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Reviewing risk for individuals with developmental disabilities

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ABSTRACT

There are many categories of risky behaviors that are of interest to individuals, agencies, and institutions interested in care for developmentally disabled persons. These include challenging behaviors such as aggression and self-injury, psychiatric diagnoses, medical problems, criminal behaviors, and victimization. The literature in this area is difficult to digest due to a number of methodological problems. This paper reviews the research on one of these behaviors, self-injury, and provides a framework that can be applied to other research on predicting risk. Additionally, it attempts to organize the findings in such a way as to maximize the utility to providers and suggest useful directions for future research.

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1. Risky business

Individuals, agencies, and institutions providing care to those with intellectual disabilities can face difficult treatment planning decisions ranging from where to place a patient to how to assess and predict management problems that might occur. Placement and planning often depend on what if any risk factors may be present for a particular patient. A risk factor is "a characteristic, experience, or event that, if present, is associated with an increase in the probability (risk) of a particular outcome over the base rate of the outcome in general (unexposed) population" (Kraemer et al., 1997). Though many research reports address the prediction of risk and management issues in this population, three major problems compromise any common conclusions on which a treatment provider might wish to depend. The first is a fundamental problem in how the extant research defines what we will refer to as "challenging behaviors." The second is the appropriateness of the methodology used in the prediction of challenging behaviors. This issue includes measurement approaches, definitions, and the methods used to draw inferences. A third issue emerges from where samples are drawn in different studies. That is, how might pre-existing groups of patients affect the conclusions drawn by different researchers? This particular problem is rampant because much but not all of this literature is situated in the context of the deinstitutionalization movement. This movement placed the burden of adequate treatment off of the government and onto individual providers and families. It also paralleled the focus on increasing quality of life without loss of treatment benefit. In evaluating these changes, research focused on rates of challenging behavior in institutional versus community settings. As many authors have previously noted, the differential rates of challenging behaviors found across settings could be an artifact of the sampling procedure used. For example, in the beginning of the deinstitutionalization movement, less severe cases were moved to residential settings. Thus, results showing higher rates of challenging behaviors within

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institutionalized populations could be due to the decision making process that removed less problematic patients from the institutional sample.

In any particular study one or all of these problems may make interpretation difficult. Across studies the occurrence of these problems makes the literature extremely difficult to assess. This paper highlights these research problems and offers tentative conclusions about the current state of knowledge. While we originally intended to cover many types of risk that are of interest to providers, we have subsequently limited our analysis to self-injury because it highlights important issues in advancing our understanding of risk. This is one of the most common forms of challenging behaviors that have been examined. We will use this line of research as an example; many of the discussion points are applicable to other outcomes of interest (e.g., other challenging behaviors, medical problems, obesity, and mortality). We will highlight three useful points from the literature: statistical predictors that have been identified, changeable predictors, and suggested directions for future research.

Statistical predictors are those variables whose presence is associated with increased risk of a certain behavior occurring above what would be predicted by chance. Such variables are typically person variables such as age, sex, abuse history, and IQ. While important at any given time point, these variables by their nature cannot be manipulated and can be contrasted with changeable variables that are useful for ameliorating risk.

Identifying changeable variables involves examining contextual variables, environmental factors which are present close in time to the occurrence of the behavior of interest and affect the probability of the behavior occurring. Environmental or contextual factors can be understood broadly; medication changes, actions of staff, and sleep deprivation can all fall under this category. In principle, identifying these variables could allow a provider to alter practices and affect the probability of occurrence of the problem behavior.

Part of the confusion in this literature is a result of there being too little emphasis on changeable predictors. Researchers have investigated the risk factors that lead to challenging behaviors and have discussed these same behaviors as risk factors of other outcomes of interest. For example, the relationship between aggression and property destruction has been examined, but this research fails to identify how to change either aggression or property destruction. An alternative path that we will emphasize is to examine the contextual variables that may impact both. For example, both property destruction and aggression could occur following some demand placed on an individual. If the patient hits something (person or property), the demand is taken away. Intervening by building alternative communication skills might lead to a decrease in both behaviors. Throughout this paper, we will emphasize the difference between a focus on the function of the behavior and the behavior's topography. Topography refers to defining the form of behavior (e.g., aggression is defined by hitting someone and property destruction is defined as hitting something) whereas function refers to defining behavior based on contextual variables (e.g., hitting someone to get him to stop asking the patient to do something rather than communicating the same thing in a more useful way).

