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## The experience of stress in adults with mental retardation.

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THE EXPERIENCE OF STRESS IN ADULTS WITH MENTAL RETARDATION

A Thesis Presented

by

SEAN B. ROBINS

Submitted to the Graduate School of the  
University of Massachusetts Amherst in partial fulfillment  
of the requirements for the degree of

MASTER OF SCIENCE

September 2004

Psychology

# THE EXPERIENCE OF STRESS IN ADULTS WITH MENTAL RETARDATION

A Thesis Presented

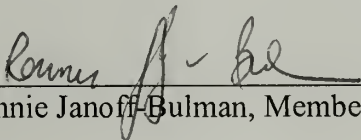
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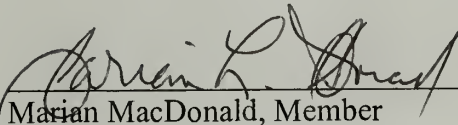
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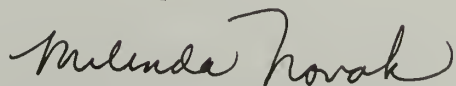
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# CHAPTER I

## THE EXPERIENCE OF STRESS IN ADULTS WITH MENTAL RETARDATION

### Introduction

Individuals with mental retardation can experience as full a range of psychological disorders as people with average or above average intelligence (Benson, 1985), but there is a continued tendency to attribute behavior related to psychopathology to an individual's mental retardation, rather than to a concurrent psychological disorder. Historically, there has been a widespread belief that people with mental retardation are either incapable of developing mental illness, or that the psychological disorders they do develop are somehow different than the mental disorders experienced by people without mental retardation. While most research in the field has not supported these beliefs about psychopathology in people with mental retardation, individuals with mental retardation are still less likely to receive a psychological diagnosis than those without mental retardation, despite presenting the same symptoms (Nezu & Nezu, 1994; Reiss, Levitan, & Szyszko, 1982). Furthermore, as Lewis and MacLeon (1986, as cited in Matson & Barrett, 1993) state, "Even in the training of professionals who work with mentally retarded clients there is a tendency to focus on disorders of cognitive development to the exclusion of emotional and social development. In some ways, because of the longstanding delineation between mental retardation and emotional disturbance, there is considerable resistance to integration of the two, particularly regarding service delivery (pg.4)." This situation has resulted in continued under-recognition, under-diagnosis and misdiagnosis of mental illness (Edelstein & Glenwick, 1997; Matson & Barrett, 1993) in people with mental retardation. At the same time, there is evidence that individuals with

mental retardation may be at increased risk for developing mental illness (Matson & Sevin, 1994; Nezu & Nezu, 1994; Reiss, Levitan, & McNally, 1982). Rates of psychopathology may be four to five times greater than in the population without mental retardation (Borthwick-Duffy, 1994; Fletcher, 1993; Matson, Kazdin, & Senatore, 1984), with estimates that range from less than 10% to more than 80% (Borthwick-Duffy, 1994).

### The Experience of Stress and Anxiety in Adults with Mental Retardation

While there is little evidence to build a clear understanding of the prevalence of psychopathology in individuals with mental retardation, there is even less research to form an accurate picture of the experience of anxiety. Although early evidence by Penrose (1938) showed 10.3% of inpatients with mental retardation to be psychoneurotic, “marked by nervous energy or anxiety,” and Tredgold (1947) found anxiety states to be the second most commonly observed neurotic pattern among those with mental retardation, a clear consensus has not emerged regarding anxiety in this population today. While anxiety symptoms have been consistently documented (Borthwick-Duffy, 1994), prevalence estimates of anxiety disorders vary widely, and range from 2-25% (Benson, 1985; Clum & Pickett, 1984). Several investigators have concluded that anxiety based problems are more common in individuals with mental retardation than in individuals without it (Feldhusen & Klausmeier, 1962; Ollendick, Oswald, & Ollendick, 1993), and evidence shows that problems related to anxiety represent the second highest reason for referral of a person with mental retardation to a mental health professional (Edelstein & Glenwick, 1997).



Not surprisingly, there is little information concerning anxiety subtype prevalence in people with mental retardation. For instance, there are no prevalence data for social phobia/anxiety. This is particularly remarkable since difficulties in learning social skills may make people with mental retardation especially prone to social phobia/anxiety (Rutter, Tizard, Yule, Graham, & Whitmore, 1976). Similarly, there are no prevalence data on PTSD, in spite of evidence that PTSD-like symptoms are often caused by the involuntary relocation of residents (particularly deinstitutionalized residents) that may be relatively common in the lives of those with mental retardation (Ollendick et al., 1993). Other evidence suggests that low levels of achievement are linked with vulnerability to agoraphobia (Weissman, 1985), again suggesting a possible relationship to mental retardation.

Research that specifically addresses the experience of stress is also sparse, despite clear evidence that people with intellectual disabilities experience and report stress (Bramston & Bostock, 1994; Bramston, Fogarty, & Cummins, 1999; Zeitlin, 1993). Research has linked stress to aggressive behaviors (Fleming & Tosh, 1984) and task performance (Ollendick et al., 1993). Furthermore, Corbett (1984) has implicated difficulties in coping with stress as a factor in emotional breakdowns, aberrant behaviors and acting out among those with mental retardation. A study of 44 adults with mental retardation (Benson & Laman, 1985) reported a stressful problem at school or work as the most frequent precipitating factor for suicidal ideation/attempt.

While the lack of research in this area may be somewhat attributable to a lack of public interest, it may also be explained by differing conceptualizations of stress in the population with mental retardation. Some believe that individuals with mental retardation

have a vulnerability to the effects of stress and experience different stressors than do individuals with average and above average intelligence (McNally, 1983). This understanding is based on several assumptions. First, life-change factors like the transition from a special education program (or institutional setting) into a mainstreamed environment increases exposure to anxiety provoking events (Parmenter, 1993) leaving individuals with mental retardation with an increased susceptibility to stress. Second, it is commonly accepted that difficulties with coping create stress (Fogarty & Bramston, 1997). One way people cope with stress is to discuss their experience with a friend or relative. Although some individuals with mental retardation may be able to cope with stress in this way, communication deficits often reduce, or eliminate, this as an effective coping strategy (Grodén, Cautela, Prince, & Berryman, 1994). Third, low cognitive abilities have been tied to increased social and educational failures, both of which have been demonstrated to create anxiety in persons with developmental disabilities (Clark & Rutter, 1979; McNally, 1983). Other research suggests that developmental immaturity, institutionalization and limited verbal language skills all increase the vulnerability of people with mental retardation to stress and anxiety (Bialer, 1970; Cochran & Cleland, 1963).

There is some evidence to suggest an inverse relationship between anxiety and intelligence: that anxiety increases as intelligence decreases. A study investigating the relationship between levels of intelligence and anxiety on a sample of children without mental retardation found that lower IQ may be a risk factor for anxiety in children (Feldhusen & Klausmeier, 1962). Longitudinal data from Richardson et al. (1979) concluded that 26% of children with mental retardation displayed neurotic problems

(defined as problems with “nerves and anxiety”), and that the frequency of these problems was highest in children with an IQ of less than 50 (moderate, severe or profound retardation). On the other hand, some studies have found the opposite pattern, indicating that higher I.Q. may in fact be associated with elevated levels of anxiety. For instance, Benson et al. (1985) found higher rates of conduct disorder and anxious-depressed withdrawal disorder among higher functioning, higher I.Q., adults with mental retardation. Similarly, Iverson and Fox (1989) found significantly increased rates of all forms of psychopathology, including anxiety disorders, in adults with lower levels of retardation (higher I.Q.s). These inconsistent findings are most likely due to vague inclusion criteria, non-random samples and other methodological problems that call into question the association between mental retardation and anxiety.

