

## Behavioral Assessment and Treatment of Anxiety in Individuals with Intellectual Disabilities and Autism

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**Abstract** Individuals with intellectual disabilities (ID) and autism spectrum disorders may be at increased risk for anxiety disorders. Unfortunately, research on the assessment and treatment of anxiety disorders in individuals with ID has lagged behind that related to typically developing individuals. This paper reviews the existing literature and also draws from the research on anxiety in typically developing persons as a basis for discussing the behavioral assessment and treatment techniques applicable to individuals with ID and autism who also have anxiety. Challenges in identifying anxiety in this population are discussed and methods of behavioral assessment discussed include rating scales, behavioral interviews, direct observation of behavior, and physiological measures are reviewed. Treatment procedures discussed include graduated exposure and reinforcement.

**Keywords** Anxiety · Intellectual disabilities · Autism · Behavioral assessment · Behavioral treatment

There is some evidence to suggest that individuals with intellectual disabilities (ID) and autism spectrum disorders may be at increased risk for anxiety disorders. For example, Dekker and Koot (2003) found that approximately 22% of a Dutch community sample of 474 individuals (age 7 to 20 years) with ID met *Diagnostic and Statistical Manual—4th Edition Text Revision* (DSM-IV-TR; American

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Psychiatric Association 2000) criteria for some form of anxiety disorder. Another study found that 13.6% of a Canadian sample of children with autism and Asperger's syndrome were found to experience "generalized anxiety" (Kim et al. 2000). More recently, Sukhodolsky et al. (2008) reported that 43% of a sample of 171 children with Pervasive Developmental Disorders (PDD) met DSM-IV criteria for at least one anxiety disorder. As a point of comparison, the 1-year prevalence of an anxiety disorder in the general population was found to be 18.1% (Kessler et al. 2005). In a direct comparison of children with and without PDD, Weisbrot et al. (2005) found more children with PDD were rated as having anxiety symptoms by parents and teachers.

Anxiety is a constellation of responses that normally occur in the face of a potential threat. Broadly speaking, an anxiety disorder is characterized by a fear response that is out of proportion relative to the actual threat, and/or extreme in its intensity to the extent that it significantly disrupts the individual's functioning. Anxious responses include behavioral avoidance of the feared situation, affective states involving subjective fear and panic, cognitions of worry and dread, and states of aversive and intense physiological arousal. Generally, anxiety disorders are classified in the DSM according to stimuli that occasion these responses and/or the nature of the anxious response. For instance, specific phobias involve fear and avoidance of particular situations or stimuli (other than social situations, which would be classified as Social Phobia). Agoraphobia involves avoidance of situations in which immediate escape might be difficult, sometimes resulting in the individual refusing to leave home. Panic Disorder may not be occasioned by any particular stimulus, but involves sudden and unexpected panic attacks and can occur with and without Agoraphobia. Obsessive-Compulsive Disorder is characterized by persistent and distressful obsessional thoughts (e.g., contamination) and compulsive behaviors (e.g., cleaning) aimed at ameliorating the distress associated with the obsessional thoughts. Post Traumatic Stress Disorder involves intense re-experiencing of a past traumatic event. Generalized Anxiety Disorder is characterized by general and excessive worry not explained by another anxiety disorder. In children, Separation Anxiety Disorder is diagnosed when there is excessive anxiety concerning separation from and concern about the well-being of major attachment figures (DSM-IV-TR 2000).

Despite increased risk for anxiety disorders in individuals with ID, research on the assessment and treatment of anxiety disorders in the individuals with ID has lagged behind that related to typically developing individuals. Our review of the literature published in the past 35 years revealed only 48 studies (about half of which are uncontrolled case reports) describing the treatment of anxiety in individuals with ID with and without an autism spectrum disorder. In contrast, the literature on the treatment of anxiety in children and adults without ID is quite extensive. We identified 60 studies published in the past 10 years alone, the majority of which are large scale controlled trials or meta-analyses. Further, hundreds of other articles describing other issues related to the treatment of anxiety disorders such as comorbidity, pharmacological treatment, and predictors of treatment outcome have been published during this same time period. In light of these discrepancies and the increased prevalence of anxiety in individuals with ID, a review and summary of existing knowledge is needed.

