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Providing Treatment for Intellectual Disability Extremes

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Abstract

This paper highlights the need for specialized treatment services for individuals who have intellectual disability concomitant with severe mental health challenges as evidenced by significant forms of intropunitive and extra punitive aggression. Limitations of current funding and regulatory approaches are discussed.

Introduction

The term, 'intellectual disability' is exceptionally broad, ranging from individuals who are unable to meet any of the basis life support needs to individuals capable of living near independently within society. Most individuals with intellectual disability have relatively milder forms of the disability. The diversity of the group of individuals encompassed by this term and the wide range of supports needed precludes the reasonable adoption of a singular policy regarding public supports and services (Hansen-Turton, Spreat, & Rosenberg, 2017). Clearly, one size will not fit all. It must be recognized that individualization is the key for the development of supports and services for people with intellectual disability because diversity is perhaps the most distinguishing characteristics of intellectual disability.

Most people with intellectual disability, by definition, need some level of support to meet the demands of everyday life (Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter, Craig, Gomez, Lachapelle, Luckasson, Reeve, Shogren, Snell, Spreat, Tasse', Verdugo, Wehmeyer, & Yeager, 2010). With the provision of appropriate supports, the overwhelming majority of individuals with intellectual disability are enabled to live within the community, work within the community, and socialize within the community. These statements have been empirically supported in the professional literature developed over the past 40 years (cf. Conroy & Bradley, 1987; Kozma, Mansell, Beadle-Brown, & Emerson, 2009). It must be recognized, however, that there are individuals with intellectual disability whose patterns of socially unacceptable behavior are so extreme that traditional supports alone may be insufficient. The field often refers to these individuals as having a dual diagnosis (intellectual disability plus some form of mental health disorder). The National Association for Dual Diagnosis (NADD) has suggested that between 30-35% of individuals with intellectual disability have concomitant diagnoses of emotional disturbance (NADD, undated). Similarly, it is estimated that roughly 21% of the general public experience some form of mental illness within a given year (NIMH, undated; NAMI, undated), with a little over 5% experiencing what would be described as "serious mental illness". Like members of the general public, most individuals with intellectual disability and emotional

disturbance or behavior problems can reasonably be served via generic publicly available community services.

There are individuals, however, whose behavior is so extreme and/or dangerous that more intensive interventions than support may be needed. These extreme behaviors fall outside of the parameters of socially tolerable behavior (Isett, Roszkowski, Spreat, & Reiter, 1983), and some form of therapeutic intervention is warranted. In a sense, treatment is needed in addition to support. Prevalence of such conditions seems to vary as a function of the sample being studied, but it is noted that those individuals who have complex medical and/or behavioral needs concomitant with intellectual disability are among the highest users of Medicaid/Medicare resources. These complex behavioral needs include extreme forms of intropunitive or extra punitive aggression that endanger the individual or members of society. Rather than the relatively simply forms of support needed by most people who have intellectual disability, these individuals are in need of mental health treatment.

The identification of those individuals whose aggressive behavior seems to warrant specialized treatment services is challenging. Direct Support Professionals, when polled, suggested three factors that defined more serious behaviors: 1) daily aggressive behavior, 2) aggressive behavior that injures others, and 3) property damage that results in injury to others (Hensel, Lunsky, & Dewa, 2013). More objective efforts to delineate those individuals whose behaviors appear to warrant specialized treatment have quantified point prevalence of aggressive behavior in various settings. Considering a variety of program types in Quebec, Crocker, Mercier, LaChapelle, Brunet, Morin, & Roy (2006) reported that whil over half of individuals surveyed engaged in some form of aggressive behavior, less than 5% actually injured anyone. Gray, Pollard, McClean, MacAuley, & Hasting (2010) reported just 4.9% in an Irish study, and Sigafoos, Elkins, Kerr, & Atwood (1994) reported jut 11% prevalence of aggression in a study that included all environments (community and institution). Sigafoos, Elkins, Kerr, & Atwood (1994) also noted that the higher rats of aggression were noted in the congregate settings. It was not determined whether the higher rates were a product of the environments themselves or admissions selection decisions.