Most contemporary research argues that individuals with mental retardation do not differ in their vulnerability to anxiety, and do not experience stressors that are any different than those for people without mental retardation. In addition, anxiety is thought to develop by a similar process in people with mental retardation, and all subtypes of anxiety disorders are believed to occur (Grodén et al., 1994). Fogarty and Bramston (1997) assert that “subjective stress as perceived by people with mental retardation is not ‘special’ but rather has the same themes as reported by other groups. Interpersonal difficulties and lack of confidence in one’s skills is an important aspect of stress, no matter who is experiencing it” (pg. 453). In one of the few laboratory studies of stress in this population, Nucci & Reiss (1987) compared task performance under three conditions, using both adults with mental retardation and adults with average or above average intelligence. In the “stress” condition, participants waited for ten minutes in a

straight-backed chair while listening to “moderately stressful levels of noise.” Participants in the control condition waited in a comfortable recliner, with magazines available to them and no “stressful noise.” In the “relaxation” condition, participants waited in a comfortable recliner and listened to relaxing music. The authors concluded that mental retardation was not associated with a reduced ability to cope with stress; furthermore, they asserted that individuals with mental retardation reacted to stress in the same way as people without an intellectual disability. Zetlin (1993) drew a similar conclusion using unstructured interviews. In earlier research, investigators (Tebeerst & Dickie, 1976) found no differences in frustration tolerance between individuals with mental retardation and control subjects. Fogarty & Bramston (1997) have suggested that while the experience of stress and anxiety among people with mental retardation originates from the same general dimensions as those without mental retardation, the salience of these dimensions might vary considerably. For example, concerns about the absence of a friend or loved one may be particularly stressful for an adult with mental retardation, and events not usually considered stressful, like receiving a gift, may create a stress reaction for those with mental retardation.

#### A Conceptual Model of Stress for Research on Adults with Mental Retardation

In 1974, Hans Selye proposed that the experience of stress is the body’s physiological reaction to life events, and that stress could be experienced both positively (eustress) and negatively (distress). What followed from Selye’s work was a gradual development of the idea that stress is an individual experience, which focuses chiefly on one’s interaction with his/her environment. In a 1984 article, Lazarus further advanced



the understanding of stress by conceptualizing it as “harms, threats or challenges, the quality and intensity of which depend on the environmental conditions and the personal agendas, resources and vulnerabilities of the person (pg. 376).” His definition of stress has become one of the most widely cited today. Some have added to this model by including other factors such as: the threat of potential stressors, actual stressors, health status, social support and personality characteristics which may increase or mediate an individual’s stress reaction (Boyle, Borg, Falzon, & Baglioni, 1995).

Lazarus’ model has proven useful to understanding stress, but it has two important limitations. First, unlike Selye’s original model of stress, contemporary understandings of stress based on Lazarus’ model generally do not interpret positive events as stressful. It is possible, however, that positive events like receiving a present or a compliment may be stressful to some individuals. As Paul Leahy (2001) describes, “Many people enjoy surprises ... Others, however, view surprise and change as disturbing, difficult to assimilate, and requiring unwanted adjustments ... The unexpected may increase anxiety, defensive posturing, and withdrawal. (pg.89).” Although Leahy is referring to work with individuals who do not have mental retardation, the possibility of the stressful nature of “unexpected positive events” seems particularly valuable in this population.

The interpretation of stress as solely an individual reaction may be unnecessarily restrictive. There is an emerging literature which attempts to view certain elements of stress as a group phenomenon (Eckenrode & Bolger, 1995). From this perspective, stress is viewed as having some shared characteristics, while having other elements that are unique to specific groups. This group model of stress assumes that members of a group



share recurring stressors like severe illness or social skills deficits. These experiences of stress share common elements with all groups, but more importantly, they display specific features which cause the subgroup to experience the stress response in a different way. This “group stress theory” has been used to develop models of stress for at risk groups including: HIV positive homosexual men (Nott & Vedhara, 1995), teachers (Borg, Riding, & Falzon, 1991), migrant East Germans (Jerusalem, 1993), and the population of mainland China (Zheng & Lin, 1994). Recently, this perspective has been used for the first time as the conceptual basis for stress research in people with a mild intellectual loss (Fogarty & Bramston, 1997), and indeed it seems a productive orientation to adopt for work with adults of all levels of mental retardation. Instead of focusing on stress as a phenomenon to be understood solely at an individual level, group stress theory can be used to identify group vulnerabilities and resiliency to stress, and is compatible with Selye’s concept of eustress. Thus, group stress theory provides an elaborated framework for understanding stress and anxiety in the population with mental retardation.

### Methods of Assessing Stress

In 1989, a review published by Elizabeth Allen concluded “with regard to the assessment of anxiety, there is a great need for construction and validation of an assessment scale which is designed specifically for use with adults with mental handicaps (pg. 57).” More than a decade later, the field has done little to meet this challenge, and systematic anxiety research on adults with severe or profound mental retardation remains virtually nonexistent. Most research conducted in this area uses scales that have been developed and standardized on people without mental retardation, despite clear evidence

that this approach is highly problematic (Silon & Harter, 1985). Instruments like the Social Readjustment Scale (Holmes & Rahe, 1967), the Daily Stress Inventory (Brantley, Cocke, Jones, & Goreczny, 1988), and the Children's Manifest Anxiety Scale (Castaneda, McCandless, Palermo, 1956) are repeatedly used, with the assumption that there is an equivalency of IQ between normal children and adults with mental retardation, and that these assessment tools validly capture the experience of anxiety in adults with mental retardation. While this is one means of measuring stress, a more fruitful and methodologically sound approach would be to use assessment devices specifically designed for use with those who have developmental disabilities. By briefly examining how stress has been measured in the population without mental retardation, important conclusions can be drawn about how to assess stress in those with mental retardation.

Common stressors for the general population, like job changes, marriage, divorce, fear of heights or airplane travel, are usually assessed in one of three ways: by clinical interview, self report or behavioral observation. All of these methods are useful for assessing stress and anxiety in adults with mental retardation, but there are distinct advantages and disadvantages to each approach.

### Clinical Interview

There is a long history to support the use of both structured and unstructured interviews for assessing stress and anxiety in the population without mental retardation, and it is considered the first-line assessment of choice by most clinicians and researchers. The primary goals of the clinical interview are to establish a positive working alliance between client and clinician and to gather specific information regarding the behavior of

interest. Clinical interviews are often cited for their flexibility and capacity to assess a wide constellation of clinically relevant information, which may be overlooked by more structured techniques. The clinical interview in the case of adults with mental retardation, however, presents several unique challenges that can make it a less reliable source of information and can create undesirable reactions in the interview participant. The most often cited problem with clinical interviews in this population is both a perceived and real deficit in expressive and receptive language skills that make reports of stress and anxiety, especially subjective reports of the internal states of anxiety, extremely problematic (Bramston & Fogarty, 2000; Heal & Sigelman, 1995). In addition, the open-ended question format generally used in clinical interviews is inadequate, as few respondents can provide thorough answers, and multiple choice options are subject to retention difficulties (Bramston, Bostock, & Tehan, 1993). Furthermore, earlier research by Rosen et al. (1977) concluded that adults with mental retardation are more likely to comply with unreasonable, or misunderstood instructions, and that there is a high probability of acquiescence (thus precluding the use of forced-choice questions). Perhaps more importantly, individuals with mental retardation often have a fear of strangers (Ollendick et al., 1993). Moreover, there is a very real danger that questions about stress and anxiety may in fact induce anxiety, when none existed before.

### Self Report Measures

In the general population, self-report measures of stress and anxiety are less costly (in terms of time and money) methods of assessment. They are also used to supplement the clinical interview. One self report measure of stress, the Lifestress Inventory (LI), has

been developed specifically for adults with a mild intellectual disability (Bramston et al., 1993; 1999). The LI was originally created by interviewing people with mental retardation, and the people who work with them, about the experience of stress. The inventory conceptualizes stress in three broad categories: general anxiety, negative interpersonal interactions and lack of skills and coping behaviors. Bramston et al. (1999) found that over 50% of people with an intellectual disability identified arguments, death and interruptions as significant stressors, and they reported an average of seven stressful events (rated as “not so good” or “bad”) each day (Bramston et al., 1993). Although the Lifestress Inventory is a significant step towards measuring stress in this population, it has only proven useful for people with mild levels of retardation, and it suffers from several important limitations inherent in self-report measures used with this population. Many of these problems, like language deficits and acquiescence, are also problems with a clinical interview; there are, however, additional problems with the use of self-report measures. For instance, poor reading ability makes self-reports time consuming, and there is a high probability of misunderstanding (Damon & Hart, 1982). Furthermore, research has found that social desirability and personal agendas are all problems (Bramston & Bostock, 1994) with using self-report measures in people with mental retardation. Individuals with severe or profound mental retardation are generally non-verbal, making the use of self-reports and clinical interviews impossible.

