

RUNNING HEAD: INDIVIDUALS WITH INTELLECTUAL DISABILITIES

Individuals with intellectual disabilities who live with family and experience psychiatric crisis:

Who uses the emergency department and who stays home?

Jonathan A. Weiss, Maggie Slusarczyk, and Yona Lunsky

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Abstract

Many individuals with intellectual disabilities who live with their families experience mental health problems and ensuing psychiatric emergencies. During periods of crisis, families may require additional services, including going to the emergency department (ED). The goal of this study was to elucidate demographic, clinical, and crisis features associated with ED use in 192 individuals who lived with family and experienced a psychiatric crisis. The presence of psychiatric symptoms, a mild (vs. moderate/severe) level of intellectual disability; a history of behaviour problems, psychiatric hospitalization and ED use; and a recent history of negative life events were related to ED use. Learning about the factors that distinguish groups is needed to make sure we develop proactive community-based resources for such people to prevent visits to the ED from occurring when possible.

Key words: family; psychiatric crisis, mental health problem; emergency department; intellectual disability

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Who uses the emergency department and who stays home?

An increasing number of people with intellectual disability (ID) live with their families into adulthood (Fujiura & Braddock, 1992; Haveman, van Berkum, Reijnders, & Heller, 1997; Lakin, Prouty, & Coucouvanis, 2007), and in such cases, family caregivers are an instrumental part of service coordination and delivery (Fiedler & Antonak, 1991; Hayden & Heller, 1997; Seltzer & Krauss, 1989; Smull, 1988). When individuals with ID develop mental health problems, service delivery extends to mental health care, and when mental health problems lead to a psychiatric emergency, service delivery extends to emergency department (ED) use (Bradley & Lofchy, 2005; Davidson et al. 1994; Lunskey, Gracey, & Gelfand, 2008). The risk of ED use as a result of psychiatric crisis is heightened by the high rates of mental health problems and challenging behaviors found in individuals with ID (Cooper, Smiley, Morrison, Williamson & Allan, 2007). The current study explores the variables that lead to ED use in individuals with ID who live with their families and have psychiatric crises.

Closer study of what leads to ED use in the ID population is particularly important when family caregivers are involved, if we are to support families in their efforts to access and coordinate effective care services for their relative (Grossman, Richards, Anglin, & Hutson, 2000; Sullivan et al., 2000). Identifying variables that place individuals with ID at risk for psychiatric crisis in the context of family care can inform policies and practices that are preventative in nature and provided before crisis and emergency services are required. For the purposes of this study, a psychiatric crisis is defined as “an acute disturbance of thought, mood, behavior, or social relationship that requires immediate attention as defined by the [individual], family, or community” (Allen, Forster, Zealber, & Currier, 2002, p. 8).

Parents often discuss the use of the ED as a last resort when their children's mental health problems become severe (Weiss, Lunskey, Gracey, Canrinus, & Morris, 2009), but little is known in terms of the specific client, family, or systemic factors that differentiate individuals who use the ED following psychiatric crisis compared to those who do not. Emergency response to a psychiatric crisis suggests that the event is related to a mental health and behavioral issue. Indeed, the presence of psychiatric or medical symptoms, and of aggressive behavior toward self or other, are the most commonly cited contributors to accessing mental health services (Cowley, Newton, Sturme, Bouras, & Holt, 2005; Davidson et al., 1994; Edelstein & Glenwick, 1997; Lunskey et al., 2008), and psychiatric issues are consistent drivers of hospitalization in this population (Balogh, Hunter, & Ouellette-Kuntz, 2005; Lunskey & Balogh, 2010). Little research exists specifically examining these variables in the context of family care, however.

There may also be variables that extend beyond issues of direct clinical need. Stressful life events, such as interpersonal difficulties, environmental changes, or trauma, often lead to an increase in maladaptive behavior, and physical or psychiatric symptoms in this population, and consequently may serve to increase an individual's level of clinical need and lead to seeking help (Grodin, Cautela, Prince, & Berryman, 1994; Hastings, Hatton, Taylor, & Maddison, 2004; Stack, Haldipur, & Thompson, 1987). Gender (Lunskey & Haverkamp, 2002), age (Davidson et al., 1994; Shoham-Vardi et al., 1996), and level of ID (Davidson et al., 1994) have also been correlated with mental health service use, although not yet examined with ED use. From a systemic perspective, a number of studies have highlighted that individuals with ID face multiple barriers to accessing primary care and mental health care (Dekker & Koot, 2003; Einfeld et al. 2006; McCarthy & Boyd, 2002; Ouellette-Kuntz, 2005; Weiss & Lunskey, 2010), which may make emergency service use more likely. As well, caregivers of individuals with ID who have experienced psychiatric crisis note a lack of meaningful daytime activities, respite services, and

mental health care (Weiss & Lunskey, 2010), although it is yet to be shown whether differences in such service receipt is related to emergency service utilization.

