

Mental Health for People With Intellectual Disability: The Impact of Stress and Social Support

Haleigh M. Scott and Susan M. Havercamp

Abstract

A large, nationally representative sample from a preexisting dataset, the National Core Indicators, was used to examine the impact of stress and social support on the mental health of adults with intellectual disability (ID). Stress was significantly correlated with both mental illness and severity of behavior problems, with each additional stressor increasing the odds of poor mental health by 20%. This relationship held, even after controlling for level of ID, gender, and place of residence. Lack of social support was associated with having a mental illness; individuals who lacked social support were twice as likely to have a mental illness. The importance of considering these factors in the prevention, diagnosis, and treatment of mental health in this population is discussed.

Key Words: *Mental health; stress; social support; adults with intellectual disability*

Background

Stressful life events have been linked to a number of mental disorders in the general population, such as depression (Kessler, 1997), psychosis (Bebbington, Bowen, & Ramana, 1997), and substance abuse (Kilpatrick, Acierno, Resnick, Saunders, & Best, 1997), as well as physical health issues (Craig & Brown, 1984; Niaura, & Goldstein, 1992). At one time, it was widely assumed that people with intellectual disability (ID) could not experience mental illness because they lacked the intellectual capacity (Potter, 1965). Similarly, people with ID were assumed to lack the capacity to feel or be adversely affected by stress. Recent research has disproved both these assumptions. In fact, individuals with ID may be at a greater risk for experiencing stress than their counterparts without a disability (Hatton & Emerson, 2004) and likely have fewer resources available to help cope with that stress (Lunsky & Benson, 2001). Some research has suggested that people with ID report levels of stress similar to that of people with other types of disabilities and to the general population of people without disabilities (Bramston, Fogarty, & Cummins, 1999; Bramston &

Mioche, 2001). Other research, such as a study by Hartley & MacLean (2009), found that compared to a matched sample of adults from the general population, 47 depressed adults with ID at the upper end of the spectrum had frequent stressful social interactions, experienced more stress, and used fewer active coping skills. People with ID may experience less control over both minor daily life decisions, such as what to eat for lunch, and major life decisions, such as where they will live (Bannerman, Sheldon, Sherman, & Harchik 1990). Lack of control has been shown to increase the impact of stressors in the general population, and may have the same effect on people with ID (Dulin, Hanson, & King, 2013).

Stress and Mental Health

As in the general population, stress experienced by people with ID is linked to many negative mental health outcomes. Individuals with ID who had experienced a recent loss or other stressful life events were rated higher on scales of mental health symptoms than those who had not experienced these events (Hulbert-Williams & Hastings, 2008). Martorell et al. (2009) looked at

the presence or absence of an ICD-10 mental illness diagnosis in relation to traumatic and stressful life events in a sample of 177 adults with ID at the upper end or middle range of the spectrum and found both were significantly related to having an ICD-10 diagnosis. A similar study with a larger sample size ($n > 1,000$), found that the presence of one or more stressful life events in the previous 12 months increased the odds ratio for affective disorders in a population of adults with ID (Hastings, Haton, Taylor, & Maddison, 2004). A second study found that this relationship held, even after controlling for demographic variables (Owen et al., 2004). In a study of 151 adults with ID at the upper end or middle range of the spectrum, the number of life events experienced in the previous 6 months predicted current depression (McGillivray & McCabe, 2007). A study that relied on self-report of stressful life events in 38 verbal adults with ID found similar patterns (Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011).

The link between stress and mental illness may be especially important to the understanding of mental health in individuals with ID as they experience mental illness or psychiatric disorders, at rates that are similar to, if not higher than, the general population (Cooper, Smiley, Morrison, Williamson, & Allen, 2007; Rutter, Tizard, Yule, Graham, & Whitmore, 1976; Tsiouris, Kim, Brown, & Cohen, 2011). This co-occurrence of ID and mental illness is known as “dual diagnosis.” The presence of ID complicates the diagnosis of mental illness due to varying symptom presentations, deficits in communication that result in an inability to self-report symptoms and self-refer for treatment, and the lack of training many professionals have in assessing mental illness in patients with ID (Rojahn & Tassé 1996; Sovner & Hurley, 1983). These difficulties and lack of training may lead to inaccurate or under diagnosis of mental illness in this population, making it important to understand what factors may be contributing the development or maintenance of mental illness in adults with ID.

Within the ID population there is a second component of mental health which is of significant concern: behavior problems. Prevalence studies estimate 10%–45% of adults with ID exhibit some form of behavior problems such as verbal or physical aggression, property destruction, or self-injurious behavior (Emerson et al.,

2001; Grey, Pollard, McClean, MacAuley, & Hastings, 2010; Jones et al., 2008). These behavior problems tend to be long lasting; Kiernan and Alborz (1996) followed 34 young adults with problem behaviors over a 5-year period and found that rates of problem behaviors stayed fairly consistent, with 70%–96% of problem behaviors being maintained at similar frequency. The presence of behavior problems is associated with many negative outcomes, such as decreased employment opportunities and increasingly restrictive residential placements (Martorell, Gutierrez-Recacha, Pereda, & Ayuso-Mateos, 2008; McIntyre, Blacher, & Baker, 2002). Due to the prevalence, pervasiveness, and negative life impact of behavior problems, it is important to gain understanding of their development and maintenance.

