (e.g., cotton clothing), or have no reaction when coming in contact with potentially noxious stimuli (e.g., hot water). As such, environmental modification is necessary to help individuals with sensory processing abnormalities cope with daily life (Klintwall et al., 2011). Inclusion of sensory behaviors as a category of RRB within the diagnostic criteria for ASD is a change from previous versions of the DSM (Grzadzinski, Huerta, & Lord, 2013). The decision to add this category to the DSM-5 criteria for ASD was based on clinical consensus in conjunction with recent research findings (Grzadzinski et al., 2013; Mandy, Charman, & Skuse, 2011; Volkmar & Reichow, 2013). Atypical sensory responses are seen in other developmental disabilities as well, including ID. In a sample of children between the ages of 10 and 14 years receiving special education services,

92% of those with ASD were found to exhibit atypical sensory behavior (hypo or hyper-reactivity to sensory input, unusual sensory interests) compared to 67% of children with non-ASD disabilities, including ID (Green, Chandler, Charman, Simonoff, & Baird, 2016).

Higher and lower order RRB. There are alternative models of RRB that predate the DSM-5. For example, Turner (1999) divided RRB into two conceptually-derived categories, higher order and lower order, based on the cognitive level required to perform the behavior. Higher order behaviors are characterized by an adherence to a rule or mental set and require more cognitive ability than lower order behaviors. Examples include repetitive speech, insistence on sameness, and restricted interests. Lower order behaviors, which require less cognitive ability, refer to repetitive motor movements, such as motor and sensory stereotypies, and SIB. It was initially hypothesized that higher order behaviors would be specific to people with at least average intelligence and that lower order behaviors would be predominately seen in people with ID and children (Turner, 1999). However, higher order and lower order behaviors do not appear to be related to intellectual level, as higher order behaviors are seen in people with ID and vice-versa (South, Ozonoff, & McMahon, 2005; Turner, 1999). Despite this, the higher and lower order dichotomy is commonly used in the RRB literature (Leekam et al., 2011).

Empirically-based classification of RRB. Empirically-based classification of RRB has been attempted through factor analysis and has had inconsistent results, with RRB typically breaking down into two, three, or five factors. This is likely due to differences in sample characteristics, such as age and developmental level, methodological procedures (e.g., sample ascertainment), and the use of different measures of RRB (Scahill et al., 2015). Most factor analyses have been conducted with toddlers, preschoolers, and/or school age children with ASD (Leekam et al., 2011). A few studies included children with non-ASD developmental disabilities,

including ID, in their sample (Mooney, Gray, Tonge, Sweeney, & Taffy, 2009; Richler, Bishop, Kleinke, & Lord, 2007).

A two-factor model was derived from a variety of factor analyses of the Autism Diagnostic Interview- Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003b). These studies found RRB to consist of two factors, repetitive sensory-motor behaviors and insistence on sameness, which seemingly correspond with the proposed higher order and lower order classification system (Bishop et al., 2013; Cuccaro et al., 2003; Mooney et al., 2009; Richler et al., 2007). For example, Richler et al. (2007) examined the factor structure of the ADI-R in young children (under age 3) using confirmatory factor analysis. A two-factor model, consisting of repetitive sensory-motor behaviors and insistence on sameness, was supported across three groups- children with ASD, children with non-specific developmental disabilities (including ID), and typically developing children. Mooney et al. (2009) also examined the factor structure of the ADI-R and found two factors corresponding to lower order and higher order behavior in a sample of children between two and four years of age with developmental disabilities, including ASD. These two factors were found when conducting exploratory factor analysis for 1) the entire sample, 2) only those with ASD, and 3) those with non-ASD developmental disabilities. However, some studies using the ADI-R in samples of children with ASD sans ID have reported a third factor related to circumscribed/restricted interests (Honey, McConachie, Randle, Shearer, & Le Couteur, 2008; Lam et al., 2008).

A five-factor model was derived from the Repetitive Behavior Scale-Revised (RBS-R; Bodfish et al., 2000), a conceptually-based instrument designed to assess RRB in ASD. Lam and Aman (2007) conducted an exploratory factor analysis using the RBS-R in a sample of children and adults with ASD between the ages of 3 and 48 and found five factors: stereotypic behavior,

SIB, compulsive behavior, ritualistic/sameness behavior, and restricted interests. Although some people in the sample had ID+ASD, there has yet to be a factor analytic study of the RBS-R in a sample of people with ID only.

Correlates of RRB. Although some RRBs can have positive effects, such as in cases where individuals with mild ASD have restricted interests related to career choice (e.g., college professor), excessive RRB is associated with a variety of problems in both ID and ASD (Honey et al., 2012; Oliver et al., 2012). For example, when compared to individuals with lower levels of RRB, those who display more severe RRB tend to demonstrate greater deficits in adaptive and cognitive functioning (Goldman et al., 2009; Troyb et al., 2016). Additionally, increased severity of RRB in both ID and ASD is associated with an increased likelihood of displaying challenging behaviors, such as aggression and self-injury (Duerden et al., 2012; Oliver et al., 2012).

Impact of RRB. RRB has a large impact on quality of life. RRB can be stigmatizing and often interferes with the acquisition of skills (Honey et al., 2012). Attempts to interrupt RRB often result in distress and anxiety for the individual and can lead to agitation, aggression, and other disruptive behaviors (Healy & Leader, 2011; Reese, Richman, Belmont, & Morse, 2005). Despite the impact of RRB, there is a relative lack of research on RRB in both ID and ASD (Honey et al., 2012; Woods, 2002).

RRB in ASD and other populations. RRB is not unique to ASD, as it is seen in both typically developing individuals and a variety of other atypical populations. Stereotypic motor movements, such as head nodding, arm flapping, finger wiggling, and body rocking, have been reported in multiple studies of typically developing infants and young children (Leekam et al., 2007). These repetitive movements, which may be important for muscular, neural, and cognitive development, tend to decrease by age four (Evans et al., 1997; Thelen, 1979). Studies have found

that children with ASD sans ID show higher rates of RRB relative to typically developing children of the same age (South et al., 2005). Additionally, RRB occurs across a larger number of topographies, or forms, in ASD relative to other populations. For example, in addition to having a restricted interest, an individual with ASD may also engage in stereotypic motor movements and perform complex rituals. Although no stereotypies are specific to ASD, some, such as body rocking, arm/hand flapping, and waving fingers in front of the face, are more prevalent in ASD than in other disorders (Schopler, 1995).

Research suggests that it is the severity, frequency, and duration of RRBs rather than their form or pattern that best distinguishes RRB in ASD from RRB in other groups (Esbensen et al., 2009; Freeman et al., 1981; Leekam et al., 2011; Lord, 1995). When compared to people with ID alone, findings suggest that those with ID+ASD display more severe RRB (Bodfish et al., 2000; Matson & Dempsey, 2008). For example, Bodfish et al. (2000) examined RRB in adults with ID+ASD and ID alone. The Repetitive Behavior Scale (Bodfish, Symons, & Lewis, 1999), an informant based measure examining SIB, stereotypy, and compulsions, was utilized in this study to assess the frequency and number of topographies of RRB. The Behavior Problems Inventory (BPI; Rojahn, 1986) was used to measure the severity of stereotypy and self-injury, while the Mental Retardation-Obsessive Compulsive Disorder Scale (MR-OCD; Vitiello, Spreat, & Behar, 1989) was used to measure the severity of compulsions. The study found that although both groups engaged in all three forms of RRB at a high level, there was an elevated pattern of occurrence for all topographies in the ID+ASD group. Additionally, based on BPI and MR-OCD scores, RRBs were more severe in the ID+ASD group.

Factors affecting the presentation of RRB. The presentation of RRB in ID may be affected by age, although studies with different populations and age ranges have had conflicting

results. For example, Esbensen et al. (2009) examined RRBs in children and adults (ages 2 to 62) with ASD using the RBS-R. RRB (total amount and specific subtypes) was found to decrease with increasing age for those with comorbid ID. However, a study of just adults with ID+ASD did not find a significant relationship between RRB and age (Hattier, Matson, Tureck, & Horovitz, 2011). Cochran, Moss, Nelson, and Oliver (2015) examined changes in ASD symptoms over two and a half years in children and adults with Fragile X syndrome and found a significant decrease in RRB over time. On the other hand, Dykens and Roof (2008) did not find a significant relationship between compulsive behavior, as measured by the Yale-Brown Obsessive Compulsive Scale (Goodman et al., 1989), and age in a sample of children and adults with Prader-Willi syndrome. Differences in sample characteristics (e.g., diagnoses, level of ID, age range) may account for the disparate conclusions. As such, age should not be discounted as a potential variable that may affect the presentation of RRB in adults with ID.

Gender is another variable which may affect the presentation of RRB in ID and ASD. The research on gender differences and RRB in adults with ID is limited. Research on adults with ASD alone have found higher rates of RRB in males compared to females (Lai et al., 2011; Wilson et al., 2016). Additionally, Hattier and colleagues (2011) examined RRB in adults with ID+ASD and found that males exhibited higher rates of RRB than females, as assessed by the Stereotypic Behavior subscale on the Diagnostic Assessment for the Severely Handicapped, Revised (DASH-II; Matson, 1995). However, the DASH-II does not capture all subtypes of RRB, such as SIB, and the effects of potential confounds, such as severity of ASD symptoms and IQ, were not addressed in the study (Cervantes & Matson, 2015; Hattier et al., 2011). Multiple studies of persons with ID only have failed to find a relationship between gender and SIB (Holden & Gitlesen, 2006; Lowe et al., 2007; McClintock, Hall, & Oliver, 2003). Additionally,

Glenn et al. (2015) assessed the severity of compulsive and routinized behavior in children and adults with Down syndrome and did not find a significant effect of gender. Felce and Kerr (2013) also did not find a relationship between gender and the presence of ASD symptoms, including RRB, in a sample of 818 adults with ID. Overall, it appears that gender differences in RRB may be more ASD-specific and not necessarily relevant to the ID population as a whole.

Severity of ASD symptoms may also affect the presentation of RRB in ID. Specifically, RRB appears to increase in severity when ASD is present. Research has found that people with ID+ASD demonstrate higher frequencies of RRB relative to those with ID alone (Bodfish et al., 2000). Lower-level RRB in particular may be associated with severity of ASD symptoms. For example, Powell, Pringle, and Greig (2017) found that severity of motor stereotypy was positively associated with the severity of ASD symptoms in children with ID. Richards, Oliver, Nelson, and Moss (2012) found that SIB was related to higher levels of ASD symptoms in children and adults with Fragile X syndrome and Down syndrome. Additionally, Richler et al. (2007) found that repetitive sensory motor behavior was positively related to severity of social-communication impairments in children with non-ASD developmental disabilities (including ID).

Level of adaptive functioning may also impact the presentation of RRB in ID. For example, Oliver et al. (2012) found that severe deficits in adaptive functioning were associated with the presence of SIB in children with ID+ASD and in those with ID alone. Additionally, Evans, Kleinpeter, Slane, & Boomer (2014) found a negative association between high levels of RRB and adaptive functioning in children with Down syndrome.

Etiology of RRB. Various theories have been proposed as to the etiology of RRB. Neuroscience research points to the role of the basal ganglia, a group of forebrain structures

implicated in motor control, cognition, and motivation, in the pathophysiology of stereotypic behavior (Leekam et al., 2011; Lewis & Kim, 2009; Turner & Pasquereau, 2014; Wichmann & DeLong, 2015). For example, studies have found that injecting dopamine or dopamine agonists into the corpus striatum, a part of the basal ganglia, increases stereotypic behavior in rats (Leekam et al., 2011; Lewis & Kim, 2009). Additionally, dopamine D2 receptor antagonists, such as haloperidol and risperidone, have shown to be successful in treating tics and stereotypic behavior in humans (Anderson et al., 1984; McDougle et al., 2005).

Lower and higher order RRB may stem from deficits in executive functioning (Leekam et al., 2011). Turner (1999) proposed the executive dysfunction hypothesis of RRB, which postulates that RRB may arise from either an inability to inhibit ongoing behavior or an inability to generate novel behavior. Executive functioning refers to a group of higher-level cognitive functions, including inhibition, working memory, cognitive flexibility, and planning, that are mediated by the frontal lobes (Otero & Barker, 2014). Deficits in executive functioning include impaired generation of goal directed behavior, lack of flexibility, and perseveration (Leekam et al., 2011). There have been studies that have found a positive correlation between executive functioning deficits and RRB in children and adults with ASD sans ID (Miller, Ragozzino, Cook, Sweeney, & Mosconi, 2015) and in children with genetically-based ID, specifically Prader-Willi syndrome and Fragile X syndrome (Woodcock, Oliver, & Humphreys, 2009), but overall, evidence for the theory is mixed (Prior & Ozonoff, 2007). However, differences in the measurement of executive functioning may account for some of the disparate conclusions (Otero & Barker, 2014).

RRB has also been explained as an operant behavior. Stereotyped behaviors often provide perceptual, auditory, or tactile stimulation (Turner, 1999). As such, it may be that lower level

RRB is maintained by its sensory consequences (Lovaas et al., 1987). Evidence for this theory stems from research into the behavioral treatment of RRB. Specifically, providing equivalent but alternative sensory stimulation has been shown to reduce levels of RRB (Turner, 1999).

However, for many stereotypic actions, it is not clear what the reinforcing sensory consequences might be (Turner, 1999). RRB may serve other functions as well, such as to elicit attention from others or to escape aversive situations (Boyd, McDonough, & Bodfish, 2012).

Both lower and higher order RRB may be related to arousal and anxiety. RRB may be a means to communicate/express feelings of anxiety (Gal, 2011). On the other hand, RRB may serve as an anxiety-reduction mechanism or coping strategy that allows individuals with ID and/or ASD to regulate high levels of arousal (Joosten, Bundy, & Einfeld, 2009). Highly arousing situations, such as change or novel environments, often result in tension, stress and anxiety in those with ID (Bull et al., 2017; Furniss & Biswas, 2012) and ASD (Leekam et al., 2011). As such, the individual may engage in RRB in these situations to reduce anxiety. According to this hypothesis, an increase in anxiety should be accompanied by an increase in RRB. Higher levels of anxiety have been shown to be associated with higher levels of RRB, particularly insistence on sameness behaviors, in children with ASD (Stratis & Lecavalier, 2013), Down syndrome (Uljarevic & Evans, 2016), and Fragile X syndrome (Oakes et al., 2016). Further evidence for the relationship between RRB and anxiety comes from research into the motivation of RRB. For example, Joosten et al. (2012) assessed the motivation for RRB in children between the ages of 5 and 17 years with ID across three different contexts, free time, transitions, and work. Transition elicited high levels of RRB and was found to be motivated by anxiety reduction and escape for those with ID+ASD and for those with ID alone. This fits in line with the idea that transitions cause stress, and therefore RRB increases during this time in

response to the individuals' increased anxiety levels. It may also be that inhibition and the ability to engage in novel behavior is reduced during times of increased arousal and stress; the extra stimulation may "overload" an already deficient executive system.

Anxiety in ID and ASD

Psychiatric conditions commonly co-occur with ID (Bakken et al., 2010; Cervantes & Matson, 2015; La Malfa et al., 2007; Pruijssers, Meijel, Maaskant, Nijssen, & Achterberg, 2014). Research suggests that anxiety disorders may occur at a higher rate in children and adults with ID than in the general population (Deb, Thomas, & Bright, 2001; Emerson, 2003). Some studies suggest that over 20% of adults with ID may have an anxiety disorder (Deb et al., 2001; Holden & Gitlesen, 2003; Reid, Smiley, & Cooper, 2011; Tsiouris, Kim, Brown, & Cohen, 2011). However, rates of anxiety in ID reported in the literature vary considerably (Prujssers et al., 2014). Variables such as age (Bailey, 2007), severity of ID (Reid et al., 2011), etiology of ID (Prujssers et al., 2014), and the presence/severity of ASD symptoms (Bakken et al., 2010; La Malfa et al., 2007) affect the rate of occurrence.