#### Behavioral Observation/Reports From Others

Although behavioral observation is generally thought to be an excellent complimentary source of information about a person’s behavior, investigators find that it



is time consuming, costly and methodologically difficult to implement reliably. Furthermore, problems inherent with any observational process, like observer drift and the reactive nature of observation (Kazdin, 1998), make behavioral observation unwieldy. While all of these drawbacks apply to research on people with mental retardation, behavioral observation is still the most widely used method of studying anxiety and fear in this population (Allen, 1989). Furthermore, it is essentially the only reliable source of information about individuals with severe and profound mental retardation (Ollendick et al., 1993). In support of the validity of behavioral observation, a study by Groden et al. (2001) found no significant differences between several developmentally disabled self-responders and reports by caregivers on the Stress Survey Schedule for Individuals with Autism and Other Pervasive Developmental Disabilities.

Assessments made by caregivers or family members based on behavioral observation are the most efficient and least intrusive methods of developing a preliminary understanding of the experience of stress in this population. Here, the distinction between anxiety and stress becomes essential. The broader study of anxiety requires the subjective reports of internal states, like feeling restless or anxious anticipation, that are not reportable by many people with mental retardation, and that have been shown to be insufficiently inferable from other reports (Edelstein & Glenwick, 1997). Stress reactions, on the other hand, do not require inference about a person's internal emotional states; instead they are external reactions that are observable. While the presence of stress does not necessarily mean a person is experiencing anxiety, the experience of anxiety necessarily indicates the presence of stress. Therefore, understanding stress in adults with mental retardation is the most elegant way to study anxiety in this population.



## The Stress Survey Schedule

In a series of three studies, Groden, Diller, Bausman, Velicer, Norman, and Cautela (2001) developed the Stress Survey Schedule for Persons with Autism and Other Developmental Disabilities (SSS) to measure stress and anxiety in a sample of children and adults with autism (ages 2-51). Initially, data were collected by asking individuals with autism and their caregivers to respond to open-ended questions regarding stress. Responses to these questions were then assimilated with information from clinical literature, and a series of card sorts was used to develop a pilot survey. The survey was then completed by caregivers of 97 clients with autism, and data were factor analyzed. Results indicated that the survey tapped six components: changes and social threats, ritual related stress, pleasant events, sensory stimuli, unpleasant events, and anticipation. In the second study 132 participants (126 caregivers, 6 individuals with autism) completed the survey, and a confirmatory factor analysis was performed to verify the underlying factor structure determined in the first study. This study failed to identify the sensory stimuli component found in study one; furthermore, a new component, "social/environmental interactions," was extracted. In the final study, eighteen items not included in the previous studies were added and the survey was completed by 129 participants (121 caregivers, 8 individuals with autism). Building on the first two studies, the third and final study yielded eight factors: change and social threats, ritual related stress, pleasant events, social/environmental interactions, unpleasant events, anticipation/uncertainty, sensory/human contact and food/reinforcement. All three studies reported acceptable reliability, and high internal consistency with Cronbach alpha's ranging between .70 - .90.

## CHAPTER II

### METHOD

#### Participants

Staff working at Monson Developmental Center, Sullivan & Associates Inc., ServiceNet of Northampton completed the Stress Survey Schedule about the clients in their care. Only staff members with a minimum of three months of contact with participants completed the survey. Surveys were completed for 61 participants. The client sample included 39 females and 22 males who ranged in age from 27 to 87, with a mean age of 55.2 (14.5, standard deviation). The sample was 95% White (n= 58) and 4.9% African-American (n=3). 52 of these participants lived in a developmental facility, while seven resided in a staff assisted apartment and two lived in a group residence. Thirty-three of the participants were described as non-verbal and 26 were identified as verbal; no information was provided for two participants. Forty-seven and a half percent of the sample (n= 29) was classified as having profound mental retardation, 18% (n= 11) have severe mental retardation, 18% (n= 11) are classified in the moderate range and 14.8% (n= 9) have mild mental retardation. The mean number of months the staff in this study have worked with the participants, 92.4 months (79.6 standard deviation, with a range from 4 to 264 months, median of 60 months), is quite high. The staff worked with participants for an average of 24 hours a week (13.64 standard deviation, range from 3 to 62).

## Questionnaires

This study used the Stress Survey Schedule for Persons with Autism and Other Developmental Disabilities, in its revised form (Grodén et al., 2001, see Appendix A). The original survey contains 62 items that are rated on a 5-point Likert scale and two open ended questions, and the authors have reported acceptable reliability (Grodén et al., 2001). Participants are asked to rate the intensity of an individual's stress response from none to mild, mild to moderate, moderate, moderate to severe, and severe. They are also asked to indicate the presence of any stressful items, or events, that are not included on the survey, and to identify the most significant stressor for the individual. For the purposes of this study, several alterations were made to the survey. First, an additional response category was added to the scale. This category, "never observed," helped to differentiate reactions the caregiver had never observed as opposed to reactions that do not create stress. Secondly, one additional open-ended question was included. This question, "What are the things you use to identify a stress reaction? What behaviors serve as clues that the person is experiencing stress?" was included as the last open-ended question. Third, a final question asked participants to rate the confidence of their responses on a three-point scale ranging from "not confident, I was unsure about most items" to "very confident, I was sure about almost all of the items."

A demographic sheet (see Appendix B), requested information concerning: estimated number of weekly hours of contact, an estimate of the total number of months the caregiver has known the subject of the questionnaire, age, ethnicity, primary medical diagnos(es), medication use, IQ, education/vocational placement, housing situation and whether the subject of the survey is verbal or non-verbal.

A consent form, designed to be readable at a fourth grade level, was developed and approved, under the guidelines provided by the Massachusetts Department of Mental Retardation Research Review Committee (see Appendix C). This form was signed by participants and witnessed by a Human Rights Officer, or designee. A copy of the consent form is on file at the University of Massachusetts at Amherst, and the original consent form was placed in the participant's file at the appropriate institution. In the event the participant had a legal guardian, the guardian was required to provide consent to participate in the study (see Appendix D).

An introductory letter (see Appendix E) and fact sheet (Appendix F) about the study were created to inform participants and caregivers about the nature of the study. The fact sheet includes information about the rationale, design, purpose, and duration of the study. It also provides contact information and sample questions.

### Procedure

In October of 2000, the Massachusetts Department of Mental Retardation was contacted for permission to conduct the study in various sites for which they oversee services. After extensive review, the committee approved the study. The Department of Psychology Human Subjects Committee at the University of Massachusetts, Amherst, also approved the study.

Four sites gave permission to conduct the study at their facility. Caregivers at each site were given the revised demographic sheet and the revised Stress Survey Schedule, and asked to rate the intensity of the stress reaction experienced by their clients to each item. A brief, on-site training program was given to caregivers at Monson

Developmental Center during the initial wave of data collection. At that time, it was concluded that the training program was unnecessary and was not included in later data collection. Caregivers then completed the survey and returned them to Nancy Haberstroh, Ph.D. (Monson Developmental Center), Seth Cassin (ServiceNet) and James Cain, M.S. (Sullivan & Associates) who mailed them to the principal investigators for data analysis.



## CHAPTER III

### RESULTS

400 surveys were distributed among the four study sites. 61 surveys were completed (15.25% response rate) and responses from these surveys were analyzed.

Means and standard deviations for each item are reported in Table 1.