The studies referenced above suggest that the percentage of individuals with intellectual disability whose extra punitive forms of aggression would appear to warrant specialized treatment is small. For those individuals who do engage in significant forms of challenging behavior, it must be recognized that these behaviors function as significant barriers to social integration. Aggressive behavior cannot be tolerated in competitive or supported forms of employment. The over-representation of persons with intellectual disability in our prison system (Spreat, 2020) lends further significance to the need to provide the additional therapeutic services to individuals with intellectual disability whose behavior falls outside the realm of social acceptability.

Contemporary efforts to provide treatment for these individuals, for the most part, have consisted of simple enhancements to existing program structures. Staffing is typically increased to the 1:1 or 1:2 level, but this staffing is typically provided by Direct Support Professionals without specialized clinical training. Clinical supports are typically provided by master-level clinicians,

although there has been some improvement in this area with the development of BCBA certification for behavioral clinicians. Despite limitations of this approach, empirical support for the general approach is available (Spreat & Stepansky, 1986).

For more extreme cases or those cases that prove resistant to supplemental treatment efforts, a different approach is warranted. Two basic clinical models are currently in operation. The first model is an acute care, short term residential treatment model. An example of this approach is the Neurobehavioral Unit at the Kennedy Krieger Institute in Baltimore, Maryland. The Neurobehavioral Unit at the Kennedy Krieger Institute offer an acute care treatment model for individuals with challenging behaviors. The program is hospital based (16 beds), and typical stay is between three and six months. Staffing is rich (minimally 1:1 during waking hours), but more important, treatment is supervised by doctoral level Board Certified Behavior Analysts, and each customer receives treatment from two to three trained therapists. Individuals treated via Kennedy Krieger are expected to return to their former setting, with Kennedy Krieger providing substantial transitional support. Larger scale variants of this enhanced professional model exist outside of hospital settings. Examples include the May Institute, the New England Center for Autism, the Bancroft Lindens Program, and Western Michigan Center for Autism Excellence.

A second model injects a high level of professionalism into an individual's current living situation. As described by Massisois, Robotham, Conagsabey, Romeo, Langridge, Blizard, Murod, & King (2009), this model supports the existing treatment team; by adding a clinical director, four to five Board Certified Behavior Analysts (or equivalent), and several behavioral associates. Emphasis is on treatment and changing challenging behavior. Temple University's Woodhaven Center used this approach in the Behavior Intervention Team in the late 1980s. Like the hospital model, the professionally enhanced residential model is substantiated by published empirical outcome data.

There are variants of each of these models in existence, but all are generally characterized by increased professional presence, higher staffing models, reduced caseloads, a reliance on learning theory-based approaches, and a commitment to evidence-based practice. These commonalities are discussed below.

Increased Professional Presence – the treatment of significant behavior problems is a specialty service, and individuals who provide this sort of service must have substantial training in the art. Persons in charge of treatment should minimally hold a doctorate in psychology with substantial training in learning theory-based approaches. They should hold a license to practice psychology and/or board certification in applied behavior analysis (BCBA-D). In addition to the treatment team leader, supervised professional staff working on cases should hold the BCBA credential and at least be in the process of pursuing their doctorates, Staff providing direct support should have specialized training in applied behavior analysis. Just as a reader would certainly prefer a certified cardiac surgeon for a heart operation rather than a family practice doctor, individuals with behavior challenges deserve the same degree of clinical expertise at all levels. To offer less is a subtle form of handicappism.

Higher Staffing Ratios – it appears that staffing ratios are minimally set at 1:1, with higher staffing levels during specific treatment phases. The primary rationale for increased staffing is not to ensure sufficient staffing during emergencies, but rather to provide sufficient staffing to ensure the implementation of relatively complex treatment protocols. It must be recognized that if a reinforce needs to be delivered every five minutes, this cannot occur under traditional staffing levels. Not only must this staffing ratio be enhanced but the persons working these positions must have substantially greater levels of training than typical Direct support Professionals. Several credentialing organizations are developing credentials for Direct Support Professionals who work with individuals who have challenging behavior.

Learning Theory Based Approach – the available professional literature offers strong evidence for the potential of changing human behavior via various learning theory-based approaches. Applied behavior analysis is the primary learning theory-based approach, and it offers the greatest degree of evidence, but other learning theory-based practices have support as well. Less strongly supported (although not refuted) are more traditional forms of therapy and the use of psychotropic medication. Note that the National Clearinghouse on Autism (Steinbrenner, Hume, Odom, Morin, Nowell, Tomaszewski, Szendrey, McIntyre, Yucesoy-Ozkan, & Savage, 2020) summarized evidenced based treatment strategies for people with autism, and the overwhelming majority of evidence-based strategies were learning theory based.