One potentially important contributor to behavior problems is stress. Research, though sparse, suggests that stress has a similar impact on problem behaviors as it does on mental illness. One prospective study found that problem behaviors were predicted by frequency counts of stressful life events (Esbensen & Benson, 2006). Several correlational studies found that individuals who scored higher on measures of behavior problems were more likely to have experienced stressful events in the past 6 (Monaghan & Soni, 1992) or 12 months (Ghaziuddin, 1988; Owen et al. 2004). Given this link between stress and behavior problems in people with ID, it is important to look for protective factors that may be available.

Social Support and Mental Health

Research in the general population has shown that *social support*, generally defined as the extent to which an individual has a network of friends and family who can provide an outlet for frustrations and fears and give assistance and encouragement in times of difficulty, can act as a buffer between the impact of stress and the mental health consequences. Social support has been extensively researched and found to improve physical and mental health as well as play a protective role in times of stress. Several studies have shown that social support is negatively correlated with depression, even after controlling for stressful life events, and promotes recovery from severe mental illness (Aneshensel & Stone, 1982; Bell, Leroy, & Stephenson, 1982; Hendryx, Green, & Perrin,

2009). In ID, higher levels of social support are positively correlated with higher quality of life and negatively correlated with depression (Lunsky & Benson, 2001; Meins, 1993; Reiss & Benson, 1985). In contrast, Hulbert-Williams et al. (2011), using self-reports of stress and social support from 38 verbal individuals, found that social support did not moderate the stress-mental health relationship. The authors do however cite a possible floor effect on the social support measure and called for further research.

Current Study

The current study examines the relationship between stress, social support, and mental health in adults with ID. Though previous studies have examined stress as a factor in mental health, these studies have generally been restricted to adults in the mild to moderate range of functioning and have been limited to small samples of convenience. In this study, we seek to explore if increased stress is related to an increased likelihood of mental health problems, specifically diagnosed mental illness and behavior problems. In addition, this study will go beyond previous research to ask if a lack of social support increases the risk of mental health problems in people with ID. As the impact of stress and social support on the quality of life and mental health is rarely considered in service planning for this population, additional research in this area may improve practice and policy.

Methods

Participants

Participants were drawn from the National Core Indicators (NCI) database for survey year 2009–2010, which includes 11,599 adults with developmental disabilities. Per NCI protocol, participants were randomly selected from a state service registry and invited to participate as part of developmental disability (DD) services quality management protocol. This sample includes individuals from 25 states in the United States: Alabama, Arizona, Arkansas, California, District of Columbia, Florida, Georgia, Hawaii, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Missouri, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, South Dakota, Texas, and Washington (see Table 1 for demographic information). The term *developmental*

disability is an umbrella term that represents a heterogeneous population. Diagnoses characterized by delays or impairments in motor, language, or social development yet lack intellectual impairment, such as cerebral palsy or an autism spectrum disorder, often qualify for developmental disability services. We hypothesize that individuals with DD with and without ID may be impacted differently by stress or have different social support needs. To better define our sample, we excluded participants who did not have ID; for example, participants with an autism spectrum disorder were included only if they also had a diagnosis of ID. Our total sample of participants with an ID diagnosis consists of 10,627 adults.

One feature of the NCI instrument is that the information is gathered from multiple sources. Questions that come from the self-report section of the survey can only be answered by the participant with ID. If the participant is unable or unwilling to answer, then the answer is coded as a non-response and no proxy measures are used. The social support variable contains only items from the self-report section of the survey and is highly susceptible to missing data due to the inability of some participants to self-report. For this reason, a subsample was created that contains participants who answered a minimum of three out of the five social support questions. If a participant answered at least three questions, any missing values on the social support measure were replaced with the mean of the other responses. Participants who responded to two or fewer support questions were dropped from the analysis. This method of replacement added 965 participants to the self-report sample, comprising 14.6% of the subsample. After this replacement method, 6,604 adults were included and will be referred to as the self-report sample. Table 1 compares the demographic characteristics of the full and self-report samples using a Pearson's chi-squared test. As would be expected, the two groups differed significantly on level of ID, with a greater number of participants in the self-report sample falling at the upper end of the spectrum, $\chi^2(1, N = 6604) = 8.1, p < .01$ and fewer at the lowest end of the spectrum, $\chi^2(1, N = 6604) = 14.8, p < .001$. Individuals living in institutions are underrepresented in the self-report sample, $\chi^2(1, N = 6604) = 7.3, p < .01$. The differences between these groups are important and have implications for the applicability of results to the ID population as a whole.

Table 1
Demographics of Full and Self-Report Sample

| Characteristics | Full Sample (10,627) | Self-report Sample (6,604) |
|---|----------------------|----------------------------|
| Male | 56.6% | 55.6% |
| Age | | |
| 18-34 years | 28.4% | 31.3% |
| 35-54 years | 47.5% | 46.0% |
| ≥55 years | 24.1% | 22.7% |
| Race/Ethnicity | | |
| White, non-Hispanic | 70.1% | 70.1% |
| Black, non-Hispanic | 19.1% | 20.3% |
| Other, non-Hispanic | 4.9% | 4.9% |
| Hispanic | 5.9% | 4.7% |
| Severity of Intellectual Disability | | |
| Upper end of spectrum ^a | 35.7% | 52.7% |
| Middle range of spectrum | 26.6% | 32.9% |
| Lower range of spectrum | 15.6% | 10.4% |
| Lowest end of the spectrum ^b | 22.1% | 4.0% |
| Other Disabilities | | |
| Autism | 10.5% | 7.1% |
| Down Syndrome | 8.2% | 8.3% |
| Alzheimer's Disease/dementia | 1.6% | 1.3% |
| Place of Residence | | |
| Family | 29.3% | 35.1% |
| Semi/Fully Independent | 17.7% | 23.4% |
| Group Home | 30.1% | 31.7% |
| Institution ^a | 22.8% | 9.9% |

Note. ^aSignificant at the .01 level. ^bSignificant at the <.001 level.