Anxiety appears to be more prevalent in persons with ID+ASD relative to those with ID alone (Bakken et al., 2010; Cervantes & Matson, 2015; La Malfa et al., 2007). For example, Bakken and colleagues (2010) compared the rates of psychopathology in adolescents and adults with ID+ASD to those with ID only. Of the classes of disorders screened for, anxiety (in general) exhibited the biggest discrepancy in rates, with 33.9% of those with ID+ASD displaying symptoms compared to only 9.1% of the ID only group. This suggests that, in those with ID, the additional presence of ASD may represent a vulnerability for developing an anxiety disorder.

Anxiety disorders feature excessive fear and worry. There are twelve different anxiety disorders included in the DSM-5, which differ according to the focus of anxiety-provoking

thoughts and in regards to the situations that trigger the anxiety. Examples include generalized anxiety disorder, panic disorder, and specific phobias (APA, 2013). Anxiety disorders occur in approximately 18% of adults in the general population (Kessler, Chiu, Demler, Merikangas, & Walters, 2005), as assessed by the text revised fourth edition of the DSM (DSM- IV-TR; APA, 2000). Studies assessing the prevalence of anxiety disorders using DSM-5 criteria have not yet been published. Symptoms of anxiety can be divided into cognitive, somatic, and behavioral domains. Cognitive/affective symptoms refer to feelings of apprehension and worry that are central to the disorder. Examples include frequent worrying, intrusive thoughts about anxiety-provoking situations, and an inability to tolerate uncertainty (Hassiotis, Stueber, Thomas, & Charlot, 2014). Somatic, or physical, symptoms are signs of physiological arousal, such as hyperventilation, sweating, shivering, and muscle aches or tightness (Hassiotis et al., 2014). Behavioral symptoms that often accompany anxiety include difficulty focusing and avoidance of certain situations (Hassiotis et al., 2014).

Diagnostic challenges. Communication difficulties complicate the diagnosis of anxiety in those with ID. Self-report is often impaired in persons with ID and clinicians often have to rely on observation and third-party informant reports to assess symptoms (Adams & Oliver, 2011; Helverschou & Martinsen, 2011; Smiley, 2005). Since identification of internal symptoms (e.g., anxious thinking, frequent worrying) is difficult in this population, the use of modified criteria that focuses on observable symptoms may be attempted. For example, the Diagnostic Manual-Intellectual Disability (DM-ID; Fletcher, Loschen, Stavrakaki, & First, 2007) utilizes amended criteria that focuses on the physiological and behavioral manifestations of psychiatric conditions (Hassiotis et al., 2014). The use of modified criteria is also related to the growing evidence that the symptom profiles of persons with ID is atypical compared to the general

population (Hemmings, Gravestock, Pickard, & Bouras, 2006; Smiley, 2005) and may not map neatly onto existing DSM-5 criteria. Atypical symptoms seen in this population are often non-specific to disorders such as anxiety and can include SIB, irritability, aggression, bizarre movements, and other challenging behaviors (Hemmings et al., 2006; Rieske & Matson, 2014). There is mixed evidence regarding the use of such “behavioral equivalents” of psychiatric symptoms for diagnostic purposes. Some studies have found associations between challenging behaviors and psychiatric conditions, such as between aggression and depression (Charlot, Doucette, & Mezzacappa, 1993; Hurley, 2008; Meins, 1995). However, there is insufficient empirical evidence to support the claim that behavioral equivalents can be used reliably and validly for diagnostic purposes (Hemmings et al., 2006; McCarthy et al., 2010; Rieske & Matson, 2014). Behavioral equivalents may be more useful as nonspecific indicators of psychopathology in general (Rieske & Matson, 2014).

In those with ID+ASD, differential diagnosis is especially challenging. People with ASD may display emotions in odd or atypical ways. For example, an adult with ASD may make a strange grimace when anxious, one that caregivers may not interpret as a “worried look” (Helverschou & Martinsen, 2011). Additionally, ASD is associated with deficits in abstract communication; adults with ASD may struggle with describing concepts such as anxiety (Helverschou, Bakken, & Martinsen, 2011). Apparent symptom overlap between ASD and anxiety can make it difficult for clinicians to determine whether a particular problem represents ASD, anxiety, or both (Kerns & Kendall, 2014). For example, behavioral avoidance, poor eye contact, and difficulty dealing with uncertainty or change can be observed in people with ASD who have a comorbid anxiety disorder and in those with ASD without a co-occurring anxiety disorder. Additionally, ASD symptoms tend to increase in rate when comorbid psychopathology

is present (Lainhart, 1999; Sukhodolsky et al., 2008): an anxiety disorder may be overlooked and wrongly attributed to the ASD. The tendency to attribute psychiatric symptoms to a more salient disability, such as ASD, is referred to as diagnostic overshadowing (Reiss, Levitan, & Syzsko, 1982). It is difficult to estimate how often diagnostic overshadowing occurs, but when it does happen, timely disorder-specific treatment is unlikely to occur.

RRB and Anxiety

Change in the baseline rate of core ASD symptoms has been associated with the presence of anxiety in individuals with ASD (Sukhodolsky et al., 2008). In ID, deviation from baseline functioning has been associated with the presence of various psychiatric conditions, including anxiety (Alim, Paschos, & Hearn, 2014). Although people with mild ID may be able to report on some of the subjective symptoms of anxiety, it is often necessary to rely on observable indicators of psychopathology, especially for those with moderate to profound ID (Glenn, Bihm, & Lammers, 2003; Holden & Gitlesen, 2003). Recent research suggests that there may be a relationship between anxiety symptoms and RRB (Joosten et al., 2012; Oakes et al., 2016; Stratis & Lecavalier, 2013; Sukhodolsky et al., 2008; Uljarevic & Evans, 2016). If anxiety is related to RRB, then changes in RRB may be an observable indicator to third parties that an anxiety disorder may be present.

Assessment of anxiety in ID is difficult, especially in those with ID+ASD. In many cases individuals with ID are not properly diagnosed with comorbid psychopathology and as a result do not receive adequate treatment. Early detection and subsequent intervention is key, as timely treatment is associated with better outcomes (Mohiuddin et al., 2011). There is a need for a method in which to identify those individuals who might have an undiagnosed anxiety disorder, so that they can then be referred for a complete diagnostic assessment. If anxiety is related to

RRB, then changes in RRB could serve as a “red flag” that an individual needs further evaluation.

Treatment of RRB and anxiety. Treatment of RRB involves reducing levels or changing the topography of RRB in order to minimize functional impairment, as opposed to curing or completely eliminating the behaviors (Leekam et al., 2011; Turner, 1999). RRB is typically treated either pharmacologically or behaviorally. Atypical antipsychotics (dopamine receptor agonists), such as Risperdal, and selective serotonin reuptake inhibitors (SSRIs), such as Zoloft, are typically prescribed to treat RRB. However, medications appear to be more effective in reducing behavioral problems associated with ID such as aggression, self-injury, and irritability, than in improving RRB symptoms (see Leekam et al., 2011). Applied behavior analysis, which involves identifying the functions of behaviors and making changes to the environmental variables that predict problem behavior in order to bring about behavior change, is also commonly used to treat RRB in in both ID and ASD (Boyd et al., 2012). Behavioral treatments that have shown to be effective in reducing RRB include differential reinforcement of alternative behavior (reinforcing a behavior that is distinct from the RRB but serves the same function), extinction procedures (withholding reinforcement for the problematic behavior), and response interruption and redirection (interrupting the problem behavior and redirecting the individual to a more appropriate behavior; Boyd et al., 2012). A combination of medication and behavioral treatment is generally viewed as the most effective method for reducing RRB (Leekam et al., 2011).

Typical treatment for anxiety consists of medication and/or cognitive-behavioral therapy (CBT). SSRIs (e.g., Prozac, Zoloft) and benzodiazepines (e.g., Xanax, Ativan) are commonly prescribed to treat anxiety in both the general population and in people with ID and ASD

(Antochi, Stavrakaki, & Emery, 2003; Mohiuddin et al., 2011). SSRIs have shown to be effective in reducing anxiety symptoms in adults with ID+ASD (Davis, Saeed, & Antonacci, 2008). Additionally, studies have demonstrated a reduction in both anxiety symptoms and RRB with SSRI treatment, thus providing further evidence for the link between anxiety and RRB (Davis et al., 2008). Benzodiazepines have not received as much attention in the literature, but some studies caution against their use in people with ID and ASD due to potential adverse effects such as increases in aggression and agitation (Antochi et al., 2003). CBT is an evidence-based treatment for anxiety that centers on the interaction between thoughts, emotion, and behavior (Corey, 2012). Specific techniques employed in CBT include relaxation strategies (e.g., counting to ten, taking deep breaths), cognitive restructuring (changing maladaptive thought patterns), and systematic desensitization (practicing calming techniques in the presence of progressively more anxiety-provoking stimuli; Corey, 2012). CBT has shown to be effective in reducing anxiety symptoms in typically developing people and in those with ASD sans ID (Hoffman & Smits, 2008; Lang, Regeister, Lauderdale, Ashbaugh, & Haring, 2010). However, many people with ID struggle with identifying internal emotions, have difficulties with self-report, and lack adequate verbal skills, making it difficult for them to participate in traditional CBT. As such, specific adaptations are needed for people with ID. Although it is difficult to adjust CBT methods to fit this population, some studies have reported success in using a modified form of CBT (e.g., slower paced, simpler questions, incorporating pictures, etc.) to reduce anxiety in adults with ID+ASD (Hassiotis et al., 2011; Unwin, Tsimopoulou, Kroese, & Azmi, 2016).

Empirical research. A handful of studies to date have examined the potential relationship between anxiety and RRB. For example, Sukhodolsky et al. (2008) examined the association between parent-rated anxiety symptoms and core ASD symptoms, including RRB, in

a sample of children between the ages of 5 and 17 years with ID+ASD. Adaptive functioning was assessed using the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) and IQ was measured using traditional tests of intelligence, such as the Wechsler Intelligence Scale for Children, Third Edition (WISC-III; Wechsler, 1991). The parent version of the Child and Adolescent Symptom Inventory (CASI; Sprafkin, Gadow, Salisbury, Schneider, & Loney, 2002) was used to assess anxiety, while the ADI-R and the Aberrant Behavior Checklist (ABC; Aman, Singh, Stewart, & Field, 1985) were used to assess ASD symptoms. Anxiety was significantly related to the ABC Stereotypic Behavior subscale ($r = .26, p < .01$), ADI-R Stereotyped Behavior scale ($r = .30, p < .01$), and VABS Communication ($r = 0.19, p < .01$), Daily Living Skills ($r = 0.20, p < .01$), and Socialization ($r = 0.20, p < .01$) subscales. Anxiety was not significantly related to social-communication as measured by the ADI-R. These results suggest that RRB and adaptive functioning is related to anxiety levels in children with ID+ASD.

Stratis and Lecavalier (2013) examined the relationship between RRB and anxiety in a sample of school-aged children with ASD, in which 36% had comorbid ID. The RBS-R was used to measure repetitive behavior. A total RRB score was produced, in addition to five subscale scores: Stereotyped Behavior, SIB, Compulsive Behavior, Ritualistic/Sameness Behavior, and Restricted Interests (Lam & Aman, 2007). The Adaptive Behavior Assessment Scale, Second Edition (ABAS-II; Harrison & Oakland, 2003) was used to assess adaptive functioning, while the Anxiety subscale of the Child Symptom Inventory, Fourth Edition (CSI-4; Gadow & Sprafkin, 2002) was used to assess anxiety symptom severity. Correlations between anxiety and RBS-R total score ($r = .558, p < .05$) and all five subscale scores were significant (Stereotypic Behavior: $r = .340, p < .05$; SIB: $r = .418, p < .05$; Compulsive Behavior: $r = .481, p < .05$; Ritualistic/Sameness Behavior: $r = .594, p < .05$; Restricted Interests: $r = .302, p < .05$).

Hierarchical multiple regression analyses were conducted to further investigate the relationship between RRB and anxiety, while also considering level of functioning as a moderator. Level of functioning (ABAS-II conceptual domain score) did not moderate the relationship between anxiety and any of the RBS-R subscale scores and was not a significant predictor of CSI-4 Anxiety score. The only significant finding pertaining to repetitive behaviors obtained from the regression analyses was for the Ritualistic/Sameness Behavior subscale, which was found to independently account for a significant proportion of the variance in anxiety ($sr^2 = .379$).

Studies in samples of genetically-based ID have also found relationships between RRB and anxiety. For example, Uljarevic and Evans (2016) examined the relationship between higher order RRBs (compulsions, rituals/routines, sameness behavior) and fear in children with ASD (sans ID), Down syndrome, and typically developing controls. The Fear Inventory (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005) was used to assess the severity of fear/anxiety symptoms. The Childhood Routines Inventory (CRI; Evans et al., 1997) measured the frequency and intensity of rigidity/insistence on sameness behaviors across three subscales. Subscales measured 1) insistence on sameness, 2) rituals and routines, and 3) sameness behavior associated with sensory features (e.g., insisting on wearing certain clothes because of how they feel). For all three CRI subscales, children with ASD had the highest scores, followed by Down syndrome, and then typically developing children. In the ASD group, all three CRI subscales were related to overall fear. The CRI subscale measuring insistence on sameness was associated with specific types of fear: fear of situations and places ($r = .46, p < .01$), and environmental fears ($r = .49, p < .01$). Additionally, the intensity of rituals and routines was related to fear of situations and places, medical fears, and environmental fears, while sameness behavior related to sensory features was related to medical fears and social fears. The only significant relationships for the Down

syndrome group were between environmental fears and insistence on sameness ($r = .43, p < .01$) and rituals and routines ($r = .52, p < .01$). There were no significant relationships between fear and RRB for typically developing children matched for chronological age. However, insistence on sameness associated with sensory features was associated with overall fear ($r = .41, p < .01$) and environmental fears ($r = .42, p < .01$) in typically developing children matched for mental age. These results suggest that the relationship between anxiety and compulsions and ritualistic/sameness behavior may be affected by developmental level and diagnosis, with the strongest relationship appearing in those with ASD.

Oakes et al. (2016) provides further evidence for the association between higher order RRB and anxiety in non-ASD developmental disabilities. The relationship between different categories of RRB and anxiety was examined in boys between the ages of 6 and 10 years old with Fragile X syndrome. The RBS-R was used to measure repetitive behavior. A total RRB score was produced, in addition to five subscale scores: Stereotyped Behavior, SIB, Compulsive Behavior, Ritualistic/Sameness Behavior, and Restricted Interests (Lam & Aman, 2007). The General Anxiety subscale of the Anxiety Depression and Mood Scale (ADAMS; Esbensen, Rojahn, Aman, & Ruedrich, 2003) was used to assess anxiety symptom severity. The Leiter-R Brief IQ Screener (Roid & Miller, 1997) was administered to participants to measure non-verbal IQ (NVIQ). The Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2001) was used to measure the severity of social-affective symptoms of ASD. Restricted Interests were found to have a negative relationship with NVIQ and a positive relationship with ASD social-affective symptom severity. No other RBS-R subscales were related to the severity of social-affective symptoms of ASD as measured by the ADOS. There were significant correlations between the ADAMS General Anxiety subscale and Compulsive Behavior ($r = .36,$

$p = .02$), Ritualistic/Sameness Behavior ($r = .44, p < .01$), and Restricted Interests ($r = .33, p = .02$). Stereotypic behavior and SIB were not significantly correlated with anxiety. Overall these findings suggest that higher order RRB (compulsive behavior, ritualistic/sameness behavior, restricted interests) is related to anxiety in children with Fragile X syndrome, and that non-verbal IQ and severity of social-affective symptoms of ASD may have an effect on specific subtypes of RRB.