## Assessment and Differential Diagnosis

### General Considerations for Assessment of Anxiety in Individuals with ID

Emotional behaviors, such as anxiety, are generally thought to include multiple response components from behavioral, physiological, verbal/cognitive, and affective domains (Davis and Ollendick 2005). Therefore, assessment of anxiety disorders is typically conducted through multimodal assessment, including direct observation of behavior, as well as self-report of cognitions, affective states, and sometimes physiological responses evoked by feared stimuli (King et al. 1997; Velting et al. 2004). However, for individuals with ID, cognitive and communication deficits may make the assessment of cognitions, and affective and physiological states through self-report challenging, and in some cases not possible (Ollendick et al. 1993). The tendency for clinicians to attribute symptoms of psychopathology to the cognitive deficits of the individual, a phenomenon known as diagnostic overshadowing (Reiss et al. 1982), also makes accurate diagnosis of individuals with ID challenging. Another issue that complicates this process is the determination of whether behavioral difficulties or negative emotional states are due to anxiety or some other problem. Described below are methods for assessment that are aimed at overcoming some of these difficulties. Tools and methods that will be discussed include rating scales, behavioral interviews, direct observation of behavior, and physiological measures, as well as considerations for differential diagnosis.

### Rating Scales

Use of rating scales may be most useful in the initial phases of assessment, primarily for ruling in and out a broad range of possible anxiety-eliciting stimuli and diagnoses. Some rating scales rely on the report of informants, whereas others require the individual to respond to questions. As noted above, completion of rating scales based on self-report may be difficult with some individuals with ID due to their language limitations. However, there is some evidence that the self-report format can be reliable and valid for certain individuals with ID. For example, researchers have found items that require a response on a likert rating scale and questions that require a yes/no response can produce appropriate responses from individuals with ID (Hartley and MacLean 2006; Heal and Sigelman 1995; Ramirez 2005). However, responses in these formats are more accurate for individuals in the borderline to moderate range of intellectual functioning (Hartley and MacLean 2006). Modifications to the format, such as including pictorial representations of response alternatives in a likert scale and limiting the number of words in the alternatives, has also been found to increase the likelihood of gaining an appropriate response (Hartley and MacLean 2006). One concern as to use of self report is acquiescence, or choosing the more positive response. Some researchers have found that individuals in the lower range of functioning are more likely to chose the more positive response alternative (Hartley and MacLean 2006); while other researchers have found no significant differences in acquiescence between children with borderline to moderate ID and those without (Ramirez 2005).

In general, there are three categories of rating scales available for the assessment of anxiety in individuals with ID. These include: 1) instruments designed specifically to assess anxiety disorders in individuals with ID, 2) instruments designed originally to assess anxiety in typically developing individuals which have been extended to individuals with ID, and 3) instruments designed to assess a broad range of psychopathology, including anxiety, but specifically for individuals with ID.

*Instruments Designed for Assessing Anxiety in Individuals with ID* Recently, a few instruments designed specifically to assess anxiety in individuals with ID have been developed. The Anxiety, Depression, and Mood Scale (ADAMS; Esbensen et al. 2003) was developed as an observationally based informant rating scale of symptoms related to anxiety, depression, and mania. Participants included individuals from the mild to profound range of cognitive functioning. Preliminary data support this instrument as a psychometrically sound tool for assessing OCD, but support for its use with other anxiety disorders is limited.

The Glasgow Anxiety Scale (Mindham and Espie 2003) is another instrument developed specifically to assess anxiety in individuals with ID. Unlike the ADAMS, this instrument is a self-rating scale using a 3-point likert scale with visual representations of response options; and it is designed to measure cognitive, behavior, and somatic symptoms of anxiety. This instrument was developed and validated with individuals in the mild to moderate range of ID and, therefore, the self-report format may not be applicable to individuals with more severe deficits. Initial results based on a small sample show that it has good reliability and validity.

The Fear Survey for Adults with Mental Retardation (FSAMR; Ramirez and Luckenbill 2007) is a self-rating scale that requires yes or no responses and was initially validated with participants in the mild to moderate range of functioning. It was developed to update older fear surveys, such as the Fear Survey Schedule for Children—Revised (FSSC-R; Ollendick 1983) and the Fear Survey Schedule for Children-II (FSSC-II; Gullone and King 1992), and to ensure that the fears assessed were applicable to individuals with ID. Research has found that adults with ID may exhibit a different pattern of fears than children or adults without ID; thus, the content of existing fear surveys may not be adequate to address their needs (Ramirez et al. 2000).