Data Source

National core indicators. The National Core Indicators (NCI) is a quality management protocol for the developmental disabilities service delivery system. The NCI was created by the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Service as a quality improvement measure to be used across states and over time to assess several key outcomes such as consumer satisfaction, family satisfaction, cost, health, and safety.

The NCI consists of three sections: (1) service coordinators provide demographic information and medical record information from case files; (2) adults with disabilities are asked questions in a face-to-face interview where only answers from that individual are accepted; and (3) if the

individual with DD is unable or unwilling to continue, the final section of the survey can be completed by an interview with a family member or someone who “knows him/her well.” This approach of using records, self-report, and a third-party responder is supported by research done in a 2002 study that found that the most accurate reports of health and health care utilization were obtained when multiple sources were consulted (Lunsky, Emery, & Benson, 2002). Interviewers receive standardized training and states follow identical protocols to ensure reliability across states. Participating states collect data annually on a random sample of at least 400 adults with DD so that benchmarks for standards of care can be established and goals for improvement set. States can measure their progress against states of similar size or composition. This large sample size,

standard measurement protocol, and random selection of participants make the NCI a beneficial tool for research and policy change.

Measures

Social support. Our social support measure consists of five NCI self-report questions (see Table 2). Alternate phrasing of these questions is provided when needed to facilitate understanding, making them an effective way to obtain perceived

levels of support from adults with ID. For example, a question on friendship, “Do you have a best friend or someone you are really close to?” can also be phrased “Is there someone you can talk to about personal things?” This allows the individual to report anyone that they feel fills this role whether this is a peer or paid staff, as many individuals with ID receive social support from caregivers and not only from a peer or family (Lunsky & Neely, 2002). It is important that this information is provided by the participant with a disability because caregivers cannot infer the internal emotional states or perceived social support of the adult with ID. Although caregivers may be able to accurately report supportive family members or caregiver’s relationships, they are less certain regarding friendships and partners (Lunsky & Benson, 1999). Our social support score ranges between 0 (no support) and 1 (full support). These scores reflect the proportion of questions in which an individual indicated support; for example, an individual who indicated support in one out of the five questions would have a social support score of .2.

Stress. We created a measure of stressful life events consisting of 13 questions that came from all three response sections of the NCI survey (see Table 2). In selecting items, previous research on stressful life events in the ID field and published life event scales such as the Lifestress Inventory were consulted (Fogarty, Bramston, & Cummins, 1997). Items were scored on a *yes/no* basis. Scores could range from 0, meaning that person had not reported experiencing any of the stressful life events listed, to 13, meaning that person had reported experiencing every stressful life event possible from our list. Any question left blank was coded as the individual not experiencing that event.

Mental health problems. Measures of mental illness and problem behaviors are also included in the NCI. As part of the record review (I) section of the NCI, case workers completed a 16-item checklist of associated conditions that included current diagnosis of mental illness (1 = diagnosed mental illness 0 = no diagnosis). *Mental illness* was defined as a diagnosed psychiatric disorder and depression was given as an example. Autism spectrum disorders, chemical dependency, and communication disorders would not have been included as they were indicated elsewhere. The NCI addresses three types of problem behaviors: self-injurious, disruptive, and destructive. Each

Table 2
National Core Indicators Items and Percentage of Sample Endorsed

NCI items comprising Social Support Measure (Self-report sample only)

1. Does not have a close (best) friend, someone to talk to about personal things. (22.4%)
2. Does not have friends and caring relationships with people. (8.5%)
3. Can't see friends when you want to. (13.4%)
4. Can't see your family when you want to. (15.5%)
5. Often or sometimes feel lonely. (11.9%)

NCI items comprising Stress Measure by Section of NCI

Case Review- Section 1

1. Having poor health. (4.5%)
2. Requiring frequent (at least once/week) medical care. (4.2%)
3. Moved in past year. (8.8%)

Self-Report- Section 2

4. Not having a job but wanting one. (18.5%)
5. Having a job but not liking it. (0.3%)
6. Not liking current day program. (1.8%)
7. Not liking current living situation. (3.2%)
8. Staff treating person disrespectfully. (0.5%)
9. Scared at home. (2.7%)
10. Scared at work or day program. (2.6%)
11. Scared in current neighborhood. (1.9%)
12. Not having a person to go to when afraid. (1.7%)

Self- or Proxy Report-Section 3

13. Not receiving needed services. (4.6%)

NCI Items comprising Mental Health Measure

1. Person has a diagnosed mental illness. (36.6%)
 2. Person shows self-injury behavior. (22.7%)
 3. Person shows disruptive behavior. (38.6%)
 4. Person shows destructive behavior. (23.3%)
-

type of problem behavior is rated on a 3-point scale by severity. Behavior problem scores range from 0 (person shows no problem behaviors), to 6 (person has behaviors severe enough to require constant intervention for all three types). Both of these questions come from the record review (I) section of the NCI. (Please see Table 2 for a summary of all NCI items and percentage of participants that met criteria for each item.)

Statistics

All data were analyzed using SPSS version 19. Two models were examined: mental illness and behavior problems. The relationship of stress and social support to mental illness diagnosis was examined using logistic regression, whereas ordinal regression was used to explore the relationship of stress and social support to behavior problems. Both models were examined using the full sample and the self-report sample. Having a mental illness or having more severe behavior problems was treated as the response variable in all analyses. Gender, level of ID, and place of residence were entered in the first step of the hierarchical regression in order to control for the variance associated with these items. Stress was entered as a second and final step in the full sample analyses. In the self-report group, social support was added as a third step in the regression model.