Present Study

This study sought to evaluate the relationship between anxiety and RRB in a population that had yet to be studied: adults with ID of varying etiologies. Participants, adults with ID, were recruited from three local Day Hab programs. Program staff completed measures assessing severity of ASD symptoms, adaptive functioning, anxiety, and RRB. A series of six multiple regression analyses were conducted to determine if anxiety accounted for a statistically significant proportion of the variance in RRB. Age, severity of ASD symptoms, and level of adaptive functioning, in addition to anxiety, were predictor variables; RRB was the criterion. If anxiety was found to independently account for a significant proportion of the variance in RRB, then change in RRB may signal the need to further evaluate for the presence of anxiety.

Research Questions

- 1) Does age, severity of ASD symptoms, level of adaptive functioning, and anxiety together account for a significant proportion of the variance in the *total amount of RRB* and/or in *specific subtypes of RRB* (stereotypic behavior, SIB, compulsive behavior, ritualistic/sameness behavior, restricted interests) in adults with ID?

It was expected that R^2 would be significant at $\alpha = .05$ for all six regression analyses. The literature suggests that age (Esbensen et al., 2009), social-communication impairments (Powell et

al., 2017; Richards et al., 2012; Richler et al., 2007), adaptive functioning (Evans et al., 2014; Oliver et al., 2012), and anxiety (Oakes et al., 2016; Sukhodolsky et al., 2008; Uljarevic & Evans, 2016) all affect the presentation of RRB in ID. As such, it was expected that all predictor variables together- age, Social Communication Questionnaire-Current (SCQ-C; Rutter, Bailey, & Lord, 2003a) score without RRB items, Adaptive Behavior Assessment System Third Edition (ABAS-3; Harrison & Oakland, 2015) raw score, and DASH-II Anxiety scale score- would account for a significant proportion of the variance in each RRB variable (RBS-R total score and all five RBS-R subscale scores).

- 2) Does anxiety independently account for a significant proportion of the variance in the *total amount of RRB* and/or in *specific subtypes of RRB* (stereotypic behavior, SIB, compulsive behavior, ritualistic/sameness behavior, restricted interests) given age, severity of ASD symptoms, and level of adaptive functioning?

It was expected that the DASH-II Anxiety scale score would uniquely account for a significant proportion of the variance in RBS-R total score and for the following RBS-R subscale scores: Compulsive Behavior, Ritualistic/Sameness Behavior, and Restricted Interests. Previous studies have found significant correlations between anxiety symptoms and overall RRB in children with ID+ASD (Stratis & Lecavalier, 2013; Sukhodolsky et al., 2008). Additionally, research suggests that anxiety reduction may be a motivator for RRB in children with ID+ASD and ID alone (Joosten et al., 2012). There is also evidence to suggest that compulsions, rituals/routines, and sameness behavior is related to anxiety in children (Oakes et al., 2016; Uljarevic & Evans, 2016) with specific genetic conditions (i.e., Down syndrome, Fragile X syndrome). Additionally, Oakes et al. (2016) found a significant relationship between anxiety and Compulsive Behavior, Ritualistic/Sameness Behavior, and Restricted Interests using the

RBS-R in a sample of young boys with Fragile X syndrome.

It was hypothesized that the DASH-II Anxiety scale score would not uniquely account for a significant proportion of the variance in Stereotypic Behavior or SIB. Research has not found a significant association between lower order RRB, specifically stereotypy and SIB, and anxiety in children with genetically-based ID (Oakes et al., 2016). Additionally, in prior research with children with ASD both stereotypic behavior and SIB did not emerge as significant predictors of anxiety (Stratis & Lecavalier, 2013).

Method

Participants

A total of 47 adults with ID participated in this study. The target population was adults with ID; this included people with ID only and those with co-occurring diagnoses, such as ASD and/or genetic conditions. All participants were required to have a diagnosis of ID based on DSM-5 criteria (deficits in intellectual and adaptive functioning, onset during the developmental period; APA, 2013). Adults with ID between the ages of 21 and 89 who were receiving Day Hab services through the Arc of Monroe County at the time of the study were eligible to participate. Eighty-nine was set as the maximum age because one of the measures used in this study, the ABAS-3, was reliable and valid only up to that age (Harrison & Oakland, 2015). People who had attended their current Day Hab program for less than six months were excluded, as the DASH-II required staff respondents to have known the participant for at least six months (see Matson, 1995). Additionally, only those who had a legal guardian or who were their own guardian were eligible to participate.

A total of 30 staff members completed measures assessing the behaviors of the participants (adults with ID). Because the DASH-II required staff respondents to have known the participant for a minimum of six months, only staff who had worked at their current site for at least six months were eligible to participate. To protect confidentiality, demographic information was not collected from respondents.

Recruitment

Participants. Participants were recruited from three local Day Hab programs run by the Arc of Monroe County. At the time of the study, there were five Day Habs run by the Arc. One

site was ineligible to participate in the study, as the researcher was an employee at that site. Permission to conduct this study at the four remaining sites was obtained from the Arc (see Appendix B). Directors of the four programs eligible to participate in the study were given information about the purpose of the study and what it would entail (see Appendix C). One site chose not to participate. The remaining three sites provided permission in writing for the study to be conducted at their site.

Each site supplied a list of potential participants to the researcher. This list included the names and core room number (if applicable) of every person attending the program who a) had a legal guardian or b) was their own guardian. For potential participants who had a legal guardian, contact information (phone number and mailing address) for their legal guardian(s) was included.

People who were their own guardian were given information about the study and informed consent materials (Appendix D) in person. The researcher was available to answer any questions. A total of six people were identified who were their own guardians. Of the six, five chose to participate in the study.

Legal guardians were contacted by phone (see Appendix E for a sample script). An envelope containing a) informed consent materials (Appendix F) and b) a postage-paid preaddressed envelope (to return signed consent forms to the researcher at RIT), was sent by mail to guardians who had expressed interest in the study (via phone) and to guardians that the researcher was unable to contact by phone (e.g., did not answer, number was out of order, etc.). A total of 118 guardians were given information about the study (either by phone and/or mail). Ten declined to participate via phone and therefore were not sent informed consent materials. Of the 108 that were mailed information about the study, a total of 63 responded (response rate of

58.3%). The final pool of participants was determined by participant assent and the availability of staff respondents to complete measures for them.

Once consent forms were received from legal guardians, the researcher met with potential participants to obtain assent. Explanation of the study was tailored to the individual, with all potential participants receiving at least a minimal description of the study (see Appendix G for sample scripts for participants with mild/moderate ID and severe/profound ID). The participant provided assent using their preferred mode of communication (e.g., verbally, using sign, gestures, etc.). Direct care staff were present during the assent process; they conveyed to the researcher whether or not the participant was capable of a reliable response (based on his or her observations) using their preferred mode of communication. The researcher completed a form documenting the assent process (Appendix H) for each participant. The form included a) a description of the participant's preferred form of communication, b) whether the participant was able to respond reliably using their preferred form of communication, c) a description of how the information about the study was presented to the individual, d) a description of the participant's response, and e) whether the participant provided assent, declined to provide assent, or did not respond. In the case of a non-response, the participant was given two more opportunities, each on a different day, to provide assent. If the participant did not respond and was able to reliably communicate, they were considered as not providing assent and did not participate in the study. If the participant did not respond and was not capable of reliably responding, they were deemed unable to provide assent and did participate (as long as consent had been provided by their legal guardian).

Only one participant was deemed unable to provide assent. This person did participate in the study, as their legal guardian had provided consent. Three potential participants declined to

provide assent and therefore did not participate in the study.

Staff respondents. Information about the study was given to potential staff respondents in person. The researcher was available to answer any questions. A brief screening survey (Appendix I) and informed consent materials (Appendix J) were given to interested staff. Of the 36 staff given information about the study, 32 returned the screening survey and consent form. These 32 staff were entered into a raffle to win a \$50 Visa gift card. Two respondents dropped out of the study prior to completing data collection. There was a total of 30 respondents who completed measures for at least one participant.

Participants were assigned to eligible staff respondents using a random number generator. Respondents were responsible for completing all measures for their assigned participant(s). Staff respondents were unable to be identified for 16 potential participants.

Measures

Staff screening survey. This survey was completed by staff interested in participating in the study. It was used to determine their eligibility to serve as informants. Specifically, the survey asked for: name, site, core room number (if applicable), and if they had worked at their current site for at least six months.

Participant demographics. Demographic information was obtained through a review of each participant's records. Records were accessed online via an electronic case record system, using an Arc computer to ensure confidentiality. Specific documents accessed included face sheet reports, Individual Plans of Protection, Plans of Nursing Services, and, if applicable, Psychiatric Medication Monitoring Plans, Behavior Guidelines, or Behavior Support Plans. Specific information collected included: age, gender, racial/ethnic status, living arrangement, ASD diagnostic status, ID severity, medical diagnoses (e.g., cerebral palsy, genetic conditions,

seizures, etc.), and psychiatric information (e.g., psychiatric diagnoses, use of medication, types of services/treatments received). All information was entered by hand into a hard copy of the record review form (Appendix K) by the researcher. No personally identifiable information was recorded.

Severity of ASD. The SCQ-C was used to assess the severity of ASD. Although the SCQ was specifically designed to screen for symptoms of ASD, it has also been used to quantify the severity of ASD symptoms (Rutter et al., 2003a). The SCQ is an informant measure that is typically completed by a parent or caregiver, although it has been completed by support staff in a variety of studies (Brooks & Benson, 2013; Sappok, Diefenbacher, Gaul, & Bolte, 2015). The measure is approximated to take less than 10 minutes to complete and has been found to be appropriate for anyone over four years of age, as long as their mental age exceeds two years (Rutter et al., 2003a).

The SCQ-C focuses on behavior within the past three months and consists of 40 yes-or-no questions. The first question assesses for the presence of spoken language. The remaining 39 questions evaluate ASD symptoms across four empirically derived factors: social interaction (20 items), communication (6 items), abnormal language (5 items), and stereotyped behavior (8 items). If a response to item 1 indicates lack of spoken language, then items 2-8 are not administered. The SCQ can also be organized into subscales that match the three domains of the ADI-R (social interaction, communication, and restricted, repetitive, and stereotyped patterns of behavior). Six questions do not fit onto the three factors and are excluded in this scoring method. The SCQ produces a numerical score, where a “1” is given for the presence of abnormal behavior and a “0” is given for the absence of abnormal behavior. The scoring algorithm of the SCQ differs depending on whether or not the individual being assessed possesses spoken

language. For individuals that have spoken language, there is a maximum score of 39, while the maximum score for those who lack spoken language is a 33. The recommended cut-off score for the presence of ASD is 15 (Rutter et al., 2003a).

Psychometric properties of the SCQ have been evaluated in adults with ID+ASD and ID alone across all levels of ID and in those with and without spoken language. Brooks and Benson (2013) examined the psychometric properties of the SCQ in a sample of adults with ID+ASD and ID alone. Level of intellectual functioning of the participants ranged from borderline (IQ = 70-84) to severe (IQ = 20-40). The SCQ was filled out by support staff, which included residential providers, vocational providers, and behavior support specialists. Internal consistency of the SCQ subscales, measured using Cronbach's alpha, were adequate for the whole measure ($\alpha = .87$), the Social Interaction subscale ($\alpha = .83$), and the RRB subscale ($\alpha = .81$). However, the Language and Communication subscale performed poorly in this population ($\alpha = .48$). Discriminative validity of the SCQ was fair: sensitivity and specificity varied considerably depending on what diagnostic cut-off score was used (Brooks & Benson, 2013). However, diagnostics were not a focus of the present study.

Sappok et al. (2015) examined the validity of the SCQ in identifying ASD in adults with ID. Results suggested that the SCQ-C, when filled out by parents or professional caregivers (e.g., residential support staff), could discriminate individuals with ID+ASD from individuals with ID only across all levels of ID severity (mild to profound). Sensitivity was better than specificity. Cohen's kappa was .47, suggesting a moderate degree of agreement on diagnostic status. With respect to concurrent validity, the SCQ-C was significantly related to the Pervasive Developmental Disorders in Mental Retardation Scale (PDD-MRS; Kraijer, 1997) with $r = 0.62$ ($p < .01$) and it also correlated significantly ($r = 0.52, p < .01$) with the ADOS (Lord et al.,

2001). Like the SCQ-C, the PDD-MRS and ADOS assess for current behavior related to ASD. The SCQ-C did not correlate significantly with the ADI-R ($r = .09, p = .63$). However, the ADI-R takes into account developmental history; the SCQ-C does not. Internal consistency was not reported.

A modified SCQ-C score was used to quantify ASD symptoms in this study. The score reflected the sum of item scores, with items assessing for RRB removed. Respondents completed the entire measure. RRB items were removed prior to conducting regression analyses because the SCQ-C was a predictor variable and measures of RRB was the criterion. Items conceptually identified as RRB (i.e., items on the ADI-R RRB subscale) and those assigned to the RRB category via factor analysis (Rutter et al., 2003a) were excluded. These included items 7 (*Does she/he ever say the same thing over and over in exactly the same way or insist that you say the same thing over and over again?*), 8 (*Does she/he ever have things that she/he seems to have to do in a very particular way or order or rituals that she/he insists that you go through?*), 10 (*Does she/he ever use your hand like a tool or as if it were part of her/his own body [e.g. pointing with your finger or putting your hand on a doorknob to get you to open the door]?*), 11 (*Does she/he ever have any interests that preoccupy her/him and might seem odd to other people [e.g. traffic lights, drainpipes, or timetables]?*), 12 (*Does she/he ever seem to be more interested in part of a toy or an object [e.g. spinning the wheels of a car], rather than in using the object as it was intended?*), 13 (*Does she/he ever have any special interests that are unusual in their intensity but otherwise appropriate for her/his age and peer group [e.g., trains or dinosaurs]?*), 14 (*Does she/he ever seem to be unusually interested in the sight, feel, sound, taste, or smell of things or people?*), 15 (*Does she/he ever have any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?*), 16 (*Does*

she/he ever have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?), and 18 (Does she/he ever have any objects (other than a soft toy or comfort blanket) that she/he has to carry around?).

Level of adaptive functioning. Level of adaptive functioning was assessed using the ABAS-3 (Harrison & Oakland, 2015). The ABAS-3 is a norm-referenced measure that was designed to evaluate the adaptive behavior of individuals from birth to age 89. The ABAS-3 has demonstrated good psychometric properties and can be used to assess adaptive skills in the ID population (Harrison & Oakland, 2015).

This study used the rated by others version of the ABAS-3 Adult Form. The Adult Form is a 239-item informant report that was designed to assess adaptive skills in adults between the ages of 16 and 89 (Harrison & Oakland, 2015). The form takes between 15 and 20 minutes to complete and can be completed by anyone who is familiar with the individual's daily living skills, including direct care staff (Harrison & Oakland, 2015). Raters assign a score for each item on a four-point scale, based on whether the individual can perform the task described independently and, if they can, how often they perform it when needed. Choices include "not able," "never or almost never when needed," "sometimes when needed," and "always when needed" (Harrison & Oakland, 2015). The informant can also indicate if their response was a guess. The ABAS-3 produces four scores, an overall score of adaptive behavior called the General Adaptive Composite (GAC; $M = 100$, $SD = 15$), and three scores for the specific domains of adaptive behavior (conceptual, social, practical) recognized by the American Association on Intellectual and Developmental Disabilities and the DSM-5 (Harrison & Oakland, 2015). For this study, level of functioning was quantified using total raw scores, as the GAC norm-referenced standard scores fell within a narrow range. In addition, aggregating GAC scores

derived from different normative subgroups (e.g., age-related subgroups) might not be appropriate. ABAS-3 total raw score was used as a predictor variable in the regression analyses.

