The Behavior Web Newsletter

CREATING ALTERNATIVES TO RESTRICTIVE INTERVENTIONS

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When One Plus One Isn't Equal a Whole

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Treating people with intellectual/developmental disabilities (ID/DD) requires specialized training, understanding of the needs of this population and the innovative ways to communicate with them. It all gets even more complicated when these individuals have a dual diagnosis with includes a severe mental health disorder (e.g. bipolar, schizophrenia, depression), substance abuse, or a chronic health condition such as diabetes, heart problems, high blood pressure. The traditional training offered in medical schools does not prepare the clinician to deal with the issues affecting this population.

In the past decade, many initiatives have increased integration of care. The more complex the needs of a subset of the population, the harder it is to accomplish this goal. Rich, Lipson, Libersky, and Parchman define patients with complex needs as those who require a variety of providers to meet their social services and medical needs. People with intellectual/developmental disabilities (ID/DD) are one such example of patients with complex needs. As patients move along the spectrum of intellectual disability (mild, moderate or severe) more complex the needs for their care will be. The higher prevalence of mental health illnesses among these patients is widely recognized (Longo and Scior, 2004; Charlot, Abend, Ravin, Mastis, Hunt, and Deutsch, 2011; Aggarwal, Guanci, and Appareddy, 2013; Gentile, Gillig, Stinson, and Jensen, 2014), yet, in the United States, hospitals that offer psychiatric inpatient service that is specialized and geared towards this population are rare.

Providers willing to accept patients with ID/DD into their outpatient practice are also not very common. Many clinicians feel unprepared to serve this population. For a population with such complex needs it is important to ensure that communication between the social services providers (i.e. residential settings, day program, vocational training, etc.) and the medical providers, both on inpatient and outpatient settings, is effective.

The inadequacy of behavioral health services for this population is noted in the emergency room. Tint and Lunsky (2015) noted that people with ID/DD use psychiatric emergency services much more often than the general population. They were interested in the variables that could affect psychiatric outcomes for patients with ID/DD in the emergency department. They conducted a qualitative analysis of 66 records of ID/DD patients who visited the

emergency room in urban centers in Ontario, Canada, where they reviewed medical records and a structured interview (Client Background Form) which was filled by caregivers. Their results showed that although crisis severity was a good predictor for psychiatric consultation at the emergency room, it was not a good predictor for admission. Of the patients who were seen by psychiatrist, those who had mild to moderate ID/DD were more likely to be hospitalized than those with moderate to severe ID/DD. In general, the patients who were seen by the psychiatrist and had a co-morbid mental health disorder were more likely to be admitted. Tint and Lunsky suggested that current admission practices for individuals with intellectual disabilities may not be so concerned with the presentation as with the cognitive level of functioning.

Diagnosing a mental health disorder on an individual with intellectual disability is not simple. Many times, patients with ID/DD offer communication challenges, and an atypical presentation that a psychiatrist without a specific training may miss. In addition, many behavioral problems may be associated with physical conditions (e.g. pain, constipation, allergies, etc.). It is important to identify the function/cause of the challenging behavior for an effective management of medical/mental health needs of people with ID/DD (Aggarwal et al., 2013). Charlot, Abend, Ravin, Mastis, Hunt and Deutsch (2011) investigated the relationship between length of stay and number of medical diagnoses at discharge. They also correlated the number of medical diagnoses with the number of psychoactive medications. They reviewed the medical charts of 198 individuals admitted to an acute care specialized inpatient psychiatric unit serving people with ID and mental health diagnoses. The results showed that the patients with the longer stay were also the ones with the higher number of medical diagnoses. They also found a significant correlation between the number of psychoactive medication and the number of medical diagnoses. They cautioned readers about the common over-reliance on medication, and suggested that a more systematic use of behavioral interventions and multi-modal treatments as an alternative.

In order to investigate the relative effectiveness of psychiatric treatment alone and when combined with behavioral support program, and/or counseling therapy, Gentile, Gillig, Stinson, and Jensen (2014) conducted an initial prospective analysis. They reviewed data for 141 patients who were attending a clinic for people with intellectual disability and psychiatric disorders. All patients received psychiatric-somatic treatment, where they were seen for 30 minutes by a nurse or psychiatrist, monthly or quarterly. Based on their scores on the Problem Severity Scale (PSS) patients were referred to a behavior support program, a counseling program, or both. They analyzed the co-occurrence of medical conditions based on the individual's level of cognitive functioning (mild, moderate or severe/profound intellectual disabilities). They analyzed the relative effectiveness of each treatment package at six and twelve months after the initial measurement of the PSS. All groups showed improvement at six months, with the greater improvement being for the group which received behavioral support. However, at twelve months all groups showed a loss of the gains, although none of the groups returned to baseline levels. The authors suggested that these findings have implications for program funding and design. They argued that perhaps short-term programs would be more effective.

When dealing with individuals with such complex needs, one measure of program success as proposed by the Triple Aim framework, is patient experience (IHI). Longo, and Scior (2004) evaluated the service users' and caregivers' perspectives, comparing inpatient stay at a traditional generic inpatient unit with a specialized unit for people with ID/DD. Fourteen individuals who had been admitted to a generic psychiatric unit, and fifteen who had been admitted to a specialized unit, and 20 caregivers participated in this study. All participants responded to a semi-structured interview which asked about the overall experience of treatment, process of admission, treatment received, relationship with main caregiver during the inpatient stay, relationship with staff and other patients, physical environment, discharge and follow up. Using the guidelines on the Interpretative Phenomenological Analysis (IPA), interview transcripts were analyzed and themes were identified. As expected, the specialized setting received more positive reviews. The authors recognize the small sample and geographical parameters of the study as limitations, but credit the study as initial evidence that service users' and caregivers' perspectives can point us to areas in which improvement can be considered.

There is a good number of papers describing the effects and implications of inpatient psychiatric treatment for individuals with dual diagnosis (ID/DD and mental health). However more research is needed to describe training guidelines for psychiatrists and social service

agencies which provide outpatient and community care to these individuals. More integration between caregivers, social service providers (e.g. schools, residential, day programs), primary care, and mental health care is needed to better serve the needs of this complex population. It is important to understand the individual so that we can be able to cater to his needs. For complex-care patients, integration and communication among providers is essential. There are a few themes on which future research is needed, such as: integration of behavioral services during inpatient stay for people with dual diagnosis; assessment guidelines, to better discern between behavioral challenges that stem from a medical diagnosis versus a mental health diagnosis. Behavior analysts had an important role and a lot of responsibility in creating this dialogue, and improving the care for people with ID/DD. How do you plan to help?

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