Table 1- Descriptive Statistics for Individual Items on the Stress Survey Schedule in a Sample of Adults with Mental Retardation

#### Descriptive Statistics for Individual Items

	N	Mean	SD
Q1	61	2.3279	.8311
Q2	61	2.9016	1.3504
Q3	61	2.2459	1.1054
Q4	60	2.9833	1.3212
Q5	61	3.5902	1.3586
Q6	61	2.9016	1.2477
Q7	61	2.8689	1.2312
Q8	61	2.8197	1.1763
Q9	61	2.7541	1.2994
Q10	61	3.1148	1.1416
Q11	61	2.2459	1.1351
Q12	61	2.9672	1.5702
Q13	61	3.8689	1.2580
Q14	61	3.1148	1.6135
Q15	61	2.8361	1.1281
Q16	60	2.5167	1.0813
Q17	61	3.0656	1.1235
Q18	60	2.2500	.7507
Q19	61	1.8525	1.1081
Q20	61	2.1475	.8532
Q21	61	2.5574	1.2453
Q22	61	2.0328	.8158
Q23	61	2.3934	1.0046
Q24	61	3.2131	1.4389
Q25	61	3.1803	1.2584
Q26	61	3.1803	1.4664
Q27	61	2.8852	1.5503
Q28	61	2.0000	1.2517
Q29	61	2.9672	1.3161
Q30	61	2.6230	1.1426
Q31	61	3.5082	1.4790
Q32	61	2.3770	1.0514
Q33	61	3.0164	1.1901
Q34	61	2.2295	1.2027
Q35	61	1.6557	1.0309
Q36	60	2.3167	.8924
Q37	61	2.5902	1.1744
Q38	61	2.1311	.9743
Q39	61	2.7541	.9773
Q40	61	2.9180	1.0999
Q41	61	1.9836	.9745
Q42	61	2.2295	.7392
Q43	60	3.2167	1.3288
Q44	61	2.0164	.8265
Q45	61	2.2131	.8188
Q46	61	2.8197	1.2584
Q47	61	2.6885	1.0090
Q48	60	2.0667	1.0715
Q49	61	2.2459	.9773
Q50	61	2.0492	1.0712
Q51	61	1.8689	.9912
Q52	61	2.4262	1.2709
Q53	61	2.1967	1.1078
Q54	61	1.7869	.6087
Q55	61	1.8689	.6946
Q56	61	3.1311	1.6681
Q57	61	2.5902	1.4304
Q58	61	1.1148	.4509
Q59	61	1.8361	1.0674
Q60	60	1.3333	.7739
Q61	61	1.0328	.1796
Q62	61	1.0492	.2180

Data from 61 surveys were factor analyzed using the principle-components method. Two items, “having parents get divorced” and “having a parent re-marry,” were removed from the final analysis as they were endorsed “never observed” by all participants. Because evidence from Groden et al.’s 2001 pilot study indicated that factors were uncorrelated, a Varimax rotation performed on the data indicated six factors that accounted for 57.79% of the total variance. Factor one, ritual related stress/changes, accounted for 12.39% of the total variance. It includes seven items and appears to measure aspects of stress associated with changes or disruption in the performance of rituals or schedules. The second factor, pleasant events, includes seven items and accounted for 12.01% of the total variance. This factor seems to measure stressful reactions to pleasurable events, like receiving reinforcement or being allowed to attend a favored event. Factor three, unpleasant events, accounted for 11.46% of the variance and includes six items. This factor appears to measure aspects of stress related to unpleasant events, like being reprimanded or receiving criticism. The fourth factor, social/environmental interactions includes five items and accounts for 8.38% of the total variance. Social/environmental interactions seems to measure stress reactions to situations such as being crowded or being touched. Factor five, anticipation, has three items and accounts for 8.15% of the total variance. This factor appears to measure stress resulting from waiting for something (e.g. – waiting for food, waiting in line, etc.). The final factor, fear of the dark, contains only one item and accounts for 5.40% of the total variance. Table 2 presents the items contributing to each factor, and their factor loadings.

Table 2 – Six-factor model for the Stress Survey Schedule in a Sample of Adults with Mental Retardation

*Items loading greater than .65 on each factor, and their factor loadings*

Factor Loading	Ritual Related Stress/Changes
.784	Being prevented from carrying out a ritual
.781	Being prevented from completing a ritual
.737	Changes in schedule or plans
.703	Having personal objects or materials out of order
.680	Being interrupted while engaging in an activity
.672	Change in task to a new task with new directions
.652	Change in environment from familiar to unfamiliar
Pleasant Events	
.772	Receiving verbal reinforcement
.751	Being allowed to attend a party or favored event
.716	Having a conversation
.716	Having a new sibling
.701	Receiving activity reinforcement
.687	Receiving tangible reinforcement
.661	Going home (from school, to visit parents)
Unpleasant Events	
.799	Receiving a reprimand
.795	Receiving criticism
.792	Having something marked incorrect
.749	Losing at a game
.653	Needing to ask for help
.651	Waiting to talk about a desired topic
Social/Environmental Interactions	
.848	Feeling crowded
.762	Fear of crowds
.705	Being touched
.699	Being in the vicinity of noise
.664	Fear of closed spaces
Anticipation	
.794	Waiting at a restaurant
.738	Waiting in line
.705	Waiting for food
Fear	
.649	Fear of the dark

*note: principle components analysis, Varimax rotation*

Factors were identified by generating factor solutions that included one, five, six, seven and eight factor solutions. The six-factor solution was the most interpretable and appeared to provide the best fit to the data, based on analysis of the Scree plot and earlier work by Groden et al. (2001) which identified a six-factor solution in their initial sample of children and adults with autism. After the six-factor solution was established, items

with factor loadings of .65, or above, were retained. There were no observed variables that loaded on more than one factor. A total of 31 items did not load above .65 on any factor (open-ended questions were not included).

Using two-tailed, single-sample t tests and  $p < .05$  criteria, differences between male and female, verbal and non-verbal and categories of mental retardation were examined. In general, men experienced more stress, with significantly higher stress reactions to eighteen stressors, ranging from reactions to changes in staff to receiving reinforcement (see Table 3).

Table 3 – Comparisons of Significant Gender Differences in the Expression of Stress, using two-tailed, single-sample t tests,  $p < .05$

Stressor	Mean, Female (sd)	Mean Male (sd)	p value	t	df
Receiving a present	2.18 (.56)	<b>2.59 (1.14)</b>	.000	-1.896	59
Waiting to talk about a desired topic	2.05 (.92)	<b>2.59 (1.33)</b>	.004	-1.869	59
Being prevented from completing a ritual	1.51 (1.41)	<b>2.91 (1.85)</b>	.034	.215	59
Having something marked correct	1.62 (.82)	<b>2.27 (1.42)</b>	.066	-2.303	59
Being allowed to attend party/favored event	2.18 (.82)	<b>2.77 (1.19)</b>	.008	-1.962	59
Having something marked incorrect	1.77 (.87)	<b>2.41 (1.68)</b>	.000	-1.962	59
Waiting in line	2.18 (.94)	<b>2.73 (1.16)</b>	.035	-2.002	59
Waiting for transportation	2.16 (.75)	<b>2.59 (1.05)</b>	.002	-1.848	58
Being unable to assert oneself with others	2.56 (1.02)	<b>2.64 (1.43)</b>	.012	-.229	59
Needing to ask for help	1.90 (.68)	<b>2.56 (1.26)</b>	.000	-2.613	59
Having change in staff, teacher or supervisor	2.72 (.92)	<b>3.27 (1.32)</b>	.031	-1.934	59
Losing at a game	1.82 (.45)	<b>2.27 (1.49)</b>	.000	-1.771	59
Waiting for reinforcement	2.10 (.60)	<b>2.46 (.91)</b>	.004	-1.820	59
Someone else making a mistake	1.80 (.47)	<b>2.41 (1.14)</b>	.000	-2.962	59
Receiving tangible reinforcement	2.03 (.58)	<b>2.55 (1.06)</b>	.001	-2.481	59
Having a conversation	1.97 (.87)	<b>2.24 (1.38)</b>	.021	-.908	58
Receiving verbal reinforcement	2.13 (.73)	<b>2.46 (1.30)</b>	.007	-1.258	59
Fear of animals	1.92 (.70)	<b>2.27 (1.51)</b>	.002	-1.229	59
Fear of the dark	<b>1.92 (.58)</b>	1.55 (.60)	.049	2.419	59
Fear of being alone	<b>1.92 (.53)</b>	1.77 (.92)	.005	.809	59
Having a new sibling	1.05 (.22)	<b>1.23 (.69)</b>	.004	-1.478	59
Moving to a new school	1.21 (.61)	<b>1.57 (.98)</b>	.007	-1.781	58

*Note: italicized, bolded text indicate higher group mean values*

Male n= 22

Female n= 39



Caregivers reported that females had higher stress reactions to only two items, “fear of the dark” (female mean 1.92, male mean 1.55) and “fear of being alone” (female mean 1.92, male mean 1.77). A pattern also emerged indicating that participants with verbal abilities experienced more stress than non-verbal participants (see Table 4). Verbal participants were rated as having more intense stress reactions to thirteen stressors. Non-verbal participants had stronger reactions to only two items, feeling crowded and receiving activity reinforcement. Similarly, those with less severe forms of mental retardation had stronger reactions to eight stressors (see Table 5).