Results

In the full sample, 36.6% of adults with ID were reported to have a co-occurring mental illness (37% of men, 36.4% of women). Adults living with family members had the lowest rate of reported mental illness (20.5%), followed by those living semi/fully independently (40.1%), those living in institutions (40.3%), and adults living in group homes had the highest reported rates of mental illness (44.3%). Adults living with family were significantly less likely to experience mental illness than adults living semi/fully independently $\chi^2(1, N = 1,763) = 9.6, p < .01$, in institutions $\chi^2(1, N = 2,271) = 9.7, p < .01$ and in group homes $\chi^2(1, N = 2,916) = 12.7, p < .001$. No other differences by place of residence were significant. Adults with ID at the upper end of the spectrum had the highest reported rates of mental illness (44.4%), followed by those with ID in the middle range of the spectrum (37.3%), those with ID in the lower range of the spectrum (32.9%), and

those with ID at the lowest end of the spectrum (26.8%). People with ID at the upper end of the spectrum were significantly more likely to be diagnosed with a mental illness than those with ID in the lower range of the spectrum $\chi^2(1, N = 1,582) = 4.0, p < .05$ or ID at the lowest end of the spectrum, $\chi^2(1, N = 2,243) = 11.6, p < .001$, and those with ID in the middle range of the spectrum more likely than those with ID at the lowest end of the spectrum, $\chi^2(1, N = 2,243) = 4.1, p < .05$.

In the full sample of adults with ID, 45% had at least some degree of behavior problems, with slightly more men (48.9%) than women (43.2%) having behavior problems, though this difference was not significant. Adults living with family members had the lowest rate of reported behavior problems (28.6%), followed by those living semi/fully independently (36%), those living in institutions (56.3%), and finally adults living in group homes had the highest reported rates of behavior problems (57%). Adults living with family were significantly less likely to have behavior problems when compared to those living in institutions $\chi^2(1, N = 2,271) = 13.6, p < .001$ and in group homes $\chi^2(1, N = 2,916) = 14.1, p < .001$. Similarly, adults living independently were less likely to have behavior problems compared to those living in institutions $\chi^2(1, N = 2,271) = 7.7, p < .001$ and in group homes $\chi^2(1, N = 2,916) = 7.3, p < .001$. Adults with ID at the upper end of the spectrum had the lowest reported rates of behavior problems (40.3%), followed by those with ID in the middle range of the spectrum (46.4%), those with ID at the lowest end of the spectrum (49.1%), and those with ID in the lower range of the spectrum (56.1%). People with ID in the lower range of the spectrum were significantly more likely to have behavior problems when compared to those with ID at the upper end of the spectrum, $\chi^2(1, N = 1,582) = 4.4, p < .05$. Approximately 24% of adults displayed behavior problems and were also diagnosed with a mental illness.

The relationship of stress and mental illness was examined with the full sample of adults using a hierarchical logistic regression (see Table 3). Level of ID was a significant predictor, with those with ID at the upper end of the spectrum having the highest risk of mental illness diagnosis followed by those with ID at the middle, lower, and lowest range of the spectrum. Place of residence was also significant; adults living with family had the lowest risk followed by adults

Table 3
Logistic and Ordinal Regression

| Characteristic | Total Sample | | | | | | Self-Report Sample | | | | | | | | | |
|---------------------------------|-----------------------------|----------------|------|--------------------------------|------|-----------------|----------------------------|-------|-------|-------------------------------|------|-------|------|-----------------|------|-------|
| | Mental Illness (n = 10,627) | | | Behavior Problems (n = 10,627) | | | Mental Illness (n = 6,604) | | | Behavior Problems (n = 6,604) | | | | | | |
| Variable | B | Wald | OR | p | B | Wald | OR | p | B | Wald | OR | p | B | Wald | OR | p |
| Gender | | 0.05 | | ns | | 14.88 | | <.001 | | 1.40 | 0.93 | ns | | 0.25 | | ns |
| Male | 0.01 | 0.05 | 0.99 | .ns | 0.16 | 14.88 | 1.17 | <.001 | -0.07 | 1.40 | | ns | .03 | 0.25 | 1.03 | ns |
| Level of ID ^a | | 276.15 | | <.001 | | 131.28 | | <.001 | | 89.99 | | <.001 | | 36.69 | | <.001 |
| Middle range | -0.32 | 28.94 | 0.73 | <.001 | 0.37 | 46.65 | 1.45 | <.001 | -0.30 | 20.83 | 0.74 | <.001 | 0.28 | 21.40 | 1.33 | <.05 |
| Lower range | -0.66 | 81.71 | 0.51 | <.001 | 0.68 | 112.41 | 1.97 | <.001 | -0.72 | 48.04 | 0.49 | <.001 | 0.46 | 25.04 | 1.58 | <.001 |
| Lowest range | -1.24 | 267.25 | 0.28 | <.001 | 0.16 | 5.58 | 1.16 | <.05 | -1.20 | 50.98 | 0.30 | <.001 | 0.30 | 4.58 | 1.35 | <.001 |
| Place of Residence ^b | | 505.42 | | <.001 | | 585.59 | | <.001 | | 327.21 | | <.001 | | 493.07 | | <.001 |
| Semi/fully Ind. | 0.82 | 128.03 | 1.97 | <.001 | 0.45 | 44.08 | 1.57 | <.001 | 0.69 | 72.76 | 1.99 | <.001 | 0.46 | 33.13 | 1.58 | <.001 |
| Group | 1.20 | 367.57 | 2.95 | <.001 | 1.20 | 462.77 | 2.97 | <.001 | 1.16 | 247.95 | 3.19 | <.001 | 1.23 | 325.0 | 3.44 | <.001 |
| Institution | 1.57 | 421.67 | 4.13 | <.001 | 1.27 | 376.75 | 3.56 | <.001 | 1.53 | 209.70 | 4.63 | <.001 | 1.74 | 334.52 | 5.69 | <.001 |
| Stress | .181 | 45.52 | 1.20 | <.001 | .17 | 52.15 | 1.19 | <.001 | .16 | 28.51 | 1.18 | <.001 | .27 | 73.52 | 1.27 | <.001 |
| Social Support | - | - | - | - | - | - | - | - | -.73 | 28.21 | .48 | <.001 | -.32 | 6.47 | .73 | <.05 |
| Significance of Model | | $\chi^2=797.3$ | | <.001 | | $\chi^2=890.70$ | | <.001 | | $\chi^2=521.38$ | | <.001 | | $\chi^2=724.58$ | | <.001 |