#### *Instruments Designed for Assessing Anxiety in Typically Developing Individuals*

Some instruments used to assess anxiety in individuals with ID were originally developed for children or adults without ID. The FSSC-R and FSSC-II have been extended for use with individuals with ID (Gullone et al. 1996; King et al. 1994). The administration was adapted to enhance understanding of the items as well as the response choices. Adaptations to the items involved both verbal and visual presentation as well as simplified language; and adaptation to the response choices involved the use of a visual analogue scale of facial expressions of fear to supplement the choices. Neutral items were also included to assess acquiescence. With these adaptations, both versions of the Fear Survey Schedule were found to be psychometrically sound instruments for assessing fears in children and adolescents with mild to moderate ID.

The Zung Self Rating Anxiety Scale was also adapted for use with adults with ID (Lindsay and Michie 1988). The scale was originally developed for assessing anxiety in children using a likert scale format, however, item presentation and response format were adapted for use with adults with ID by verbally presenting the items, using simplified language and clarifying responses, and requiring yes-no responses. This adaptation was compared with the standard presentation and found to be reliable in individuals with mild to moderate ID; whereas the standard presentation was not reliable (Lindsay and Michie 1988). The adapted version has also been found to have good convergent validity for individuals with ID (Masi et al. 2002).

*Instruments Assessing a Broad Spectrum of Psychopathology in Individuals with ID* The final category of rating scales consists of instruments designed to assess a broad spectrum of psychopathology in individuals with ID and includes the Diagnostic Assessment for the Severely Handicapped (DASH; Matson et al. 1991), Diagnostic Assessment for the Severely Handicapped-II (DASH-II; Matson et al. 1997), Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson et al. 1984), Assessment for Dual Diagnosis (ADD; Matson and Bamburg 1998), Emotional Disorder Rating Scale for Developmental Disabilities (EDRS-DD; Feinstein et al. 1988), Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD; Moss et al. 1998), and the Aberrant Behavior Checklist (ABC; Aman et al. 1985). Each of these scales includes several different subscales aimed at screening individuals for various psychiatric disorders, including anxiety. However, subscales designed to assess anxiety are generally limited to a few items. Items typically target more general anxiety (e.g., worry) and may be most appropriate in the early stages of assessment or when there are concerns that there may be other forms of psychopathology besides anxiety. Finally, with the exception of the PIMRA, which also has a self-report version, each of these assessment tools are informant based rating scales. This method of assessment may be necessary for certain individuals with ID because of their cognitive, and specifically language deficits, however this format is prone to observer bias and interpretation and may not assess the appropriate components of anxiety. The majority of these instruments have been validated only with individuals with borderline, mild, and moderate ID. The only instruments that have been validated with individuals with severe and profound ID are the DASH and DASH-II.

### Behavioral Interviews

While rating scales can be helpful in providing a broad overview with regard to the range of feared stimuli and other forms of psychopathology, behavioral interviews should be conducted to gather more individualized information about anxiety-related behaviors and their controlling variables. Behavioral interviews should be conducted with individuals with ID to the extent possible given the individual's cognitive and language capabilities. In many cases, parents and other care providers may be the primary informants. However, impairments across social, communicative, emotional, and adaptive domains that characterize ID may make it difficult for care providers to identify possible variables controlling anxiety. For example, an individual with ID

and OCD may be limited in his/her ability to verbalize obsessional thoughts that trigger compulsive behavior, making impossible for the care provider to identify something in the environment that triggered the compulsion (or anxiety when the compulsion was blocked). Nevertheless, the interview is probably the best starting point for both defining the anxious response (including each of the response components), as well as developing hypotheses about the controlling antecedent and consequent variables. Additionally, understanding the nature of the anxious response and the conditions under which it occurs is key to formulating a diagnosis which is important for both appropriate classification as well developing a treatment plan.

Behavioral interviews generally focus on operationally defining problematic behaviors and identifying their controlling variables (events that may occasion anxiety/avoidance as well as those events that may reinforce these behaviors). Generally, individuals avoid certain situations or stimuli that induce anxiety by refusing to move toward the stimulus (avoidance) or actively moving away from those stimuli (escape). For young children and individuals with ID who may be unable to verbally express fear or their desire to avoid a situation, avoidance may be more likely to occur with other responses such as aggression, property destruction, and self-injury—particularly when initial attempts to avoid or escape are ineffective (e.g., Hagopian et al. 2001; Riccardi et al. 2006). Although avoidant and escape responses are generally maintained by negative reinforcement (i.e., escape or avoidance of the feared stimulus), it is important to identify what other consequences these behaviors produce that may inadvertently strengthen them (such as adult attention, consoling, or access to preferred activities).