Table 4 – Comparisons of Significant Differences between Verbal and Non-verbal Participants, using two-tailed, single-sample t tests,  $p < .05$

Stressor	Mean	Mean	p	t	df
	Verbal (sd)	Non-verbal (sd)	value		
Receiving a present	<b>2.54 (1.10)</b>	2.15 (.51)	.000	1.791	57
Waiting to talk about a desired topic	<b>3.12 (1.07)</b>	1.58 (.56)	.000	7.124	57
Being in the vicinity of noise/disruption	<b>3.85 (1.12)</b>	3.42 (1.54)	.005	1.172	57
Having personal objects missing/out of place	<b>3.42 (1.41)</b>	2.24 (.90)	.001	3.889	57
Receiving activity reinforcement	2.36 (1.00)	<b>2.91 (1.18)</b>	.001	1.040	56
Having something marked as correct	<b>2.39 (1.42)</b>	2.15 (.51)	.000	3.447	57
Having unstructured time	<b>2.31 (1.05)</b>	1.82 (.53)	.023	2.334	57
Being allowed to attend party/favored event	<b>2.58 (1.24)</b>	2.30 (.77)	.005	1.042	57
Having something marked incorrect	<b>2.65 (1.47)</b>	1.52 (.80)	.001	3.808	57
Going home (from school, to visit parents)	<b>2.04 (1.31)</b>	1.39 (.66)	.008	2.461	57
Waiting for transportation	<b>2.46 (1.14)</b>	2.22 (.66)	.020	1.015	56
Feeling crowded	2.96 (1.11)	<b>3.44 (1.48)</b>	.020	-1.357	56
Receiving tangible reinforcement	<b>2.46 (1.03)</b>	2.06 (.56)	.002	1.915	57
Receiving verbal reinforcement	<b>2.50 (1.14)</b>	2.03 (.81)	.046	1.849	57
Having a new sibling	<b>1.23 (.65)</b>	1.03 (.17)	.001	1.696	57

*Note: italicized, bolded text indicate higher group mean values*

Verbal n= 26  
Non-verbal n=33

Table 5 – Comparison of Significant Differences Between Participants with Mild or Moderate Mental Retardation and those with Severe or Profound Mental Retardation, using single-sample t tests,  $p < .05$

Stressor	Severe or Profound (n= 20)	Mild or Moderate (n= 40)	p value	t	df
Receiving activity reinforcement	2.21 (.57)	<b>2.30 (1.03)</b>	.005	-4.56	57
Having something marked as correct	1.53 (.72)	<b>2.50 (1.50)</b>	.000	-3.472	58
Having something marked as incorrect	1.40 (.50)	<b>3.20 (1.47)</b>	.000	-7.023	58
Being able to assert oneself with others	2.38 (1.06)	<b>3.05 (1.32)</b>	.047	-2.139	58
Losing at a game	1.68 (.47)	<b>2.60 (1.39)</b>	.000	-3.810	58
Waiting for reinforcement	2.10 (.63)	<b>2.45 (.89)</b>	.010	-1.761	58
Fear of animals	1.93 (.76)	<b>2.35 (1.50)</b>	.018	-1.462	58
Fear of the dark	1.75 (.44)	<b>1.90 (.85)</b>	.013	-.904	58

*Note: italicized, bolded text indicate higher group mean values*

Mild/Moderate n=20  
Severe/Profound n=40

All responses from the open-ended question “What are the things you use to identify a stress reaction? What behaviors serve as clues that the person is experiencing stress?” were reviewed and six categories were formed (see Table 6). Most caregivers appeared to interpret physical signs such as hitting, or isolating oneself, as indications of stress, and several caregivers noted more than one signal they use to identify a reaction in a particular individual.

Table 6 – Caregiver Responses to Open-ended Questions

# responses	Response to question “Please list any other stressors on the lines below”
9	Grooming (bathing/showering, haircuts, nail care, dressing)
3	Medical issues (allergies, asthma, PMS)
2	Death (family member, pet)
1	Fear of assault by a peer
1	Belief others are talking about them
1	Unannounced visitors
1	Contact with family member
1	Repeated phone calls

*Collected from 20 respondents*

Responses from “Please list any other stressors” and “Which do you consider the most significant stressors of those you have identified?” yielded important information about stressors not contained in the SSS that may be relevant to this population. In particular, stress resulting from grooming was noted for nine participants as a stressor not included in the SSS and also as the most significant stressor for these nine participants.

Table 7 - Responses to question “Which do you consider the most significant stressors of those you have identified?”

# responses	
20	Disruption to schedule/routine
12	Crowded/noisy place
9	Grooming
6	Being told “no”
5	Waiting for something
3	Receiving instructions/directions
2	New staff
2	Going to the doctor
2	Jealousy/others getting attention
2	Others doing something wrong
2	Being touched
1	Believing something is wrong medically
1	Being unable to communicate needs
1	Bright lights
1	Moving to a new location
1	Going from a preferred to a non-preferred activity

*Collected from 46 respondents*

## CHAPTER IV

### DISCUSSION

This study describes the first attempt at validating the Stress Survey Schedule (Grodén et al., 2001) for use among adults with mental retardation. While the current study did not obtain an adequate number of participants to achieve this goal, several important trends were identified and valuable information that may strengthen future work with this population was noted.

Most importantly, this study demonstrates that people with mental retardation experience stress. Many of the stressors they experience are similar to those experienced among people without mental retardation, while some stressors may be particularly stressful to people with mental retardation. While certain environmental factors can create a loss of equilibrium and stress in people without mental retardation, this study provides evidence that stressors related to the environment may be particularly stressful for people with mental retardation. Across the sample, “having a change in environment from comfortable to uncomfortable,” produced the highest mean stress score, with an average rating of “moderate to severe.” This sensitivity to change may be related to earlier work that identified a tendency to prefer sameness and symmetry in children with mental retardation (Milgram, 1971), a trend that has been noted in other populations with developmental disabilities (Grodén, 1994) as well. While most information about the desire to “maintain sameness” is anecdotal or based on single case studies, this study raises the possibility that change, in and of itself, may be a significant stressor for people with mental retardation. Stress related to the environment also emerged in data indicating that noise and disruption by others was a considerable stressor. This item produced an



average rating of “moderate to severe” and exposure to crowded or noisy places was listed as the most significant stressor for twelve participants in open-ended question responses. Coupled with research linking stress to expressions of aggression (Fleming & Tosh, 1984) and decreased performance (Ollendick et al., 1993) in this population, this study’s finding that noise is a considerable stressor helps to shed light on previous research relating noise to a variety of performance and behavioral domains. For example, increased noise and crowding were shown to increase maladaptive behaviors (aggression and non-compliance) and decrease self-helping skills in adults with severe mental retardation (Walker et al., 1985). Similarly, exposure to a noisy room was shown to reduce motor performance (Heitman et al., 1985) and decrease social interactions during mealtime (Wentworth, 1991) among adults with mental retardation.

