



THE NADD BULLETIN

THE OFFICIAL PUBLICATION OF NADD

NADD

An association for persons with
developmental disabilities and
mental health needs.

VOLUME 22 NUMBER 2
APRIL-JUNE 2019



THE NADD

BULLETIN

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ISSN 1065-2574

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NOTE FROM THE EDITORS

We are pleased to bring you the first issue of our new publication schedule. In this issue we have authors that have presented thoughtful articles that address complex issues. Rick Blumberg, PhD provides considerations for assessment and intervention with persons with intellectual and developmental disabilities who struggle with suicidality. Kerrie Husband presents a paper that addresses biopsychosocial concerns through Medical Family Therapy (MedFT). Kendra Thomson, Ph.D. and colleagues from Brock University discuss a comprehensive, multi-modal decision model of assessment and treatment of sexual offending by persons with intellectual and developmental disabilities.

Bob Klaehn, M.D., in his Klaehn's Kolumn, encourages us to 'pay it forward' by sharing our expertise. Jarrett Barnhill, M.D. presents the first in a series of articles that expands our understanding of the pathophysiology of anxiety disorders. Julia Pearce, our Editor of Family Corner, explains within her column what it means to 'remain perpetually on watch for bears.'

We wish you all an enjoyable and productive summer. Please consider sharing your work with our readership by submitting an article.

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Suicidality in Persons with IDD: Assessment and Intervention

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Although suicide is the 10th leading cause of death for persons of all ages in the U.S. (CDC, 2017), there is very little research about suicide in adults with IDD, and even less is known about suicide in children and youth with IDD. In the past, it has been thought that lower levels of intellectual functioning protected individuals from suicidal thoughts and behaviors. However, the few studies that do exist suggest that the characteristics and risks for suicidality in individuals with IDD are very similar to persons without IDD (Merrick, Merrick, Lunsy, & Kandel, 2005).

As in the general population, assessment of protective factors, present within the person and/or her environment, is an essential step in evaluating individual risk for individuals with IDD. Protective factors may be thought of as characteristics at the biological, psychological, family, or community (including peers and culture) level that are associated with a lower likelihood of problematic outcomes and reduce the negative impact of risk factors (Joiner, 2005). Some of the protective factors that have been identified in the literature include secure attachment with caregivers, positive physical development, academic achievement and intellectual development, and high self esteem. Additional protective factors include skills for emotional self regulation, good coping and problem solving skills, and engagement and connection in at least two of the following: school participation, peer relationships, friends, athletics, employment, and participation in faith communities.

Risk factors are those characteristics that are associated with higher likelihood of problem outcomes. Individual risk factors in persons with IDD include previous suicide attempts, major physical illness and chronic pain; central nervous system disorders; co-occurring mental health disorders, substance abuse, impulsive and aggressive behaviors. Assessment of an individual's risk factors include: history of trauma and/or abuse, family history of suicide, and identification of triggering events that may lead to the person experiencing humiliation, shame, or despair.

Identification of social/environmental risk factors is particularly important when assessing risk in children and adults with IDD. Some social risk factors that have been identified as common

to the experience of individuals with IDD include a chaotic family history, changes in caregivers or living arrangements, and lack of social support and isolation. Environmental risk factors common to the experience of persons with IDD (and the general population) include easy access to and familiarity with lethal means (guns, drugs, medications), legal difficulties and/or incarceration, and barriers to accessing health care, especially mental health and substance abuse treatment.

Some risk factors have been identified that may be particular to individuals with IDD. Lunsy (2004) found that approximately one third of interview respondents with ID reported that "life is not worth living." A study by Joiner (2005) suggested that an intense desire to die may result from an individual with ID feeling that she is a burden to others or from a feeling of social isolation, a belief that one does not "belong."

Other risk factors associated with ID include "chronic suicidality" involving suicide attempts and deliberate self harm with no intent to die (Welch, 2001). Smith and Cukrowicz (2010) found that adolescents with ID at risk for suicide may express intent without an effort to do so. These individuals are at increased risk as through "mental practice," over time, they may acquire the ability for lethal self-harm.

The Components of Risk Assessment

The course and sequence of risk assessment for suicidality in persons with IDD is similar to the steps clinicians would take to assess an individual who does not present with an IDD diagnosis. Following an assessment of risk factors, a clinician should conduct a suicide inquiry evaluating the frequency and intensity of suicidal ideations; the existence and specificity of a plan for suicide; the strength of the person's intent; and their access to the means to carry out their plan.

The clinician should assess for protective factors including social supports and engagement in social activities. Individuals who are socially isolated and who lack meaningful social activities are at significant risk. Persons with a history of impulsivity and poor emotional regulation, and who lack problem solving and coping skills, should also be considered at high risk.

If in the clinician's judgement significant risk factors are present, she should ask the person directly about suicide or seek collateral information from family or caregivers. Interview of the person should be conducted in a non-judgmental, matter of fact manner. When interviewing the person directly, simple, clear, and succinct language should be used. The clinician should check for understanding, provide descriptions or examples, and allow time for the person to process the questions and formulate answers. The following are some sample initial inquiry questions that may be used:

- Sometimes people in your situation (describe, provide examples) don't think things will ever get better. Do you think things will ever get better (describe, provide examples)?
- Have you ever thought things would be better if you were dead?
- With this much pain, stress or loneliness in your life, have you thought of hurting yourself?
- Have you ever tried to hurt or kill yourself?