The rated by others version of the ABAS-3 Adult Form has been found to demonstrate good psychometric properties. Psychometrics were computed for the measure in general and for different age ranges (16-21, 22-29, 30-39, 40-49, 50-64, 65-74, 75-89 years; Harrison & Oakland, 2015). Internal consistency was high, with reliability coefficients for the GAC and three domain scores ranging from .96 to .99 (Harrison & Oakland, 2015). Interrater reliability was acceptable for clinical use, with Pearson correlation coefficients for the different age groups ranging from .80 to .87 for the three adaptive domains and from .85 to .88 for the GAC (Harrison & Oakland, 2015). Test-retest reliability was within the acceptable range for clinical use as well. The mean test-retest correlation, with an average of three weeks between tests, was .85 for the three adaptive domains and .89 for the GAC score (Harrison & Oakland, 2015).

Anxiety symptoms. The Anxiety subscale of the DASH-II (Matson, 1995) was used to measure anxiety symptoms. The DASH-II is an informant measure that can be completed by direct care staff who have worked with the subject for at least six months (Cervantes & Matson, 2015). The DASH-II was designed specifically for assessing psychopathology in severe and profound ID and focuses on observable symptoms of psychiatric disorders (Matson, 1995). The DASH-II Anxiety scale consists of eight items. Items can be rated on three dimensions, frequency (how often the behavior has occurred), severity (how serious the behavior has been), and duration (how long the behavior has been a problem). Raters score each item on a 3-point Likert scale based on their observations over the last two weeks (Matson, 1995). The Anxiety subscale was administered as a rating scale in this study. Frequency scores were used to measure anxiety; raters did not complete the severity and duration scales. Raters gave each item a score of

0 (did not occur at all), 1 (occurred 1-10 times), or 2 (occurred more than 10 times). Anxiety subscale raw score (sum of scores for each item) was used in the multiple regression analyses.

Overall the DASH-II has been found to have acceptable psychometric properties. Specifically, the DASH-II has demonstrated good inter-rater reliability for the frequency (.86), severity (.85), and duration (.95) dimensions (Sevin, Matson, Williams, & Kirkpatrick-Sanchez, 1995). Additionally, test-retest reliability (across a span of two weeks) was high, with percent agreements of .81, .81, and .91 for frequency, severity, and duration (Sevin et al., 1995). Validity of the DASH-II has been examined as well. Total DASH-II and total ABC scores were significantly correlated ($r = .75, p < .01$), thus demonstrating the concurrent validity of the DASH-II (Paclawskyj, Matson, Bamburg, & Baglio, 1997). Evidence for the diagnostic validity of the Anxiety scale is mixed. Matson, Smiroldo, Hamilton, and Baglio (1997b) examined the validity of the Anxiety scale of the DASH-II by comparing scores on the subscale to DSM-IV diagnoses. All participants who were diagnosed with anxiety via the DSM-IV scored above the cutoff score (endorsed more than half of the items) on the DASH-II. It was not specified which dimensions, frequency, severity and/or duration, were used to measure anxiety. There was a high number of false positives, with 26 out of the 33 people scoring above the cutoff score on the DASH-II not receiving an anxiety diagnosis via the DSM-IV. However, this discrepancy may have been due to difficulty in using the DSM-IV diagnostic criteria to diagnose anxiety; raters were only able to reliably identify observable symptoms and were unable to report on a number of subjective or internalizing DSM-IV items.

The DASH-II focuses on observable symptoms of anxiety, while the DSM-5 assesses behavioral, physiological, and cognitive symptoms. The DASH-II does not address cognitive symptoms of anxiety, but does contain items assessing behavioral and physiological symptoms

(Matson, 1995). The symptoms of anxiety assessed by the DASH-II appeared to be appropriate for the participants in this study, as the sample was hypothesized to include people with all levels of ID severity (mild to profound). Although the DASH-II was intended to be used in those with severe and profound ID, it may be appropriate for people with mild and moderate ID as well. Although people with mild ID may be able to report on some cognitive symptoms of anxiety, informant report on observable symptoms might provide a more reliable estimate of the participants' anxiety levels, albeit at the expense of capturing the full range of anxiety symptoms.

More research seems warranted on the criterion-related validity of the DASH-II Anxiety scale. However, the focus of the present study was not diagnostic accuracy, but the extent to which anxiety symptoms that can be reliably observed and measured by third parties are related to observable RRB behaviors. The DASH-II seemed appropriate for this purpose.

RRB. The RBS-R was used to measure RRB. The RBS-R is an informant measure that was developed to assess the variety of RRBs seen in ASD (Lam & Aman, 2007). The measure consists of 43 items that break down into six conceptually-derived categories: Stereotyped Behavior, SIB, Compulsive Behavior, Ritualistic Behavior, Sameness Behavior, and Restricted Behavior. The items are rated on a four point Likert-scale, based on the presence of a behavior and how much of a problem it has been over the past month, with scores ranging from (0) the behavior does not occur, to (3) the behavior occurs and is a severe problem (Lam & Aman, 2007). The RBS-R produces intensity and frequency scores for the subscales as well as for the measure overall. Intensity is obtained by adding together the ratings for each item in the subscale. Adding together all of the intensity scores from each subscale results in the total intensity score. Frequency refers to the number of items endorsed. Frequency for subscales is obtained by counting how many items on the subscale had a score of 1 or above. Adding the

frequency scores for all of the subscales produces the total frequency score (Radonovich, Fournier, & Hass, 2013).

An alternative model based on exploratory factor analysis was proposed by Lam and Aman (2007). Participants ($n = 307$) ranged in age from 3 to 48 years; all had a diagnosis of ASD. Caregivers completed the RBS-R in its original 43-item form, assigning a score from 0 to 3 for each item. Total score and subscale scores were obtained using the intensity scoring method. They found that a five-factor model best fit the data; five items were removed that did not load sufficiently on any factor. The factors found by Lam and Aman (2007) were similar to the conceptually derived factors; the main difference was that ritualistic behavior and sameness behavior loaded onto a single factor. The five factors were Stereotypic Behavior, SIB, Compulsive Behavior, Ritualistic/Sameness Behavior, and Restricted Interests. Collectively the five factors accounted for 47.5% of the variance. Internal consistency for the subscales were all within or above the acceptable range for research; with Cronbach's alpha ranging from 0.78 (Restricted Interests) to 0.91 (Ritualistic/Sameness Behavior). Interrater reliability was adequate as well, with intraclass correlation coefficients ranging from 0.57 (Compulsive Behavior) to 0.73 (Stereotypic Behavior). Age-based norms, where people with ASD are compared to others with ASD of the same age, ranging from young children (ages 0 to 5) to adults (ages 21 and older), were created based on this amended scoring criteria (Lam & Aman, 2007).

Esbensen et al. (2009) administered the RBS-R to a sample of children, adolescents and adults (2 to 62 years old) with ASD, in which 62% had a comorbid diagnosis of ID. Lam and Aman (2007)'s 38 question format was utilized to determine a total RRB score and the five subscale scores. Total RRB was obtained by adding together the ratings for all 38 items. Subscale scores were obtained by finding the mean item score, as the subscales had different numbers of

items. As in Lam and Aman (2007), the internal consistency of the measure was high, with subscale scores ranging from .74 (Restricted Interests) to .89 (Ritualistic/Sameness Behavior). Internal consistency of the total RRB score was .93.

The current study used Lam and Aman's (2007) amended scoring criteria, due to its good psychometric properties and because it was empirically derived. In addition to its utility in adults with ASD and favorable psychometric properties, the RBS-R captures a broader range of RRB than other commonly used measures (e.g., the ABC, ADI-R, CRI, etc.). Additionally, this study used the scoring method employed in Lam and Aman (2007) to determine the total raw score (sum of scores on all 38 questions) and subscale raw scores (sum of scores for items on each scale).

Data Collection Procedures

Code keys. The researcher created two code keys, one for participants (adults with disabilities) and one for staff respondents, to protect confidentiality (see Appendices L and M). The keys contained numerical codes associated with the names of participants and staff respondents. For participants, numbers were assigned according to their Day Hab site, core room number, and their location in an alphabetized series of last names (i.e., Site 1, Room 1 individual who came first alphabetically was coded 1-1-1). This number appeared on all measures and other research materials (e.g., assent documentation, record review form, etc.). For staff respondents, numbers were assigned using a random number generator. This number, instead of name, appeared on research materials and was used to identify which staff respondent was assigned to complete measures for each participant.

Data collection. The researcher met with respondents to explain how to properly fill out each measure and to answer any questions. Per Arc policy, staff respondents were allowed to

work on measures in the morning before program participants arrived and in the afternoon after they had left. It was made clear that participation in the study could not interfere with normal work activities. It was estimated to take 30-45 minutes to complete all four measures. Staff were told that the measures did not need to be completed all in one sitting, they could start and stop as needed. Measures were distributed to respondents in envelopes that were coded. Each measure was coded and places for identifying information (e.g., name, date of birth, etc.) were blacked out. Respondents were given instructions to complete all measures for their assigned participant, put them back in the manila envelope, and to notify the researcher (by email, phone, or in person) when they were completed. The researcher checked each measure to make sure all measures were completed in entirety. The researcher then gave the respondent the envelope for their next participant (if applicable).

Data compilation. Data from all measures were entered into SPSS and was stored electronically on a flash drive. The data file used for analysis did not contain any personally identifiable information.

Data Analysis

All analyses were conducted using the Statistical Package for Social Sciences (SPSS; SPSS Inc., 2013) and AMOS 5.0 (Arbuckle, 2003).

Demographics. Descriptive statistics were computed for all questions on the record review form. Specific variables that were analyzed included general information (age, gender, ethnic/racial status, ASD diagnosis, ID severity, housing arrangement), medical history, and current psychiatric information.

Psychometrics. Internal consistency was computed for all measures using Guttman's Lambda-2 (Guttman, 1945). For the SCQ-C, internal consistency was computed for the sum of

SCQ items (without RRB items and without items specific to people with spoken language). For the ABAS-3, internal consistency was computed for the total raw score (because this number was used to quantify adaptive functioning in the regression analyses). For the DASH-II, internal consistency was computed for the Anxiety scale. For the RBS-R, internal consistency was computed for the total measure and for each of the five subscales.

Inferential statistics. The extent to which anxiety symptoms uniquely account for variance in RRB was assessed using multiple regression. Based on power analysis, a minimum of $N = 53$ subjects was needed to have an 80% chance of detecting at least medium size effects ($R^2 = .20$, $sr^2 = .10$) at $\alpha = .05$, which are values often tested in behavioral research when the true population values are not known (see Cohen, Cohen, West, & Aiken, 2003). The four assumptions of multiple regression (normality, linearity, homoscedasticity, independence) were assessed for all regression analyses. A series of six regression analyses were conducted with the following predictor variables: age, SCQ-C score (without RRB items), ABAS-3 raw score, and DASH-II Anxiety scale score. Criterion variables for the six regression analyses were as follows: 1) RBS-R total score, 2) RBS-R Stereotypic Behavior subscale score, 3) RBS-R SIB subscale score, 4) RBS-R Compulsive Behavior subscale score, 5) RBS-R Ritualistic/Sameness Behavior subscale score, and 6) RBS-R Restricted Interests subscale score. Significance tests were conducted on: R^2 and on the squared semi-partial correlation (sr^2) between the anxiety variable (DASH-II Anxiety scale score) and each RRB variable (RBS-R total score, 5 RSB-R subscale scores).

Results

Participant Demographics

Demographic information about the participants ($N = 47$) was obtained via record review. Age ranged from 21 to 82 years ($M = 52.68$, $SD = 14.94$). This information is presented in Table 1. Females ($n = 25$) slightly outnumbered males ($n = 22$). The majority of participants were white/Caucasian (86.7%); only six participants (13.3%) were black/African American. Two (4.3%) identified as Hispanic/Latino. Only ten participants (21.3%) had a diagnosis of ASD. Ten participants (21.3%) had Down syndrome and one participant (2.1%) had Fragile X syndrome. All levels of ID severity were represented in the sample; moderate ID had the greatest number of participants ($n = 23$). The majority of participants lived in group homes run by the Arc ($n = 26$) or another agency ($n = 12$). Only nine participants lived with family.

Medical information was also obtained via record review and data are reported in Table 1. The table indicates that all participants had at least one co-occurring medical condition. Digestive disorders were the most common medical condition, occurring in 76.6% of the participants. Other commonly identified conditions included visual impairments (63.8%), seizures (44.7%), and osteoporosis (40.4%).

Psychiatric information obtained via record review is presented in Table 2. The table indicates that comorbid psychopathology was high in this sample; 72.3% of participants had at least one co-occurring psychiatric condition and 59.6% had two or more. Depression and anxiety were the most common, with each occurring in 44.7% of the participants. In regards to treatments, 31 participants (66.0%) were taking psychotropic medication. Twenty-two participants (46.8%) received psychiatric services and nine (19.1%) received psychological

services (e.g., counseling). Participants also received occupational therapy (19.1%), speech therapy (34.0%), and physical therapy (29.8%). No participants were receiving behavioral intervention for RRB (including SIB).

Descriptive Statistics

Descriptive statistics for measures used in the regression analyses were calculated. Table 3 presents this information. The table indicates that all participants demonstrated at least some ASD-related symptoms. The highest score was a 24, which is relatively low compared to the maximum scores that can be obtained on the SCQ-C (39 for people with spoken language, 32 for people without spoken language). The mean SCQ-C score was lower than the widely used screening cut-off score of 15, which is considered a positive screen for the presence of ASD. When RRB items were removed, the mean SCQ-C score decreased, bringing the mean even further away from the cut-off score. The range changed slightly with the removal of RRB items, with the maximum score decreasing from 24 to 21. This suggests that the sample as a whole endorsed more of the social-communication symptoms of ASD than RRB. These data indicate that the staff respondents did not endorse a high level of ASD symptoms in this sample as a whole, which appears consistent with the fact that only 10 participants had an existing ASD diagnosis.

For the ABAS-3, the table indicates a small range of scores on the GAC standard scores. Raw scores showed more variability, with scores ranging from 15 to 550 ($M = 268.51$, $SD = 122.418$). GAC scores can be converted to qualitative scores. The mean GAC score of 59.62 ($M = 100$, $SD = 15$) corresponds to extremely low adaptive functioning. The majority of participants (93.6%) were classified as extremely low (GAC score of 70 or less), 4.3% were low (score between 71 and 80), and 2.4% were below average (score of 80 or above). The highest GAC

score obtained was 80. There were no participants scoring in the average (90-109), above average (110-119), or high (120 and above) range, meaning that all participants exhibited deficits in adaptive functioning. The majority of participants were categorized as having extremely low adaptive functioning. This is in line with findings obtained via record review. Specifically, record review indicated that there was a higher proportion of individuals with profound/severe/moderate ID than what is seen in the ID population as a whole.

The mean score on the DASH-II Anxiety subscale was low, indicating that staff participants did not endorse a high level of anxiety for the sample as a whole. A score of 2 or higher indicates that anxiety may be present. Based on this cutoff, a total of 36.2% of the sample may have an anxiety disorder. However, record review indicated that 44.7% of the sample were diagnosed with an anxiety disorder.

The sample as a whole exhibited relatively low levels of RRB. According to the sample norms created by Lam and Aman (2007), the mean RBS-R total score for adults with ASD is 31.80. In the current study, the average RBS-R total score was only 9.04. Subscale scores were relatively low as well. Ritualistic/sameness behavior had the highest mean; SIB had the lowest. This suggests that, as a whole, ritualistic/sameness behavior was the most prevalent (and/or most severe) form of RRB seen in this sample.

Reliability

Reliability of the SCQ-C, ABAS-3, DASH-II, and RBS-R was assessed using Guttman's Lambda-2. To keep the number of items equal across participants with and without spoken language, items specific to those with spoken language on the SCQ-C were removed, in addition to RRB items, prior to the analysis. Reliability was assessed for the ABAS-3 as a whole (subscales were not analyzed). The reliability analysis for the DASH-II included only items

assessing anxiety. For the RBS-R, reliability was assessed for the overall score and for the five subscales. Table 4 presents the results of the reliability analysis.

