

Psychopathology and intellectual disability

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Current Opinion in Psychiatry 2011, 24:367–371

Purpose of review

To provide an update on recent trends and developments in the study of psychopathology in persons with intellectual disability. This topic is of considerable importance to mental health professionals as rates of psychopathology are much higher for persons with intellectual disabilities relative to the general population.

Recent findings

The number of studies on this topic is growing. The development of several areas is of particular significance. These topics include the impact of the burgeoning study of autism; the development of more specialized measures of psychopathology specific to particular forms of psychopathology, levels of intellectual disability and age; the development of psychologically based treatments, specifically the rise of functional assessment; the recognition that pharmacotherapy treatments are best aimed at core symptoms of classic forms of psychopathology such as psychosis, bipolar disorder, anxiety, and depression versus behavioral equivalents of psychopathology such as aggression, self-injurious behavior, property destruction, and pica; and establishing co-occurring patterns of personal features as they relate to psychopathology and intellectual disability.

Summary

A better understanding of psychopathology and how to assess and treat it in persons with intellectual disability is occurring. However, much is yet to be learned in this relatively new field of study.

Keywords

assessment, intellectual disability, psychopathology, treatment

Curr Opin Psychiatry 24:367–371
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0951-7367

Introduction

Intellectual disability is defined as a functioning that is two SDs or below the mean on a standardized intelligence test and a measure of adaptive behavior [1]. These persons have marked deficits in social skills, communication, and independent living skills, all of which are compounded when psychopathology is present [2–4]. The disorder is evident before 18 years of age and occurs on a continuum from mild to profound intellectual disability. For persons in the mild range, cultural factors appear to play a major role, whereas those with the most severe intellectual disability typically have an identifiable genetic syndrome.

Psychopathology as defined here involves the disorders typically identified in the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision (DSM-IV-TR) and International Classification of Disease-Tenth Revision [1,5]. The full range of disorders is believed to be present in persons with intellectual disability, although at rates four to five times higher than what is seen in the general population. Particularly com-

mon conditions are autism, self-injurious behavior, attention deficit hyperactivity disorder, anxiety, depression and psychosis [6–8]. Although intellectual disability has been a topic of considerable interest since the inception of the mental health field, this has not been the case with respect to co-occurring psychopathology. Rather, for many years, professionals and researchers did not believe that these two phenomena could both be present in the same person. Thus, most of the research on this topic has occurred in the last 4 decades [9,10]. A particularly good sign is the fact that the pace of new developments and new trends is escalating. The focus of the present article involves a review of major themes in recent research, particularly during the last 2 years.

Impact of autism diagnosis

Autism has become a hotbed of research and practice in the field of developmental disabilities, particularly given the large overlap in intellectual disability and autism. The diagnostic category has been broadened markedly in recent years; thus many persons who previously would have been identified as having childhood schizophrenia,

or intellectual disability with challenging behaviors, now fall under the category of autism. For example, the rate of challenging behaviors, although independent of autism, is four times more prevalent in this group versus individuals with intellectual disability only [11^{••}]. At the same time, the autism with intellectual disability group is no more vulnerable to other comorbid psychopathology than intellectual disability alone [12[•]]. Also, studies that are designed to differentiate intellectual disability from autism have received a good deal of attention. For example, social relatedness as discussed in DSM-IV appears to be particularly critical in differentiating intellectual disability and autism symptoms [13[•],14]. Given the attention and funding for autism, and the high number of persons with autism who also have intellectual disability, continued high levels of activity in these areas are likely. Descriptive data such as the examples just provided should prove valuable in better understanding the disorder and how to diagnose and treat it.

Specialized measures of psychopathology

Measures designed specifically to measure psychopathology in persons with intellectual disability have been available for several decades. Most of these tests can be completed in 15–30 min and are designed to screen for multiple types of psychopathology. The tests are largely of two types; tests keyed to DSM criteria, and those wherein factor analysis was used as the primary means of establishing diagnostic categories. A number of these tests are now well established. Caregivers are typically interviewed and serve as the primary data source. Current research differs from earlier efforts in that the focus is more and more on tests that can aid in the diagnosis of a specific form of psychopathology in persons with intellectual disability. Examples include measuring comorbid psychopathology in severe and profoundly intellectually handicapped adults [15[•]], a measure to assess stereotypes in children with intellectual disability [16], and measures specific to depression [17[•]] and anxiety [18,19]. This move toward more specialized scales as a follow-up to more general measures is likely to continue and should prove to be invaluable for improving the accuracy of diagnoses, a better understanding of the nature of the disorders themselves, and what specific symptoms should be targeted for treatment.

Development of psychological treatments

There is a move to limit mechanical and chemical restraint and replace these methods at least in part with methods that can serve as alternative treatments, including noncontingent reinforcement (NCR) and other reinforcement schedules, social and coping skills treatments, token systems, and cognitive behavior therapy. The centerpiece of this development, however, is func-

Key points

- This article is a review of trends and current research in the area of psychopathology and intellectual disability.
- The authors summarize information concerning assessment, treatment, and challenging behaviors.
- Also of interest in this article is the emphasis on using specific treatments (e.g., psychotropic medications, behavior therapy, etc.) for specific problems (challenging behaviors versus psychiatric disorders).

tional assessment. The purpose of these assessments is to establish if there is an environmental cause and if so what factors maintain challenging behaviors such as aggression, self-injury, tantrums, pica, and property destruction [20]. Mental health symptoms have been found to be largely unrelated to environmental factors [21]. Conversely, challenging behaviors, such as those just listed, tend to be independent of psychopathology and largely caused by environmental variables. Among these maintaining factors are efforts to gain attention, edibles, demands in the form of instructions/directions, and escape from an undesirable activity (e.g., being allowed to go home when tantruming versus staying at the workshop). This technology is being recognized for psychiatry and clinical psychology, as considerable overlap in the evaluation and treatment of challenging behavior and psychopathology exists, particularly when selecting the least intrusive, yet effective treatment is factored into one's decision-making [22]. Thus, establishing more specialized interventions for symptom clusters that often covary (challenging behaviors, psychopathology, and intellectual disability) is becoming better accepted.

Focus of pharmacotherapy

The intellectual disability population is among the most medicated groups in society. Pharmacotherapy has an important role to play in managing psychopathology. However, a more limited role in dealing with challenging behaviors is warranted based on present knowledge relative to current practice. This situation is the case because, as noted above, functional assessment methodology has helped markedly in identifying environmental causes and thus psychologically oriented interventions. Additionally, although psychotropic medications, particularly antipsychotics, have often been used for these problem behaviors, their effectiveness may be questionable [23]. Conversely, pharmacotherapy is the better choice for co-occurring symptoms of psychopathology at present. Better methods of assessment should lead to better tailored and more effective psychological/pharmacological treatment packages in the future.

Co-occurring patterns of behavior

One of the earliest areas to be studied involved autism research on factors such as level of intellectual disability, social skills, challenging behaviors, ethnicity, and the relationship between seizures and psychopathology in persons with intellectual disability [11^{••},24,25[•],26,27[•],28]. Some of the trends include the finding that personality disorders were more frequently diagnosed in persons living independently, whereas anxiety disorders were more common in persons living with their families [29[•]]. Higher rates of psychopathology were evident in persons with intellectual disability and may in part be due to greater exposure to adverse socioeconomic factors. Along these same lines, minorities were more likely to be diagnosed with schizophrenia or autism [27[•]]. Issues such as epilepsy and challenging behaviors occur at higher rates in persons with intellectual disability, although these disorders are independent of psychopathology. These factors have important implications for cause and treatment, and more research of this type can be expected.

Conclusion

The manifestation of these symptoms and disorders of psychopathology occurs across all age groups. For persons in the mild-to-moderate range of intellectual disability, symptoms are believed to be similar to what is observed in the general population. However, for the most severely intellectually disabled persons, symptom presentation may vary from persons with milder intellectual disability. This is one area now under investigation, along with developing more specialized tests for specific forms of psychopathology. For the most intellectually impaired persons, some controversy exists as to whether and how different types of psychopathology are manifested [30,31]. Additionally, variations in expression are likely to differ by disorder, and more focus on nonverbal behaviors is emphasized, such as lack of interest in activities, emotional lability, and change in routines, for diagnostic purposes.