Finally, we will highlight potential directions for future research. These suggestions emphasize identifying changeable variables. Thus, the ultimate goal of this paper is to help understand the current state of this type of research and suggest how the next wave of studies might approach the question of how to better anticipate and create treatment approaches for problematic behaviors based on more useful personal or environmental characteristics.

2. Definition, prevalence, and statistical predictors

The first hurdle in reviewing this literature was isolating the research on self-injurious behavior (SIB). SIB has been classified as a challenging behavior. There has been considerable research on challenging behaviors (also known as problem behaviors, maladaptive behaviors, etc.) in general, as well as research that focused on SIB.

The definition of what constitutes a challenging or problem behavior varies significantly across studies. For example, the most common behaviors in this category are self-injury, aggression, and stereotyped behaviors. However, other studies will exclude stereotyped behaviors but include property destruction. Still others will include stereotyped behaviors under the category of self-injurious behaviors. Some studies examine relationships among each of these behaviors and the factors that might lead to risk, while others only look at the relationship between these factors and the aggregated variable "challenging behaviors". Further difficulty results from the fact that most studies use ad hoc operational definitions of the behaviors for the purposes of the specific study rather than validated assessment approaches. These differences in definition make it difficult to draw conclusions across studies and lead to seemingly discrepant or inconsistent results.

As with the general category of challenging behaviors, the research on self-injury is plagued with definitional and assessment problems. Many studies employ ad hoc operational definitions of self-injurious behavior thus making comparisons across studies difficult (Rojahn, 1994). For example, many studies use databases that are already in existence and self-injurious behavior is defined as those instances that were recorded by staff using unknown or variable criteria. Also, some studies will include stereotyped behaviors as SIB while others will study these topographies separately. Co-variation of stereotyped behavior and SIB is estimated to be approximately 65% (Rojahn, 1984). Using validated assessments could reduce a major source of confusion. However, a recent review of assessments of SIB concluded that most measures have problems with reliability and validity, lack uniformity and specificity of definitions, and fail to provide information about contextual variables related to SIB (Claes, Vandereycken, & Vertommen, 2005). It is not hard to appreciate that information about the context in which SIB occurs is crucial to help the service provider evaluate the actual risk of SIB for a particular patient. Consider how differently one would interpret an incident rate collapsed across all contexts versus information that reported SIB in individuals with and without structured activities.

As a consequence of the different definitions of SIB used, results from studies of the prevalence of SIB have varied widely, 2%–50% (Borthwick-Duffy, 1994b; Collacott, Cooper, Branford, & McGrother, 1998; Emerson et al., 2001b; Hill & Bruininks, 1984; Rojahn, 1984, 1994; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001; Salovitta, 2000; Schroeder, Matson, & Mulick, 1991; Sturmey, Burcham, & Shaw, 1996). Increased rates of self-injury have been observed in those who are more severely disabled (Matson et al., 1997). Similarly, a logistic regression analysis demonstrated that age, developmental quotient, hearing status, immobility and number of autistic symptoms predict SIB (Collacott et al., 1998). Wieseler, Hanson, and Nord (1995) reported that SIB was not associated with an increased mortality rate but was associated with a higher rate of visual and hearing impairments in their sample of individuals with developmental disabilities living in a residential facility.

The need to examine self-injurious behaviors separately from other challenging behaviors is unclear as studies have shown that many individuals who exhibit SIB also exhibit aggressive and other challenging behaviors. An epidemiological study by Qureshi and Alborz (1992) found that of the population that exhibit challenging behaviors, 46% emitted self-injurious behavior (although, by their definition, SIB was a serious problem for 17%). Emerson et al. (2001a) examination of SIB showed that 50% of those who self-injured showed some other type of challenging behavior. Furthermore, the general category of challenging behavior has been related to similar variables: severity of mental retardation, mobility, adaptive/communication skills, dual diagnosis, medical problems, and increase risk of negative