The behavioral interview should result in formulation of hypotheses about the controlling variables of anxiety, with an eye toward designing subsequent behavioral observations. For example, if interview findings are not definitive with regard to which stimuli actually elicit anxiety, then it may be useful to obtain larger behavioral samples in naturalistic settings (via parent or teacher monitoring; see below under Direct Observation of Behavior). Alternatively, more definitive interview findings suggesting that anxiety occurs reliably and exclusively under certain conditions may guide the development of a behavioral avoidance test (BAT; described further below). Further, the information obtained in the interview may indicate additional assessment tools or techniques to further define some or all of the response components. For example, if the interview reveals that the individual has intense physiological responses, then including additional measures of this response component may be appropriate. Although direct psychophysiological recording would be ideal and is often recommended (see below), there is no study to date documenting the use of such measures in the assessment of anxiety in individuals with ID. A more practical alternative in such cases might be to include behavioral observation measures indirectly indexing physiological responding such as ratings of respiration or perspiration.

### Direct Observation of Behavior

As described above, information obtained via interviews of the individual and care providers, and findings obtained from self- and other-report should be used to guide initial behavioral observations. While findings from interviews and self-report measures can help narrow the focus of the problem and guide the formulation of

hypotheses regarding the controlling variables of anxiety and avoidant behavior, direct behavioral observation is needed to clarify and validate these findings. As will be discussed later, use of formalized observation procedures can be instrumental in the process of assessment, treatment development, and objectively evaluating treatment outcomes.

Determining whether the stimuli that occasion anxiety can be precisely identified and presented in a controlled manner is critical to designing formalized behavior observational procedures. For example, some studies have described cases in which anxiety was elicited by specific stimuli such as water, needles, or dental care (Conyers et al. 2004; Rapp et al. 2005; Shabani and Fisher 2006). Certain anxiety disorders, such as specific phobias, obsessive compulsive disorder, social phobia, and separation anxiety disorder are characterized by anxiety that is often elicited by a specific stimulus or classes of stimuli. In these cases, presentation of the anxiety-inducing stimulus in a controlled fashion may be possible. In other cases, however, the stimuli that occasion anxiety may be difficult to identify or control, precluding their presentation in a controlled manner. For example, individuals with generalized anxiety disorder may not be able to identify specific stimuli that reliably elicit fear. In other cases, stimuli may be identifiable but difficult to present and terminate with the level of control required in treatment—such as the behavior of peers and certain internal stimuli (such as physiological sensations).

*Behavioral Avoidance Test* In cases where the anxiety-inducing stimulus is identifiable and can be presented in a controlled fashion, it is possible to arrange conditions to directly observe the anxious response *in vivo*. A Behavioral Avoidance Test (BAT; Dadds et al. 1994) is a highly structured method of assessing avoidant behavior associated with the feared stimulus. Generally, this procedure involves progressively exposing the individual to the feared stimulus along some dimension (e.g., distance, time), and recording the point at which the avoidant response is displayed. BATs can be highly individualized based on the specific stimuli that elicit fear to the person being observed. In addition to the benefit of observing the anxiety responses directly and in a controlled manner, one can use the same method of stimulus presentation during treatment to systematically expose the individual to the stimulus and to evaluate intervention outcomes in a highly rigorous and objective manner. Although the BAT has been a widely utilized observational measure for assessing certain anxiety disorders across populations, it may be especially important to include a BAT in the assessment of anxiety disorders in individuals with ID given that self-report and interview data may be limited. Many of the available clinical case studies that report on the assessment and treatment of anxiety in this population describe the use of a BAT (e.g., Erfanian and Miltenberger 1990; Matson 1981).