Intervention strategies of both pharmacological and learning-based models (typically behavior therapy and applied behavior analysis) have been effective to some degree. At this point, much is yet to be learned and many interventions are acts of faith versus decisions based on data.

Antipsychotic medications have been the most broadly prescribed drugs for persons with intellectual disability and psychopathology [32–34]. Psychological treatments with the best evidence base include applied behavior analysis, functional assessment, token systems, social skills training, and reinforcement methods such as

differential reinforcement of other behavior, NCR, and differential reinforcement of alternative behavior. The psychological methods have been more effective with challenging behaviors than psychopathology [35^{••},36–38,39[•],40]. These psychological methods are the most researched, and have the best results for this group of symptoms. However, these psychological methods have been focused primarily on challenging behaviors that co-occur with psychopathology for persons with intellectual disability, rather than core symptoms of psychopathology. Pharmacotherapy is the better bet for these core symptoms at this point. For research purposes and for clinical purposes, it is important not to confuse or mix these symptom clusters when attempting to evaluate pharmacology effectiveness. Symptoms that are core features of a disorder (e.g., depression, loss of interest in activities, flat affect, unresponsiveness, etc.) should be outcome measures versus challenging behaviors.

Another prominent theme has been to decrease the use of more restrictive methods such as contingent restraint, either mechanical or chemical [41]. This push has been spurred by professional organizations that emphasize the use of least restrictive treatments. Similarly, advocacy/legal groups have stressed human rights issues. Some decreases in the more severe restraint methods have occurred. However, at present, elimination of such methods is far off [40]. The problem is technical. There are simply no effective methods that can serve as a substitute for restraint in 100% of cases. This trend is evident on both sides of the Atlantic.

North America has seen movement away from the study of many forms of psychopathology, to a focus largely on autism. Europe appears to have maintained a more balanced approach to research across various forms of psychopathology. A particularly positive development is the emergence of research on intellectual disability and psychopathology in Asia during the last decade. China and Taiwan are especially notable in this regard.

There are areas that are particularly in need of study. One of the most critical areas is the establishment of intervention packages that involve both pharmacological and behavioral treatments. At this point, such research is largely nonexistent. Similarly, the comparison of various interventions in controlled outcome studies is rare. Studies of persons with intellectual disability and psychopathology are far behind treatment research on the general population of individuals with psychopathology. Unfortunately, the development of more interdisciplinary treatment approaches has made little progress to date. Rather, clinical psychology and psychiatry have generally functioned in parallel universes. Applying the strengths of both disciplines in a more coordinated

fashion would undoubtedly result in better and more seamless interventions.

There is also a need for research and mental health initiatives on how to bridge the widening gap between research and practice. Often practice is driven by workshop leaders and drug representatives as opposed to empirical research. There is plenty of blame to go around. Clinicians have not been diligent in following the literature, and researchers have often failed to develop user-friendly assessment and intervention strategies. Furthermore, assessment and intervention strategies have too often been fad-driven. For those of us who have been in the field for some time, we have seen effective methods dropped for the new kid on the block. For example, token economies are effective and well researched, but they have rarely been a research priority in recent years. Integrating newer methods with more established technologies is in order.

Differential diagnosis is complex and requires skill, experience, and data-based methods to assist in decision-making. Scaling methods are a particular key in achieving this goal, given that many mental health professionals have limited expertise in making such evaluations. Thus, tests that can aid the professional in differential diagnosis of mental health issues are particularly critical for persons with intellectual disability. These methods can aid in structuring the evaluation and in helping the mental health professional better determine relevant information. Internationally, scale development continues at a brisk pace. General measures of a broad range of disorders are available for initial screening and evaluation [41,42]. The focus of research has shifted somewhat to the development of specialized tests of specific mental health conditions such as depression. This development is remarkable, considering that as recently as 15 years ago professionals were questioning whether common mental health conditions such as anxiety disorders were present in persons with intellectual disability [43].

These specialized tests can serve as a secondary method to back up or confirm a diagnosis, and may prove useful for targeting symptoms for treatment. The development of these specialized measures has been a relatively new trend, but professionals should continue to see considerably more advancement in this area in the near future.

In sum, recent developments in better understanding, assessing, and treating psychopathology and collateral challenging behaviors in persons with intellectual disability has seen continued positive movement. Perhaps most striking is the generally accepted notion that the presence of psychopathology in persons with intellectual disability is now common in the mental health field. The current challenge is to attempt to catch up to the broader

mental health field in terms of specialty training and in the knowledge of how these disorders are manifested, assessed, and effectively treated.

Acknowledgement

This project was funded in part by the Louisiana Office for Citizens with Developmental Disabilities. No other external sources of funding were used.

Conflicts of interest

There are no conflicts of interest.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 447–450).

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CHAPTER TWO

UNDERSTANDING CHALLENGING BEHAVIOR

William I. Gardner

As persons who provide personal and program supports, we often wonder, "What should I do when someone acts aggressively? What is the best way to respond to a person who is destructive?"...and the list goes on. There are no specific answers to these and similar questions. There is no pill for aggression or a magic strategy to reduce destructiveness. As emphasized in later discussion, a person's behaviors when viewed separately from the various *contexts* in which these occur tell us nothing either about the causes or how to treat these. Challenging behaviors do, however, have several features in common.

Challenging behaviors often:

- *Appear unpredictable* as to when these may occur,
- *Vary in frequency and severity* across time,
- *Are chronic* and have been present for an extended period of time,
- *May be frightening* and or dangerous to self or others,
- *Appear to be beyond the control* of the person,
- *Are puzzling* relative to the specific situations in which these occur, and
- *Occur across different settings* or situations.

These chronic challenging behaviors typically have been "managed" or "treated" in a number of different ways, but frequently have been resistant to change. As noted earlier, a critical reason for this lack of success in our view is that interventions are not based on an understanding of why the behaviors occur. A number of factors make our understanding of the "why" of behavior difficult. As examples of these barriers:

- *Challenging behaviors seldom occur in isolation.* That is, seldom does a person demonstrate only aggression or only self-injury. Rather, challenging behaviors frequently occur in clusters such as being aggressive, self-injurious, and engaging in episodes of property destruction. These multiple problem areas frequently reflect multiple causes and may require multiple interventions.
- *The manner in which challenging behaviors occur may change over time and across situations.* Aggressive acts, in illustration, may be minor in severity when occurring in the morning hours and quite severe during late afternoon, or may occur following minor provocation in the group home but require major and repeated provocation in the work setting prior to occurrence. This variation may reflect the effects of multiple causes which in turn increase the difficulty of successful interventions.
- *These behaviors, as suggested, seldom are caused by one factor.* Most typically, a number of different conditions influence various of the behaviors at different times and in different situations. As noted, multiple interventions may be needed for successful treatment of the multiple conditions that produce the challenging behaviors.

The challenging behaviors most likely to require formal intervention programs are those of physical aggression, threats of violence, self-injury, property destruction, chronic social disruption, agitation, pica (eating inedible objects) and excessive negative or uncooperative behavior. These behavioral challenges, when viewed in isolation, tell us nothing about what causes the behaviors or what behavioral supports are needed. These challenging behaviors have been described as "*nonspecific behavioral symptoms*" because when viewed in isolation are not specific in any cause or set of causes (Gardner, 1996).

To elaborate, the term "*nonspecific*" means that challenging behaviors (e.g., aggression, self-injury) are not categorically the result of any specific cause but rather may be produced by a variety of conditions. An analogy in physical medicine would be the presence of a headache. A headache is a nonspecific physical symptom because in isolation it is not indicative of any particular physical cause. Rather, a multitude of physical ailments may result in a headache, just as a variety of biomedical and psychosocial conditions can influence occurrence of a nonspecific behavioral symptom such as aggression.