If the initial inquiry questions indicate the presence of suicidal ideation, the clinician should assess for frequency, intensity, and triggering events. The following questions may be used to assess suicidal ideation:

- When did you begin to have these thoughts?
- Did something happen (provide examples) that caused you to have these thoughts?
- How often do you have these thoughts, when do you have them, how long do they last, and how strong are they?
- What do you do when you have these thoughts?

The next step in suicide inquiry is assessing the plan. The following questions may be used to evaluate the specificity, means, and likelihood of the individual implementing a plan for suicide:

- Do you have a plan, or have you been planning, to end your life? How would you do it? Where would you do it?
- Do you have the things you need to end your life (drugs, gun, rope)? Where are they right now?
- Do you have a plan for when you'll end your life? Is there something that would trigger that plan or make you do it?

If the person appears unwilling or unable (lack of verbal language, cognitive ability) to provide useful responses to the clinician's inquiry, family members, caregivers, or others who know the person may be interviewed. Non-verbal individuals should be assessed for the use of other communication methods, writing or drawing, use of

visual aids, or assistive communication technologies. Collateral interview should assess for significant risk factors including statements made by the person, behaviors indicating potential for self harm (self injurious behavior, putting self at risk for injury or death), recent traumatic events (abuse, personal loss), impulsive behavior, substance use, and/or social withdrawal.

Determining the extent to which the person expects to carry out their plan, or level of intent, is the next step in suicide assessment. Clinicians should explore with the person their reasons for wanting to die versus their reasons for wanting to live. Have there been aborted attempts in the past, rehearsals, or self injurious behaviors? An assessment of the person's judgement and impulse control are important at this stage. The following are some questions to assess for intent:

- What have you done to begin to carry out your plan?
- What makes you feel better/worse
- How likely is it that you will carry out your plan?
- What stops you from carrying out your plan?

The final step in the process of assessment is a clinical judgement of the level of suicide risk. The level of assessed risk helps to identify appropriate intervention plans.

High risk: The person has a clear and detailed plan. The person has engaged in preparatory or rehearsal behavior.

Medium risk: The person has entertained suicidal ideations. The person may have engaged in self injurious behaviors. There is no clear plan or intent.

Low risk: The person has thoughts of death, but no plan or at-risk behaviors.

Mental health professionals have an ethical responsibility to prevent clients from harming themselves and others. The following interventions are recommended for individuals determined to be at high, medium or low risk of suicidality.

Low Risk: Evaluate the person for psychiatric disorders, stressors, or additional risk factors. Encourage social support by involving family, friends, and community resources such as faith communities. Refer the individual for therapeutic supports.

Medium risk: Develop a self-care plan that includes regular daily activities and monitoring of the person by family members. Increase frequency of therapy sessions. Involve the individual, family, and friends in the development of a crisis plan.

High Risk: Take action to prevent the individual from implementing their suicide plan (e.g.; access to means). Develop a no suicide contract. Consider voluntary hospitalization or, if individual refuses, use of 911 and/or involuntary hospitalization (if state law allows).

Summary

The extant research on suicidality in persons with intellectual with intellectual and developmental disabilities suggests that the characteristics and risks among these individuals are similar to persons without IDD. A clinical assessment should include an in-depth exploration of protective and risk factors. Identification of social/environmental risk factors is particularly important when assessing risk in children and adults with IDD. When cognitive and or communication barriers prevent a thorough assessment, clinicians should consider involving family and caregivers in assessment of risk.

Most individuals with IDD are capable of participating in suicide assessment and intervention planning. Social support networks should be mobilized in the prevention of suicidal behavior and the amelioration of risk factors present in the person's environment.

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Medical Family Therapy for Parents of Children with Intellectual and Developmental Disabilities

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Abstract

This paper explores the possible use of Medical Family Therapy (MedFT) to address the biopsychosocial (biological, psychological, and social) concerns that arise for individuals parenting children diagnosed with intellectual and developmental disabilities (IDD). Research has shown that there is a strong correlation between parenting a child with IDD, elevated levels of parental stress, and elevated risk for developing physiological and psychological issues (Doherty, McDaniel, & Hepworth, 2014; Lindo, Kliemann, Combes, & Frank, 2016; Neece & Lima, 2016; Woodman, 2014). Despite this, a review of current empirical literature found that there are few evidence-based interventions (EBIs) specifically adapted for this population, the most common of which are either behavioral parent training (BPT) or coping skills interventions (CSI) (Lindo

et al., 2016; Neece & Lima, 2016). This paper evaluates current research into MedFT and proposes modifications that would adapt this intervention to serve as a potential treatment modality to prevent and/or ameliorate the biopsychosocial concerns that arise for individuals parenting children with IDD.