The goal of this study was to describe a clinical profile that differentiates individuals with ID who use the ED as a result of psychiatric crisis compared to those who do not use the ED. In terms of demographic differences, we expected to find that younger individuals and those who were male would be more likely to use the ED. In terms of clinical need, we hypothesized that individuals who used the ED would be more likely to have crises related to aggression, and more severe levels of aggression, compared to individuals who experienced a psychiatric crisis but did not use the ED. We also expected that the presence of a diagnosed psychiatric disorder would differentiate the two groups. In addition, we expected that significant negative life events, and a lack of daytime activities would differentiate the two groups.

Method

Participants

Our sample includes 192 individuals with ID (131 males, 61 females) who are living with families and who represent a subgroup of a larger study of crisis in individuals with ID. All individuals in the current sample came from one large and two medium-size urban centers in Ontario, Canada. Individuals with ID ranged from 10 to 65 years of age ($M = 25.3$ years, $SD = 10.45$). The majority of individuals were identified as Caucasian (62%). Individuals were noted by staff as having borderline IQ (8.9%); mild (30.7%), moderate (31.8%) or severe/profound (12.5%) ID; with the remainder classified as unknown (16.1%). As shown in Table 1, there was no significant difference in the age, gender distribution, or visible minority status of individuals who used the ED and those who did not.

Insert Table 1 here

All study participants were receiving social services or clinical services from agencies that support people with ID (e.g. residential, daytime services, or case management). To qualify for the study, individuals had to have experienced at least one psychiatric crisis over the duration. Informants were staff from participating mental health or social services agencies who worked directly with the persons with ID included in the study. Data was collected from these agency staff, not from the family members or the individual with ID directly, and no information on demographics of the informants was collected.

Measures

The *client background form* included information on age, gender, ethnicity, place of residence, daytime activities, psychiatric diagnoses, medical diagnoses, medication profile, life events over the past 12 months clinical services received (counseling/psychotherapy, behavior therapy, psychiatry, crisis planning, family physician), and variables describing history related to forensic involvement, hospitalizations and ER visits. The life events checklist used as part of the background form was based on a list of 21 life events from the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (Moss et al., 1998) and included items such as a change in the individual's residence; serious problems with a close friend; change in primary staff/worker and serious illness of a close relative, caregiver or friend. The *crisis incident report* described antecedents; the crisis itself, the seriousness of the aggression (if it was present/exhibited); and the consequences or outcome of the crisis, including whether it resulted in a visit to the hospital ED. Informants provided open-ended descriptions of antecedents and the crisis event which were later reviewed and coded (see Data Analysis).

Procedure

Deidentified information was collected on 751 individuals with ID who experienced crises over a 2-year period (June 2007-May 2009) from staff across 34 out of 47 agencies that provide services to people with ID in the Toronto, Peel and Kingston regions of Ontario. For the purposes of this study, 192 individuals (out of 751) were identified as living with family and used as our target sample. Each time a crisis occurred, agency staff completed a client background form and a crisis incident report, which included whether the crisis resulted in a visit to the hospital ED. If the crisis incident occurred with agency staff, the background form and the crisis incident report were typically completed within a few days of the event as part of agency protocol. If the crisis incident occurred outside of the agency, staff completed the forms after hearing about the crisis from the client or his/her family member, which could be some time later depending on the amount of support the individual received from the agency. Completed forms were forwarded to the research team. All participating agencies were trained in the completion of these forms by the two project research coordinators. As part of this training, agencies were provided with the study's definition of crisis articulated above by Allen and colleagues (2002), along with a series of vignettes to help them understand the crisis definition. When staff were uncertain about whether and how to rate a situation, they contacted one of two research coordinators. This study received ethics approval from the hospital research ethics board.