While stress related to environmental factors was identified across the sample, men experienced more stress than women. These findings are contrary to previous evidence showing that adult females (Benson, 1985) and girls (Feldhusen & Klausmeier, 1962) with mental retardation tend to experience higher rates of anxiety and higher rates of many forms of psychopathology (Lunsky, 2003). It is also inconsistent with rates of anxiety disorders among those without mental retardation, where females are twice as likely to be diagnosed with an anxiety disorder (Clum & Pickett, 1984). Several factors could contribute to the gender pattern that emerged in this sample. First, the sample included almost twice as many women ( $n = 39$ ) as men ( $n = 22$ ) and men’s scores were more variable suggesting that the inclusion of more men may have produced less variability in these scores and possibly a lower mean value. Secondly, qualitative differences between mean scores were not large. For instance, the largest mean stress

reaction difference was from “none to mild” to “mild to moderate.” Third, the women in this sample tended to be older (58, mean age) than the men (48, mean age) and there is some evidence that anxiety is more likely to emerge as depression (Wetherell et al., 2001) in older adults.

Consistent with prior research, “higher functioning” participants tended to react more strongly to a number of stressors (Iverson & Fox, 1989; Benson et al., 1985). As this sample tended to be skewed more heavily towards people on the severe to profound range of mental retardation and there were not enough participants with mild mental retardation to perform analyses, verbal status was used as a proxy for level of functioning. Participants with the ability to communicate verbally are considered more highly functioning (acknowledging that participants may be non-verbal for a variety of reasons not related to functioning), none of those in the mild or moderate range were non-verbal. Furthermore, of the participants where IQ information was provided, those with higher *IQs* tended to be verbal). In this sample, verbal participants averaged significantly higher scores on thirteen stressors, most notably from receiving tangible or verbal reinforcement. While this finding is interesting, it does call into question some methodological issues. For instance, it is possible that non-verbal participants experience the same amount of stress when exposed to these stressors, but that their reaction is more difficult to identify. Furthermore, several of the items on the survey, such as “waiting to talk about a desired topic” or “having a conversation” are not applicable to non-verbal participants and this may create the artificial impression that they experience less stress. Although not as statistically powerful, participants with moderate and mild mental

retardation were collapsed into the “less severe” category and those with severe and profound mental retardation were collapsed into a “more severe” category.

One of the primary purposes of this study was to compare the factor structure from this sample with Groden et al.’s (2001) work with children and adults with autism. Although the current study’s sample size does not meet the minimum suggested for a factor analysis (Velicer & Fava, 1998; Guadagnoli & Velicer, 1988), examination of the existing data indicate strong resemblances to Groden et al.’s (2001) work, although there were also important differences. Similar to Groden et al.’s (2001) pilot study, these data were best explained by a six-factor model and several factors were theoretically equivalent to those identified in the initial development of the SSS. Factor two in this study, pleasant events, conceptually replicated factor three, pleasant events, in Groden’s work. Similarly, unpleasant events, the third factor in this study, mirrored factor five, unpleasant events, in SSS development work and the sixth factor from that work, anticipation, was found in this sample as factor five. In subsequent work, however, Groden found that separating items that had to do with food (i.e. – waiting at a restaurant, waiting for food) from those that did not have to do with food (i.e. – waiting for preferred events, waiting for transportation), provided a better fit with the data. In this study, the factor accounting for the most variance, ritual related stress and changes, was conceptually different than Groden et al.’s (2001) “changes and social threats” factor. While some items from the current study that related to change (i.e. changes in environment from comfortable to uncomfortable, changes in tasks, etc.) loaded on the first factor in Groden’s pilot study, many items loading on this study’s first factor emerged as a separate factor, ritual related stress, in Groden et al.’s (2001) work.

Furthermore, stressors related to crowding included as part of their first factor, were more strongly associated with factor four, social and environmental interactions, in the present work. Factor four in Groden et al.'s (2001) study, sensory stimuli (identification of this factor was not replicated in any of Groden et al.'s subsequent work on the survey), failed to emerge in this sample and the lack of any open-ended responses related to sensory stimuli would seem to indicate that it may not be a significant stressor for this population. An additional factor, fear of the dark, emerged as a separate factor in this sample, although it contains only one item. Fear of the dark is subsumed under social/environmental interactions in Groden et al.'s (2001) work. Taken together these data would seem to indicate that the experience of stress might be very similar in people with autism and mental retardation, although this sample appears to be more acutely sensitive to interruption or changes associated with rituals. This tendency, noted as a need for sameness in earlier work, deserves more empirical attention and is similar to qualities found in autistic samples (Ornitz & Ritvo, 1985). Similarities between Groden et al.'s (2001) work and this sample are not surprising given the high degree of overlap between autism and mental retardation (American Psychiatric Association, 2000), and comparable symptom profiles between the two conditions (i.e. - possible deficits in communication, social skills, and cognitive abilities). While similarities exist between Groden et al.'s (2001) sample and the current study, the stressors identified seem to be different in salience and quality to those experienced by people without mental retardation. This inference, however, should be made with consideration, as the SSS has not been tested in a population without mental retardation.



Responses to the open-ended questions suggest modification for future use of the SSS and provides further evidence that it is a useful tool for measuring stress in this population. Two stressors not included on the original SSS emerged as stressors in this sample and may indicate stressors unique to adults with mental retardation. Identification of stress related to grooming (i.e. – bathing, dressing, having nails cut, etc.) was noted by nine caregivers and emerged as the third ranked most significant stressor. In addition, stress resulting from medical conditions, such as allergies or asthma, appeared as a significant source of stress for members of this community and may prove useful to include in future versions of the SSS. Consistent with evidence from the factor analysis and previous research linking aggression to the termination of ritual related activity (Murphy et al., 2000), disruptions to schedules, routines and rituals were identified as the most significant stressors for twenty participants. Exposure to crowds and noise, conceptually similar to many of the items subsumed under factor four, social and environmental interaction, was identified as the most significant stressor for 19.7% of participants. Interestingly “being told no,” identified by six caregivers as the most significant stressor, did not load on any of the factors in this study. In Groden et al.’s (2001) work this item emerged on the “unpleasant events” factor, while its correlation reached only .297 on the unpleasant events factor in this study. Perhaps being told no is simply not a stressful event for this sample. It may be interpreted in a different way, as helpful, instructive or non-threatening, or it may be such a common occurrence that participants have habituated to it and do not find it stressful. Furthermore, the younger sample used to develop the SSS may find being told no more aversive than older participants do.



Given that the average caregiver in this study has over seven years of experience working with the participants, data from the open-ended question concerning how caregivers identify stress reactions in their clients, offers a better glimpse into the lives of the participants. At the same time, it also raises an important methodological question about measuring stress in this population. Caregivers interpreted vocalizations such as yelling, moaning or talking, and outward physical expressions like arm movement, hitting and kicking as the primary means of identifying stress in this population. Many of the behaviors that caregivers interpreted as signals of stress are related to aggression. Traditionally, aggressive behavior has not been considered a measure of stress. Instead, verbal reports of the experience of stress or physiological signals such as muscle tension or elevated heart rate have been used as indicators of stress. This indicates a potential problem with the term stress and caregivers' understanding of it. Future research in this area would benefit from a more thorough exploration of the concept of stress as it applies to this population.

Several cautions should be noted when interpreting data from this study. First, due to the limited sample size, this project might best be considered as a pilot study with this population. A larger sample may have resulted in a different factor solution, as occurred with Groden et al.'s (2001) subsequent work with the SSS. If a similar factor interpretation emerged in the context of a second, larger, sample these data could be viewed as a more accurate representation of the experience of stress among adults with mental retardation. While there is a high degree of comorbidity between autism and mental retardation, none of the participants in this study was identified as having autism, suggesting that reactions to stress across these two samples may be different. Finally, the

factor structure of the SSS may differ based on a number of important variables. The profile of stressors might vary considerably at differing levels of IQ, type of residential placement, comorbidity with other psychological and medical disorders, and medication use, that may impact the way one experiences stress and may lead to the need for a unique survey, or interpretation, to accurately understand stress in this population. Unfortunately, these factors could not be adequately investigated with the current sample.