Medical Family Therapy for Families of Children with IDD

The parents of children with intellectual and developmental disabilities (IDD) often face higher levels of parenting stress when compared to parents raising typically developing children; in fact, one third of parents raising children with IDD report levels of stress that require clinical intervention (Lindo et al., 2016; Neece & Lima, 2016). Higher levels of parenting stress are, in turn, correlated to an increased risk of developing

psychological and physical problems for both the parent and the child (Doherty et al., 2014; Lindo et al., 2016; Neece & Lima, 2016). Research has found that highly stressed parents are more vulnerable to depression, marital conflicts, and poor physical health, while the children of individuals with high parental stress have an increased likelihood of developing behavioral problems, lower social competence, and psychopathology (Doherty et al., 2014; Lindo et al., 2016; Neece & Lima, 2016; Raina et al., 2005; Smith, Oliver, & Innocenti, 2001). This information is especially pertinent now, as system changes over the past two decades have caused a shift away from institutionalization and toward out-patient community- and home-based care (Lindo et al., 2016; Raina et al., 2005). This shift has greatly increased the number of parents caring for children with complex disabilities and has also increased the number of responsibilities and stressors these parents experience (Doherty et al., 2014; Lindo et al., 2016; Raina et al., 2005). Unfortunately, many individuals who are parenting children with IDD are unable to find treatment in a program that addresses all of their concerns; therefore, the author proposes the use of a modified version of Medical Family Therapy (MedFT) to meet the unaddressed and under-addressed biopsychosocial needs of this population (Doherty, McDaniel, & Hepworth, 1994; Doherty et al., 2014; Lindo et al., 2016; Neece & Lima, 2016; Smith et al., 2001).

Existing Empirical Research

Current empirical research presents little in the way of interventions specifically targeted toward the parents of children with IDD despite numerous studies finding that this population suffers from clinically significant levels of parental stress (Lindo et al., 2016; Neece & Lima, 2016). Lindo et al. (2016) claim that the few interventions most commonly used to address parental stress for this population can be split into two categories: (1) behavioral parent training (BPT), which are interventions that aim to “indirectly address parent stress levels by teaching parents to use strategies to modify their child’s challenging behaviors”; and (2) coping skills interventions (CSI), a category which includes interventions that “teach parents strategies to modify their [own] response to the challenges [they face]” (p. 210). A systematic review by Neece and Lima (2016) found that the most commonly utilized intervention with this population is parent-led support groups (a type of CSI).

However, the impact that this intervention has on parental stress has not been adequately assessed at this time (Neece & Lima, 2016). Other interventions that have been suggested to aid the population of interest include cognitive-behavior therapy and mindfulness-based interventions, both of which are types of CSIs (Neece & Lima, 2016). Unfortunately, as with parent-led support groups, research thus far has been unable to definitively establish the efficacy of these interventions when it comes to reducing parental stress and associated biopsychosocial issues for this population (Neece & Lima, 2016).

What researchers have determined is that the mental, emotional, and physical health of individuals parenting children with IDD is predominantly affected by: (1) the child’s behavior; (2) the magnitude of caregiving demands; (3) the availability of social support; (4) the availability of supportive services for caregiving; and (5) family functioning (Lindo et al., 2016; Raina et al., 2005; Smith et al., 2001; Woodman, 2014). Of these five factors, family functioning is the determinant that researchers have found to be most significant (Lindo et al., 2016; Raina et al., 2005; Smith et al., 2001; Woodman, 2014). In fact, family function had been found to have a direct impact on caregiver health, and appropriate family functioning can even mediate the effects of negative self-perception, a lack of social support, and heightened levels of stress (Raina et al., 2005; Woodman, 2014). It is therefore unsurprising that researchers argue that an ideal intervention for this population will not simply address and intervene in parental stress, but will also address and intervene with family functioning (Neece & Lima, 2016; Raina et al., 2005; Smith et al., 2001; Woodman, 2014).

Additionally, a systematic review of the interventions most commonly used with parents of children with IDD established that multiple-component interventions (e.g. the simultaneous use of interventions from both the BPT and the CSI categories) have shown to be the most efficacious treatment option to ameliorate parental stress and concurrent biopsychosocial issues (Lindo et al., 2016). As such, current data encourages the use of “biopsychosocial frameworks that are family centered” to address the multiple factors contributing to parental stress; this supports the author’s suggestion of MedFT as an effective intervention option (Doherty et al., 1994; Doherty et al., 2014; Lindo et al., 2016; Raina et al., 2005, p. e627; Smith et al., 2001; Woodman, 2014).

Medical Family Therapy (MedFT)

It is an unfortunate truth that cultural bias tends toward a split between the mind and the body, resulting in health professionals that specialize in either the biomedical or the psychosocial aspect of healthcare (Doherty et al., 1994; Doherty et al., 2014). When a client presents with mental health issues that are intertwined with issues relating to physical health, it is extremely rare for him/her to find the degree of inter-professional collaboration necessary for effective treatment (outside of a specialized integrated-care setting) (Doherty et al., 1994). Although the presence of integrated-care facilities continues to spread, they are still few and far-between; financial barriers are likely the primary contributing factor to the continuing sparsity of integrated-care facilities, as many healthcare professionals struggle to receive reimbursement from insurance companies for time spent in collaboration (Doherty et al., 1994). MedFT has the potential to fill a large gap in services, as MedFT providers utilize knowledge from both biomedical and psychosocial systems (Doherty et al., 1994). Some MedFT therapists may focus on obtaining a basic understanding of the kinds of major chronic illnesses most commonly found in the population (e.g. diabetes, hypertension, cancers, etc.), whereas others may focus on gaining more in-depth knowledge about certain specific medical conditions (e.g. cerebral palsy, autism, etc.) (Doherty et al., 1994). Since parental stress and related physical/psychological issues are inevitably linked to individual biopsychosocial factors, family functioning, and the medical complexities and needs of the disabled child, MedFT presents as an attractive potential intervention in addressing the multifaceted and interconnected elements that are negatively affecting both the parents and the children who make up this population (Lindo et al., 2016; Neece & Lima, 2016; Raina et al., 2005; Smith et al., 2001; Woodman, 2014).