With the exception of perhaps two measures, the measures used in this study appeared to have adequate reliability for research purposes. Like Coefficient alpha, Lambda-2 values less than .60 indicate low levels of reliability for research (see Clark & Watson, 1995, for a review). Lambda-2 was low for the RBS-R Restricted Interests subscale. The low value may have been due to the small number of items on the scale. This scale had the fewest number of items, and Lambda-2 is sensitive to the number of items. The mean inter-item correlation for the RBS-R Restricted Interests subscale was .325. This value was acceptable, as the Restricted Interests subscale is somewhat broad in content. The mean inter-item correlation for scales that measure a broad construct should be between .15 and .50; for scales that measure narrowly defined constructs, the mean inter-item correlation should fall between .40 and .50 (Clark & Watson, 1995). Mean inter-item correlations were acceptable for all scales except the SCQ-C. However, Lambda-2 was acceptable.

Regression Analyses

Simultaneous multiple regression was used to evaluate the relationship among age, severity of ASD symptoms, level of adaptive functioning, anxiety symptoms, and RRB. A series of six regression analyses were conducted. Predictors were age, SCQ-C score without RRB items, ABAS-3 raw score, and DASH-II Anxiety subscale score. The criterion variables for the six regression analyses were as follows: RBS-R total score, RBS-R Stereotypic Behavior subscale score, RBS-R SIB subscale score, RBS-R Compulsive Behavior subscale score, RBS-R Ritualistic/Sameness Behavior subscale score, and RBS-R Restricted Interests subscale score.

Pearson correlations. Pearson r correlation coefficients among the predictors and

criterion variables are presented in Table 5. The table indicates that there were some statistically significant correlations between predictor and criterion variables. Specifically, RBS-R total score was significantly correlated with SCQ-C score ($r = .295, p = .022$) and DASH-II Anxiety subscale score ($r = .347, p = .008$). RBS-R Stereotypic Behavior had a positive correlation with SCQ-C score ($r = .458, p = .001$) and a negative correlation with age ($r = -.306, p = .018$). RBS-R Ritualistic/Sameness Behavior and DASH-II Anxiety subscale score had a significant correlation ($r = .427, p = .001$). RBS-R Restricted Interests subscale was significantly correlated with SCQ-C score ($r = .511, p < .001$) and had a significant negative correlation with ABAS-3 raw score ($r = -.262, p = .037$). Compulsive behavior and SIB did not have any statistically significant bivariate correlations with any of the predictors.

The correlations among the predictor variables themselves were fairly small. The only significant correlation between predictor variables was for age and ABAS-3 raw score, which had an inverse relationship ($r = -.257, p = .041$) and indicated that these variables shared 6.60 percent of variance with one another. The lack of inter-correlations among predictor variables indicates a lack of redundancy among individual predictors and increases statistical power when analyzing the percentage of variance uniquely accounted for by individual predictors.

Assessment of assumptions. The four assumptions of multiple regression, 1) multivariate normality, 2) homoscedasticity, 3) independence, and 4) linearity, were assessed for each regression analysis. Studentized deleted residuals, Cook's d , leverage, and standardized difference in beta statistics were used to identify outliers and influential cases. Outliers were identified for all analyses. They were retained in the analyses because their influence on the results was not substantial and there was no conceptual basis for their removal.

For all six regression analyses, the assumption of multivariate normality appeared to be

violated. This conclusion was drawn from both quantitative (Shapiro-Wilk test, skewness and kurtosis indices) and qualitative assessment (histogram, stem-and-leaf plot, box plot, normal p-p plot, detrended normal q-q plot). The distributions of standardized residuals appeared positively skewed. The assumption of homoscedasticity appeared to be violated for all six analyses as well. This is not surprising, given that the data was skewed. The assumption of independence appeared to be met, as all analyses had Durbin-Watson statistics within the acceptable range of 1.5 and 2.5. The assumption of linearity was tenable for all six analyses.

Due to the violation of normality, bootstrapping using maximum likelihood was used to perform the regression analyses. This approach helps to lessen the bias in regression results that might be obtained when using ordinary least squares regression on non-normal data. The approach allows for the creation of bias-corrected confidence intervals for regression coefficients and R^2 as well as the p-values. With bootstrapping, the sample data serves as the “population” and each bootstrap sample is treated as a sample from this population. Mean regression statistics are computed by aggregating data across the bootstrap samples allowing for the creation of bias-corrected confidence intervals. Using AMOS, 10,000 bootstrap samples with replacement were generated. The squared semipartial correlation coefficients (sr^2) were obtained from the ordinary least squares regression analysis in SPSS. The results of the bootstrap slightly differed from the ordinary least squares regression analysis for RBS-R Compulsive Behavior and RBS-R Ritualistic/Sameness Behavior. The results of significance tests are based on the bootstrap-derived p-values because of the correction for bias.

Total RRB. Table 6 presents the regression results for RBS-R total score. Together, the four predictors accounted for a statistically significant ($\alpha = .05$) proportion of the variance in RBS-R total score ($R^2 = .219, p = .003$). Significance tests of individual predictors indicated that

only the DASH-II Anxiety subscale score was statistically significant ($p = .013$). Based on the squared semi-partial correlation, DASH-II Anxiety subscale score uniquely accounted for 10.8% of the variance in RBS-R total score.

Stereotypic behavior. Table 7 presents the regression results. Together the four predictors accounted for a significant proportion of the variance in RBS-R Stereotypic Behavior subscale score ($R^2 = .323, p = .006$). Significance tests of individual predictors indicated that age ($p = .011$) and SCQ-C score without RRB items ($p = .003$) were statistically significant. Age had a significant inverse relationship with RBS-R Stereotypic Behavior. Examination of squared semi-partial correlations indicated that age independently accounted for 7.4% of the variance in RBS-R Stereotypic Behavior subscale score and that SCQ-C score without RRB items independently accounted for 10.6 % of the variance.

SIB. Table 8 presents the regression results. Together the four predictors did not account for a statistically significant proportion of the variance in RBS-R SIB subscale ($R^2 = .028, p = .074$).

Compulsive behavior. Table 9 presents the regression results. R^2 was statistically significant ($R^2 = .078, p = .024$). Significance tests of individual predictors indicated that DASH-II Anxiety subscale score independently accounted for a statistically significant proportion of the variance (5.3%) in the criterion ($p = .022, sr^2 = .053$).

Ritualistic/sameness behavior. Table 10 presents the regression results. R^2 was statistically significant ($R^2 = .194, p = .006$), Significance tests of individual predictors indicated that DASH-II Anxiety subscale score ($p = .009, sr^2 = .181$) independently accounted for a statistically significant proportion of the variance in RBS-R Ritualistic/Sameness Behavior subscale. Based on the semipartial squared correlation coefficient, DASH-II Anxiety subscale

score uniquely accounted for 18.1% of the variance in the criterion.

Restricted interests. Table 11 presents the regression results. Together, the four predictor variables accounted for a statistically significant proportion of the variance in RBS-R Restricted Interests subscale score ($R^2 = .307, p = .003$). Significance tests of individual predictors indicated that only SCQ-C score without RRB items independently accounted for a statistically significant proportion of the variance in RBS-R Restricted Interests subscale score ($p = .001, sr^2 = .200$). Based on the squared semipartial correlation coefficient, SCQ-C score without RRB items uniquely accounted for 20.0% of the variance.

Discussion

This study sought to examine the relationship between RRB and anxiety in adults with ID, in order to determine whether changes in RRB could be an observable indicator of anxiety in this population. It was expected that some forms of RRB and anxiety are related. Anxiety was found to independently account for a significant proportion of the variance in total RRB, compulsive behavior, and ritualistic/sameness behavior. This suggests that changes in the overall level of RRB, in compulsive behavior, and in ritualistic/sameness behavior may be a “red flag” that an anxiety disorder may be present.

Relationship between Anxiety and Overall RRB

As expected based on previous research, age, severity of ASD symptoms, level of adaptive functioning, and anxiety together accounted for a significant proportion of the variance in RBS-R total score and anxiety emerged as a significant predictor (Bodfish et al., 2000; Esbensen et al., 2009; Evans et al., 2014; Joosten et al., 2012; Stratis & Lecavalier, 2013; Sukhodolsky et al., 2008). RBS-R total score quantifies the total amount of RRB; it reflects the intensity (how often the behavior occurs and how much of a problem it is) of stereotypic behavior, SIB, compulsive behavior, ritualistic/sameness behavior, and restricted interests. Therefore, the results of this study suggest that anxiety is related to changes in the frequency and severity of RRB in general. Changes in the total amount of RRB that a person exhibits may indicate the presence of anxiety in adults with ID.

Relationship between Anxiety and Specific Forms of RRB

Anxiety accounted for a significant proportion of the variance in two subscales of the RBS-R: Compulsive Behavior and Ritualistic/Sameness Behavior. It was expected that anxiety

would be a significant predictor of compulsive behavior and ritualistic/sameness behavior, based on prior research in children with ASD sans ID and children with genetically-based ID (Oakes et al., 2016; Uljarevic & Evans, 2016).

Anxiety was not a significant predictor of the RBS-R Stereotypic Behavior, SIB, or Restricted Interests subscales. Previous studies have concluded that lower level RRBs, including stereotypic behavior and SIB, are not related to anxiety (Stratis & Lecavalier, 2013). However, it was unexpected that anxiety did not account for a significant proportion of the variance in RBS-R Restricted Interests, as prior research using the RBS-R had found a significant relationship between anxiety and restricted interests in a sample of children with Fragile X syndrome (Oakes et al., 2016).

Overall, these results suggest that changes in compulsive behavior and/or ritualistic/sameness behavior may be an observable indicator of anxiety in adults with ID. Compulsive behaviors seen in adults with ID include arranging and ordering objects, a need for completeness, such as having doors either open or closed, and hoarding items (Bodfish et al., 2000). Ritualistic/sameness behavior, on the other hand, involves strict adherence to routines/rituals (e.g., taking the same route/path every day), difficulty with transitions, and resistance to change. Referral for a complete diagnostic evaluation may be warranted if significant changes in these types of behaviors are observed. Significance is judged on an individual basis. For example, a slight increase in body rocking for an individual who engages in high levels of stereotypic behaviors may not be considered significant. On the other hand, if a person without a history of SIB suddenly starts to engage in repetitive head banging, it may be a cause for concern.

Differences between this study and Oakes et al. (2016) with respect to restricted interests

may be due to differences between the methods and measures used for the assessment of RRB and anxiety, as well as sample characteristics. Although the current study and Oakes et al. (2016) both used the RBS-R to measure RRB, different scoring methods were used. Item content of the Restricted Interests subscale differed between the two studies. The current study used Lam and Aman's (2007) empirically derived scoring method, in which there was an additional item assigned to the Restricted Interests subscale (likes the same CD, tape, record or piece of music played continually; likes same movie/video/part of movie). Additionally, different measures of anxiety were used. Although both studies utilized rating scales completed by third-party informants, there were differences in content between the two measures. Specifically, the ADAMS General Anxiety subscale measured symptoms specifically related to generalized anxiety disorder, while the DASH-II Anxiety subscale assessed anxiety in general, and therefore was broader in content (Esbensen et al., 2003; Matson, 1995).

Differences in sample characteristics may also explain the disparate conclusions. Specifically, Oakes et al. (2016) examined RRB and anxiety symptoms in a sample of young boys with Fragile X syndrome, whereas all participants in the current study were adults of both genders and differing etiologies of ID. The current study did not examine the effects of gender on the relationship between anxiety and restricted interests, and also did not make comparisons across different age ranges; future studies should look to investigate these variables. Additionally, all participants in the current study had ID; it was not reported what percentage of the sample in Oakes et al. (2016) had ID, although the mean NVIQ of 59.26 ($SD = 14.90$) would indicate that at least some participants had deficits in intellectual functioning. In contrast, the current study examined adaptive behavior, not IQ. Oakes et al. (2016) did not report the extent to which their participants exhibited deficits in adaptive behavior.

RRB and Relationship to Other Variables

Age and severity of ASD symptoms emerged as significant predictors of RBS-R Stereotypic Behavior. Age was a negative predictor of Stereotypic Behavior subscale. A negative relationship between stereotypic behavior and age has been found in previous research in children and adults with ASD alone and in those with comorbid ID (Esbensen et al., 2009). Severity of ASD symptoms (SCQ-C score without RRB items) was a positive predictor of Stereotypic Behavior. Prior studies have found an association between severity of social-communication symptoms of ASD and higher levels of stereotypic behavior (Richler et al., 2007). Additionally, stereotypic behavior tends to occur at a higher rate and is more severe in persons with ID+ASD relative to those with ID alone (Bodfish et al., 2000). Therefore, the finding that stereotypic behavior is predicted by social-communication impairments may be due to the fact that the sample contained persons with ASD. Overall, the results of this study indicate that anxiety may not be a motivating variable for stereotypic behavior. Stereotypic behavior may be maintained by automatic reinforcement related to sensory consequences as opposed to escape from aversive stimulation (i.e., anxiety).

The results of this study suggest that SIB is related to variables other than those examined in the regression analyses, as the combination of predictor variables did not account for a significant proportion of the variance. Although not expected, this finding may be related to characteristics of the sample in this study. Research on the relationship between SIB and age in adults with ID has had mixed results. Some studies have found decreases in SIB with age, whereas others have found no relationship or have found SIB to increase with age (Deb et al, 2001; Rojahn, Schroeder, & Hoch, 2007; Tsiouris et al., 2011). The relationship between SIB and age may be affected by level of functioning, as assessed by IQ scores. Specifically, in

mild/moderate ID SIB tends to decrease with age, but in those with severe/profound ID SIB appears to increase with age (Rojahn et al., 2007). The inclusion of participants across all levels of ID severity may explain why a significant relationship between SIB and age was not found. Another interesting finding was that in the current study, SIB was not significantly correlated with the other RBS-R subscales. Prior studies using the RBS-R did find all subscales to be significantly correlated with one another (Esbensen et al., 2009; Stratis & Lecavalier, 2013). There is debate on whether or not SIB falls in the category of RRB or if it is better described as another kind of challenging behavior (Matson & Nebel-Schwalm, 2007; Rojahn et al., 2001). However, further research on the presentation of SIB in adults with ID, and on the association between SIB and other forms of RRB, is needed.

Severity of ASD symptoms (SCQ-C score without RRB items) emerged as a significant predictor of Restricted Interests. Previous studies have found an association between restricted interests and social-communication impairments in children and adolescents with ASD sans ID (South et al., 2005). Oakes et al. (2016) found a significant relationship between ASD symptom severity and restricted interests in boys with Fragile X syndrome, as well as between restricted interests and anxiety. Future research should examine the relationship between RRB and restricted interests across different diagnoses (e.g., Fragile X with and without ASD) to evaluate the effect that ASD has on the relationship between restricted interests and anxiety.

Limitations

Sample characteristics. Only 21.3% of participants in the sample had a diagnosis of ASD. Occurrence of ASD in the ID population is thought to be around 40%. The low level of participants with ASD in this study may be due to sampling procedures. Participants were not recruited from the Day Hab site where the researcher works. The majority of individuals at that

site have a diagnosis of ASD, as the site is home to the agency's specialized autism program. Had that site participated, the percentage of participants in the sample with ASD would have likely increased. The sample as a whole exhibited relatively low levels of RRB, which may also be related to the small number of participants with ASD. Replication in a sample with higher levels of RRB is needed. In addition, this study was not able to confirm ASD diagnostic status for the participants, and methods used for diagnosis might have varied across individuals. Gender was not used as a predictor variable or co-variate in this study, as prior research suggested that gender effects may be more ASD-specific. Each gender was represented relatively equally in the current study, with slightly more females than males. Using gender as a co-variate may have provided valuable information about the effects of gender on the RRB-anxiety relationship, and should be examined in future studies.