The term "*symptom*" is used to emphasize that any challenging behavior is a "symptom of," that is, the end result of or produced by, some other conditions. The primary target of individual centered interventions thus must be the *conditions that produce the challenging behaviors* rather than the behavioral symptoms themselves. That is, a challenging behavior such as aggression or property destruction does not represent the direct target of intervention efforts. We must "look beyond" these behavioral symptoms and seek to identify, and modify, the conditions that account for their occurrence. Although, due to their severe

destructiveness, disruption, or danger to self or others, the challenging behaviors may need to be managed or controlled with various temporary measures, just as a headache can be managed temporarily with aspirin. These symptoms, however, will occur again in the future unless the causes are modified or eliminated.

In summary, to report that someone is aggressive tells us nothing to assist in understanding the factors influencing this challenging behavior.

A Biopsychosocial Perspective For Understanding Challenging Behavior

As is obvious to all of us, the challenging behaviors of persons with mental retardation and mental health concerns typically are rather complex and not readily understood. An integrated approach that recognizes the possible joint effects of biomedical, psychological, and social/environmental influences on challenging behaviors is described in this Manual. An integrated approach means that we combine, or integrate together, information about various aspects of the person and his/her physical and social worlds. With this integrated approach, we minimize the problem of "behaviorizing" challenging behaviors that have a major medical or psychiatric basis or "medicalizing" other challenging behaviors that have a primary psychosocial basis. The following vignette illustrates this benefit:

Mr. Wills Irving, with a dual diagnosis of mental retardation and schizophrenia, currently resides in a group home in the community. A recent increase in his aggressive outbursts resulted in an injury to one of the home support

staff. Under the assumption that the mental illness caused the violence, medication dosage was increased but had no positive results. A multimodal contextual assessment, however, suggested that the major influences for the increase in frequency and severity of aggression were psychosocial rather than psychiatric in nature. It was discovered that a new support staff, under the belief that his duties included that of insuring that all men in the group home attend all scheduled programs, persistently prompted Wills to attend a community outing that he did not wish to attend. As Mr. Irving's verbal refusals had been ignored, he expressed his aggravations through becoming physically aggressive. As the aggression was effective in accomplishing his purpose of avoiding programs that he did not like, these outbursts became more frequent. When staff repeatedly prompted him to attend program, the aggressive outbursts became more intense.

In this scenario, the mental illness represented at best only a minimal influence on the increase in aggressive episodes. Staff behavior was identified as the major source of instigation of this challenging behavior. The intervention program shifted from medication to a focus on changing staff approaches and on providing related coping skills training for Wills. Specifically, after removing staff provocation, the intervention focus shifted to increasing the attractiveness of scheduled programs. Additionally, Wills was taught coping alternatives to aggression as means of expressing his aggravations.

An integrated *biopsychosocial* perspective is described in this training manual (Gardner & Sovner, 1994). The view stresses an integrated systems approach to challenging behavior and recognizes that such behavior is the end result of conditions representing different modalities of influence. The *bio-* modality refers to biomedical (physical, psychiatric, and neuropsychiatric) conditions. The *psycho-* modality refers to psychological characteristics of the person. The *social-* modality refers to features of the physical, social/interpersonal, and program environments in which the person resides and experiences. This perspective also emphasizes that each of the three *modality of influence* affects and is affected by every other modality. To illustrate these interactions:

Psychiatric conditions such as schizophrenia or a bipolar disorder may result in changes in cognitive functions, mood and affective states, emotional regulation, and psychomotor behaviors. These changing psychological and physical characteristics may result in new behavioral or emotional difficulties or may influence occurrence or increased severity of challenging behaviors that predated a current psychiatric episode. These symptoms in turn create more than usual changes in the manner in which the social environment responds to and interacts with the person and his/her challenging behaviors. These experiences with the social environment may in a reciprocal manner reinforce the challenging behaviors or intensify the emotional arousal and the person's perceptions of social feedback. As examples, a person's depressive symptoms such as crying or complaining of physical ailments may be strengthened by the social feedback that these produce. Interventions to be most effective must be

sensitive to these reciprocal interrelations, and provide attention to each set of influences. Illustrations of this integrated treatment approach are provided in later chapters.

In sum, this perspective indicates that the combination of influences account for the *occurrence, severity, variability, and persistence* of challenging behaviors. This multimodal perspective represents a central component of a Multimodal Contextual Behavior Analytic Model that we shall use to develop our understanding of the "why" of challenging behaviors.

This Model suggests that any challenging behavior is best viewed as the joint effects of a person (with physical and psychological characteristics) in interaction with physical, social/interpersonal, and program environments. This dynamic process may be illustrated as follows:

$$\text{CBs} = (\text{re}) \text{P} \Leftrightarrow \text{E}$$

CBs refers to challenging behaviors,

= (re) denotes that any occurrence of a challenging behaviors results from,

P refers to a person's current *biomedical* (physical, psychiatric, and neuropsychiatric) and *psychological* features,

↔ denotes the dynamic interactions between features of the person and features of the environments, e.g., a person without alternative coping skills may engage in a bout of self-injurious face slapping when exposed to a noisy environment only when in a highly irritable mood state. Exposure to the noisy environment when not highly irritable does not result in self-injury. In this example, neither the irritable mood nor the noisy environment in isolation is sufficient to produce the challenging behavior.

E denotes the physical, social, interpersonal, and program features of the person's environments.

As is evident, behavioral supports can be individual centered only to the extent that these supports are derived from an understanding of the multiple influences that in combination result in the challenging behaviors. Again, knowing that the person is aggressive does not provide us with sufficient information about the conditions involved in producing a particular aggressive outburst. It is necessary, as described below, to "lodge" the aggressive behavior in the *multiple contexts* in which it occurs.

Without a clear understanding of what is producing the behavioral "symptom," interventions frequently become reactive or hit and miss in nature. If we went to a physician because of a nonspecific stomach pain, we would insist that any treatment provided would be based on *diagnostic formulations* about what was causing the pain. To arrive at these diagnostic hunches about causes, various examinations and laboratory tests would be completed. Specific

treatment offered would be those logically related to these diagnostic findings. Thus the physician develops a *diagnostic-treatment formulation* that guides selection of the specific treatment offered.

Similarly with challenging behaviors, the initial step following description of the behavior is that of gathering information that will assist us in formulating diagnostic hunches about factors that appear to contribute to occurrence, severity, variability, and recurrence of the challenging behavior. These diagnostic hunches are gained by examining the various *contexts* in which specific challenging behaviors occur. Just as the physician examines various physical or bodily systems to determine the location and nature of factors that may contribute to the stomach pain (e.g., context of an ulcer, context of excessive smoking and eating foods with high acid content, context of liver pathology), an analysis of challenging behaviors in the three contexts of (a) *instigating* conditions, (b) *vulnerability* conditions, and (c) *reinforcing* conditions is completed. Each of these contexts represents a focus of analysis. Each is described in Chapter Three.

What this *Multimodal* (bio-psycho-social modalities) *Contextual Behavior* (focus of analysis is on the "why" of the nonspecific challenging behavior) *Analytic* (analysis of multiple factors as potential sources of influence on occurrence, severity, fluctuation, and durability of the challenging behavior) *Model* tells us is that the concept of "cause" is complex. To emphasize, it is quite rare that we would find just one reason such as "gets social attention" or "is schizophrenic" to explain someone's challenging behaviors. Usually, current influences from several areas of a person's current life (e.g., impoverished social environment,

minimal social skills, heightened emotional neediness following move of a long-term friend), each serving specific roles, jointly affect that person's challenging behaviors.

This is of particular relevance in the case of a person with a developmental disability and chronic and severe challenging behaviors. We must investigate multiple facets of the person as he/she interacts with social and physical environments on a daily basis to understand what is "causing" the behaviors.

To summarize, each person with challenging behaviors is quite unique. Each has his/her own physical and mental health characteristics, personalities, families, specific environments, and the list is extensive. These become the individualized total package that makes each person unique in the factors that influence his or her challenging behaviors.