Guiding Theory for MedFT

According to Doherty et al. (1994), MedFT is described as an intervention that brings “a biopsychosocial systems perspective to the treatment of individuals and their families” (p. 33). Doherty et al. (1994) go on to posit that MedFT is based on the fundamental tenet that “all human problems are biopsychosocial problems” (p. 34). In practice, MedFT utilizes a systems paradigm to approach family therapy, and it encourages therapist collaboration with other medical professionals in order to appropriately treat the client’s biological,

psychological, and social issues (Doherty et al., 1994). Upon analyzing the existing research related to the high levels of stress found in families that are raising children with IDD, it was discovered that researchers often apply models of stress based on family systems theory (Lindo et al., 2016; Woodman, 2014). For example, Perry’s model of stress posits that parental stress outcomes related to raising a child with IDD are the “result of child and other life stressors intersecting with personal and family resources as well as informal and formal supports” (Woodman, 2014, p. 41). In other words, high stress levels related to parenting a child with IDD can be attributed to a number of biopsychosocial factors; these factors would be best addressed by utilizing an intervention that is based on a systems theory model, such as MedFT.

Framework for Application

In utilizing a family-focused approach (e.g. MedFT) to manage chronic medical conditions, an emphasis is placed on: “(1) defining and assessing the relational context in which disease management takes place; (2) including the family environment and other family members as potential targets for intervention; (3) addressing the educational, relational, and personal needs of the patient and other members of the family; (4) viewing the disease not as a series of acute episodes, but as an ongoing process that requires continuity of care between the health care team and the family; and (5) including the patient and other family members as part of a comprehensive program of outcomes assessment” (Fisher & Weihs, 2000, p. 562). While no definitive structure for MedFT has been brought forth, Fisher and Weihs (2000) claim there are three aspects in the framework of family-based preventative interventions like MedFT (Tyndall, Hodgson, Lamson, White, & Knight, 2014). The aim of these aspects is to reduce the negative biopsychosocial effects of caregiving and of disease management for both the patient and the patient’s family (Fisher & Weihs, 2000). The first aspect of the framework is the utilization of psychoeducation to provide information about the chronic condition in question and how it may affect family functioning over time (Fisher & Weihs, 2000; Hodgson, Lamson, Mendenhall, & Crane, 2014). The goal of this aspect is to improve personal and relational coping skills for the client (and, in this case, the members of the family unit most involved with/affected by the chronic condition) (Fisher & Weihs, 2000; Hodgson et al., 2014). The second

aspect of the framework is to address family relationships (Fisher & Weihs, 2000; Hodgson et al., 2014). This may include a number of therapeutic techniques, such as the use of role-playing and/or problem-management techniques; the goal is to “foster emotional expressiveness, reduce social isolation, prevent the disease from dominating family life, promote collaboration and problem solving among family members, enhance conflict resolution, and reduce stigma” (Fisher & Weihs, 2000, p. 563). The third aspect of the framework involves the use of either individual and/or family psychotherapy; this is especially recommended for instances where there exists exceptionally problematic relationship dysfunction among family members (Fisher & Weihs, 2000; Hodgson et al., 2014). Hodgson et al. (2014) also include an additional aspect of MedFT’s framework, which involves referring the clients for additional services, such as substance abuse treatment, legal services, respite options, etc. However, as noted previously, there is currently no consensus regarding a specific structure for the application of MedFT, nor is there an accord among clinicians and researchers regarding what skills and/or trainings should be required to become a medical family therapist beyond the general agreement that, as an intervention, MedFT should adhere to a biopsychosocial model of systems theory (Tyndall et al., 2014).

Potential Adaptations for Cultural Reliance

According to Tyndall et al. (2014), in the early 2000s, “MedFT was at the point where it was building general clinical skills, and thinking about how to do so with cultural sensitivity, while building a theoretical infrastructure central to its practice” (p. 17). However, the author recommends some adaptations when applying MedFT specifically to the population of parents raising children with IDD. MedFT often focuses on the patient as the primary client, and the patient’s family members—while vitally important to the proper application of the intervention—are considered secondary clients (Fisher & Weihs, 2000; Hodgson et al., 2014). In this case, however, the parents of the patient are the population of interest; therefore, the application of MedFT would need to be adapted so that the parents are considered the primary client. However, while some small adaptations are necessary to create a version of MedFT that will adequately address the high levels of parental stress and associated biopsychosocial issues experienced by parents of children with IDD, the de-

velopment of such adaptations would be neither onerous nor particularly time-consuming. The primary obstacle to the proposed use of this intervention is that the importance of addressing the needs of this population, and the subsequent necessity of creating an adapted version of MedFT, must become more widely acknowledged among researchers, public funders, healthcare professionals, and society as a whole.

Conclusion

Despite some acknowledged limitations, MedFT shows great promise as a biopsychosocial-focused intervention and as an incredible opportunity to unify the currently disparate physiological and psychological healthcare sectors. With collaborative and integrated health care beginning to gain traction, this intervention will become even more essential, which will result in an increase in MedFT research. As a result, the body of literature related to MedFT will grow, and researchers will continue to explore additional populations with which it can be applied, creating an opportunity for different adaptations of this intervention to be developed and refined. Thus, there is a high likelihood of adapted versions of MedFT being created to address the needs of underserved and disadvantaged populations, including the caregiving parents of children with IDD.