Note. ID = intellectual disability.

^aID at the upper end of the spectrum as comparison group. ^bLiving with family as comparison group.

living semi/fully independently, living in a group home, and living in an institution. Stress was a significant predictor of a having been diagnosed with a mental illness; after controlling for demographic variables individuals who experienced greater numbers of stressful events were more likely to have a diagnosis of a mental illness.

An ordinal regression analysis was used to examine the relationship between stress and severity of behavior problems (see Table 3). Gender was a significant predictor of behavior problems, as was level of ID. Adults with ID at the upper end of the spectrum had the lowest risk of severe behavior problems and those with ID in the lower range of the spectrum had the highest. Place of residence was a significant predictor of behavior problems; adults living with family had the lowest risk followed by adults living semi/fully independently, living in a group home, and living in an institution. Stress was a significant predictor of severe behavior problems after controlling for demographic variables.

All social support analyses were conducted on the self-report sample only ($n = 6,604$). A one-way ANOVA was used to test for differences in social support scores by presence of a mental illness and presence of behavior problems. There were significant differences between adults with and without a mental illness diagnosis, $F(1, 6,187) = 51.32, p < .001$, and those with and without behavior problems, $F(1, 6,187) = 30.04, p < .001$. Adults with either behavior problems or a mental illness diagnosis reported lower levels of social support than their counterparts.

Logistic regression was used to examine the effects of social support on the stress-mental illness relationship in the smaller self-report sample (see Table 3). Level of ID was a significant predictor of mental illness with likelihood of having a mental illness decreasing as level of ID became more severe. Place of residence was also a significant predictor; those living in more restrictive settings were more likely to have a mental illness diagnosis. As with the full sample, stress was a significant predictor. Social support was a significant predictor of mental illness even after controlling for gender, level of ID, place of residence, and stress.

The role of social support in the stress-behavior problems relationship was examined using ordinal logistic regression (see Table 3). Though gender was a significant predictor of severe behavior problems in the full sample, it was

not a significant predictor in the self-report sample. Adults with ID at the upper end of the spectrum had the lowest risk of severe behavior problems and those with ID in the lower range of the spectrum had the highest. Adults living with family had the lowest likelihood of having severe behavior problems and likelihood increased with more restrictive placement. Stress was a significant predictor of severe behavior problems as was lack of social support.

Discussion

Two components of mental health were explored in this study, mental illness and behavior problems. We felt that this was a more complete way to examine the mental health of people with ID, as both mental illness and problem behaviors contribute unique information and can be extremely detrimental to personal relationships and overall quality of life. In this sample, the prevalence of mental illness was approximately 36%, a rate which aligned fairly well with previous studies and adds to the body of research demonstrating that mental illness in the ID population exceeds that of the general population (Cooper et al., 2007). The overall prevalence of behavior problems was 45%, a finding consistent with the current literature (Grey et al., 2010). There was also significant comorbidity of mental disorders and behavior problems, with 24% of the sample displaying both.

A significant relationship between stress and negative mental health outcomes was found. In the full sample of adults with ID, 39.1% reported at least one stressful life event. For every additional stressor, the likelihood of having a mental illness diagnosis increased by 20% and severe behavior problems by 19%. These results confirm previous studies which showed stress as an important factor in mental health for people with ID (Hulbert-Williams & Hastings, 2008; Hulbert-Williams et al., 2011; McGillivray & McCabe, 2007). The results of this study add to the literature by showing that this relationship holds in a representative sample of adults across functional levels. Understanding the impact of stress in people with ID in the lower range of the spectrum is especially important given that they are often underrepresented in research and may lack the ability to communicate their mental health status. The stress-mental health relationship was similar in the self-report sample, with

each stressor increasing the likelihood of mental illness by 18% and the severity of behavior problems by 27%. Although demographic differences between the two samples were evident, they yielded similar patterns with regards to the variables of interest. This finding increased our confidence in generalizing the self-report sample findings to the population of people with ID.

The relationship between stress and behavior problems was greater in the self-report sample ($OR = 1.27$) when compared to the full sample ($OR = 1.19$). One difference between these samples was that the self-report sample was largely comprised of individuals with ID at the upper end of the spectrum who are able to communicate. This finding may suggest that stress is experienced or reported differently by these individuals versus those with ID in the lower range of the spectrum. It is also possible that behavior problems may serve different functions based on level of intellectual functioning. Additional research is needed to clarify and explain this finding.