Data Analysis

Following descriptive analyses on the entire sample, the dependent variable was coded as a binary response with persons who visited an ED at least once over the 2-year study period coded 1 and those who did not visit an ED over the same time period coded 0. Because of the small sample size, ethnicity was recoded as Caucasian or Visible Minority. Incident descriptions were reviewed by two raters and classified into 1 of 12 crisis categories: physical

aggression/injury to others, suicidal behavior/injury to self, other psychiatric symptoms, suicidal voicing/ideation only, property damage only, verbal aggression only, victim of verbal/physical abuse, missing/AWOL, accident, sexual deviance, respite/lack of resources, and other. Each category was mutually exclusive and descriptions were classified into a single category based on the primary issue of the incident and the severity of the behavior. There was an initial agreement between the two raters of 84%. Incidents in question were reviewed by a third rater, discussed and recoded until an agreement of 100% was reached. A total historical risk variable was also calculated to represent the risk of behavior problems, psychiatric hospitalization and ED visits, which comprised the following: history of aggression, history of self-injury, history of forensic involvement, history of sexual deviance, history of fire setting, history of ED visits, and prior psychiatric hospitalizations. If there was more than one crisis and only some of the crises went to the ED, we used the first visit that went to the ED for analysis. Given the small sample size and the bivariate level hypotheses, a series of independent samples *t* tests and chi-square tests of independence were planned. In cases where cell sizes were less than 5, Fisher's exact test was used. Logistic regression was used to examine if the significant bivariate predictors were independent predictors of ED visits and assess the explanatory power of the combined variables. All statistical analyses were completed using SPSS Version 17.0. The threshold for statistical significance was set at $p < 0.05$.

Results

As shown in Table 1, no significant differences were noted in age, gender, or visible minority status between groups. As shown in Table 2, individuals who used the ED were more likely to have borderline/mild (vs. moderate/severe) levels of intellectual impairment than those who did not use the ED (67% of the ED group had borderline/mild levels vs. 40% of the non-ED group, $p = .002$). Those who used the ED experienced significantly more negative life events,

$t(189) = 3.13, p = .02$, and had a greater number of historical risk items, $t(189) = 4.98, p < .001$, compared with individuals who did not use the ED after experiencing a psychiatric crisis. As shown in Table 2, individuals who used the ED had a greater number of psychiatric diagnoses than those who did not and were more likely to have a diagnosis of anxiety disorder (24% vs. 10%) or psychotic disorder (28% vs. 6%). There was no difference in the percentage of individuals in each group with an autism spectrum disorder diagnosis (40% vs. 33%).

Insert Table 2 here

Individuals who visited the ED showed a trend to be less likely be involved in structured daytime activities (37%), $\chi^2(1, N = 188) = 3.35, p = .07$. There was no difference in the type of clinical care received between groups (all $p > .10$). It is important to note, however, that a significant relationship between level of cognitive impairment and day program use was found, with adults with borderline/mild levels being more likely to receive no daytime activities compared to adults with moderate/severe ID (36% vs. 15%), $\chi^2(1, N = 161) = 8.80, p = .003$.

Binomial logistic regression analyses were conducted to test the capacity of the significant characteristics to predict ED use. Historical risk factors, negative life events, the level of cognitive impairment, and the presence of a psychotic and anxiety disorder were entered in a standard fashion. The model was significant, $\chi^2 = 30.09, df = 6, p < .001$, and correctly predicted 78% of participants. As shown in Table 3, historical risk and the presence of a psychotic disorder emerged as significant individual predictors.

Insert Table 3 here

With regard to the crisis event itself as a precipitant to ED utilization, Table 4 highlights the few crisis categories that differed between the two groups. Although the most frequently occurring type of crisis for both groups was “physical aggression/injury to others,” there was no difference in the percentages between those who used the ED and those who did not. In contrast, rates of self-injury were significantly higher in the group whose crises resulted in an ED visit when compared to those who did not (22% vs. 4%). Crises with psychiatric symptoms were also more evident in those who visited the ED versus those who did not (15% vs. 5%).

Insert Table 4 here

Discussion

Up to 40% of adults with ID will have comorbid mental health problems or significant challenging behavior at any one time point (Cooper et al., 2007), and there is a trend for individuals with ID to live with their families well into adulthood, creating an increasing burden of care for family members. For instance, data regarding adults with ID in the United States receiving U.S. Medicaid waivers indicates that rates of adults living with family members rose from approximately 6% in 1992 to 39% in 2006 (Lakin et al., 2007). Families of individuals with dual diagnosis will often strive to handle the mental health problems themselves, until they are unable to cope, and crisis ensues (Weiss & Lunskey, 2010). Yet not all crises lead to the ED. Of the 192 individuals with ID in the current sample who lived with their family and experienced crises, only 22% used the ED as a result. Understanding the characteristics of individuals with ID who use the ED is important for hospital staff, who perceive that families come to the ED for the wrong reasons or too quickly (Lunskey et al., 2008). Conversely, identifying the features of the

person with ID who does not use the ED, but who experiences crisis, is important for community services and clinicians who work with families in order to identify high risk clients and tailor supports to better meet their needs.