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A Brief Overview of a Multi-Component Applied Behavior Analytic Model of Assessment and Treatment for Sexual Offending in Persons with Intellectual Disabilities

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In response to the lack of research and practice guidelines on how to effectively assess and treat sexual offending behavior in persons with intellectual disabilities (ID), NADD recently published our book that proposes an integrated model of assessment and treatment, *Sex Offending Behavior of Persons with an Intellectual Disability: A Multi-Component Applied Behavior Analytic Approach* (Griffiths, Thomson, Ioannou, Hoath, & Wilson, 2019, foreword by Dr. Peter Sturmey). The book describes a comprehensive, multi-component decision model that was informed by research, best practice standards, and years of combined clinical experience. The model is situated in current best practice for working with individuals with ID and mental health challenges (i.e., holistic and strengths-based) and the well-established applied behavior analysis (ABA) literature. The model also incorporates current practice for working with individuals with ID who have engaged in sexually offensive behaviors (see Blasingame, Boer, Guidry, Haaven and Wilson, 2014 for a thorough review of the literature and best practice). The components of the model are not new, but, in our view, the integrated nature of various approaches makes a novel contribution the field.

History Informing the Proposed Model

Although society has come a long way in treatment of individuals with ID in the past 40 years,

a lot of work is left to be done. We have moved beyond the Eugenics Movement which led to mass institutionalization and sterilization, however misconceptions and stereotypes still exist, especially regarding ID and sexuality. Individuals with ID are often seen as sexually promiscuous on one hand, or childlike and innocent in need of protection on the other (Griffiths & Federoff, 2008). These opposing perspectives have led to a lack of sexual education and muted freedom of expression under the veil of protection of the individual themselves or of others. In fact, a century ago, persons with intellectual disabilities were considered sexually dangerous to society (Simmons, 1982). The history of treatment of problematic sexual behaviors is rife with ethical challenges including the use of punishment procedures such as shock (Foxy, Bittle, Bechel, and Livesay, 1986). In fact, until the normalization movement took hold in the 1970s, sanctions for sexual behaviors included sterilization and/or institutionalization (Scheerenberger, 1983). The normalization movement led to institutions downsizing, and there was a shift to supporting individuals in community-based residential, vocation, and other support services. With individuals with ID and problematic sexual behavior now living in the community, therapeutic supports had to be replicated in the community in order for deinstitutionalization to be successful. Additionally, behavioral supports needed to be

readily available in the community in order to appropriately respond to behavioral crises that could lead to further institutionalization. One example was York Behaviour Management Services (YBMS) that opened in Ontario, Canada in the 1970s. Leading researchers, Gene Abel and Vernon Quinsey, worked with practitioners to design a model to assess and treat offending behavior in individuals with ID.

When YBMS first opened, it was a program designed to provide behavioral treatment for persons with ID and problematic behavior that was interfering with their lives. Sexualized behavior, however, was not a typical referral at that time. The response to problematic sexual behavior, especially sexually offensive behavior, was to place the person in an institution. When a referral came in for a 16-year old male living in the community who had sexually assaulted a child in his neighborhood, practitioners at YBMS investigated the literature for treatment options and found it to be severely lacking. In response to this gap, YBMS created a treatment program for the young man that would be delivered in the community, in consultation with world-renowned experts Abel and Quinsey. As such, the first community-based program for the treatment of persons with ID who sexually offended was established in Canada.

Gene Abel had already developed a community-based program for sex offenders in Atlanta. When consulting with YBMS, he suggested that many aspects of an effective treatment program were already being used by other behavioral services, such as teaching social skills and anger management. He then suggested that treatment for this young man could be done in a community setting, with the addition of sex education, a focus on relationship training, and adding the expertise of a psychologist that was skilled in reducing deviant sexual arousal. Vernon Quinsey, one of Canada's leading experts in sexual offending behavior, then joined the team to provide necessary expertise on the use of covert sensitization and to provide psychological oversight for this case. Griffiths, Hingsburger, and Christian (1985) published the treatment approach from this first case and then later expanded upon it (Griffiths, Quinsey, & Hingsburger, 1989). It is important to point out that at that time, despite the normalization movement calling for services and supports to be community-based and for people with ID to have the most normalized life experiences, even Wolfensburger, a leader in the normalization and inclusion movement, was hes-

itant to normalize sexuality. He proposed that there were too many challenges associated with sexuality that could not be integrated with the North American culture of the time: "Maybe tomorrow, I can write of not only another but even a different sexual frontier for the impaired, but today I can see it no more than I could see the present one some years back" (Wolfensburger, 1972, p. 174).

In 1983, Murphy, Coleman, and Abel called for an end to the longstanding oppression of sexuality in persons with ID. In their paper, they wrote that, "one sees a progression from a tentative limited approach seemingly designed to benefit the institution, rather than giving the [intellectually disabled] individual a more global and liberal approach to deal with emotional and physical needs" (p. 596). Also in 1983, Murphy, Coleman, and Haynes produced the classic article on the assessment and treatment of persons with ID who sexually offended, which stated, "many of the problems outlined for the [intellectually disabled] offender are very similar to those for the [non-disabled] offender" (p. 40). This paper was a seminal piece of work, as it merged the two fields of sexual offending and ID. They identified four key areas for assessment which built upon the integrated model of behavioral assessment and treatment by Abel, Blanchard, and Becker (1978): sexual arousal (excessive or deficient), social skills, sexual knowledge, and cognitive factors such as attitudes and perceptions. From clinical experience, they suggested that persons with mild ID who sexually offended could benefit from approaches like covert sensitization and satiation, social skills, and sex education.