The results of this study suggest that stress is an important variable that should be considered a part of the assessment of both mental illness and behavior problems. Stress should be considered a risk factor for mental illness and preventative measures should be taken to minimize stress and provide additional support in times of unavoidable stress, such as the death of a family member or change in residence. Improving the supports and services available to individuals with ID during transition periods and other stressful life changes may be important to reduce the impact of stress on mental health. Given the results of this study, it would be beneficial to develop tools for measuring stress in people who are unable to verbally communicate. Taking the stressors present in a person's life into consideration could help identify the cause of behavior problems or identify individuals who are at risk for developing future behavior problems. This would allow for preventative steps to be taken for high-risk individuals. This also has implications for treatment of behavior problems. Current treatment approaches for behavior problems are often pharmacologically based, in fact, people with ID are considered to be one of the most heavily medicated populations (Reiss & Aman, 1997). Alternative treatments, such as behavioral or cognitive-behavioral approaches, may also be well-suited for the ID population by teaching individuals skills for coping with stress.

Social support accounted for a significant amount of the variance in mental illness and behavior problems, and 42.7% of our self-report sample reported lacking social support on at least one of the five social support questions. This finding contributes to a relatively sparse area of research in the ID field and has serious implications for prevention and treatment of mental illness as well as for quality of life. Previous research has demonstrated that social support is negatively correlated with depression in individuals with ID; however these studies used either a proxy report to determine social support or limited their sample to adults with high levels of functioning, rendering these findings less generalizable to the ID population as a whole (Lunsky & Benson, 2001). This study is unique in that adults at all levels of functioning were included and the measure of social support obtained through direct report. Additionally, this study examined the relationship between social support and behavior problems, a new addition to the literature. Having adequate social support was associated with a greater than 50% decrease in the odds of having a mental illness. Though still significant, social support's impact on behavior problems was less pronounced ($OR = .73$).

Social support measures may help to identify those at risk for developing mental health problems and should be considered when looking at factors that contribute to their maintenance. Social support considerations should weigh heavily on service plan decisions that affect treatment and life style. For example, an individual with ID may be moved out of a family home into a residential or community placement without due consideration to the familial or community supports that might be left behind. It is important to be aware that our social support analyses were conducted on a subset of the full sample and therefore may not be representative of the population of adults with ID. Because our social support measure relied on self-report, these findings may be most representative of adults with expressive language. However, it should be noted that approximately 15% of the self-report sample was comprised of people with severe or profound ID, suggesting that this subgroup was represented.

Future Directions

The results of this study suggest that stress and social support are important factors to consider

when examining the mental health of people with ID at all functioning levels. Future research in stress may examine how to best measure stress, especially in individuals who are nonverbal. Ways to mitigate the impact of stress and provide supports is also an area that would benefit from additional research. Further research, especially longitudinal studies that include people at all levels of functioning, is needed to better define how social support may be related to mental health in this population. Especially important is developing tools to effectively measure social support in adults with no communication skills, in order to better understand this often overlooked population.

Limitations

Because our study did not have a longitudinal design, we are unable to draw causal conclusions from our results. Though stress was a strong predictor of poor mental health outcomes, we cannot determine if it was a cause, a consequence, or a correlate. It is likely that a bidirectional relationship exists, with stress both contributing to and exacerbated by mental health problems. Due to the retrospective nature of this study, there is no way to determine whether mental health problems contributed to the stressors experienced by the participants, or whether social support was negatively impacted by the presence of mental health problems. Simply put, the direction of this relationship could not to be determined in this study. Studies that examine these factors prospectively are needed to further explore this topic.

The mental illness variable used in our analyses was not ideal. Presence or absence of a mental illness was determined by a review of case records and was not independently confirmed. Information on specific diagnoses, severity, longevity, and participation in any form of treatment such as psychotherapy or pharmacological intervention was unavailable. Future research examining how these variables are related to specific mental health diagnoses is needed. The measure of stress used in this study was based upon environmental stressors and not an individual's perceived levels of stress. Perceived stress is an important area of future research, as well as how factors such as personal choice and control may impact how stressful events are perceived. Additionally, it is important to note that the NCI data is collected from a population of adults receiving

DD services. This study cannot generalize to the all the adults with ID in the community who are not receiving services and though our results suggested that the self-report group is similar to the full sample, caution should be used in generalizing the results to the population of adults with ID. It is also important to take into consideration the vast heterogeneity present in this population. Analyses looking at specific groups (e.g., ASD) may help to better understand mental health in this population.

Despite its limitations, this study uniquely contributed to the field of dual diagnosis in several ways. First, it examined several variables that are key to understanding mental health issues using a large random sample of adults in the United States receiving DD services. This is extremely rare, as is the fact that the sample included many adults with ID in the lower and lowest end of the spectrum. Second, it was able to demonstrate that large scale survey data can be adapted to provide state or national data that speak to a topic of interest. Lastly, it highlighted the importance of stress and social support for mental health and provided the basis for future studies to explore these factors as impacting the mental health of people with ID.