Chapter 8

Working in a Trauma-Informed Way with Clients Who Have a Developmental Disability

Anna M. Palucka and Yona Lunsky

People with developmental disabilities are far more likely to be victimized than the general population, yet have fewer resources to deal with these experiences. Their response to the trauma may also be different. Therefore, trauma-informed practice with this population requires certain modifications. The goal of this chapter is to demystify the tailored approach to trauma-informed care for people with developmental disabilities. It addresses the types of trauma they may experience, the impact of cognitive impairments on how they may report trauma and how to apply a trauma-informed approach in work with people who have developmental disabilities.

In general, developmental disability refers to impairments in cognitive functioning accompanied by impairments in adaptive skills that emerge in the developmental period (prior to age 18). The term developmental disability¹ allows for inclusion of individuals whose IQ might be a little higher but who nevertheless have significant cognitive and functional difficulties. People with fetal alcohol spectrum disorders and autism spectrum disorders (ASD) are also considered to have developmental disabilities. Individuals with ASD may have ways of understanding and interpreting their social and non-social world that are different than those of neurotypical individuals.² They may experience

1. Diagnostic criteria for mental retardation in DSM-IV: Intellectual functioning markedly below average (IQ below 70–75, or two standard deviations below the mean); impairments in at least two areas of adaptive functioning; onset before age 18. (The term “mental retardation” will be replaced by “intellectual disability” in DSM-5.)
2. For more about “social stories” among people with ASD, see www.thegraycenter.org.

relatively minor events, such a falling off a bicycle or losing an object of attachment, as traumatic. Their difficulties in communicating and interacting socially and their behaviours associated with ASD will affect how they communicate and process their experiences.

Working with individuals with developmental disabilities who have experienced trauma often requires working with caregivers (family members or paid staff), and depending on the source of trauma, recognizing that abuse is not the only type of trauma the person may have experienced. The involvement of caregivers can be crucial, as many people with developmental disabilities do not live independently and may need others' assistance for transportation, decision-making and implementing treatment strategies. If it is safe to do so, it is these caregivers who can provide information about personal and clinical history, significant relationships, dreams and goals or preferences.

The following vignette illustrates key elements of trauma-informed practice involving a person with a developmental disability and those who work with her.

Tracy is 34 years old but looks and acts like a teenager. She has moderate intellectual disability and attention-deficit/hyperactivity disorder. She was admitted to hospital because her group home placement broke down due to her aggression. On one occasion, she entered a bedroom of another resident at night and started to punch him. Her records indicate that she experienced physical and emotional abuse and severe neglect in her family home. She was sexually assaulted by a stranger when she was 19, but her family refused the offer of counselling at that point. More recently, after Tracy left home, her sisters disclosed that they were sexually abused by their father and suspected that Tracy, too, might have been abused. Group home staff wanted Tracy to engage in psychotherapy, but following the initial evaluation, the therapist felt that she would not be able to tolerate it. Behavioural approaches were unsuccessful and staff continued to request individual therapy to help with challenging behaviours: Tracy was highly reactive, impulsive, intrusive and pushy, and at times of distress, she would become combative and verbally and physically aggressive, display sexualized behaviour and speak in a deep masculine voice.

In hospital, Tracy presented with high anxiety and agitation, excitability, need for attention and exaggerated display of somatic complaints, including leg or

stomach pain and difficulty swallowing. Given her dramatic presentation, somatic complaints might have been easily dismissed as attempts to engage staff, particularly since she would settle in response to staff reassurance; however, medical examination revealed underlying medical conditions. Further observations identified triggers to her agitation that seemed to be directly related to her experience of neglect and trauma: triggers included doing something incorrectly, such as spilling her drink; being criticized, ignored or dismissed; being sent for time out; perceiving unfairness or rejection; noticing attention being given to someone else; hearing other people breathing loudly or making “noises”; and having her family visit her. Attempts to talk with Tracy about those issues led inevitably and rapidly to behavioural escalation. The intervention approach was shifted from therapy and behavioural contingencies (i.e., providing consistent consequences for specific behaviours, such as cancelling an outing if she was verbally aggressive to staff) to a focus on staff understanding and being sensitive to Tracy’s experiences, both past and present. To support Tracy, staff had to keep the present impact of her history of trauma at the forefront of all interactions and acknowledge and validate her experiences. That was particularly important given the neglect and secrecy she had experienced with her family.

A trauma-informed plan of care was developed that emphasized the role of staff in addressing Tracy’s trauma-related behavioural difficulties. It included:

- educating staff about the effects of trauma on Tracy, her triggers and the importance of validating her experiences and how to tailor the teaching of self-soothing skills using visual aids
- creating a safe environment through recognizing and minimizing situations and responses that might be retraumatizing, such as sending Tracy for time out when she was upset about attention given to another client
- providing choices and increasing opportunities for positive experiences
- assisting Tracy to use calming strategies, employing specially tailored comic strips that illustrate deep breathing
- establishing a working relationship with Tracy’s family
- developing a support network beyond paid staff; for example, encouraging Tracy to attend her local church.

Tracy’s story illustrates how helpful trauma-informed practice can be, regardless of whether clients are able to describe their experiences as related to trauma. The therapeutic team’s awareness of how trauma may be expressed is critical to

trauma-informed services. With this awareness, the team can support the client by using creative approaches to applying the practices of creating safety, providing opportunities for relational connections and teaching skills.

The Nature of Trauma for People with Developmental Disabilities

In addition to issues such as sexual abuse, as illustrated by Tracy's story, there are other sources of trauma for people with developmental disabilities. Clinicians may not always consider the types of trauma that affect them and how their response to trauma may be different.

Abuse

People with developmental disabilities are more likely to experience emotional, physical and sexual abuse and life-threatening neglect than the general population. As in Tracy's case, this abuse is more likely to be perpetrated by someone they know rather than a stranger. They experience high rates of bullying and teasing by peers in youth and even in adulthood. One in three is sexually abused before age 18 and women are at higher risk than men of being victimized and revictimized. People with developmental disabilities who have been sexually abused may display sexualized behaviour (including sexual threats or accusations) under stress. Some individuals with developmental disabilities remain at lifelong risk for repeated trauma: acquiescence, social naiveté, poor judgment and social skills and a reluctance, fear or inability to disclose abuse make them more likely to experience traumatic events. Higher-functioning individuals may repeatedly place themselves in abusive or exploitive situations because of a desire to present as normal or to have relationships with "normal people."

Loss through Separation, Abandonment or Death

Loss can be experienced by being separated from or abandoned by family—being placed in a foster or group home or institution—or from the death of a

parent. In these situations, the person with a developmental disability is often removed from the family home and placed in the care of strangers. This means the person loses not only his or her parent, but a way of life and his or her possessions. Women with mild developmental disabilities, as with other women, may experience trauma when they give birth to children they are unable to care for, or when children are removed from their care. They may continually re-experience the loss of the mother role through exclusion from the child's life, for example, being denied participation in significant events such as birthdays due to concerns about their behaviour.

Natural Disasters, War, Displacement and Accidents

Caregivers, and sometimes clinicians, can wrongly assume that people with developmental disabilities are not aware of, or that they can be sheltered from, the psychological impact of a natural disaster, war, displacement or accident. Even when individuals are clearly aware of their circumstances, it might be difficult to determine their actual understanding and experience of the trauma. For example, a young woman with a mild developmental disability whose parents and several siblings were killed during Rwanda's genocide when she was 14 repeatedly expressed the desire to "go back home." When looking at the impact of these events, the clinician may find it helpful to consider how a similar situation might affect a young child who is reliant on a caregiver who has been harmed or killed.

Hospitalization

There are several factors to consider in relation to hospitalization and trauma. People with developmental disabilities experiencing mental health issues are generally hospitalized for difficulty managing aggression or for displaying self-injurious or severely disruptive behaviour. These behaviours are often precipitated by or exacerbated by significant life events in the preceding months and indicate the person's difficulties in dealing with them. Being admitted to hospital can be very traumatic, particularly if it involves the use of force and police. The hospital environment itself can be traumatizing for people with developmental disabilities.