*Naturalistic Behavioral Observation* In cases where a BAT is not possible because the anxiety-inducing stimulus cannot be readily presented in a controlled manner, one may need to rely solely on naturalistic observations. Direct observations by therapists in the naturalistic setting can be helpful at various points in the assessment and treatment process. However, it may not be feasible for therapists to obtain a sufficient sample of behavioral data over the course of treatment to the extent necessary required for treatment evaluation. Therefore, enlisting care providers to



monitor anxious behavior (as well as antecedent and consequent events) may yield the most complete information. In contrast to self- and other-report measures described above which involve the retrospective reporting of behavioral patterns or tendencies (often using questionnaires), behavioral monitoring refers to the observation and recording of discrete behaviors in real time. For example, behavioral monitoring may involve a mother recording each time she observes her child checking to see if a door is locked along with any observable antecedents and consequences for this behavior. Parents can also provide ratings of subjective distress based on observable indices of affect such as crying, trembling, or flushed facial expressions. Knox et al. (1996) evaluated exposure and response prevention for four typically developing children with OCD during which the children and their parents monitored the frequency of compulsions, subjective distress, as well as the triggers and parental consequences during the assessment phase and throughout the treatment. This information was used not only during the assessment phase, but also to establish a pre-treatment baseline and monitor the effectiveness of the treatment. Other researchers have used parental monitoring or self monitoring in children without ID to assess and treat school refusal (Chorpita et al. 1996; Hagopian and Slifer 1993) and other fears (Hagopian et al. 1990). Although all of these examples involved children without ID, a similar type of monitoring can also be used with children with ID, and in some cases may be the best source of data.

### Physiological Measures

Although researchers commonly recommend psychophysiological measurement for the assessment of anxiety (e.g., see King et al. 1997; Silverman and Lopez 2004), they also caution against its regular use in clinical practice. Knowledge is limited with regard to the selection of measures, appropriate conditions under which to measure physiological responding, and the validity of this measure (Turpin 1991). In addition to these issues is the concern of practicality or whether clinicians have access to the appropriate equipment as well as the technical knowledge for utilizing it. For individuals with ID, physiological measurement may be even more challenging because they may have more difficulty tolerating the equipment and procedures. As of this writing, no studies were identified that included physiological measures during a behavioral observation of an individual with ID and an anxiety disorder. Despite these limitations, the potential use of physiological measures should be explored as these could provide additional information regarding the situations that cause increased arousal for individuals with ID; especially for those individuals who are unable to reliably verbalize or report this information due to language deficits.

### Differential Diagnosis

Great caution must be taken in inferring presence of anxiety in this population based primarily on the observation of behavioral avoidance and apparent negative emotional states. Individuals with ID may display negative emotional behaviors and behavioral avoidance when encountering situations that are simply non-preferred as opposed to situations so aversive that they induce fear. Functional



behavioral assessment of avoidant behavior can help make this distinction. For example, demands to complete academic tasks, the removal of preferred items, or transitioning from higher to lower preferred activities have been shown to elicit problem behavior and negative emotional responses in this population. In the case of non-compliance, avoidance may occur as a function of the individual not having the necessary skills, insufficient reinforcement to support the desired response, or the failure to discriminate what response is expected (i.e., insufficient stimulus control of behavior). Avoidance and escape of academic demand situations through the display of problem behavior is one of the more commonly observed operant functions of problem behavior (e.g., Iwata et al. 1994). In the case of competing reinforcement, the individual may avoid a situation because there is relatively more reinforcement associated with an alternative response that competes with the one being prompted (e.g., the individual refuses to go to school because there is more reinforcement available at home; Meyer et al. 1999).

Despite these caveats, presence of avoidance in combination with other indicators of fear including fearful facial expressions and intense physiological arousal should alert the clinician to the possible presence of anxiety. In addition to the intensity of the emotional response, the continued display of fearful responses long after the eliciting stimulus has been removed might also suggest anxiety. In contrast, avoidant behavior related to non-compliance or decrements in reinforcer density may not be associated with extremely intense or lengthy displays of the classic indicators of fear, but often quickly abate once the eliciting stimulus conditions are removed. Such observations in combination with other sources of assessment data (interviews, rating scales, other observational data) can be important to differential diagnosis.