Shortly after, Foxx et al. (1986) published the first review of behavioral treatments for problematic sexual behavior in persons with ID. They conducted an extensive review of the literature and found 13 articles that included a range of behaviors including exhibitionism, fetishism, pedophilia, public masturbation, sexual aggression, and promiscuity. The responses to these behaviors according to the review, were primarily aversive and included Faradic stimulation (shock), aversive imagery, contingent confinement, contingent lemon juice, and facial screening. Teaching appropriate behaviors and prosocial sexual skills was notably missing, which resulted in their call for a focus in socio-sexual teaching for prevention and treatment of problematic sexual behavior. Foxx and colleagues (1986) recognized a significant shortfall in the field, "the gap in literature may indicate our failure to acknowledge

the maladaptive sexual behavior of [intellectually disabled] persons rather than the absence of such behavior” (Foxy et al., 1986, p 315). By identifying this gap, the authors aimed to push for more behaviorally based research in the field.

By the late 1980s, 40 treatment programs had been identified in the literature (Knopp & Lackey, 1987). In 1990, Haaven, Little, and Petre-Miller described their treatment program for persons with ID which was institutionally based. However, treatment that focused on behavioral principles did not emerge at this time although Foxy and colleagues (1986) had encouraged it. The field advanced in risk assessment and treatment approaches for problematic sexual behavior in the typically developing population. These treatment models were explored in terms of their relevance and applicability to people with ID who sexually offend. By no means exhaustive, the following section will briefly describe two of the most widely adopted treatments used today for neurotypical persons who sexually offend.

Assessment and Treatment for Offenders without ID

The most widely accepted and commonly used treatment approaches for offenders without ID are the Good Lives Model (GLM; Ward & Stewart, 2003; Yates, Prescott, & Ward, 2010) and the Risk, Needs, Responsivity model (Andrews & Bonta, 2010). The GLM provides a theoretical foundation towards a model of rehabilitation that focuses on enhancement of quality of life and well-being and thereby reduces risk of re-offending. Through a holistic, strengths-based approach, GLM examines the individual’s goals and strengths and how they achieve these goals. The model proposes that persons engage in offending behavior in order to achieve a specific goal that is commonly sought by all humans; however, it is not the goal that is the problem, but rather the route they take to achieve the goal (e.g. offending). By assessing an individual’s goals and what is important to the person, a treatment plan can be developed that teaches the individual how to achieve their goals in pro-social, non-offending ways, thereby increasing their quality of life and reducing the risk of re-offending (Yates, et al., 2010). This model has behavioral components as it considers what motivates and reinforces a person’s behavior and teaches functional ways to access reinforcing consequences. If the means of attaining reinforcement are inappropriate, then the focus would be on teaching functional replacement skills and building reinforcement in their life that compete

with offending behavior. Although the GLM’s theoretical underpinnings have been adopted by offender treatment programs internationally, the model has been criticized for not focusing enough attention on the importance of responsivity needs (Ward, Melsner, & Yates, 2007).

The Risk, Need, Responsivity (RNR) model (Andrews & Bonta, 2010) is one of the most influential models of assessment and treatment for offenders in the typical population. The RNR model focuses on three core principles: *risk*, *need*, and *responsivity*. The *risk* principle states that the intensity of treatment must match the person’s assessed risk (e.g. a low risk individual should have less intensive treatment, a high-risk individual should have high, intensive treatment). The *needs* principle emphasizes that treatment must be focused on the person’s specific criminogenic needs. Criminogenic needs are dynamic (changing) risk factors that are directly related to criminal behavior. For example, substance abuse is one criminogenic need that increases the risk of offending; therefore if a person abuses substances, the needs principle posits that this must be directly targeted in treatment. Lastly, the *responsivity* principle, perhaps one of the most important considerations for persons with intellectual disabilities, states that the approach to treatment must be guided by effective cognitive social learning practices, such as building therapeutic rapport and modifying the teaching approach to match the person’s cognitive and learning needs. This is a brief summary of the RNR model for the purposes of this overview; however it should be noted that the RNR model extends beyond these core principles.

In response to the criticism of the GLM not considering issues of responsivity, Wilson and Yates (2009) suggested that RNR is the overarching framework in which successful interventions are likely to succeed; and that GLM falls under this framework as one approach to be used that focuses on risk and need, under a responsivity umbrella. Therapeutic interventions that are not tailored to people with intellectual disabilities are rarely effective (Barron, Hassiotis, & Banas, 2004); therefore, an integrated strategy is needed to ensure treatment responsiveness and reduced risk of offending.

Components of the Proposed Multi-Component Applied Behavior Analytic Model

Although the field is lacking consensus about which approaches are best for determining appro-

appropriate intervention for individuals with ID and co-occurring mental health or sexual offending behaviors, there is agreement that best practice approaches should be holistic, multi-factorial, and strength-based. In our model, we argue that the comprehensive evidence base from applied behavior analysis (ABA), which includes years of published research supporting the effectiveness of various behavioral assessment and treatment procedures needs to also be integrated. ABA has demonstrated effectiveness for treating challenging behavior of various type and function across many profiles of people.