FACTORS THAT CONTRIBUTE TO HIGH RISK OF (RE)TRAUMATIZATION IN HOSPITAL

- use of intrusive interventions such as time out, seclusion, mechanical and chemical restraints
- being assigned to or being restrained by a staff member of the same sex as an abuser
- witnessing others being restrained
- being assaulted or witnessing assaults by co-patients (not feeling safe)
- separation from family (caregivers)
- separation from familiar environment and routines
- prolonged admissions
- not understanding reason for hospitalization and not knowing for how long (forever)

WAYS TO MINIMIZE THE RISK OF (RE)TRAUMATIZATION IN HOSPITAL

- Assign same-sex staff to assist with personal hygiene (two staff if needed).
- Use least restraint policy: understand escalation continuum and use prevention; allow person to select preferred mode of restraint when required.
- Address vulnerability: Separate female bedrooms from male bedrooms.
- Debrief incidents that involve or are witnessed by the individual.
- Avoid hospitalization or keep it to a minimum.
- Facilitate caregiver contact and visits.

Impact of Cognitive Impairments on Reporting Trauma

People with developmental disabilities have a range of cognitive impairments that affect their ability to understand what has happened to them and to communicate the trauma to someone else. Impairments may occur in these areas:

Concrete thinking: People with developmental disabilities may have difficulty identifying their emotional or internal experience. They may actually not realize that what happened to them was traumatic or wrong, and that they could talk to someone about it.

Communication issues: They may not have words to explain their experience and may express it through their behaviour instead, or express it in ways that are misunderstood by others.

Individuals with developmental disabilities may experience their own thoughts or memories as voices. Their reporting of voices telling them upsetting things or telling them to do things may be misdiagnosed as psychotic.

Attention and memory issues: They may not be able to recall significant details of a traumatic experience, such as the names of people or places involved. Or they may confuse details and provide inconsistent information at different times, so that people do not believe them.

Concept of time: They may not be able to report when things happen and their report might be confusing, with remote events being reported as recent.

HOW SERVICE PROVIDERS CAN COMPENSATE FOR CLIENTS' COGNITIVE DIFFICULTIES

- Be explicit about interventions.
- Provide clear explanations, using:
 - concrete language
 - short sentences
 - visual aids (drawings, photos)
 - frequent repetition.
- Check for understanding (ask clients to explain in their own words).
- Allow time for processing.
- Provide engaging and fun activities.
- Repeat information over several sessions.
- Record sessions so the client can listen or even view them again.

A Trauma-Informed Approach with People Who Have Developmental Disabilities

This section applies and adapts the principles of trauma-informed practice articulated by Elliot et al. (2005) to the realities of people with developmental disabilities.

Recognize the impact of victimization and trauma on the person's behaviour and coping strategies. The person's childhood history may be unknown. Bizarre or disturbed behaviour might signal that the person is re-experiencing trauma or extreme distress, or that she or he is trying to self-soothe in the best way possible. It can be important, as in Tracy's situation (see p. 110), for the service provider to consider unrecognized trauma as an explanation for disturbed behaviour and to seek to understand it.

QUESTIONS ABOUT TRAUMA FOR SERVICE PROVIDERS TO CONSIDER

- When did the trauma occur?
- What is the nature of the trauma?
- What symptoms has the individual experienced?
- What support and treatment have been received?
- Is there a previous history of trauma? (McCarthy, 2001)

Note: These questions are not intended to be posed directly to the client; rather they are questions for service providers to keep in mind.

Identify recovery from trauma as a primary goal. Recovery from trauma should be a primary goal of treatment, as it would be with any other population. Specialized services—for developmental/dual diagnosis and trauma—need to be integrated into treatment. Furthermore, trauma work with this group extends beyond the individual with a developmental disability; when it is safe to do so, caregivers need to be involved, as their support can be critical to the recovery process. Caregivers may need education about trauma in general and about issues specific to the person in their care to better understand the person's behaviour and their own comfort level and ability to assist the person.³

Empower the individual. Be aware of a tendency that people with developmental disabilities have to acquiesce to caregivers or treatment providers. Recognize that they might feel that they did something wrong and may get in trouble if they reveal abuse. It is important to teach about privacy in interaction (e.g., not talking about sensitive or private topics in public places, checking with the person whether information he or she revealed may be shared with caregivers) and that saying no or refusing things does not mean the person is being unco-operative.

Maximize choices and control over recovery. People with developmental disabilities may have little sense of self-agency. They may not have skills to identify and express preferences and might need to be taught in small steps.

3. For more information about supporting a person with a disability who is experiencing posttraumatic stress disorder, see www.dimagine.com.

Provide them with situations where they can choose and assert preferences (e.g., what to wear or eat, where to go). Emphasize opportunities for positive experiences such as engaging in fun activities or fostering relationships with supportive others.

Create an environment that is safe, respectful and accepting. Take time to understand how the person communicates. Include people the person feels safe with, even in the therapy itself. Carefully consider the choice of therapist. This includes considering gender-specific services (i.e., a female therapist for a female client), or specialized dual diagnosis services, particularly if a diagnosis of psychotic spectrum disorder is being considered.

Create a predictable and consistent environment. Be aware of clients' current living circumstances: if they live somewhere they do not want to be and which is interpersonally stressful, they may need help to recognize and deal with that.

Emphasize strengths and resilience over pathology. See the person as someone to be admired rather than as a problem to be solved, recognizing his or her resilience in the face of impairments and traumas (Wilson & DuFrene, 2008). Identify and focus on relative strengths or the things the person enjoys doing.

Minimize possibilities for retraumatization. It is important to work with caregivers whose role is to protect the person from revictimization. Recognize that the person may be at risk in any placement—in the community as well as in an institutional setting (jail or hospital).

Be culturally competent and competent around the “culture” of developmental disability. In addition to being sensitive to the person's racial and cultural background, it is important to appreciate the different ways trauma might be expressed by people with developmental disabilities. Use your creativity to modify your interactions and treatment interventions to compensate for the cognitive impairment. You may have to adjust your expectations about what is helpful; take cues from the person about what type of interactions he or she finds supportive.

Solicit input from clients with developmental disabilities directly. Soliciting client input is an important aspect of providing trauma-informed services for any population. Even if it is more difficult to obtain input from people with

developmental disabilities, try to find ways to elicit feedback and consider it, even if it is limited (e.g., using simplified visual analogues of rating scales—smiling/upset faces). We recognize the possible importance of including caregivers, but not at the cost of excluding the person with the disability from being central and sharing his or her own perspective and experience of the services.

Monica is 40 years old and lives semi-independently with limited hours of support. She was admitted to hospital because of concerns about her aggressive behaviour, for which she was criminally charged. In contrast to her relatively high cognitive and adaptive abilities, Monica presented in a very childlike way in her speech and emotional reactions. In hospital, she described hearing the voices of her dead parents. She heard her mother, who had abused, neglected and later abandoned her, telling her to hurt herself or damage things. Monica was very distressed by hearing this. The voice of her father, on the other hand, was very protective, telling her mother to “shut up” or telling Monica to ignore her.

The main intervention was to explore Monica’s experience of the voices and “give” her power over them. In a concrete way, she decided to use a visual aid to help her contain the voices—she would “lock her mother (the voice) in a closet.” This helped her to stop paying attention to her mother’s voice and stop getting distressed by it.

Conclusion

The concept of trauma should be viewed very broadly in developmental disabilities; it is important to understand what is traumatizing for the person. Given the high probability of trauma in the lives of people with developmental disabilities, all interventions should be trauma sensitive, emphasizing coping, safety, choice and having a voice. It is also crucial to involve caregivers and help them understand the person’s behaviours in relation to trauma. The presence of trauma should become part of the clinical formulation, provide a framework for understanding the person’s experiences and be taken into account when planning supports and interventions. Hospitalization should be carefully considered because it will likely (and potentially unavoidably) be traumatizing.