While the current study was limited by its small sample size and inadequate number of participants to test hypotheses about stress and gender, level of mental retardation and residential setting, corroborating evidence from the quantitative data and the open-ended questions does suggest that the SSS can be a useful means of identifying stress in persons with mental retardation. With further development, use of the SSS could prove invaluable in this population. For example, the SSS can be used to identify constellations of stressors for an individual. A treatment program could then be designed around these stressors and the SSS could prove useful as an outcome measure. Similarly, profiles for individual respondents could be compiled and this information could be transmitted across environments, for instance from residential to school to vocational settings. These profiles could also be useful to educate new staff about a person's likely stress reactions (especially important for individuals who express stress in the form of aggression). Perhaps most importantly, further development of the SSS could stimulate research in an area where very little information exists. The SSS helps to clarify that people with mental retardation do in fact experience stress and that their stress often reaches significant levels.

APPENDIX A  
THE STRESS SURVEY SCHEDULE FOR PERSONS WITH AUTISM  
AND DEVELOPMENTAL DISABILITIES

Please rate the intensity of the stress reaction to the following events by filling in the appropriate circle:

	Never Observed	None to Mild	Mild to Moderate	Moderate	Moderate to Severe	Severe
1. Receiving a present.....	(1)	(2)	(3)	(4)	(5)	(6)
2. Having personal objects or materials out of order.....	(1)	(2)	(3)	(4)	(5)	(6)
3. Waiting to talk about desired topic.....	(1)	(2)	(3)	(4)	(5)	(6)
4. Having a change in schedule or plans.....	(1)	(2)	(3)	(4)	(5)	(6)
5. Being in the vicinity of noise or disruption by others.....	(1)	(2)	(3)	(4)	(5)	(6)
6. Waiting for preferred events.....	(1)	(2)	(3)	(4)	(5)	(6)
7. Having a cold.....	(1)	(2)	(3)	(4)	(5)	(6)
8. Being touched.....	(1)	(2)	(3)	(4)	(5)	(6)
9. Having personal objects or materials missing.....	(1)	(2)	(3)	(4)	(5)	(6)
10. Having a change in task to a new task with new directions.....	(1)	(2)	(3)	(4)	(5)	(6)
11. Going to the store.....	(1)	(2)	(3)	(4)	(5)	(6)
12. Being prevented from completing a ritual.....	(1)	(2)	(3)	(4)	(5)	(6)
13. Having a change in environment from comfortable to uncomfortable.....	(1)	(2)	(3)	(4)	(5)	(6)
14. Being prevented from carrying out a ritual.....	(1)	(2)	(3)	(4)	(5)	(6)
15. Moving from one location to the next.....	(1)	(2)	(3)	(4)	(5)	(6)
16. Playing with others.....	(1)	(2)	(3)	(4)	(5)	(6)
17. Having a change in environment from familiar to unfamiliar.....	(1)	(2)	(3)	(4)	(5)	(6)
18. Receiving activity reinforcement.....	(1)	(2)	(3)	(4)	(5)	(6)
19. Having something marked as correct.....	(1)	(2)	(3)	(4)	(5)	(6)
20. Being in the vicinity of bright lights.....	(1)	(2)	(3)	(4)	(5)	(6)
21. Following a diet.....	(1)	(2)	(3)	(4)	(5)	(6)
22. Having unstructured time.....	(1)	(2)	(3)	(4)	(5)	(6)
23. Being allowed to attend a party or favored event.....	(1)	(2)	(3)	(4)	(5)	(6)

Please rate the intensity of the stress  
reaction to the following events by  
filling in the appropriate circle:

	Never Observed	None to Mild	Mild to Moderate	Moderate	Moderate to Severe	Severe
24. Receiving a reprimand.....	1	2	3	4	5	6
25. Transitioning from preferred to non-preferred activity.....	1	2	3	4	5	6
26. Being told "no".....	1	2	3	4	5	6
27. Receiving criticism.....	1	2	3	4	5	6
28. Having something marked incorrect.....	1	2	3	4	5	6
29. Being interrupted while engaging in a ritual.....	1	2	3	4	5	6
30. Receiving hugs and affection.....	1	2	3	4	5	6
31. Having to engage in not-liked activity.....	1	2	3	4	5	6
32. Waiting in line.....	1	2	3	4	5	6
33. Being unable to communicate needs.....	1	2	3	4	5	6
34. Waiting at a restaurant.....	1	2	3	4	5	6
35. Going home (from school, to visit parents).....	1	2	3	4	5	6
36. Waiting for transportation.....	1	2	3	4	5	6
37. Being unable to assert oneself with others.....	1	2	3	4	5	6
38. Needing to ask for help.....	1	2	3	4	5	6
39. Participating in group activity.....	1	2	3	4	5	6
40. Having a change in staff, teacher or supervisor.....	1	2	3	4	5	6
41. Losing at a game.....	1	2	3	4	5	6
42. Waiting for reinforcement.....	1	2	3	4	5	6
43. Feeling crowded.....	1	2	3	4	5	6
44. Someone else making a mistake.....	1	2	3	4	5	6
45. Receiving tangible reinforcement.....	1	2	3	4	5	6
46. Waiting for food.....	1	2	3	4	5	6
47. Waiting for routine to begin.....	1	2	3	4	5	6
48. Having a conversation.....	1	2	3	4	5	6
49. Receiving verbal reinforcement.....	1	2	3	4	5	6



Please rate the intensity of the stress reaction to the following events by filling in the appropriate circle.

	Never Observed	Nons to Mild	Mild to Moderate	Moderate	Moderate to Severe	Severe
<b>FEARS</b>						
1. Fear of animals.....	(1)	(2)	(3)	(4)	(5)	(6)
2. Fear of water (pool, lake, ocean, etc) .....	(1)	(2)	(3)	(4)	(5)	(6)
3. Fear of crowds .....	(1)	(2)	(3)	(4)	(5)	(6)
4. Fear of closed spaces .....	(1)	(2)	(3)	(4)	(5)	(6)
Fear of the dark .....	(1)	(2)	(3)	(4)	(5)	(6)
Fear of being left alone .....	(1)	(2)	(3)	(4)	(5)	(6)
<b>LIFE STRESSORS</b>						
Going to the doctor or dentist.....	(1)	(2)	(3)	(4)	(5)	(6)
Having seizures .....	(1)	(2)	(3)	(4)	(5)	(6)
Having a new sibling.....	(1)	(2)	(3)	(4)	(5)	(6)
Moving to a new house .....	(1)	(2)	(3)	(4)	(5)	(6)
Moving to a new school.....	(1)	(2)	(3)	(4)	(5)	(6)
Having parents get divorced.....	(1)	(2)	(3)	(4)	(5)	(6)
Having a parent re-marry.....	(1)	(2)	(3)	(4)	(5)	(6)

APPENDIX B  
DEMOGRAPHIC SHEET

## THE STRESS SURVEY SCHEDULE

- Prior to completing this survey, please make sure a consent form is on file for this client
- If you are unsure of an answer, please provide your most accurate assessment/guess, please do not ask the client for who you are completing this survey any questions. Thank you for your help.

1. Date: \_\_\_\_\_
2. Your Name: \_\_\_\_\_
3. Name of individual who is the subject of the survey \_\_\_\_\_
4. Please estimate the number of hours of contact you typically have with this individual each week:

\_\_\_\_\_ hours

Please estimate the total length of time you have had contact with this individual\*

\*(If you have less than three months of contact with this individual, please do not complete the survey at this time)

\_\_\_\_\_ months

5. Individual's age: \_\_\_\_\_ 6. Gender: \_\_\_\_\_ Female \_\_\_\_\_ Male
7. Ethnicity: \_\_\_\_\_ Caucasian \_\_\_\_\_ African American \_\_\_\_\_ Latino
- \_\_\_\_\_ Asian American \_\_\_\_\_ Native American
- Other (please specify) \_\_\_\_\_

8. If available, please indicate the individual's primary medical diagnoses:

\_\_\_\_\_

9. Please list any medications this individual is currently taking:

\_\_\_\_\_

10. Individual's IQ score, if available: \_\_\_\_\_

Designation: \_\_\_\_\_ mild \_\_\_\_\_ moderate \_\_\_\_\_ severe \_\_\_\_\_ profound

11. Is this individual: \_\_\_\_\_ Employed \_\_\_\_\_ in a vocational program \_\_\_\_\_ in a sheltered workshop

Other (please specify) \_\_\_\_\_

12. Is this individual: \_\_\_\_\_ verbal \_\_\_\_\_ nonverbal

13. This individual lives: \_\_\_\_\_ with family \_\_\_\_\_ in a group residence
- \_\_\_\_\_ apartment (with staff) \_\_\_\_\_ developmental facility
- \_\_\_\_\_ other (please specify) \_\_\_\_\_

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Study ID Number \_\_\_\_\_

APPENDIX C  
CONSENT TO PARTICIPATE

**Informed Consent to Participate in a Study:  
Anxiety Issues in Adults with Mental Retardation**

*Staff Member: As per instructions from the DMR Research Review Committee, please place the original of the completed consent form in the participant's record and return a photocopy of the form to a member of the research staff prior to answering any questions on the survey..*

We are talking with your staff about what kinds of things you might get anxious about. For example, some people get nervous about their van not coming to pick them up, or some people feel anxious about going to visit a new place. We would like to find out what types of worries and stress you feel and how often you feel them. By talking to your staff and asking them to fill out a checklist about what things cause you stress, we think that we can better understand what anxieties people have.