## Treatment

In contrast to the extensive body of research on the treatment of anxiety in typically developing individuals, research describing the treatment of anxiety in individuals with ID is quite limited. Our review of the literature on the treatment of anxiety in persons with ID identified 48 treatment studies published over the past 35 years. These studies included a variety of individuals with ID, including individuals with and without autism, individuals across the full range of impaired intellectual functioning (i.e., mild to profound) and in different age groups from childhood to adulthood. Of the 48 identified studies, 18 are controlled clinical case reports and 5 are controlled group studies (search terms used are available from the authors upon request). A significant proportion of these studies describe the clinical nature of the problems in detail, but fail to include formal DSM diagnoses. Five of the 48 studies identified describe the treatment of OCD (although only 2 of the 5 cases were reported to have met formal DSM criteria for OCD). The remaining three studies describe the treatment of Panic Disorder with Agoraphobia, Generalized Anxiety Disorder, and Post-Traumatic Stress Disorder (but again, formal DSM criteria are not described). For 39 of the 48 studies, the clinical problems described involved avoidance of particular situations or stimuli that are characterized by authors as associated with anxiety or fear (Jennett and Hagopian (2008) used the term “phobic avoidance” to describe these problems).

Review of the literature on treatment of phobic avoidance revealed that behavioral procedures, involving the use of graduated exposure and reinforcement, have been sufficiently researched as a treatment for phobic avoidance in this population to characterize this class of interventions as a “well established” empirically supported treatment (Jennett and Hagopian 2008; based on APA Divisions 12 and 16 criteria for empirically supported treatments). This finding is consistent with literature on the treatment of specific phobias in typically developing children (Ollendick and King 1998). Given the sparse literature describing the treatment of anxiety disorders other than phobic avoidance, it is not possible to designate treatments for other anxiety disorders in individuals with ID as efficacious according to the same classification scheme. Therefore, our discussion of treatment will be limited to behavioral procedures for phobic avoidance.

It should be noted that a wide range of terms such as “operant procedures” and “reinforced practice” is used across studies to describe interventions involving exposure to the feared stimulus combined with reinforcement. Similarly, the exposure component has been described using various terms such as “stimulus fading,” or “graduated exposure.” The term “graduated exposure” will be used throughout the remainder of this paper to describe treatment components involving gradually and systematically exposing the individual to the feared stimulus.

### Graduated Exposure

With typically developing individuals, graduated exposure involves developing a fear hierarchy of stimuli ranging from least to most feared based on the individual’s verbal report. The individual is gradually exposed from lesser to more feared stimuli while maintaining appropriate approach responses and low levels of anxiety. For individuals with ID who may not be able to generate a fear hierarchy based on verbal report, the hierarchy may be developed based on the results of a behavioral avoidance test (as described above), or derived by the therapist based on other assessment findings. In the latter case, the therapist may generate a range of stimulus variations by altering the feared stimulus along some physical dimension, such as its distance from the individual, the duration of contact, or size of the stimulus. Regardless of how the hierarchy is developed, graduated exposure involves systematically exposing the participant to variations of the feared stimulus that progress to closer approximations of the actual feared stimulus. Progression along the hierarchy is based on the participant successfully completing the previous step, ideally with minimal anxiety. Based on the participant’s progress, the hierarchy can be changed by including intermediate stimulus variations.

Based on the basic learning process of respondent extinction, exposure aims to extinguish any associations between the feared stimulus and aversive events by presenting the feared stimulus in the absence of those aversive events. Consequently, for this approach to successfully result in extinction, it is critical that exposure to the feared stimulus not be paired with any aversive events (including extreme anxiety), or result in escape/avoidance from the stimulus which could strengthen avoidance and produce counter-therapeutic effects. However, there may be situations when it may be appropriate to permit escape/avoidance. Ideally, the exposure session should be arranged to minimize the likelihood that the target stimulus will be avoided by: 1)

gradually progressing from lesser to more anxiety provoking stimuli, and 2) programming reinforcement for successful approach during stimulus presentations.

For example, Riccardi et al. (2006) described an exposure hierarchy developed along one dimension (distance from the stimulus) in order to treat an 8-year-old diagnosed with autism and a specific phobia of animatronic objects. In this case, three different animatronic toys were placed in a room 5 m from the entrance. Tape was placed on the floor between the animatronic toy and the door 0.3 m apart in order to mark distance. In the initial phase of the treatment, the participant was permitted to play with preferred toys outside of the open door. Following this, his distance was systematically decreased from 5 m, 4 m, 3 m, 2 m, to the final criterion of 1 m from the animatronic toy. The distance was decreased after he had successfully remained at the current distance for 90% of the observation period for two consecutive sessions.