References

- Aneshensel, C. S., & Stone, J. D. (1982). A test of the buffering model of social support. *Archives of General Psychiatry*, 39(12), 1392–1396. <http://dx.doi.org/10.1001/archpsyc.1982.04290120028005>
- Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis*, 23(1), 79–89. <http://dx.doi.org/10.1901/jaba.1990.23-79>
- Bebbington, P., Bowen J., & Ramana R. (1997). Life events and psychotic disorders. In T. W. Miller (Ed.), *Clinical disorders and stressful life events* (pp. 89–120). Madison, CT: International Universities Press.
- Bell, R. A., Leroy, J. B., & Stephenson J. J. (1982). Evaluating the mediating effects of social support upon life events and depressive symptoms. *Journal of Community Psychology* 10(4), 325–340. <http://dx.doi.org/10.1002/1520-6629>

- (198210)10:4<325::AIDJCOP2290100405>3.0.CO;2-C
- Bramston, P., Fogarty, G., & Cummins, R. A. (1999). The nature of stressors reported by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 12*(1), 1–10. <http://dx.doi.org/10.1111/j.1468-3148.1999.tb00046.x>
- Bramston, P., & Mioche, C. (2001). Disability and stress: A study in perspectives. *Journal of Intellectual and Developmental Disabilities, 26*(3), 233–242. <http://dx.doi.org/10.1080/13668250120063403>
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allen, L. (2007). Mental ill-health in adults with intellectual disability: Prevalence and associated factors. *The British Journal of Psychiatry, 190*, 27–35. <http://dx.doi.org/10.1192/bjp.bp.106.022483>
- Craig, T. K. J., & Brown, G. W. (1984). Goal frustration and life events in the etiology of painful gastrointestinal disorder. *Journal of Psychosomatic Research, 28*, 411–421. [http://dx.doi.org/10.1016/0022-3999\(84\)90073-4](http://dx.doi.org/10.1016/0022-3999(84)90073-4)
- Dulin, P. L., Hanson, B. L., & King, D. K. (2013). Perceived control as a longitudinal moderator of late-life stressors on depressive symptoms. *Aging & Mental Health, 17*(6), 718–723. <http://dx.doi.org/10.1080/13607863.2013.784956>
- Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., ... Hatton, C. (2001). The prevalence of challenging behaviors: A total population study. *Research in Developmental Disabilities, 22*, 77–93. [http://dx.doi.org/10.1016/S0891-4222\(00\)00061-5](http://dx.doi.org/10.1016/S0891-4222(00)00061-5)
- Esbensen, A. J., & Benson, B. A. (2006). A prospective analysis of life events, problem behaviors, and depression in adults with intellectual disability. *Journal of Intellectual Disability Research, 50*(4), 248–258. <http://dx.doi.org/10.1111/j.1365-2788.2005.00816.x>
- Fogarty, G. J., Bramston, P., & Cummins, R. A. (1997). Validation of the Lifestress Inventory for people with a mild intellectual disability. *Research in Developmental Disabilities, 18*(6), 435–456. [http://dx.doi.org/10.1016/S0891-4222\(97\)00021-8](http://dx.doi.org/10.1016/S0891-4222(97)00021-8)
- Ghaziuddin, M. (1988). Behavioral disorder in the mentally handicapped. The role of life events. *British Journal of Psychiatry, 152*, 683–686. <http://dx.doi.org/10.1192/bjp.152.5.683>
- Grey, I., Pollard, J., McClean, B., MacAuley, N., & Hastings, R. (2010). Prevalence of psychiatric diagnoses and challenging behaviors in a community-based population of adults with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities, 3*(4), 210–222. <http://dx.doi.org/10.1080/19315864.2010.527035>
- Hartley, S. L., & MacLean, W. E. (2009). Depression in adults with mild intellectual disability: Role of stress, attributions, and coping. *American Association on Intellectual and Developmental Disabilities, 114*(3), 147–160.
- Hastings, R. P., Hatton, C., Taylor, J. L., & Maddison, C. (2004). Life events and psychiatric symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 48*(1), 42–46. <http://dx.doi.org/10.1111/j.1365-2788.2004.00584.x>
- Hatton, C., & Emerson, E. (2004). The relationship between life events of psychopathology amongst children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 109–117. <http://dx.doi.org/10.1111/j.1360-2322.2004.00188.x>
- Hendryx, M., Green, C. A., & Perrin, N. A. (2009). Social support, activities, and recovery from severe mental illness: STARS study findings. *Journal of Behavioral Health Services and Research, 36*(3), 320–329. <http://dx.doi.org/10.1007/s11414-008-9151-1>
- Hulbert-Williams, L., & Hastings, R. P. (2008). Life events as a risk factor for psychological problems in individuals with intellectual disabilities: A critical review. *Journal of Intellectual Disability Research, 52*, 883–895. <http://dx.doi.org/10.1111/j.1365-2788.2008.01110.x>
- Hulbert-Williams, L., Hastings, R. P., Crowe, R., & Pemberton, J. (2011). Self-reported life events, social support and psychological problems in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(5), 427–436. <http://dx.doi.org/10.1111/j.1468-3148.2011.00624.x>
- Jones, S., Cooper, S. A., Smiley, E., Allan, L., Williamson, A., & Morrison, J. (2008). Prevalence of, and factors associated with, problem behaviors in adults with intellectual disabilities. *The Journal of Nervous and Mental Disease, 196*(9), 678–686. <http://dx.doi.org/10.1146/annurev.psych.48.1.191>
- Kessler, R. C. (1997). The effects of stressful life events on depression. *Annual Review of Psychology, 48*, 191–214. <http://dx.doi.org/10.1146/annurev.psych.48.1.191>