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Emergency Psychiatric Services for Individuals With Intellectual Disabilities: Perspectives of Hospital Staff

Yona Lunsky, Carolyn Gracey, and Sara Gelfand

Abstract

Strains on the mainstream mental health system can result in inaccessible services that force individuals with intellectual disabilities into the emergency room (ER) when in psychiatric crisis. The purpose of this study was to identify clinical and systemic issues surrounding emergency psychiatry services for people with intellectual disabilities, from the perspective of hospital staff. Focus groups were conducted with emergency psychiatry staff from 6 hospitals in Toronto, Canada. Hospital staff reported a lack of knowledge regarding intellectual disabilities and a shortage of available community resources. Hospital staff argued that caregivers need more community and respite support to feel better equipped to deal with the crisis before it escalates to the ER and that hospital staff feel ill prepared to provide the necessary care when the ER is the last resort. Input from hospital staff pointed to deficiencies in the system that lead caregivers to use the ER when other options have been exhausted. Both staff and caregivers need support and access to appropriate services if the system is to become more effective at serving the psychiatric needs of this complex population.

DOI: 10.1352/2008.46:446–455

In Canada and other parts of the world, psychiatric services were once provided through state institutions for individuals with intellectual disabilities. In the 1970s, plans to downsize and close these institutions were initiated, and, since then, individuals with intellectual disabilities have been directed to the mainstream mental health system for their psychiatric needs (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007; Ouellette-Kuntz et al., 2005). As many as 40% of adults with intellectual disabilities living in the community are believed to have mental health issues (Bouras & Drummond, 1992; Reiss, 1990), and psychiatric issues account for a considerable proportion of their hospital admissions in Ontario, Canada (Balogh, Hunter, & Ouellette-Kuntz, 2005). Researchers have suggested that the inability of individuals with intellectual disabilities to access appropriate mental health services in a timely manner leads to crises resulting in visits to hospital emergency rooms (ERs; Bradley & Lofchy, 2005). A more in-depth study of what leads to ER visits by people with intellectual disabilities

and what occurs in the ER is vital if we are to begin to understand and intervene to correct deficiencies at both the clinical and systems levels.

“A psychiatric emergency is any behaviour that cannot be dealt with as rapidly as needed by the ordinary mental health, social service, or criminal justice system in a community” (Hillard, 1994, p. 541). Understanding what occurs in the ER is an indication of how other components of the system of care delivery are functioning (Dawe, 2004; Hillard, 1994; Spurrell, Hatfield, & Perry, 2003). High rates of ER visits by individuals with intellectual disabilities may be caused, in part, by insufficient primary and mental health care and poor links between health and social services (Bradley & Lofchy, 2005; Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007). Although about half of all adults with intellectual disabilities are taking psychotropic medication (Lunsky, Emery, & Benson, 2002; Molyneux, Emerson, & Caine, 1999; Robertson et al., 2000), many do not have access to psychiatrists. As a result, these adults’ mental health care is often man-

aged by general practitioners who feel ill equipped to provide psychiatric care for this population (Lennox, Diggins, & Ugoni, 2000; Lunsky et al., 2007). In addition to a lack of health services, many adults with intellectual disabilities lack more basic services such as housing, meaningful daytime activities, and case management (Lunsky & Puddicombe, 2005). A lack of basic supports can lead to coping difficulties and crisis, which can ultimately lead to ER visits (Morris, Bradley, Gitta, Nugent, & Summers, 2004).

Emergency physicians and allied health staff have limited expertise in serving individuals with intellectual disabilities (Bradley & Lofchy, 2005; Grossman, Richards, Anglin, & Hutson, 2000; Iacono & Davis, 2003; Sowney & Barr, 2006; Sullivan et al., 2000). In a recent Toronto study (Mitchell et al., 2005), ER physicians were asked how confident they felt in recognizing and diagnosing psychiatric disorders. They listed developmental disorders as one of the three disorders they felt least comfortable diagnosing. This is not surprising given that intellectual disabilities are minimally addressed in training for family medicine (Special Olympics, 2005; U.S. Department of Health and Human Services, 2002), internal medicine (Grossman et al., 2000), and psychiatry (Lunsky & Bradley, 2001), as well as in nursing (Ailey, 2003; Haut & Hull, 2000; Sowney & Barr, 2006; Summers et al., 2005) and social work (Burge, Druick, Caron, Ouellette-Kuntz, & Paquette, 1999).

Performing ER assessments of patients with intellectual disabilities is very challenging (Houghton, 2001; Lunsky & Bradley, 2001). In making a diagnosis, the psychiatrist must differentiate among underlying medical disorders that may appear psychiatric, reactions to emotional upsets (e.g., grief or trauma), and psychiatric disorders (Bradley et al., 2002, 2007). The stressful and unfamiliar environment of a hospital emergency department can intensify the patient's communication problems, attentional difficulties, memory impairments, and sometimes challenging behavior that are common in individuals with an intellectual disability and mental health problems (Bradley & Lofchy, 2005; Grossman et al., 2000; Houghton, 2001; Sullivan et al., 2000). To complicate matters, many of these individuals are prescribed multiple psychotropic medications that can play a role in triggering or exacerbating the psychiatric crisis (Robertson et al., 2000; Valdovinos, Caruso, Roberts, Kim, & Kennedy, 2005), and their capacity to provide consent

to treatment is often unclear (Heng & Sullivan, 2003; Sowney & Barr, 2007). Research is required to determine the assistance that clinicians require during such challenging assessments.

A handful of studies have considered the experiences of individuals with intellectual disabilities in a hospital or in the ER, from their perspective (Hart, 1998; Iacono & Davis, 2003; Parkes, Samuels, Hassiotis, Lyngaard, & Hall, 2007) or the perspective of their caregivers (Fox & Wilson, 1999; Iacono & Davis, 2003; Slevin & Sines, 1996; Sowney & Barr, 2007). These studies have demonstrated that the experience is stressful for patients and caregivers and that hospital staff display negative attitudes (Slevin & Sines, 1996) and a lack of knowledge that impacts patient care (Barr, 2004). It is as important to examine the perspective of hospital staff who serve individuals with intellectual disabilities as it is to know about the perspective of the service user. More needs to be learned about the experiences, challenges, and potential solutions of hospital staff, if the ER interface is to be improved. Only with information from both groups (i.e., ER users and ER staff) can change be made.

In our review of the literature, we found only one project that solicited emergency nursing staff perspectives on treating patients with intellectual disabilities from five hospitals in Ireland (Sowney & Barr, 2006, 2007). The main themes nurses spoke about were lack of knowledge about intellectual disability, nurses' dependence on caregivers, consent issues, and communication problems. However, from the quotes in the two articles, it appears that nursing staff focused on patients treated for physical rather than mental health issues and on admitted patients rather than patients at the emergency assessment phase. This Irish study was also limited by its exclusive focus on the perspectives of nurses, when ER assessments typically involve an interdisciplinary team of individuals.

The purpose of our research was to identify issues and concerns raised by interdisciplinary emergency psychiatry–crisis-response teams at six hospitals in an urban setting in Canada, when dealing with patients with intellectual disabilities and mental health or behavioral issues (i.e., dual diagnosis). In particular, we wanted to understand the typical clinical presentation, barriers in the health system that contribute to ER visits, challenges encountered in the ER, and suggestions for improvement and prevention.

Method

Focus groups were conducted with emergency psychiatry staff from six high-volume general hospitals in Toronto, a large, urban setting with an ethnically diverse population of approximately 2.5 million. These six hospitals were selected because they were known to be frequently used by individuals with intellectual disabilities. Initial contact was made with the hospital psychiatrist responsible for emergency psychiatry services, who was informed of the study and invited to select suitable emergency psychiatry staff to participate. In total, 44 hospital staff members, including psychiatrists and psychiatry residents, nurses, social workers, and other crisis workers—allied health professionals and managers, participated in the focus groups. The makeup of each group varied by hospital, with the three teaching hospitals having more psychiatrists ($n = 4$) and psychiatry residents ($n = 2$) present than the three community hospitals ($n = 2$ psychiatrists and no psychiatry residents).