Caseloads – changing significant behavior challenges via a learning theory-based approach is labor intensive at all levels. Clinical caseloads must be maintained at exceptionally low-levels. Note that in traditional talk-based psychotherapy, the therapist might meet with the patient once or twice a week, with the remainder of the time available for processing by the patient. In applied behavior analysis, the therapy is woven into the context of daily living and prompted and shaped by staff. This promotes generalization and affords more rapid learning, but it requires substantially greater levels of contact than the one to two hours per week allotted to individuals in talk therapy.

Commitment to Evidence Based Practices – each of the above-described models adheres to the belief that treatments must be demonstrably effective. Therefore, treatment derives from practices that have been demonstrated to be efficacious. Data are routinely collected and scrutinized to ensure continued progress. One also sees an increased dedication to publishing empirical findings of treatment outcomes, the rationale being that a contributor to the professional literature must remain on top of the empirical literature. In some models, one will find a reduced reliance on psychotropic medications, largely because of the limited (but not absent) empirical evidence of effectiveness.

Are Needs Being Met with These Approaches?

While multiple examples of intensive treatment practices are in existence, not all needs are being met. Several factors suggest that the needs of individuals with extreme forms of behavior are not being met. Instances of out-of-control behavior can result in arrest or hospitalization, rather than enhanced treatment. Some individuals are in jails or long-term congregate care who might be responsive to these intensive treatment approaches. People with intellectual disability are

overrepresented among the prison population by a factor of seven (Spreat, 2020a). Pennsylvania annually includes a budget request for specialized behavioral treatment facilities in both the western and eastern portions of the commonwealth. Funding shortages, however, limit the development of both hospital-based programs and professional supplementation programs. Programs willing to treat individuals with significant challenging behaviors typically have waiting lists. Perhaps the greater concern is that many providers do not believe that their compensation for undertaking such cases would cover their costs. On a more positive note, the Center for Autism and Related Disorders announced in April 2021 that it planned to open 46 applied behavior analysis centers nationwide (Open Minds, 2021). Minimally this action suggests the presence of a market and the need for such services.

Let us recognize that social services for people with intellectual disability have been systematically underfunded for over 20 years. For example, while the Pennsylvania general budget went up over 90% over a recent 20-year period, funding for intellectual disability services over that same time increased only 23% (Spreat, 2020b). There are not enough Kennedy Krieger Institutes in the United States because there is not enough funding to support a sufficient number of Kennedy Krieger Institutes. There are not enough enhanced Behavior Intervention Teams for the same reason. Instead, providers and funding agencies attempt to make do, and attempt to ensure that their budgets are spend in a manner to maximize benefit.

Recommendations

1. Pennsylvania needs to develop an intensive treatment approach for those individuals who emit extreme forms of socially devalued behaviors. The orientation should be applied behavior analysis, supplemented by pharmacotherapy and traditional therapy forms where appropriate. The key elements will be the assurance of a national level behavior analyst directing the operation, supported by a team of doctoral-level analysts and highly trained Direct Support Professionals. The wisdom present in repeated Pennsylvania budget requires seems completely evident.

2. A dedicated funding stream must be developed for these specialized services. Base funding and HCBS waiver-based funding cannot be stretched to accommodate these needs. Medicaid and Medicare should be the basis for funding of such services, but funding should be processed through appropriate Departments of Health, rather than areas that oversee intellectual disability services. It must be recognized that for these individuals, the primary problem is not the intellectual disability but rather the mental health problems that present as significant behavioral challenges.

3. The provision of these specialized treatment services must be recognized as healthcare rather than mere residential care. Both the funding and the regulatory oversight should derive from the healthcare segment of the government. Services must be provided by licensed health care providers, and they should be working under regulations that pertain directly to therapeutic services rather than residential supports. It must be recognized that the current Pennsylvania regulations (6100, 3800, etc.) were not developed to oversee

highly specialized treatment services. There must be a regulatory care-out for individuals with extreme behavioral challenges.

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