**Risks/Benefits:** We would like you to know that anything that your staff tells us will be confidential, and we will do everything possible to make sure any information your staff gives to us will be kept private. Even though it is not likely, there is a small chance that someone could find out what your staff told us about the things that make you feel stress. After we have put the information your staff gives to us into our computer, we will shred the part of the questionnaire that has any identifying information on it, to help to ensure your privacy. We strongly feel that the things your staff can tell us about stress will help us better understand stress and anxiety, and be able to help people who sometimes feel anxiety.

It is important for you to know that you do not have to let your staff talk to us if you do not want to. Whether you decide to let them talk to us or not, you will still receive all of the same services from DMR that you receive now.'

If you would like to talk to someone to get more information about being in this study, or if you have any questions about this study, you can call Sean Robins at (413) 746-4763. If Sean is not there when you call him, leave a message and he will call you back. Other people who are involved with this project are: Patricia Wisocki, Ph.D. at the University of Massachusetts, Nancy Haberstoh, Ph.D. at the Monson Developmental Center, and David Cowles, Ph.D.

When you put your name on the line at the bottom of this paper, that will mean that you have agreed to let your staff talk to us. If you change your mind and decide not to let your staff talk to us, that is fine, and it will not change any of the services that you have now.

Thank you.

\_\_\_\_\_  
signature

\_\_\_\_\_  
date

\_\_\_\_\_  
guardian signature (if applicable)

\_\_\_\_\_  
date

\_\_\_\_\_  
\*witness signature (if client does not have a guardian)

\_\_\_\_\_  
date

\*witness, by signing this document (in the absence of a guardian) you are attesting that the participant understands the contents of this consent form. Witness signature is acceptable only if you are a Human Rights Officer, or designee.



APPENDIX D  
GUARDIAN CONSENT TO PARTICIPATE

## **Informed Consent to Participate in a Study: Anxiety Issues in Adults with Mental Retardation**

*Staff Member: As per instructions from the DMR Research Review Committee, please place the original of the completed consent form in the participant's record and return a photocopy of the form to a member of the research staff prior to answering any questions on the survey..*

We are talking with staff members who treat adults with mental retardation about what types of things make them anxious. For example, some people get nervous about their van not coming to pick them up, or some people may feel anxious about going to visit a new place. We would like to find out what types of worries and stress adults with mental retardation may experience. By talking to staff members and asking them to fill out a checklist about what things create stress for clients in their care, we think that we can better understand what anxieties adults with mental retardation have.

**Risks/Benefits:** Anything that a staff member tells us will be confidential, and we will do everything possible to make sure any information given to us will be kept private. Although it is not likely, there is a small chance that someone could find out what staff members have told us about the things that create stress for their clients. To reduce this likelihood, after we have put the information staff members give us, into our computer, we will shred the part of the questionnaire that has any identifying information on it, to help to ensure privacy. We strongly feel that the things staff members can tell us about stress will help us better understand stress and anxiety, and be able to help people who sometimes feel anxiety.

It is important for you to know that you do not have to give permission to allow staff members who treat the person you are a guardian for, to talk to us. Whether you decide to let them talk to us or not, there will be no change in the services provided by DMR.

If you would like to talk to someone, or receive more information, about this study, please contact Sean Robins at (413) 746-4763. If Sean is not there when you call him, leave a message and he will call you back. Other people who are involved with this project are: Patricia Wisocki, Ph.D. at the University of Massachusetts, Nancy Haberstoh, Ph.D. at the Monson Developmental Center, and David Cowles, Ph.D.

By signing this consent form, you will authorize staff members who provide services for the person you are the guardian of, to participate in this study by filling out a questionnaire designed to measure stress and anxiety.

Thank you.

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guardian signature

---

date

APPENDIX E  
LETTER OF INTRODUCTION TO THE STUDY

Dear Guardian,

We are currently conducting a study to learn more about the experience of stress and anxiety in a group of adults with mental retardation. At this time, very little research exists concerning stress in adults with mental retardation. We feel that this study will help us to better understand what types of events can create stress, and how often these events occur in daily life. We strongly believe that this study will give us important information about stress and anxiety that can be used to provide more informed and effective client care.

The study will be conducted by asking direct care staff, in institutional and residential settings, to complete a survey that tries to identify stressful experiences for clients in their care (e.g. receiving criticism, or feeling crowded). The study will not require any clients to answer questions, be exposed to stressful things, or have any change in the care they receive. Clients will have no direct involvement with the study; instead, staff will be asked to reflect on their experiences with the clients in their care. Because the information collected from staff members will be about the person for whom you are currently the legal guardian, we would like to ask your permission to have staff members complete this survey for us. The enclosed consent form provides us with this permission.

We will do everything possible to make sure that information collected during this study will be kept confidential and information from the study will not be recorded in client's files. Only the original study consent form will be placed in the client file. You are under no obligation to sign the enclosed consent form, or to allow staff members to provide us with any information. If you decide that you do not want to give us your permission, the services provided by the Massachusetts Department of Mental Retardation will not be affected.

If you have any questions, or would like to discuss the study, please contact Sean Robins at (413) 746-4763.

Thank you.

APPENDIX F  
STUDY FACT SHEET



Purpose	The study of Anxiety Issues for Adults with Mental Retardation (A.I.M.) seeks to measure the extent and type of stress and anxiety experienced by adults with mental retardation, using a standardized scale.
Rationale	At this time very little research exists concerning the experience and measurement of stress and anxiety in adults with mental retardation. This study will contribute to both research and caregiver knowledge, leading to more informed and effective client care
Design	Caregivers will be asked to complete the Stress Survey Schedule for Persons with Autism and Developmental Disabilities (SSS), for clients in their care. This questionnaire was developed and factor analyzed by Groden et al. (2001) and found to be useful for people with autism and developmental disabilities. It is composed of 62 items that have been found to elicit stress in this population. It also contains 2 open-ended questions about other stressors and 10 questions eliciting demographic information. The responses of the caregivers will be factor analyzed for the development of a profile of anxiety among this population. The results of this study will also be compared with the findings reported by Groden, et al. (2001) in their study of individuals with developmental disabilities.
Sample	Instructions: Please rate the intensity of the stress reaction to the following events (answer choices are on a five point scale from no stress reaction, to severe stress reaction) Sample Items: receiving a present, being told "no," feeling crowded, moving to a new house, being touched, being unable to communicate needs.
Subject	Massachusetts Department of Mental Retardation staff, working with adults with mental retardation in community-based residences and institutions, will be the informants for the study.
Duration	Caregivers will be asked to complete a 72-item questionnaire for clients in their care. The questionnaire should take about 10-15 minutes to complete for each client.
Contacts	Patricia Wisocki, Ph.D., University of Massachusetts, Amherst.  Sean Robins, University of Massachusetts, Amherst
Info.	For more information, please contact: Sean Robins at (413) 545-5953, by email at <a href="mailto:sbrobins@psych.umass.edu">sbrobins@psych.umass.edu</a> , or  Dr. Patricia Wisocki at (413)545-1359, or <a href="mailto:wisocki@psych.umass.edu">wisocki@psych.umass.edu</a>

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