This study did not touch on the issue of whether or not the relationship between RRB and anxiety is ASD specific. Severity of ASD symptoms only accounted for a significant proportion of the variance in the Restricted Interests subscale. However, comparing the relationship between RRB and anxiety in adults with ID+ASD vs. those with ID alone would provide a better understanding of the impact of ASD on the presentation of RRB in adults with ID. Additionally, this study did not examine the relationship between RRB and anxiety across different subgroups of ID (e.g., ID+ASD, different genetic conditions, idiopathic ID). As such, the results of this study speak to the ID population as a group. The results may reflect RRB-anxiety relationships that pertain to all people with ID or that pertain only to specific subgroups, such as those with comorbid ASD. Future research should examine the relationship between RRB and anxiety across different subgroups of ID.

Relative to the ID population as a whole, the sample in this study had a higher percentage

of those with severe-profound ID. This justifies the use of the DASH-II in this study which was developed for this subgroup of the ID population. External validity is affected by the over-representation of individuals with moderate to profound ID. Nonetheless, very few studies examine lower functioning individuals.

Respondents. Respondents may not have had sufficient opportunity to observe the people that they completed measures for. All respondents were Day Hab staff. Participants attend program Monday through Friday for roughly five hours a day. With the high rate of staff turnover, there was a limited number of staff who had been at their current site for six months. As such, respondents may not have necessarily observed the participant that they completed measures about for the entire six months. Staff are often required to work in different core rooms and occasionally at different sites. It is unlikely that a staff would have worked with the same person every day over a six month period. Due to the setup of their site, some respondents only worked with their participant(s) a few times a week as opposed to every day. Future studies should take the issue of staff familiarity with participants into account. Inequalities in the amount of exposure staff have to different participants is inevitable. It may be beneficial to have staff rate how familiar they were with each participant.

Additionally, this study examined behavior only in one setting. It is possible that the participants behave differently at home than they do at program. Recruiting respondents only from Day Hab may have added error to the study, as some questions (especially on the ABAS-3) applied more to home than to program. Residential staff, who work with the people before and after program and all weekend may have been better able to complete the measures for this study.

Sample size. Based on power analysis, a sample size of $N = 53$ was needed to have an

80% chance of detecting a significant relationship at $\alpha = .05$. Due to difficulty in recruiting staff respondents, only 47 adults with ID participated in the study. This decreases power, ultimately increasing the likelihood of a Type II error (failing to reject the null hypothesis when it is false). The small to moderate sample size in this study also made ordinary least squares regression less robust to violations of the normality assumption. This necessitated the use of bootstrapping to lessen the effect of bias. A larger sample size in future studies would make the analyses more robust to issues of non-normality, and would help to determine the extent to which the present results are replicated.

The results of this study speak to ID as a group. Due to small sample size, it was not possible to assess whether these results pertain only to specific subgroups (e.g., ASD and ID, specific genetic conditions, idiopathic ID) or to all people with ID.

Error due to multiple comparisons. Every comparison was made to its own separate alpha of .05. Since there were multiple comparisons, the chance of Type I error (rejecting the null hypothesis when it is actually true) were increased. The Bonferroni correction is one way to account for multiple comparisons. If the Bonferroni correction was applied, alpha would have been equal to .008. When comparing the p values obtained via bootstrapping to the more stringent alpha of .008, changes in the overall results of the study occur. Specifically, R^2 would not be significant for RBS-R Compulsive Behavior. However, the four predictor variables together would still account for a significant proportion of the variance in total RRB, Stereotypic Behavior, Ritualistic/Sameness Behavior, and Restricted Interests. Anxiety would no longer account for a significant proportion of the variance in total RRB or in Ritualistic/Sameness Behavior, which would lead to the conclusion that changes in RRB were not related to anxiety.

By controlling for Type I error via the use of a more stringent alpha level, there is an

increased risk of making a Type II error. Given the nature of the current study, increased risk of false positives (Type I error) is preferable to making a Type II error (i.e., erroneously concluding that there is not a relationship between RRB and anxiety). Such error, resulting from overly stringent alpha levels, may result in practitioners missing important red flags that could suggest the presence of an anxiety disorder. As a result, practitioners may not assess for anxiety, and people ultimately may not receive the disorder-specific treatment that they need.

Implications for Practice

The results of this study suggest that changes in RRB may be an observable correlate of anxiety in adults with ID. Increases in the frequency and/or severity of RRB in general may indicate the presence of anxiety. Specifically, changes in ritualistic/sameness behavior and compulsive behavior might suggest the presence of anxiety. Other forms of RRB, namely stereotypy, SIB, and restricted interests, might be related to different factors, or might even be related to other forms of psychopathology not investigated here, such as depression. Although anxiety seems to be related to increases in RRB, decreases in RRB may be related to different psychiatric conditions (e.g., decreases in restricted interests may be indicative of depression). Practitioners working with persons with ID should routinely (annually) assess for any changes in baseline levels of RRB, especially for individuals with a history of anxiety disorder(s) and for those in which mental health issues are suspected, regardless of ID etiology. Multiple methods and measures should be used, appropriate to the individual's developmental characteristics. Any significant changes in baseline behavior might necessitate a referral for a formal diagnostic evaluation. A functional behavioral assessment is also important to determine what function(s) RRB may serve which helps inform intervention. When deriving behavioral treatments for RRB, clinicians should take into account that certain forms of RRB may serve as a coping mechanism.

As such, it may be beneficial to teach more effective coping skills, especially when implementing behavior programs designed to reduce RRB.

Implications for Research

Future studies should utilize improved sampling methods to help ensure samples are representative of the ID population as a whole, especially in regards to severity of ID, ASD diagnostic status, race/ethnicity, and gender. Replication within different levels of functioning is also an important area for future research. Additionally, future studies should look to compare findings across diagnostic groups (ID+ASD vs. ID alone). Future studies should look to confirm ASD diagnostic status. It would also be beneficial to utilize multiple assessment methods (e.g., rating scales, interview, clinical observation, etc.), which are appropriate to developmental level, when assessing anxiety. Examining the relationship between anxiety and RRB across Day Hab and residential settings would also be beneficial area for future research. It may also be helpful to have both Day Hab and residential staff complete measures for each participant. This could highlight discrepancies in the person's behavior across settings, and evaluate the effect of respondent on results. Replication in a larger sample is needed. The sample in the current study was smaller than samples in comparable studies. The target number of participants was not met. A larger sample may help address the issue of non-normality, or at least make ordinary least squares regression more robust to violations of the normality assumption. In order to obtain a larger sample, it may be helpful to recruit participants from more than one agency.

Conclusion

Accurate identification of co-occurring psychiatric disorders in the ID population is imperative. Untreated psychopathology is associated with increased impairment and a need for more support. This study sought to determine if changes in RRB may be an observable indicator of anxiety in adults with ID. Anxiety was found to independently account for a statistically significant proportion of the variance in total RRB, compulsive behavior, and ritualistic/sameness behavior. As such, changes in RRB in general and in compulsive and ritualistic/sameness behaviors may indicate the presence of anxiety. Routine assessment for changes in baseline levels of RRB is critical, regardless of ID etiology. Ultimately, this study highlights the need for more research on the relationship between anxiety and RRB, especially between different populations, across settings, and in larger samples.

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Appendix A

List of Abbreviations

ABAS-II	Adaptive Behavior Assessment System, Second Edition
ABAS-3	Adaptive Behavior Assessment System, Third Edition
ABC	Aberrant Behavior Checklist
ADAMS	Anxiety Depression and Mood Scale
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation Schedule
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
BPI	Behavior Problems Inventory
CASI	Child and Adolescent Symptom Inventory
CBT	Cognitive Behavioral Therapy
CDC	Centers for Disease Control and Prevention
CRI	Childhood Routines Inventory
CSI-4	Child Symptom Inventory, Fourth Edition
DASH-II	Diagnostic Assessment for the Severely Handicapped, Revised
Day Hab	Day Habilitation
DM-ID	Diagnostic Manual- Intellectual Disability
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSM-IV-TR	Fourth Edition of the DSM, Text Revision
DSM-5	Fifth Edition of the DSM

GAC	General Adaptive Composite Score
ID	Intellectual Disability
ID+ASD	Co-Occurring Intellectual Disability and Autism Spectrum Disorder
MR-OCD	Mental Retardation- Obsessive Compulsive Disorder Scale
NVIQ	Non-Verbal IQ
PDD-MRS	Pervasive Developmental Disorders in Mental Retardation Scale
RBS-R	Repetitive Behavior Scale-Revised
RRB	Restricted, Repetitive Behavior
SCQ-C	Social Communication Questionnaire-Current Version
SIB	Self-Injurious Behavior
SPSS	Statistical Package for Social Sciences
SSRIs	Selective Serotonin Reuptake Inhibitors
VABS	Vineland Adaptive Behavior Scales
WISC-III	Wechsler Intelligence Scale for Children, Third Edition

Appendix B

Arc Approval



David J. Irish
Chairperson

Barbara S. Wade
President

Rochester Institute of Technology Institutional Review Board
Human Subjects Research Office (HSRO)
University Services Center, Suite 2400
141 Lomb Memorial Dr.
Rochester, NY 14623-5608

December 27, 2016

Dear Rochester Institute of Technology IRB,

On behalf of the Arc of Monroe County, I am writing to grant permission for Casey Mazzola to conduct her master's thesis titled, "The Relationship between Restricted, Repetitive Behavior and Anxiety in Adults with Autism Spectrum Disorder and Intellectual Disability" at the following Day Habilitation programs: Ballantyne Day Services, Community Arts Connection, Henrietta Day Services and Lambert Day Services. We are happy to participate in this study and contribute to this important research.

Michael Zazzara
Sr. Administrator

Appendix C

Information Provided to Day Habilitation Sites

The goal of this study is to investigate the relationship between anxiety and restricted repetitive behavior (RRB) in adults with intellectual and developmental disabilities (IDD). If RRB is related to the presence of anxiety, changes in RRB may serve as a “red flag” that a person needs to be evaluated for anxiety. As a result, we may be able to detect cases of anxiety in people who would have been otherwise overlooked.

1. Recruiting Participants

- Participants for this study will be adults with intellectual disability (with and without a diagnosis of autism spectrum disorder) attending local Day Habilitation programs run by the Arc of Monroe County.
- The researcher will meet with each site to explain the study and to get a list of program attendees that meet the initial screening criteria. Participants must be between the ages of 21 and 89, have a legal guardian (or are their own guardian) and have been in their current core room for at least 6 months.
- Each site will provide the researcher with contact information (phone number and mailing address) for the guardian of each potential participant.

2. Recruiting Staff Respondents

- Staff at each Day Program site will be recruited to serve as respondents (will complete measures about the participants).
- The researcher will meet separately with each participating Day Habilitation program. She will describe the study and will distribute informed consent

documents and the staff screening survey to interested staff. Interested staff will complete the forms and return them to the researcher.

- All staff informants will be entered in a raffle to win a \$50 Amazon gift card.

3. Informed Consent and Assent

- The researcher will obtain consent from potential participants' legal guardians.
- Once the signed form is received, the researcher will need to meet with the individual and room staff to obtain assent. The study is explained to the individual and they choose whether or not they want to participate.
- It is expected to take about 5 minutes to obtain assent for each participant.

4. Data Collection

- Once assent is obtained the researcher will need to access individual records through PrecisionCare to collect demographic information. This will occur using an Arc computer, to ensure confidentiality.
- Participants will be randomly assigned to staff respondents working in their core room.
- Respondents are responsible for completing all measures for their assigned participant(s).
- Respondents can work on measures in the morning before program participants arrive and in the afternoon after they have left and after all end of the day tasks have been completed (documentation, cleaning the core room, etc.). The researcher will let staff respondents know that participation in the study cannot interfere in their normal work activities.

- It is estimated that it will take 30-45 minutes to complete all of the measures. The measures do not need to be completed all in one sitting; staff can start and stop as needed.

5. Presentation of Results

- The researcher will present the results of the study to all participating Day Habilitation programs and will distribute copies of the final paper to any interested parties.

Appendix D

Informed Consent Document: Participants

INFORMED CONSENT DOCUMENT**THE RELATIONSHIP BETWEEN RESTRICTED, REPETITIVE BEHAVIOR AND ANXIETY IN ADULTS WITH AUTISM SPECTRUM DISORDER AND INTELLECTUAL DISABILITY****INTRODUCTION**

We are asking people who attend your day program to participate in a research study. This study is being run by a college student at the Rochester Institute of Technology (RIT). This study was approved by the Arc and by RIT.

RESEARCHERS

Casey Mazzola will be running this study. She needs to do this project to get her master's degree. She works at one of the Arc's day programs. Dr. Pandolfi is a teacher at Casey's school who is helping her with this project. He is a psychologist and has worked with people with disabilities for over 20 years.

WHY ARE WE DOING THIS STUDY?

This research study is about anxiety and behavior. We want to learn about how people with disabilities behave when they feel anxious, worried or scared. This will help us tell when people with disabilities feel anxious, worried or scared, so we can help them.

YOUR CHOICE

Participating in this study is your choice. Please take your time and think about what you want to do. You can talk about it with your friends and family. It is O.K. to say "no" and not be in the study. Even if you say "yes," you can change your mind at any time. There will be no consequences for saying "no."

WHAT WILL YOU DO?

Being in the study will not take any of your time. The only thing you need to do is tell Casey if you want to be in the study.

If you want to be in the study, a staff person who knows you well will answer questions about you. The questions will ask about how you seem to feel, how you act, and what you talk about each day. The staff person will write answers to the questions on papers I give them. This is a research study so staff cannot tell you what they wrote about you. The staff person cannot tell anyone what they wrote about you.

Also, Casey will get some information about you from your IPOP like your age, your health, what kind of disability you have, and what kind of services you get. She will write this down on other papers. Casey needs this because it will help her understand the results of this study better. Casey will not share this information with anyone.

RISKS

We will do our best to make sure that all information about you stays private. Only Casey and her teacher Dr. Pandolfi will be able to see this information. If you feel upset about this study or have any questions about this study, your staff, Casey or Dr. Pandolfi can help you.

BENEFITS

Taking part in this study will not help you with any problems you might have with worry or feeling scared. If you need help with problems you are having in your life, you can do what you usually do- talk to your staff, your therapist or your nurse or doctor. But, by being in this study you can take part in helping people with disabilities in the future who feel anxious, scared, or worried.

PRIVACY

What staff writes about you is private. The staff person will not tell anybody what they wrote about you on the papers. Your name will not be on any of the papers. Casey will keep all of your papers in a safe place- in a locked office. Only Casey and Dr. Pandolfi are allowed to see your papers and they are not allowed to tell anyone anything about you.

INCENTIVES

You will not get anything for participating in the study. Being in the study is your choice.

YOUR RIGHTS

You can say no. If you say yes and change your mind later, you can leave the study at any time. If you say no it will not affect what you do or how you are treated at program.

CONCLUSION

Thank you for reading this and thinking about being in the study.

CONTACTS FOR QUESTIONS OR PROBLEMS

Please contact Casey Mazzola by phone at 585-698-5518 or by email at cmm6783@rit.edu or Dr. Vincent Pandolfi at vxpgla@rit.edu if you have any questions or concerns about the study.

Contact Heather Foti, at (585) 475-7673 or hmfsrcs@rit.edu if you have any questions or concerns about your rights.

PERMISSION TO PARTICIPATE IN RESEARCH

Signature: _____ Date: _____

Appendix E

Sample Script: Phone Call to Guardians

Hello Mr. Green,

My name is Casey Mazzola. I am a student at the Rochester Institute of Technology. I also am an employee of the Arc of Monroe County. I am going to be conducting a research study looking at the relationship between anxiety symptoms and repetitive behaviors in adults with intellectual and developmental disabilities. The Arc has approved this study. The study is a part of my degree program and is not being conducted on behalf of the Arc of Monroe or the Office for People with Intellectual and Developmental Disabilities (OPWDD).