The function-based approach moved the field from reliance on applying powerful reinforcers and sometimes aversive stimuli to change behavior or an over-reliance on default (punishment) technologies (Mace, 1994), to a more comprehensive and skill-building approach. This approach can be traced back to an article by Edward Carr (1977), in which he posited that all behaviors could be logically linked to specific categories of consequences such as obtaining preferred items, activities, or attention or escaping demanding or aversive situations. Wulfert, Greenway, and Dougher (1996) suggested a logical functional analysis of sexual behavior (i.e., pedophilia) would form a stronger link between assessment and treatment and therefore better intervention outcomes. The proposed model also argues that a comprehensive and functional behavioral assessment is vital for understanding the conditions under which sex offending behaviors are, more or less, likely to occur and which factors in the environment precipitate and maintain behavior. This information is necessary for guiding effective intervention.

The proposed model is comprised of three main components: 1) *Assessment*, which includes determining the antecedents and consequences, motivating operations, and the function(s) the behavior serves; 2) *Treatment*, which includes teaching alternative or coping skills and providing remedial consequences; and 3) *Generalization and Maintenance*, which aims to ensure that favorable behavioral outcomes maintain over time and occur across various conditions, people, settings, etc. (Figure 1).

A comprehensive functional behavior assessment (FBA) for sexualized behavior should include other types of assessments such as: biomedical, risk, deviance/paraphilia (see DSM-5, American Psychiatric Association, 2013), cognitive distortion/attitudes, and sexual knowledge/skill deficits. The assessment process gathers in-

formation from a variety of sources to attempt to determine why a behavior is occurring vs. treating topography has grown substantially since then. An FBA is made up of a combination of: *indirect measures*, which can include interviews or questionnaires like the *Questions about Behavior Function* (QABF; Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000); *descriptive/direct measures*, which can include direct observation of what happens before or after the behavior without any environmental manipulation (e.g., antecedent, behavior, consequence data); and *experimental functional analysis*, which includes direct observation of behavior with systematic manipulation of environmental events based on the hypothesize function (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994). Once the function is determined (if it is possible to determine why the behavior is occurring), the intervention is designed to address the cause and decrease challenging behaviors while increasing positive or prosocial behaviors (Scott, Anderson, & Spaulding, 2008).

In the case of sexually offending behavior, treatment may include getting a sexual need met in a more functional, non-offending way (McGuire, 2001). Treatment should consider all environmental variables and first rely on the least intrusive and/or reinforcement-based intervention strategies. However, it is important to note that for very severe problem behavior, a punishment-based procedure such as response cost (e.g., loss of privileges) can be the most ethical treatment option since punishment strategies, which do not necessarily mean aversive, lead to more immediate decreases in behavior. Any punishment procedures should be combined with reinforcement procedures and skill building (Evans & Meyer, 1985).

A challenging goal of any behavioral treatment program is to produce desirable outcomes that generalize across people, environments, and behaviors (Stokes & Baer, 1977). The final component of the model includes generalization and maintenance of reduced challenging behavior and increases in more appropriate behaviors. Behavior change is considered generalized if it occurs at other times and other places than the intervention setting, without being retrained, or if a behavior that is functionally equivalent to the target behavior emerges untrained (Cooper, Heron, & Heward, 2007). The full description of the model in the book outlines strategies to program for generalization and maintenance (reducing recidivism and maximizing treatment outcomes).

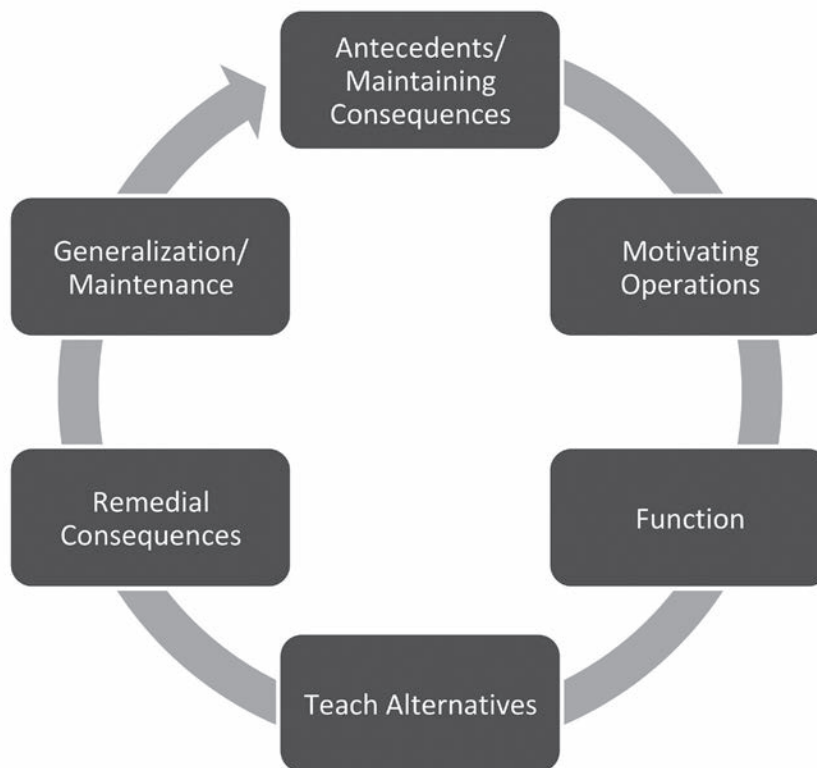


Figure 1. Components of the decision model for assessment and intervention for sexualized offending behavior (reprinted with permission from NADD).