These groups were organized within the emergency psychiatry programs at a time convenient to staff (e.g., during monthly educational rounds) between June and July 2005 and held on-site at the hospitals. Focus groups were 1 hr in length and were facilitated by the first author (Y.L.), a clinical psychologist with experience conducting focus groups. Focus groups were selected for this study rather than individual interviews to capitalize on the interactions among participants (Owen, 2001).

Hospital staff were asked to discuss the most common presenting problems they encountered in patients with intellectual disabilities, their comfort level treating these patients, common challenges encountered in the ER, and supports or services required by ER staff. In addition, hospital staff were asked to suggest potential resources as well as prevention and intervention strategies. Each group was asked the same set of questions, in the same order (see the Appendix). Questions were developed based on input from a panel with expertise in health research and intellectual disability (Lunskey et al., 2005–2008). Responses were recorded in writing simultaneously by the first author and a research assistant. Notes from the two research team members were synthesized immediately after each focus group met and were reviewed again after all the group interviews had been conducted. When inconsistencies arose, the notes were discussed until a consensus was reached. In addition, the records

were reviewed by a third researcher who did not participate in the focus groups. The narrative data were analyzed and emerging themes were identified.

This study received ethics approval from the Research Ethics Board at the Centre for Addiction and Mental Health. Hospital staff understood that participation was voluntary and responses remained confidential. Staff signed written consent forms prior to starting the focus groups. No one declined to participate or ended the focus group early. Staff were offered refreshments during the group session, and after the group session they were given a booklet on managing individuals with intellectual disabilities in the ER (Bradley et al., 2002), along with a CD of helpful resources for their emergency room.

Results

Findings from the focus groups revealed a number of themes that centered on a lack of knowledge, training, support, and resources for both hospital staff and caregivers. The findings are organized below by study question rather than by theme and are substantiated by quotations from the focus groups.

Description of Client Population

When staff were asked about the typical presentation of individuals with intellectual disabilities and mental health issues (i.e., dual diagnosis) and the frequency with which they visited the ER, they reported that one or two people with a dual diagnosis would use the ER each week. When asked about the level of disability, hospital staff reported that individuals with both mild and severe disabilities visited the ER. There was agreement that, although they saw very few people with intellectual disabilities compared with other populations, serving these individuals required a great deal of effort.

We don't see a lot, but when we do, they are time consuming and difficult. Sometimes the same person comes 3 to 4 times in a row.

When asked how patients arrived at the ER, hospital staff reported that some patients arrived alone, but most were accompanied by either a paid or unpaid caregiver, and, in some situations, they were accompanied by police due to safety concerns.

When questioned about the main reasons that individuals with intellectual disabilities come to the ER, staff from five of the six hospitals said that the primary reason was behavior/aggression (see Table 1). Staff from four of the same hospitals reported

Table 1 Hospital Staff Responses Regarding the Main Reasons for ER Visits

Responses	No. of hospitals (<i>N</i> = 6)
Aggression/behavioral issues	5
Burn out/respite/last resort	4
Housing crisis	2
Food/social contact	2

Note. ER = emergency room.

that many individuals were brought to the ER because caregivers did not have the professional support needed to adequately deal with the crisis and were unable to cope with the situation on their own.

They bring the patient to the ER looking for a miracle pill or wanting the hospital because they can't cope.

It is more about the staff's difficulties and burn out and less about the behaviour of the person.

We are more likely to admit this population for respite—more than any other type of population. We don't like doing that, but the bottom line is that there is no other option and everyone is burnt out.

Staff from two hospitals said that a lack of adequate housing and an inability to place a client were often reasons that patients came to the ER. Staff from two of the hospitals also mentioned that many of the individuals who arrived alone often visited the ER looking for food and social contact.

One to two regulars walk in on their own (1/month). [They are] lonely, agitated, and hungry. One client calls 911 and just needs to chat, have some food and then goes home.

When asked what makes hospital staff uncomfortable during these visits, staff from three of the hospitals identified the use of restraints to handle aggressive behavior. Staff from three of the hospitals mentioned that the ER environment was inappropriate for dealing with this type of behaviour.

There is a safety issue—[it's a] small space here. Patients can be confined for days and can be victims of other patients—[they are] easy to be preyed upon.

We will do our best to avoid restraints—try to get them a room on the unit. One-to-one attention helped them get control back, but it's harder to do in the ER than on the unit.

Barriers—Challenges

Hospital staff were also asked about what they perceived to be the main challenges during ER visits (see Table 2). Staff from all of the hospitals re-

ported that they did not have enough information about potential services to access for these clients, and staff from four of the hospitals reported that they lacked the knowledge and experience to serve the population well.

How can I engage with this person? We don't have that expertise.

Dual diagnosis is not something mental health staff have skills or experience with.

Staff from four of the six hospitals identified the lack of understanding of the client or the caregiver about procedures and limitations of the hospitals as a significant barrier.

They don't understand the standard processes that all patients go through.

Coming to emergency is not a ticket to a hospital bed. . . . People have a fantasy that everything will be right if they come to the hospital.

We are limited to medicate, control environment, and send them back. [There's] not much crises nurses can do.

Everybody expects us to have a solution to a problem that's been brewing for years.

Staff from four of the hospitals reported that they were typically provided with very little background information and that it was difficult and time consuming to gather the information that they needed. Even basic information on current medications and psychiatric-medication history were unknown.

Assessments require collateral information, but often there is little, which makes the assessment hard.

It's a lot of legwork to gather history.

Staff from four of the hospitals were concerned with an inability to find respite and community placements at discharge.

Housing is very difficult. They are often admitted not because of medical [concerns], but because they have no place to go which will take them, especially when they are on the verge of losing housing.

Staff from three of the hospitals mentioned that it was often difficult to communicate effectively and efficiently with other service providers and caregivers.

Sometimes there are complex family dynamics to work through.

[It is] not easy to work with staff from other programs and agencies.

They don't call back or come in to see the patient.

Staff from two of the hospitals identified care-

Table 2 Hospital Staff Responses Regarding the Main Challenges During ER Visits

Response	No. of Hospitals (<i>N</i> = 6)
Lack of information on available services	6
Lack of knowledge and experience with dual diagnosis	4
Misunderstanding of clients and caregivers about role of ER	4
Insufficient client background information available	4
Limited respite and residential placement options	4
Communication with service providers or caregivers	3
Caregiver burnout	2
Time-consuming population	2
ER an inappropriate environment	2
Complex medical issues	2

Note. ER = emergency room.

giver burnout and the amount of time it took to conduct a proper assessment as significant barriers. The ER setting was described as a very distressing environment for this population, especially when in crisis.

They are triggered by the environment. A lot of people in a small space.

It's too stimulating.

There are questions about the suitability about this environment for the patient. It is not safe for the client. It is the opposite of what you would want for any patient with a cognitive handicap.

Furthermore, staff from two of the hospitals mentioned the complexity of medical issues in individuals with intellectual disabilities and the long wait times to go through medical clearance as challenges in the ER.

The complexity of medical issues. Like paediatrics or veterinary medicine—it's like peeling an onion.

Directions for Intervention

Hospital staff were asked what could be done to prevent individuals with intellectual disabilities from going to the ER in a psychiatric crisis. Staff from five of the six hospitals suggested that more caregiver support and a greater emphasis on respite would help decrease the number of visits. Staff from three of the hospitals mentioned that caregiver training, rapid onsite treatment, and communication with the case manager or management team in the community could all be effective in preventing a crisis from escalating to the point of the person using the ER.

In response to the question of what might be helpful before or during a visit, several suggestions

were offered. Staff from four of the hospitals suggested that calling in advance would give them enough time to prepare for the client (e.g., gather information, set up a private space away from the ER) and would provide an opportunity to inform caregivers of what information to bring. This would ultimately help alleviate some of the stress for both hospital staff and clients.

Staff from four of the hospitals also thought that improving interagency communication would be very helpful to communicate about either specific patients or available services. Hospital staff wanted to spend less time leaving messages to various agencies, in attempts to get more information or prepare for discharge.