I am recruiting participants from the Day Habilitation site that your son/daughter/ward/family member attends. I will be sending out an information packet that includes informed consent materials, details about what participation entails and the potential benefits the study has to offer. Participation is completely voluntary and will not have any impact on the services your son/daughter/ward/family member receives. Is it OK for me to send you the information about my study (IF SPEAKING DIRECTLY TO THE GUARDIAN RATHER THAN LEAVING A VOICE MAIL MESSAGE). If you have any questions please contact me by email at cmm6783@rit.edu or by phone at 585-698-5518. Thank you for your time.

Appendix F

Informed Consent Document: Guardians

INFORMED CONSENT DOCUMENT**THE RELATIONSHIP BETWEEN RESTRICTED, REPETITIVE BEHAVIOR AND ANXIETY IN ADULTS WITH AUTISM SPECTRUM DISORDER AND INTELLECTUAL DISABILITY****INTRODUCTION**

Legal guardians of adults with developmental disabilities who attend day program at the Arc of Monroe are being asked to consider providing informed consent for your ward to take part in a study about repetitive behaviors and anxiety. This study was approved by the Arc of Monroe and the Rochester Institute of Technology's Institutional Review Board, which reviews studies such as this one to make sure that the rights of research participants are protected.

STUDENT RESEARCHER AND FACULTY ADVISOR

This study is being conducted by Casey Mazzola, a Master's student in the Experimental Psychology Program at the Rochester Institute of Technology (RIT) who also is an employee at the Arc of Monroe. The study is a part of the student researcher's degree program and is not being conducted on behalf of the Arc of Monroe or the Office for People with Developmental Disabilities (OPWDD). Dr. Vincent Pandolfi, Associate Professor in the Psychology Department is the faculty advisor and will supervise all work on this project. Dr. Pandolfi is also a licensed psychologist who has over 20 years of experience working with individuals with developmental disabilities and in conducting research.

WHY ARE WE CONDUCTING THIS STUDY?

Research indicates that many adults with intellectual disability including those with and without autism spectrum disorder (ASD) also have problems with anxiety. Because many people with disabilities often have problems recognizing anxiety and communicating their needs to others it is often difficult for professionals to accurately assess them for anxiety. Cases often go undetected and many people do not receive appropriate treatment. Untreated mental health conditions can increase impairment and decrease a person's quality of life.

The goal of this study is to see if restricted, repetitive behaviors (RRB) can predict the presence of anxiety in adults with intellectual disability, including those individuals who also have autism spectrum disorder. RRB is an observable behavior that is observed in many people with disabilities, with and without ASD. Examples include hand flapping, asking the same question over and over, repeatedly flicking light switches, and difficulty with transitions. Studies with children suggest that RRB may be associated with the presence of anxiety. However, the relationship between anxiety and RRB has yet to be studied in adults.

THE CHOICE TO PARTICIPATE

Please take time to think about the study. Feel free to discuss it with friends and family. Participation is voluntary. You may choose at any time to withdraw your ward from the study without penalty. If you provide consent for your ward to participate in the study, he or she will be

asked to provide assent (agree to being in the study). Information about the study will be presented using his or her preferred form of communication (e.g., verbal, iPad, picture cues, etc.) in terms her or she can understand. Your ward will be asked if he or she would like to join or not join the study. He or she will provide their answer using his or her preferred form of communication.

If he/she communicates that he/she wants to join the study then he/she will participate. If your ward communicates that he/she does not want to join the study then he/she will not participate. If your ward does not respond he/she will be given two more chances. Members of your ward's day program team that know him or her best will decide if the your ward is capable of accurately communicating a choice using the preferred form of communication. If he/she is capable of communicating a choice but does not respond he/she will be considered as not providing assent and will not participate in the study. If your ward does not respond and cannot accurately communicate his or her choice then he/she will be deemed unable to provide assent; however, he or she will be allowed to participate in the study if you provided consent for him/her to participate. We expect each attempt to obtain assent will take five minutes.

WHAT ARE PARTICIPANTS REQUIRED TO DO?

Your ward will not be asked to do anything other than provide assent. A staff member who works with your ward every day will complete four questionnaires about your ward. To protect the confidentiality of staff research participants you will not be provided with the identity of the staff member who completes measures for your ward. Staff will complete the measures on their own; your ward will not be involved. The first questionnaire asks about autism symptoms. Even if your ward is not diagnosed with autism, that is OK- we expect that a number of participants will have few if any autism symptoms. The second measure evaluates adaptive functioning: it asks questions about how much support your ward needs to perform daily living tasks. The third measure assesses the presence and severity of different types of RRB. The fourth survey assesses anxiety symptoms. All of these questionnaires are needed to complete the study.

The researcher will need to access your ward's records to get other important information. We will need to know the following: your ward's age, gender, racial/ethnic status, housing arrangement/type of residence, if her or she has an autism diagnosis, severity of intellectual disability, medical diagnoses (e.g., cerebral palsy, genetic conditions, seizures), and psychiatric information (e.g., use of medication, psychiatric diagnoses, types of treatments received). All of this information is needed so that we know who the results of this study apply to. No personally identifiable information will be recorded such as name, date of birth, or social security number.

At the end of the study, your ward will be given a short description of what we found, using the preferred mode of communication, if he or she is interested and able to understand the summary of the results. All attempts will be made to tailor the summary of the results to your ward's level of understanding. Additionally, you will be sent a brief summary of the results of the study. None of the information collected about your ward will be used for treatment planning or for any decisions about him or her.

RISKS

This study has minimal risks: your ward is not likely to experience any risks over and above what he or she might experience on a typical day. Every effort will be made to protect confidentiality and is described below.

Should your ward experience any discomfort related to this study, such as when deciding about joining the study, the student researcher, Arc staff and professionals can provide assistance to support his or needs.

BENEFITS TO TAKING PART IN THE STUDY

Others in the future, including perhaps your ward, might benefit from the results of this study. If RRB is related to anxiety, changes in RRB may be a “red flag” that a person needs to be further evaluated for anxiety and perhaps other problems. As a result, we may be able to detect cases of anxiety in people who would have been otherwise overlooked. These people would then be able to receive specific treatments to reduce symptoms and overall lead to a better quality of life.

This study also adds to the research base on RRB. The results of this study could lead to a better understanding of what causes RRB. A better understanding of the cause of RRB is necessary in order to develop effective treatments. This study also provides more information on RRB in a population that is rarely studied: adults with intellectual and developmental disabilities. Most studies RRB are restricted to children with a diagnosis of autism who do not have impairments in intellectual functioning.

CONFIDENTIALITY

Every effort will be taken to maintain confidentiality. Participant names will only be on the informed consent document. Informed consent documents will be kept separate from all other research materials. Signed consent forms will be placed in an envelope and will be stored in the locked office of the student researcher’s faculty advisor at RIT.

A code key will be created to protect participant confidentiality. Only the student researcher and her faculty advisor will have access to the code key. This key contains the names of each participant and a number that is assigned to him or her. This number, instead of your ward’s name, will be recorded on all research materials. There will be a code key made for each day program site consisting of the participants’ names and corresponding numbers. They will be stored in the faculty advisor’s locked office at RIT, separately from the informed consent documents. All measures, record review forms and assent documents will not have names on them, only participant number. These will all be stored in separate envelopes and will be kept in the faculty advisor’s locked office. Research materials will be kept for the amount of time required by federal law and university policy.

Participant records will be accessed using Arc computers, which have been properly encrypted to ensure confidentiality. Data from all measures will be entered into Excel and will be stored electronically on a password protected flash drive that only the researcher and the faculty advisor will have access to. All data analysis will occur at RIT and no data including personally identifiable information about participants will be stored on university computers. The data file used for analysis will not contain any personally identifiable information.

Data will be analyzed and results will be presented in group form only. No names or personally identifiable information will be used in the write up of the study. Any conferences this study is presented at or publications of this study will not contain names or personally identifiable information.

INCENTIVES

There are no incentives for participating in this study.

YOUR RIGHTS AS A RESEARCH PARTICIPANT

Participation in this study is voluntary. You and your ward have the right not to participate at all and can leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which your ward is entitled, and it will not harm his/her relationship with staff or the researcher. If you or your ward choose to leave the study early, all data collected up to that point will be destroyed.

CONTACTS FOR QUESTIONS OR PROBLEMS

Please contact Casey Mazzola (researcher) by phone at 585-698-5518 or by email at cmm6783@rit.edu or Dr. Vincent Pandolfi (faculty advisor) at vxpgla@rit.edu if you have any questions or concerns regarding the study.

Contact Heather Foti, Associate Director of the HSRO at (585) 475-7673 or hmfsrcs@rit.edu if you have any questions or concerns about your rights as a research participant.

CONCLUSION

Thank you for taking the time to read about the study, and for considering whether to consent to your ward’s participation.

PERMISSION TO PARTICIPATE IN RESEARCH

As legal guardian, I authorize _____ (ward’s name) to become a participant in the research study described in this form.

Legal Guardian’s Signature: _____ Date: _____

Print Legal Guardian’s Name: _____

Appendix G

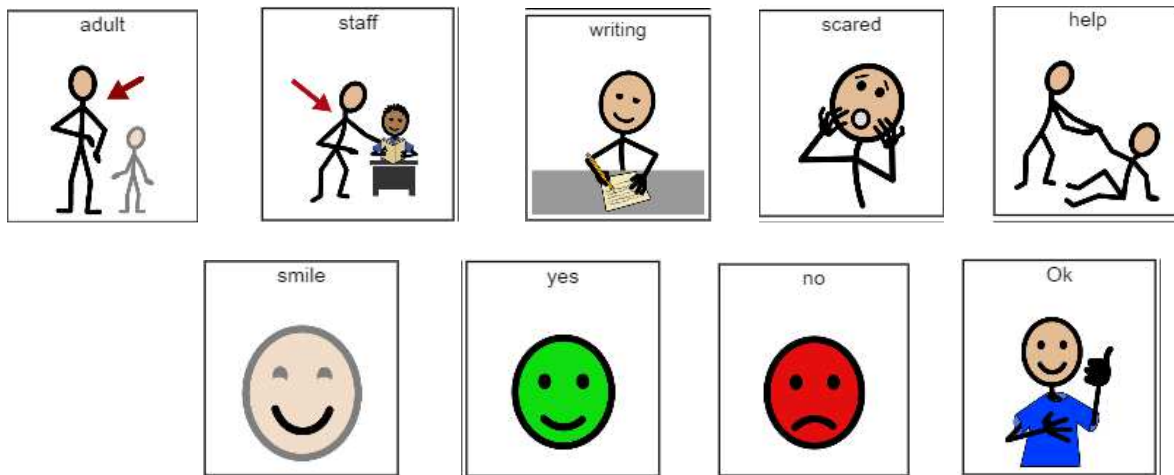
Sample Script: Participant Assent

Participants with Mild to Moderate Intellectual Disability: I am doing research about anxiety, RRB and behavior. I am asking people with disabilities to be in the study. If you want to be in the study, staff who know you well will answer questions about you. The questions will ask them how you seem to feel, how you act, and what you talk about each day. They will write answers to the questions on papers I give them. What they write is private and your name will not be on any of the papers. You can say “no” and not be in the study. Even if you say “yes” you can change your mind at any time. There will be no consequences for saying “no.” The research study will help us know how to tell when people with disabilities feel anxious, worried, or scared. Do you have any questions? Do you want to be in the study?

Participants with Severe to Profound Intellectual Disability: I am doing research. I want to learn how to know when people with disabilities feel upset, like worried, or scared. Staff will tell me how you seem to feel, and how you act each day. What they say is private. This study will help us know how to help people with disabilities when they feel upset. You can say “no.” It is OK to say “no.” There are no consequences. Would you like to be in the study? OK, you can change your mind at any time if you want to (if assent provided). Thank you for your help.

NOTE: Icons depicting key terms in the narrative will be used for those with significant receptive language problems. These icons can be used with any potential participant regarding level of intellectual disability. The use of icons will be based on what is known about the

potential participant given daily behavioral observations and case history. Icons (pictured below) were made for using SymbolStix PRIME (n2y LLC., 2016) for the following key terms: adult, staff, writing, scared, help, smile, yes, no, ok, question.



Appendix H

Participant Assent Documentation

Participant Assent Documentation

Participant Number: _____

Witnesses: _____

Trial Number: _____

1. Description of method of communication: _____

2. Can the participant respond reliably using this method of communication? Y/N

3. Description given to participant: _____

4. Participant's response: _____

5. Assent provided?

- Yes
- No
- No response

Appendix I

Staff Screening Survey

Name:

Site:

Core Room:

Please answer the following question to determine your eligibility to participate in this study.

1. How long have you worked in your current core room/site? _____

Appendix J

Informed Consent: Staff Respondents

INFORMED CONSENT DOCUMENT**THE RELATIONSHIP BETWEEN RESTRICTED, REPETITIVE BEHAVIOR AND ANXIETY IN ADULTS WITH AUTISM SPECTRUM DISORDER AND INTELLECTUAL DISABILITY****INTRODUCTION**

You are invited to take part in a study about repetitive behaviors and anxiety in adults with intellectual disabilities including those who also have autism spectrum disorder. We are looking for staff who work in Day Services at the Arc of Monroe to participate in the study. This study was approved by the Arc of Monroe and the Rochester Institute of Technology's Institutional Review Board, which reviews studies such as this one to make sure that the rights of research participants are protected.

STUDENT RESEARCHER AND FACULTY ADVISOR

This study is being conducted by Casey Mazzola, a Master's student in the Experimental Psychology Program at the Rochester Institute of Technology (RIT) who also is an employee at the Arc. The study is a part of the researcher's degree program and is not being conducted on behalf of the Arc of Monroe or the Office for People with Developmental Disabilities (OPWDD). Dr. Vincent Pandolfi, Associate Professor in the Psychology Department is the faculty advisor and will supervise all work on this project. Dr. Pandolfi is also a licensed psychologist who has over 20 years of experience working with individuals with developmental disabilities and in conducting research.

WHY ARE WE CONDUCTING THIS STUDY?

Research indicates that many adults with intellectual disability including those with and without autism spectrum disorder (ASD) also have problems with anxiety. Because many people with disabilities often have problems recognizing anxiety and communicating their needs to others it is often difficult for professionals to accurately assess them for anxiety. Cases often go undetected and many people do not receive appropriate treatment. Untreated mental health conditions can increase impairment and decrease a person's quality of life.

The goal of this study is to see if restricted, repetitive behaviors (RRB) can predict the presence of anxiety in adults with intellectual disability, including those individuals who also have autism spectrum disorder. RRB is an observable behavior that is observed in many people with disabilities, with and without ASD. Examples include hand flapping, asking the same question over and over, repeatedly flicking light switches, and difficulty with transitions. Studies with children suggest that RRB may be associated with the presence of anxiety. However, the relationship between anxiety and RRB has yet to be studied in adults.

THE CHOICE TO PARTICIPATE

Please take time to think about the study. Feel free to discuss it with friends and family. Participation is voluntary. You may choose at any time to withdraw from the study without

penalty. Your decision as to whether to participate will not affect your employment at Arc of Monroe.

WHAT ARE PARTICIPANTS REQUIRED TO DO?

You will be asked to complete a screening survey assessing your eligibility to serve as an informant. The survey will ask you to provide your name, site and core room and will ask if you have worked in your current core room for at least six months. All information you provide will be kept confidential. Eligible staff respondents who consent to participation will be assigned participants (people in their core room) who they will complete measures for. Measures will be completed only for those adult participants for whom consent and assent (where applicable) was received. Guardians that consented for their ward's participation in the study will not be informed of who completed the measures for their ward. Guardians will not be provided with the identity of staff completing measures for their ward. In the case that there are no individuals from your core room who choose to participate in the study, you may not be assigned any participants. If you are the only staff in your core room participating in the study, you may complete measures for as many participants in your room as you like.