A similar procedure was used by Runyan et al. (1985) to treat three adults with severe to profound mental retardation who exhibited avoidant behaviors when required to ride an escalator. A 25 step hierarchy was developed and included: walking up and down non-moving stairs that were located near an escalator, approaching the escalator, standing at the bottom (or top) of a moving escalator for at least 10 s, and riding up (or down) with decreased physical guidance and proximity of a therapist. In this case, stimuli were faded on multiple dimensions including movement, distance, and proximity of the therapist.

## Reinforcement

In addition to systematically exposing the individual to the feared situation, treatment should involve reinforcement for approach responses. In the case of anxiety disorders, the maintaining consequence for avoidant behavior is typically negative reinforcement, in the form of either avoidance or escape from the feared situation. Therefore, it is important impose reinforcement procedures targeting approach responses that are strong enough to counter or compete with the negative reinforcement maintaining escape or avoidance. Although typically developing individuals may be able to identify powerful reinforcers based on verbal report, for individuals with ID, a systematic preference assessment (based on non-verbal choice responses) should be conducted to identify preferred items that may potentially serve as reinforcers. See Hagopian et al. (2004) for a review of the preference assessment procedures for individuals with ID.

Reinforcers are typically delivered using response contingent schedules. For example, in a study by Hagopian and colleagues (2001), tokens were provided every 10 sec during participation in each step of a hierarchy for a blood draw. The tokens were then traded in at the completion of the session for preferred items or activities that were identified via a preference assessment. Tangible reinforcers, such as toys or preferred snacks, may also be used to reinforce approximations of the approach response (e.g., Love et al. 1990).

## Other Behavioral Treatment Components

Other behavioral components are often used in conjunction with graduated exposure and reinforcement, such as prompting, modeling, response prevention, or the use of distracting stimuli. All of these components are based on learning principles and

focus on directly exposing the individual to the feared stimulus while reinforcing approach responses.

Prompting may be included in the treatment package as way to assist the participant to comply with the steps of the exposure hierarchy and come into contact with the reinforcement contingencies in place. This may especially be important when the participant is exhibiting highly intense anxiety behaviors or not approximating the targeted approach response. For example, in the Runyan et al., (1985) study described above, a least-to-most prompting hierarchy was used to help the participants complete the steps of the hierarchy in order to successfully ride an escalator. The prompting sequence consisted of a model, verbal prompt, physical prompt (e.g., touching elbow, holding hands), and finally manually guiding the participant's body through the step. A wide variety of prompting methods are available and routinely used with individuals with ID and autism (e.g., MacDuff et al. 2001).

Modeling involves arranging for the participant to observe another person (model) engaging with or approaching the feared stimulus appropriately. Models may either be live (e.g., Love et al. 1990) or observed via video (e.g., Conyers et al. 2004). In a study by Love and colleagues (1990), two young children with autism were treated for avoidance of going outside and running water. Prior to prompting each participant to engage in an approach step of the exposure hierarchy, their mothers would model the step and verbalize their lack of fear. Similarly, in a study by Erfanian and Miltenberger (1990), two adults diagnosed with moderate to profound mental retardation were treated for fear of dogs: prior to exposure along the hierarchy, each participant would engage in a preferred activity with the therapist at a far distance from a dog while observing another adult interact positively with the dog.

Conyers and colleagues (2004) provided video modeling as a treatment for the avoidance of or resistance to dental procedures in three adults with severe to profound mental retardation. In this context, the participants observed a familiar person exhibiting appropriate behaviors and receiving praise during each step of a task analysis for undergoing dental treatment. This treatment, however, was provided in the absence of an exposure hierarchy and reinforcement. Results indicate that it was not effective in increasing compliance with the steps of the dental procedures, possibly because it did not include these other behavioral components found to be necessary for the treatment of anxiety. It is possible that using video modeling as a supplement to graduated exposure with reinforcement could increase compliance in the same manner as live models (however, this awaits empirical demonstration).

Response prevention is another component that is sometimes used in conjunction with prompting or modeling in order to ensure that the individual comes into contact with the feared stimulus. Response prevention is typically done in order to implement extinction, which may involve preventing an escape response or prompting a behavior that is incompatible with avoidance (e.g., approach). In either case, it typically involves not allowing the individual to leave the feared situation until the targeted step is completed. For example, Rapp and colleagues (2005) treated an adolescent with autism and severe mental retardation for self injurious behaviors, elopement, and dropping associated with the avoidance of swimming pools. The participant was physically guided to approach and then occupy the pool. Attempts to drop or elope were blocked by prompting the participant to sit in a

rolling chair. Two therapists physically guided her toward the pool by rolling the chair. When she reached the pool, another therapist provided her with edible reinforcement. Although this study describes an effective response prevention procedure, most studies published to date that describe the behavioral treatment of anxiety in individuals with ID do not include response prevention or escape extinction (Jennett and Hagopian 2008). That is, in most cases, the individual is permitted to escape or avoid the situation. However, not enough research has been conducted to determine whether this component should be routinely included as part of a treatment package.