- Kiernan, C., & Alborz, A. (1996). Persistence and change in challenging and problem behaviors of young adults with intellectual disability living in the family home. *Journal of Applied Research in Intellectual Disabilities, 9*(3), 89-93.
- Kilpatrick, D. G., Acierno, R., Resnick, H. S., Saunders, B. E., & Best, C. L. (1997). A 2-year longitudinal analysis of the relationship between violent assault and substance use in women. *Journal of Counseling and Clinical Psychology, 65*, 834-847. <http://dx.doi.org/10.1037/0022-006X.65.5.834>
- Lunsky, Y., & Benson, B. A. (1999). Social circles of adults with mental retardation as viewed by their caregivers. *Journal of Developmental and Physical Disabilities, 11*(2), 115-129. <http://dx.doi.org/10.1023/A:1021843003671>
- Lunsky, Y., & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcomes for adults with mild intellectual disability. *Journal of Intellectual Disability Research, 45*(2), 106-114. <http://dx.doi.org/10.1046/j.1365-2788.2001.00334.x>
- Lunsky, Y., Emery, C. F., & Benson, B. A. (2002). Staff and self-reports of health behaviors, somatic complaints, and medications among adults with mild intellectual disability. *Journal of Intellectual & Developmental Disability, 27*(2), 125-135. <http://dx.doi.org/10.1080/13668250220135079-4>
- Lunsky, Y., & Neely, L. C. (2002). Extra-individual sources of social support as described by adults with mild intellectual disabilities. *Mental Retardation, 40*(4), 269-277. [http://dx.doi.org/10.1352/0047-6765\(2002\)040<0269:EISOSS>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2002)040<0269:EISOSS>2.0.CO;2)
- Martorell, A., Gutierrez-Recacha, P., Pereda, A., & Ayuso-Mateos, J. L. (2008). Identification of personal factors that determine work outcome for adults with intellectual disability. *Journal of Intellectual Disability Research, 52*(12), 1091-1101. <http://dx.doi.org/10.1111/j.1365-2788.2008.01098.x>
- Martorell, A., Tsakanikos, E., Pereda, A., Gutiérrez-Recacha, P., Bouras, N., & Ayuso-Mateos, J. L. (2009). Mental health in adults with mild and moderate intellectual disabilities: The role of recent life events and traumatic experiences across the life span. *Journal of Nervous and Mental Disease, 197*(3), 182-186. <http://dx.doi.org/10.1097/NMD.0b013e3181923c8c>
- McGillivray, J. A., & McCabe, M. P. (2007). Early detection of depression and associated risk factors in adults with mild/moderate intellectual disability. *Research in Developmental Disabilities, 28*(1), 59-70. <http://dx.doi.org/10.1016/j.ridd.2005.11.001>
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *Journal of Intellectual Disability Research, 46*(3), 239-249. <http://dx.doi.org/10.1046/j.1365-2788.2002.00371.x>
- Meins, W. (1993). Prevalence and risk factors for depressive disorders in adults with intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities, 18*(3), 147-156.
- Monaghan, M. T., & Soni, S. (1992). Effects of significant life events on the behavior of mentally handicapped people in the community. *British Journal of Mental Subnormality, 38*(2), 114-121.
- Niaura, R., & Goldstein, M. G. (1992). Psychological factors affecting physical condition: Cardiovascular disease literature review: II. Coronary artery disease and sudden death and hypertension. *Psychosomatics: Journal of Consultation Liaison Psychiatry, 33*, 146-155. [http://dx.doi.org/10.1016/S0033-3182\(92\)71990-2](http://dx.doi.org/10.1016/S0033-3182(92)71990-2)
- Owens, D. M., Hastings, R. P., Noone, S. J., Chinn, J., Harman, K., Roberts, J., & Taylor, K. (2004). Life events as correlates of problem behavior and mental health in a residential population of adults with developmental disabilities. *Research in Developmental Disabilities, 25*(4), 309-320. <http://dx.doi.org/10.1016/j.ridd.2004.01.003>
- Potter, H. W. (1965). Mental retardation: The Cinderella of psychiatry. *Psychiatric Quarterly, 39*(1), 537-549. <http://dx.doi.org/10.1007/BF01569484>
- Reiss, S., & Aman, M. (1997). The international consensus process on psychopharmacology and intellectual disability. *Journal of Intellectual Disability Research, 41*(6), 448-455. <http://dx.doi.org/10.1111/j.1365-2788.1997.tb00736.x>
- Reiss, S., & Benson, B. A. (1985). Psychosocial correlates of depression in mentally retarded adults: I. Minimal social support and stigmatization. *American Journal of Mental Deficiency, 89*(4), 331-337.

- Rojahn, J., & Tasse, M. J. (1996). *Psychopathology in Mental Retardation*. Washington, DC: American Psychological Association.
- Rutter, M., Tizard, J., Yule, W., Graham, P., & Whitmore, K. (1976). Isle of Wight studies, 1964–1974. *Psychological Medicine*, 6, 313–332. <http://dx.doi.org/10.1017/S003329170001388X>
- Sovner, R., & Hurley, A. D. (1983). Do the mentally retarded suffer from affective illness? *Archives of General Psychiatry*, 40(1), 61. <http://dx.doi.org/10.1001/archpsyc.1983.01790010063008>
- Tsiouris, J. A., Kim, S. Y., Brown, W. T., & Cohen, I. L. (2011). Association of aggressive behaviours with psychiatric disorders, age, sex and degree of intellectual disability: A large-scale survey. *Journal of Intellectual Disability Research*, 55(7), 636–649. <http://dx.doi.org/10.1111/j.1365-2788.2011.01418.x>

Received 4/24/2013, accepted 11/4/2013.

Special thanks to HSRI and NASDDDS for the use of the NCI data.

Authors:

Haleigh M. Scott, The Ohio State University, IDD Psychology; **Susan M. Havercamp**, The Ohio State University, The Nisonger Center.

Correspondence concerning this article should be address to Haleigh Morgan Scott, The Ohio State University, IDD Psychology, 1056 W 6th Ave., Columbus, Ohio 43212, United States of America (e-mail: haleigh.scott@gmail.com).