You will complete four measures for each participant that you are assigned. The first measure asks about the person's autism symptoms, such as how they interact with others and how they react to change. This measure is expected to take less than 10 minutes to complete. The second measure evaluates adaptive functioning. It asks questions about how much support the person needs to perform daily living tasks. This measure is expected to take between 15 and 20 minutes to complete. The third measure assesses the presence and severity of different types of RRB and will take approximately 10 minutes to complete. The fourth survey assesses anxiety symptoms and is expected to take less than 5 minutes to complete. In total, it is likely to take between 30 and 45 minutes to complete all of the measures for one participant.

The researcher will give you an envelope containing all of the measures for your first participant and will answer any questions you may have. You must complete all measures for one participant before moving onto the next participant. When you have completed all of the measures, the researcher will check the measures for completion and will then give you the materials for your next participant. Measures do not need to be completed in one sitting; you can start and stop as needed. You can work on measures in the morning before program participants arrive and in the afternoon after they have left and after all end of the day tasks have been completed. Participation in this study cannot interfere with normal work activities.

At the end of the study, you will receive a brief write-up detailing the results of the study. The researcher will also present the findings at staff meeting. Copies of the final paper will be distributed to any staff who are interested.

RISKS

This study has minimal risks: you are not likely to experience any risks over and above those encountered in your everyday work setting. Every effort will be made to protect confidentiality and is described below.

Should you experience any discomfort related to this study, such as balancing work duties with participation in the study, the student researcher and professionals can provide assistance to support your needs.

BENEFITS TO PARTICIPATING

Although this study will not benefit you directly, others in the future, including perhaps the people you support, might benefit from the results of this study. If RRB is related the anxiety, changes in RRB may be a “red flag” that a person needs to be further evaluated for anxiety and perhaps other problems. As a result, we may be able to detect cases of anxiety in people who would have been otherwise overlooked. These people would then be able to receive specific treatments to reduce symptoms and overall lead to a better quality of life.

This study also adds to the research base on RRB. The results of this study could lead to a better understanding of what causes RRB. A better understanding of the cause of RRB is necessary in order to develop effective treatments. This study also provides more information on RRB in a population that is rarely studied: adults with intellectual and developmental disabilities. Most studies RRB are restricted to children with a diagnosis of autism who do not have impairments in intellectual functioning.

CONFIDENTIALITY

Every effort will be taken to maintain confidentiality. Your name will appear on the informed consent document and the staff screening survey. These will be stored in separate envelopes in the faculty advisor’s locked office.

A code key will be created to protect staff participant confidentiality. Only the student researcher and her faculty advisor will have access to the code key. This key contains the names of each staff participant and a number that is assigned to him or her. This number, instead of your name, will be recorded on all research materials. The code key will be stored in the faculty advisor’s locked office at RIT and will be kept separate from all other research materials.

Signed consent forms will be placed in an envelope and will be stored in the faculty advisor’s locked office at RIT. These will be kept separately from all other research materials. No personally identifiable information will be entered into Excel, such as your name. Research materials will be kept for the amount of time required by federal law and university policy. All data analysis will occur at RIT and no data will be stored on university computers. The data file used for analysis will not contain any personally identifiable information.

Data will be analyzed and the results will be presented in group form only. No names or personally identifiable information will be used in the write up of the study. Any conferences this study is presented at or publications of this study will not contain names or personally identifiable information.

INCENTIVES

All staff participants will be entered into a raffle to win a \$50 visa gift card. All staff who sign the consent form and return it to the research will be entered into the raffle. Even if you leave the study early or are not assigned any participants, you are still eligible to win the gift card.

YOUR RIGHTS AS A RESEARCH PARTICIPANT

Participation in this study is voluntary. You have the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which you entitled, and it will not harm his/her relationship with staff or the researcher. If you choose to leave the study early, all data collected

up to that point will be deleted/destroyed. Your employment at Arc of Monroe will not be affected in any way regardless of how much you wish to participate.

CONTACTS FOR QUESTIONS OR PROBLEMS

Please contact Casey Mazzola (researcher) by phone at 585-698-5518 or by email at cmm6783@rit.edu or Dr. Vincent Pandolfi (faculty advisor) at vxpgla@rit.edu if you have any questions or concerns regarding the study.

Contact Heather Foti, Associate Director of the HSRO at (585) 475-7673 or hmfsrcs@rit.edu if you have any questions or concerns about your rights as a research participant.

CONCLUSION

Thank you for taking the time to read about the study, and for considering whether to participate in the study.

CONSENT TO PARTICIPATE IN RESEARCH

By signing this form I am stating that I understand the above information and consent to participating in this study.

Signature

Date

Printed Name

Appendix K

Record Review Form

Record Review Form

Participant Number: _____

I. General Information

Age:

Gender:

Race:

Ethnicity:

ASD Diagnosis: Y/N

ID Severity: Mild Moderate Severe Profound Unspecified

Living Arrangement: Arc Group Home Other Agency Group Home Lives with Family

Other (specify/describe):

II. Medical Information

Genetic Condition: Y/N

If yes list what condition(s): _____

History of Seizures: Y/N

Cerebral Palsy: Y/N

Other Medical Conditions: _____

III. Current Psychiatric Information

Diagnosis of a Psychiatric Disorder: Y/N

If yes list what condition(s): _____

Taking Medication: Y/N

Receiving Psychiatric Services: Y/N
Receiving Psychological Services: Y/N
Receiving Behavior Intervention for RRB: Y/N
Receiving Occupational Therapy: Y/N
Other Services (specify):

Appendix L

Sample Code Key: Participants

All names are fictional. Participant number is assigned based on site (1st number), core room (2nd number) and location in the alphabetized series of last names in their core room (3rd number). Only those participants whose legal guardian provided consent will appear on this form. Staff participant number, not name, will appear on this form.

Code Key
Site #1

Name	Participant Number	Assent provided? (Y/N/Unable)	Staff Completing Measures	Data collection completed (Check when complete)
Albert Green	111			
Ashley Austin	121			
Alfred Jones	122			

Code Key
Site #2

Name	Participant Number	Assent provided? (Y/N/Unable)	Staff Completing Measures	Data collection completed (Check when complete)
Ryan Gold	211			
Ralph Jackson	212			
Ricky Rose	213			

Code Key
Site #3

Name	Participant Number	Assent provided? (Y/N/Unable)	Staff Completing Measures	Data collection completed (Check when complete)
James Thomas	311			
Jordan Williams	312			
Jackie Jones	321			

Appendix M

Sample Code Key: Staff

All names are fictional. Staff participant number will be assigned using a random number generator. Only staff who provided informed consent will appear on this form.

Staff Code Key

Name	Participant Number
Angela Avery	12
Gary Harris	38
Julia Jordan	7

Table 1

Participant Demographics

	Number	Percent
Gender		
Male	22	46.8
Female	25	53.2
Race (<i>n</i> = 45)		
White/Caucasian	39	86.7
Black/African American	6	13.3
Ethnicity		
Non-Hispanic/Latino	45	95.7
Hispanic/ Latino	2	4.3
Living Arrangement		
Arc Group Home	26	55.3
Other Agency Group Home	12	25.5
Family	9	19.1
ASD Diagnostic Status		
Diagnosis of ASD	10	21.3
No ASD Diagnosis	37	78.7
Severity of ID		
Mild	14	29.8
Moderate	23	48.9
Severe	3	6.4
Profound	6	12.8
Unspecified	1	2.1
At least one medical condition	47	100.0
Specific Conditions		
Allergies	17	36.2
Anemia	10	21.0
Arthritis	11	23.4
Asthma	2	4.3
Cancer	3	6.4
Cerebral Palsy	11	23.4
Dementia	5	10.6
Dental condition	10	21.3
Dermatitis	16	34.0
Diabetes	5	10.6
Digestive	36	76.6
Gallbladder	3	6.4
Genetic condition	11	23.4
Down syndrome	10	21.3
Fragile X	1	2.1
Hearing impairment	16	34.0

Table 1 Continued

	Number	Percent
Heart condition	16	34.0
Hormone abnormality	3	6.4
Hypertension	10	21.3
Kidney disorder	13	27.7
Metabolic disorder	9	19.1
Neurological condition	14	29.8
Osteoporosis	19	40.4
Reproductive disorder	11	23.4
Seizures	21	44.7
Sleep disorder	9	19.1
Speech- language disorder	14	29.8
Spine disorder	16	34.0
Thyroid disorder	15	31.9
Visual impairment	30	63.8
Vitamin B-12 deficiency	4	8.5

Notes. $N = 47$ unless otherwise specified.

Table 2

Psychiatric Diagnoses and Treatments

	Number	Percent
Diagnosed with at least one psychiatric condition	34	72.3
Diagnosed with two or more psychiatric conditions	28	59.6
Specific Diagnoses		
Depression	21	44.7
Anxiety	21	44.7
Unspecified mood disorder	9	19.1
Psychosis	8	17.0
Impulse control disorder	8	17.0
Bipolar disorder	5	10.6
OCD	3	6.4
ADHD	3	6.4
Personality disorder	3	6.4
PTSD	2	4.3
Treatments		
Taking psychotropic medication	31	66.0
Psychiatric services	22	46.8
Speech therapy	16	34.0
Physical therapy	14	29.8
Psychological services	9	19.1
Occupational therapy	9	19.1
Behavioral treatment for RRB	0	0.0

Notes. $N = 47$

Table 3

Descriptive Statistics of Measures used in the Regression Analyses

	Mean (SD)	Range
SCQ-C		
Total Score	13.36 (4.52)	4 - 24
Without RRB Items	11.34 (3.55)	4 - 21
ABAS-3		
GAC	59.62 (6.48)	49 - 80
Sum of Raw Scores	268.51 (122.42)	15 - 550
DASH-II		
Anxiety Subscale Score	1.53 (2.17)	0 - 10
RBS-R		
Total Score	9.04 (9.42)	0 - 40
Stereotypic Behavior Subscale Score	1.83 (3.22)	0 - 16
SIB Subscale score	1.00 (2.13)	0 - 11
Compulsive Behavior Subscale Score	1.32 (1.97)	0 - 8
Ritualistic/Sameness Behavior Subscale Score	3.83 (4.78)	0 - 17
Restricted Interests Subscale Score	1.06 (1.39)	0 - 5

Notes. $N = 47$.

Table 4

Reliability of Measures Used in the Regression Analyses

	# of Items	Mean Inter-Item Correlation	Lambda-2
SCQ-C	24	.091	.742
ABAS-3	215	.354	.992
DASH-II	8	.264	.769
RBS-R (Lam & Aman, 2007 Version)			
Total score	38	.151	.895
Stereotypic Behavior	9	.348	.853
SIB	8	.287	.842
Compulsive Behavior	6	.245	.642
Ritualistic/Sameness Behavior	12	.274	.835
Restricted Interests	3	.325	.590

Notes. $N = 47$.

Table 5

Correlations between Predictor and Criterion Variables

	RBS-R Total Score	RBS-R Stereotypic Behavior	RBS-R SIB	RBS-R Compulsive Behavior	RBS-R Ritualistic/Sameness Behavior	RBS-R Restricted Interests	Age	SCQ-C Score	ABAS-3 Raw Score	DASH-II Anxiety Score
RBS-R Total Score		.763**	.343*	.622**	.843**	.703**	-.142	.295*	-.151	.347**
RBS-R Stereotypic Behavior			.238	.232	.457**	.591**	-.306*	.458**	-.221	.172
RBS-R SIB				.000	-.013	.287	-.144	.109	.041	-.005
RBS-R Compulsive Behavior					.565**	.318*	.113	.077	-.011	.235
RBS-R Ritualistic/Sameness Behavior						.437**	-.044	.044	-.086	.427**
RBS-R Restricted Interests							-.043	.511**	-.262*	.162
Age								-.208	-.257*	-.015
SCQ-C Score									-.182	.069
ABAS-3 Raw Score										-.002
DASH-II Anxiety Score										

Notes. $N = 47$.

* $p < .05$

** $p < .01$

Table 6

Regression Results for RBS-R Total Score

Predictor	<i>b</i>	<i>SE</i>	95% <i>CI</i> ^a	<i>sr</i> ²	<i>p</i> ^a
Age	-.081	.088	-.294, .075	.014	.293
SCQ-C Score without RRB Items	.582	.365	-.128, 1.278	.043	.266
ABAS-3 Raw Score	-.011	.011	-.036, .009	.018	.089
DASH-II Anxiety Subscale Score	1.435	.568	.368, 3.404	.108	.013
<i>R</i> ²	.219		.033, .421		.003

Notes. *N* = 47.

^a Bias corrected 95% confidence interval and *p* value derived from 10,000 bootstrap samples with replacement.

Table 7

Regression Results for RBS-R Stereotypic Behavior Subscale

Predictor	<i>b</i>	<i>SE</i>	95% <i>CI</i> ^a	<i>sr</i> ²	<i>p</i> ^a
Age	-.063	.028	-.148, -.014	.074	.011
SCQ-C Score without RRB Items	.312	.116	.100, .624	.106	.003
ABAS-3 Raw Score	-.006	.003	-.014, .001	.048	.082
DASH-II Anxiety Subscale Score	.213	.181	-.185, .991	.020	.379
<i>R</i> ²	.323		.063, .498		.006

Notes. *N* = 47.

^a Bias corrected 95% confidence interval and *p* value derived from 10,000 bootstrap samples with replacement.

Table 8

Regression Results for RBS-R Self-Injurious Behavior Subscale

Predictor	<i>b</i>	<i>SE</i>	95% <i>CI</i> ^a	<i>sr</i> ²	<i>p</i> ^a
Age	-.017	.022	-.063, .020	.012	.327
SCQ-C Score without RRB Items	.054	.092	-.156, .201	.007	.552
ABAS-3 Raw Score	.000	.003	-.003, .004	.001	.798
DASH-II Anxiety Subscale Score	-.013	.143	-.215, .343	.000	.993
<i>R</i> ²	.028		(..., .078)		.074

Notes. *N* = 47.

^a Bias corrected 95% confidence interval and *p* value derived from 10,000 bootstrap samples with replacement.

Table 9

Regression Results for RBS-R Compulsive Behavior Subscale

Predictor	<i>b</i>	<i>SE</i>	95% <i>CI</i> ^a	<i>sr</i> ²	<i>p</i> ^a
Age	.020	.020	-.028, .063	.019	.381
SCQ-C Score without RRB Items	.056	.083	-.141, .170	.009	.476
ABAS-3 Raw Score	.001	.002	-.006, .005	.002	.849
DASH-II Anxiety Subscale Score	.209	.129	.035, .704	.053	.022
<i>R</i> ²	.078		.005, .190		.024

Notes. *N* = 47.

^a Bias corrected 95% confidence interval and *p* value derived from 10,000 bootstrap samples with replacement.

Table 10

Regression Results for RBS-R Ritualistic/Sameness Behavior Subscale

Predictor	<i>b</i>	<i>SE</i>	95% <i>CI</i> ^a	<i>sr</i> ²	<i>p</i> ^a
Age	-.022	.045	-.129, .068	.004	.679
SCQ-C Score without RRB Items	-.025	.188	-.475, .280	.000	.908
ABAS-3 Raw Score	-.004	.006	-.018, .008	.010	.475
DASH-II Anxiety Subscale Score	.942	.293	.353, 1.636	.181	.009
<i>R</i> ²	.194		.016, .387		.006

Notes. *N* = 47.

^a Bias corrected 95% confidence interval and *p* value derived from 10,000 bootstrap samples with replacement.

Table 11

Regression Results for RBS-R Restricted Interests Subscale

Predictor	<i>b</i>	<i>SE</i>	95% <i>CI</i> ^a	<i>sr</i> ²	<i>p</i> ^a
Age	.001	.012	-.020, .023	.000	.962
SCQ-C Score without RRB Items	.185	.051	.086, .272	.200	.001
ABAS-3 Raw Score	-.002	.001	-.005, .001	.026	.203
DASH-II Anxiety Subscale Score	.083	.079	-.092, .290	.017	.257
<i>R</i> ²	.307		.089, .497		.003

Notes. *N* = 47.

^a Bias corrected 95% confidence interval and *p* value derived from 10,000 bootstrap samples with replacement.