In this study, a greater proportion of individuals with ID who lived with family and experienced a crisis were male and a young adult (compared with female and an older adult), which is in line with previous studies that have reported that young males are more likely to have psychiatric issues than females or older individuals (Davidson et al., 1994; Lunsky & Havercamp, 2002; Shoham-Vardi et al., 1996). In contrast to expectations, though, ED use was equally likely across demographic variables - client age, visible minority status, and gender did not differ between those who went to the ED and those who did not. Past research on emergency service utilization did not control for the presence of crisis, and by examining differences in ED utilization in a sample who had all experienced crisis, we were able to disentangle the confound.

As hypothesized, individuals with mild levels of ID were more likely to go to the ED than those with moderate/severe levels. As a result of their stronger cognitive skills, people with mild ID may be perceived as being more able to profit from the care received in the ED than individuals with more severe impairments. In contrast, parents may be more hesitant to take their child with a severe disability to the ED because of how stressful that environment is to someone with minimal communication (Elford, Beail, & Clarke, 2010). It is also possible that individuals who have mild ID have behaviors that are worse than individuals who have moderate or severe ID. Caregivers of individuals with ID who have used the ED as a result of increasing challenging behavior often note that emergency staff can focus on the disability as the reason for the challenging behavior (i.e., a form of diagnostic overshadowing; Weiss et al., 2009), and it is possible that this overshadowing increases with the level of a person's apparent impairment (Jopp & Keys, 2001).

The presence of psychiatric issues and self-injury emerged as the two types of crisis events that were more related to ED visits. Both caregivers and emergency staff have noted that the ED is not an effective venue to address long-standing behavioral issues (Lunskey et al., 2008; Weiss et al., 2009), and that the selective use of the ED for psychiatric symptoms and risk of self-injury may highlight situations where the ED can actually help: obtaining medications to address rising psychiatric symptoms and providing basic containment in cases of serious self-harm. Contrary to expectations, the presence of physical aggression or destruction of property were not related to ED visits, even though past research has associated these externalizing behaviors with hospitalization (Cowley et al., 2005) and considerable parent distress (Minnes, Woodford, & Passey, 2007). The presence of physical aggression to others did emerge as the most frequent type of crisis across groups, and the fact that it was not related to ED use suggests that emergency service engagement may not be a defining feature of crisis in the context of family care. Many families deal with aggression quietly and without seeking help because of the fear of what could happen if they report it (Elford et al., 2010).

Psychiatric diagnoses are also more commonly seen in the ED. The presence of a psychotic disorder, although infrequently occurring in the non-ED group (6%), occurred in approximately one third of individuals who went to the ED. Emergency psychiatric care is designed to quickly assess for the presence of thought disorder, and thus may be well equipped to focus on psychotic issues. Psychotic episodes are also serious alterations of a person's typical functioning, and community service providers and family may feel particularly incapable of managing these symptoms. Our regression analysis confirmed that the presence of a psychotic disorder was a significant unique predictor of ED use. Anxiety disorders were also found to occur more often in the ED group. Severe anxiety can be manifestations of an incongruence between environmental supports and clinical needs, and if left untreated, can develop into serious

problems of panic, aggression, or escape-related behavior, and escalate to full blown crisis (Cooray & Bakala, 2005; Stavrakaki, 2002).

Interestingly, some diagnoses that are quite impairing did not differ in the two groups. The presence of autism was found to occur in 33% of the ED group and 40% of the non-ED group, reflecting a strong presence related to crisis but not to emergency service utilization. Similar to our hypothesis on differences in IQ and ED use, families of people with autism may have learned that the ED environment is not a helpful place to take a person who has hypersensitivities; impairments in socialization and communication; and a desire for predictability, calm, and familiarity (in some cases, it may even have a negative effect). Parents may go to extra lengths to avoid such visits for these children.

Life events have been reported in previous research to frequently occur prior to hospitalization in people with ID (Carter, 1984; Stack et al., 1987) and clearly differed in individuals who used and did not use the ED in the current study, as did historical risk, which includes having a history of behavior problems, psychiatric hospitalization, and emergency service use. Supporting families of individuals with ID who experience multiple negative life events and have a history of challenging behavior, psychiatric crisis, and ED use is necessary to enhance clinical response and may be an important protective factor in preventing individuals with ID from going to the ED during future crisis situations (Lunsky & Elserafi, 2011). It is important to note that although reports of significant life events in the months leading up to the crisis and the subsequent ED visit infer a causal link between the two, it is possible that other factors may have contributed to the life events in question, such as worsening mental health, which can lead to an increase in disruptive behavior and in turn result in losing one's residence or being asked to leave a daytime activity.