Finally, use of distracting stimuli is another component that may be used in conjunction with graduated exposure and reinforcement. Distracting stimuli involves the noncontingent access to items during exposure, ostensibly as a means of providing alternative reinforcement of responses incompatible with avoidance. Luscre and Center (1996) incorporated distracting stimuli along with an exposure hierarchy, modeling, and reinforcement for the treatment of children with autism displaying anxiety and resistance during dental exams. Each participant was provided with access to items such as music and preferred toys with the intent to promote relaxation. The intervention was effective for all cases, however, data on the participants' level of relaxation were not reported (nor is it possible to determine the contribution of each treatment component). Although providing distracting stimuli during exposure is relatively easy and a seemingly benign component, it is possible that free reinforcement can weaken the effects of contingent reinforcement provided for successful approach behavior. Additional research is needed before the routine use of distracting stimuli can be recommended.

### Outcome Evaluation and Experimental Design

Collecting data to be used for the evaluation of treatment outcomes is another important component when treating individuals with ID and anxiety behaviors. Variables of interest should be operationally defined, particularly subjective ratings of fear or facial expressions; and data should be collected throughout the assessment and treatment phases. Use of single subject experimental designs can assist clinicians in evaluating treatment outcomes by demonstrating that the programmed intervention is responsible for changes in anxiety-related behavior. The changing criterion design is particularly well suited when using graduated exposure. This design demonstrates control through the repeated observation that changes in responding (e.g., approach) occur as a function of changes in the treatment criterion (e.g., steps of a hierarchy). The first step of the evaluation is to establish a baseline against which to measure future progress in the treatment phase. An appropriate baseline can be derived from the BAT; that is, baseline sessions should permit the participant the opportunity to advance along the exposure hierarchy up to the point he/she is able to do so voluntarily (without extreme anxiety or intensive pressure from the therapist). Data should be collected on how many steps of the hierarchy are completed, as well as approach and other anxiety-related behaviors at each step of the exposure hierarchy. Treatment should begin at a step within the hierarchy that is likely to be completed successfully (i.e., one step below that achieved during baseline). The goal is to gradually and systematically complete the exposure hierarchy based on the

individual's ongoing performance and use the data to guide decision making. Aside from the changing criterion design there are also other single subject designs that may be appropriate for evaluating treatment outcomes as well; see Kazdin (1982) for a review of single subject designs.

## Conclusions

Review of the existing literature suggests that many of the behavioral assessment strategies traditionally employed with non-ID populations may be applicable to individuals with ID and autism, despite the communication deficits that may make self-report limited or entirely unavailable. Direct behavioral observation via behavioral avoidance tests and behavioral monitoring (by parents or teachers) in natural settings may be the primary sources of information during both the assessment and treatment evaluation phases. Behavioral treatment procedures consisting of graduated exposure and reinforcement have been established as “empirically supported” for the treatment of phobic avoidance in this population (Jennett and Hagopian 2008; as with typically developing children and adults with phobias; Ollendick and King 1998; Chambless et al. 1998). In light of this and other support for behavioral procedures for the treatment of other behavioral problems exhibited by individuals with ID, such as self-injury, aggression, and property destruction (Didden et al. 1997), behavioral interventions may be applicable to the treatment of other types of anxiety disorders (however, the literature on other types of anxiety disorder is limited to just a few studies). Behavioral procedures may be effective in this population because these types of interventions rely little on the participant's expressive or receptive communication skills, but rather establish new behavioral histories through programmed experiences designed to extinguish anxiety and avoidance and concurrently reinforce approach behavior. Despite significant gaps in the literature, research conducted thus far is sufficient to guide clinicians on how to proceed clinically with assessment and treatment of anxiety in individuals with ID. Nevertheless, additional research designed to examine the presence of other types of anxiety disorders, to develop additional assessment strategies, and to further examine treatment efficacy for anxiety in individuals with ID and autism, is needed.

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