The system is fragmented. We don't know what's out there and it's hard to navigate—the right arm doesn't know what the left arm is doing.

Staff suggested developing a resource list of available services, which could be useful not only for clients and caregivers but for staff in the ER. In terms of format, staff thought both a Website and a 24-hr telephone line would be helpful. Hospital staff agreed that improved access to experts in dual diagnosis would help ease some of the stress involved in psychiatric crises in the ER.

Furthermore, staff from four of the hospitals suggested that clients and caregivers receive training on how to provide ER staff with a more comprehensive history (i.e., diagnoses, current treatment plan, crisis plan, baseline, etc.). Staff from four hospitals suggested that hospitals create an alternative, less distressing place to wait during a crisis than the ER waiting area. Staff from two of the

six hospitals suggested that their staff would benefit from more training in dual diagnosis.

Discussion

A handful of articles have reported the experience of nurses or psychiatry staff on working with individuals with intellectual disabilities (Edwards, Lennox, & White, 2007; McConkey & Truesdale, 2000; Slevin & Sines, 1996; Sowney & Barr, 2006, 2007). However, to our knowledge, this is the first article to provide detailed descriptions of the experience of staff in emergency psychiatry specifically, along with their recommendations on how to improve the situation. Focus groups revealed that, although relatively few individuals with intellectual disabilities and psychiatric issues accessed emergency services in these hospitals, aggressive behaviour and a lack of knowledge, training, and services all contributed to the significant challenges that this complex population posed for hospital staff in the ER.

It is not surprising that the most common issue presenting in the ER is aggression and that hospital staff have discomfort with this. Several studies have reported that the experiences of staff when responding to this behavior are particularly distressing (Fish & Culshaw, 2005; Hawkins, Allen, & Jenkins, 2005; Raczka, 2005; Rose, Horne, Rose, & Hastings, 2004). A number of studies have reported that aggression is one of the most common reasons for referral to any kind of health service (Alexander, Piachaud, & Singh, 2001; Cowley, Newton, Sturmey, Bouras, & Holt, 2005; Edelstein & Glenwick, 1997). However, other studies on the experiences of hospital staff who treat individuals with intellectual disabilities have focused more on the general discomfort with the population as a result of their lack of knowledge (e.g., McConkey & Truesdale, 2000; Sowney & Barr, 2006, 2007), rather than on their specific discomfort with aggression management.

It is worth noting that, in our study, hospital staff did not identify problems diagnosing and treating psychiatric disorders in people with intellectual disabilities. Perhaps this is because they had an understanding of how to recognize and treat such disorders but less comfort treating aggression, when the cause of the aggression was not clear. It is also possible that hospital staff were not seeing psychiatric disorders without serious aggression because such disturbances are treated outside of the emer-

gency department (see Edelstein & Glenwick, 1997; Lunsky et al., 2006). A final possibility is that hospital staff were not aware of how complex it can be to diagnose a psychiatric disorder in these individuals, and, hence, they did not consider their efforts to do so in the ER to be problematic.

A related concern is that hospital staff did not discuss the possibility that the challenging behavior could have had a medical cause. This could have been because individuals with medical concerns were identified in the triage process and never were assessed by psychiatry. However, numerous articles have stressed the importance of recognizing that medical conditions in this population can result in challenging or aggressive behavior, particularly in individuals with limited communication skills (Bradley et al., 2002; Bradley & Lofchy, 2005; Sullivan et al., 2000, 2006). This issue highlights the concern that a lack of knowledge and experience with this population can result in diagnostic overshadowing, where ER psychiatry staff focus on the behavior or mental health issue and fail to acknowledge the presence of an underlying medical condition. Because of this problem, there is the need for ER psychiatry and triage to work closely together to better distinguish between medical and psychiatric issues, especially with individuals who may not be able to communicate their concerns themselves.

It is interesting that staff commented on the need for guidelines and resources, given that the study was conducted in a city where published guidelines exist (Bradley et al., 2002), as does a network of crisis and support services for people with intellectual disabilities (Gapen, Dart, & Macdonald, 2007). When Bradley et al.'s (2002) guidelines were published, they were sent to each of the hospitals surveyed. Similarly, information on the network of services has been made available to hospitals. The lack of awareness of some hospital staff about these resources speaks to the challenge of making information accessible regarding a low-profile, minority population. A similar finding was reported in Sowney and Barr (2007), where nurses did not make use of specialist services and did not know how to access them even though specialist community intellectual disability teams existed across the region. In their study, Sowney and Barr recommended developing inclusive services and strengthening links with community providers and specialists. Any future attempts in Toronto to implement interventions for individuals with intellectual disabilities in the ER must include staff from

the ER so that resources supplied to the hospitals are accessible and used over the long term. As an example of this, psychiatry residents at the University of Toronto are now educated about resources during a 3-hr, mandatory seminar on treating individuals with intellectual disabilities in the ER, where representatives of the network of services present information on their services. It would be interesting to examine whether such teaching is having an impact in the hospitals. Additional research is needed in this area.

This study has several limitations that should be considered. First, although the focus groups involved a variety of emergency staff, other perspectives (e.g., clients, paid and unpaid caregivers) are needed to fully understand the clinical and systemic issues around visits to the ER for this population. In addition, although having a single facilitator ensured that facilitation was similar across focus groups, there is a possibility that it may have also hindered the diversity of responses from hospital staff. In addition, there is a need for substantive data not only on the characteristics of the individuals the hospitals are serving but on what happens to these individuals in the ER (e.g., information on restraint use, percentage of individuals with intellectual disabilities in hospital). Last, focus groups were conducted within six high-volume hospitals in an urban setting, and findings cannot be generalized to emergency departments in more rural locations or to settings where specialist services and expertise are more readily available than is the situation in Ontario, Canada.

Input from hospital staff in this study points to deficiencies in the system that lead caregivers to use the ER because they believe that all other options for help have been exhausted. If hospital staff is to become more effective in a psychiatric emergency, they need support and access to appropriate services for these clients. Hospital staff offered some very practical suggestions that are relevant to caregivers on how to make a visit to the ER less stressful and more productive. In particular, hospital staff noted that people with intellectual disabilities and their caregivers need guidance on the role of hospitals and how to best prepare for a hospital visit in case an emergency arises. Sowney and Barr (2007) reported similar suggestions made by emergency nurses in regards to medical emergencies. It is our intention to develop such resources in collaboration with hospitals and community agencies in the To-

ronto region in the near future and then evaluate their effectiveness.

Little is known about what happens when individuals with intellectual disabilities and mental health problems access the ER in a psychiatric crisis. In this study, focus groups among emergency psychiatry staff provided insight into the perspectives and experiences of the hospital providers that were responsible for this care. It is important that staff not only expressed the challenges that they faced but highlighted what anticipatory measures and modifications could be set in place to relieve some of the discomfort and stress for ER staff, caregivers, and clients during these visits. Caregivers and community agencies require more support—respite services to feel better equipped to deal with crises, and hospital staff need more support and training with this population when the ER is the last resort. Furthermore, what seems to be needed is a greater awareness of the services that are available for this population and a more readily accessible and collaborative network of resources. Although research in this area is limited, studies like this into emergency psychiatric services for individuals with intellectual disabilities are critical to our understanding of the mental health needs and systemic issues that exist for this population.

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This research was funded by the Dean's Fund New Staff Competition through the Faculty of Medicine at the University of Toronto. We would like to thank the hospital staff for offering their time and insight to this project. We also wish to acknowledge the efforts of Jennifer Puddicombe, who assisted with data collection.

Received 7/11/07, first decision 2/5/08, accepted 3/5/08.

Editor-in-Charge: Steven J. Taylor

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Appendix

Focus Group Questions

1. How often does someone with a dual diagnosis come to the ER?
2. What are the main reasons why patients with a dual diagnosis come to the ER?
3. What are the main challenges you have encountered during an ER visit?
4. Are there any services within the hospital or outside of the hospital that you think are missing, which would reduce ER visits in the future?
5. Do you have any ideas about what resources might be helpful for you during ER visits or before ER visits?

Note. ER = emergency room.