A sample of 192 individuals with ID who live with their families was evaluated; still, it remains unclear how representative these individuals are of the entire ID population that resides with their families. Although we are learning about what drives individuals with ID who live with families and who are in crisis to use the ED as a result of the crisis, this does not speak to the larger community of individuals with ID who do not experience crisis and who do not live with families. It is also possible that there are many other families who experience crisis who were unknown to participating agencies, or that some families did not report crises that occurred to the paid staff who completed the crisis forms. If individuals with ID were with families at the time of the crisis, these caregivers were dependent on the family member or client to tell them about the incident. Another limitation is that findings of the current study relate to the Canadian healthcare system in which health services are publicly funded and accessible to all. In other words, anyone can visit the ED without paying for it. It would be interesting to extend this study to different countries where ED visits often have costs associated with them to see how or if this would influence the type of care available to individuals with ID.

Clearly, many individuals with ID who live with families experience crisis, yet only a minority use the ED. There are a number of clinical features that differ between groups, including the presence of psychiatric symptoms and self-injurious behaviors, having a mild level of ID, a history of psychiatric risk (including a history of behaviour problems and psychiatric hospitalization), and the presence of negative life events. Learning about the factors that distinguish groups is needed to make sure we develop proactive community based resources for such people and situations to prevent visits from occurring when possible. Future research is required to understand what takes place when individuals go to ED, including the quality of the care received.

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Table 1: *Demographic differences in those using and not using ED*

Variables	ED visit N=46	No ED visit N=146	t-value
Age (M, SD)	25 (9.0)	25 (10.9)	0.04
Gender	n (%)	n (%)	χ^2
Female	13 (28)	48 (33)	0.34
Male	33 (72)	98 (67)	
Ethnicity			
Caucasian	27 (60)	91 (64)	0.24
Visible minority	18 (40)	51 (36)	

Table 2: *Clinical profile differences in those using and not using ED*

Variables	ED visit N=46	No ED visit N=145	<i>t</i> -value
	M (SD)	M (SD)	
Negative life events (past year) total	1.89 (1.56)	1.21 (1.20)	-3.13**
Total psychiatric diagnoses	1.20 (0.93)	0.89 (.08)	-2.19*
Number of psychotropic medications	0.20 (0.40)	0.28 (0.58)	0.96
Total historical risk	2.43 (1.29)	1.32 (1.34)	-4.98**
	n (%)	n (%)	χ^2
Axis 1 Diagnosis			
Mood	8 (17)	19 (13)	0.56
Anxiety	11 (24)	14 (10)	6.34*
Substance	1 (2)	1 (0.7)	0.75
Psychotic	13 (28)	9 (6.2)	16.83***
Autism spectrum disorder	15 (33)	59 (40)	0.90
Personality disorder	1 (2)	6 (4)	0.37
Cognitive level			
Borderline/mild	29 (37)	49 (63)	9.24**
Moderate/severe	14 (16)	72 (84)	
No daytime activity	17 (37)	32 (23)	3.35+

+ $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 3: *Binomial Logistic Regression Results Predicting ED Use*

Factors	B	SE	Wald	Exp (B)
Constant	-.711	.91	.62	.49
Age	-.01	.02	.28	.46
Cognitive level	-.77	.42	3.40	.46
Life events	.12	.16	.53	1.13
Historical risk	.31	.15	4.27	1.36*
Presence of psychotic disorder	1.28	.57	5.01	3.60*
Presence of anxiety disorder	.88	.51	2.98	2.42

* $p < .05$, ** $p < .01$

Table 4: *Description of crisis types*

Description	Overall % of crisis in sample	ER visit <i>N</i> = 45 n (%)	No ER visit <i>N</i> = 145 n (%)	χ^2
Physical threat/injury to self	34.2%	16 (35)	49 (34)	0.05
Respite/lack of resources	14.7%	3 (7)	25 (17)	3.06
Other (e.g. arson)	11.1%	5 (11)	16 (11)	0
Risk of injury to self	8.4%	10 (22)	6 (4)	14.56***
Victim of abuse verbal/physical	8.4%	2 (4)	14 (10)	1.14
Other psychiatric symptoms	7.4%	7 (15)	7 (5)	5.80*
Verbal aggression only	4.2%	1 (2)	7 (5)	0.58
Accident	3.6%	1 (2)	6 (4)	0.36
Property damage only	3.2%	0 (0)	6 (4)	1.92
Sexual deviance	3.2%	0 (0)	6 (4)	1.92
AWOL	1.6%	0 (0)	3 (2)	0.95

* $p < .05$, ** $p < .01$, *** $p < .001$

Note: 2 clients lacked sufficient information to describe the type of crisis