Conclusion

The dearth of research in this area suggests that people with ID who have sexual offending behaviors may not receive access to assessment and treatment that is based in empirical evidence and best practice standards. This proposed model attempts to provide clinicians with a thorough review of the literature and practice standards in specific and related areas and hopefully prompts further research.

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*Klaehn's Kolumn***Mentorship: Pay It Forward***Bob Klaehn, M.D.*

In my first column, I wrote about my first mentor in medical practice – my father. This time, we return the subject of mentorship and its importance for developing the next generation of practitioners. Because the exposure in psychiatric residencies, child psychiatric fellowships, and other training programs to the treatment of persons with autism spectrum disorder (ASD) and intellectual disability (ID) is quite variable, finding a mentor with expertise in their treatment is essential. My own path to expertise in the treatment of persons with developmental disabilities began in my second year of residency at University of Wisconsin Hospital, when I had a six month, four hours a week, rotation at the Waisman Center, Wisconsin's University Affiliate Program in Developmental Disabilities. I worked with Dr. Mary Pearlman, a Child Psychiatrist, who was my first instructor and mentor at the Waisman Center during this rotation. She introduced me to the fun of working with children with ASD and to the relief that parents feel when their concerns regarding their child are taken seriously. With this early experience with working with persons with ASD and ID, I replaced Dr. Pearlman at the Waisman Center for a few years and have continued to treat persons with developmental disabilities throughout my career.

It is extremely important to “pay it forward” and mentor others. I have been on the faculty of the lo-

cal Psychiatric Residency and Child Fellowship for over twenty years and have played an active role in teaching our residents and fellows regarding the community treatment of persons with developmental disabilities. I have also done trainings for clinical staff and case management in every psychiatric administration position I have held during my career. Last year, I co-chaired a day-long program at the Annual Meeting of the American Academy of Child and Adolescent Psychiatry on the Community Treatment of Children and Adolescents with Developmental Disabilities. As a part of the program, we invited trainees to present papers on their own research into the treatment of person with ASD and ID and their co-occurring mental health diagnoses – each resident presenting a poster had a mentor to work with them.

So, there are many opportunities available to those of us with expertise in the treatment of persons with developmental disabilities. We must share this knowledge to the next generation so that the number of persons of all disciplines who have knowledge of and a comfort in working with persons with developmental disabilities continue to increase!

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*Neuroscience Reviews***Anxiety Disorders***Jarrett Barnhill DLFAPA, FACAAP*

In the DSM-5 and DM-ID-2, the diagnosis of Anxiety Disorders relies upon a descriptive/categorical approach that requires the presence of specific clinical signs and symptoms, a significant level of functional impairment, and the use of specifiers and exclusion criteria. This phenomenological approach does not seem to address the role of specific genetic, neuroimaging or neurobiological markers, acquired brain disorders, or various life stresses (trauma, abuse). In this sense, the DM-ID-2 diagnostic approach seems to de-emphasize searching for variations in etio-

pathogenesis and pathophysiology. We will explore this issue in greater depth in later articles.

As discussed in previous articles, this approach casts a wide net and draws in a heterogeneous group of internalizing disorders. This comprehensive approach is very useful for clinicians who need to produce a diagnosis for various reasons. Most of us do not consider anxiety disorders in terms of their complex neurobiology and genetic heterogeneity when the patients respond to our treatments. But here lies the rub—many patients improve but are not in remission, and nearly as

many do not respond at all. Both of these groups demand a more systematic approach, especially if we are to understand the source of their nonresponse. Our current strategies involve changing approaches, combination, or augmentation strategies. For example, many physicians fall back on a form of pharmacological layering or polypharmacy (add-on therapies) but fall short when it comes to time-limited use or slowly eliminating ineffective psychotropics.

This series of articles attempts to avoid a treatment arms race and focuses instead on attempts to expand our understanding of the pathophysiology of Anxiety Disorders. In doing so, we will explore the neurodevelopment of anxiety, neurobiological subtypes of anxiety, and the role of biomarkers that influence both diagnosis and treatment. These include:

1. Developing protocols that accentuate resilience (protective).
2. Modulate and reduce the impact of stressful life events. This includes reducing their intensity, exaggerated physiological response, enhancing stress response-adaptive skills (precipitation), and reducing the impact of factors that contribute to chronicity (perpetuation).
3. Fine-tune our assessments to take into account the neurodevelopmental, genetic, and biopsychosocial complexity of anxiety, pathological anxiety, and Anxiety Disorders.

The next article in this series will focus on fine tuning diagnosis by addressing the neurodevelopmental pathways from “normal” anxiety as an adaptive response to Anxiety Disorders. This developmental sequence moves from a generalized pattern of typical and atypical development towards more specific Anxiety Disorders. Variations in predisposing factors such as common biomarkers, internalizing/externalizing phenotypes, temperamental profiles, atypical patterns of attachment and attachment behaviors;

1. Vulnerabilities to setting or precipitating events (sensitivity and vulnerability to psychosocial stresses, resistance to change, need for sameness, and patterns of skill deficits).
2. Deficits in adaptive skills that contribute to increased support needs (conceptual, social, and practical domains) and atypical developmental trajectories.
3. Limited protective factors (resilience; intact executive functions and cortico- limbic input; processing, storing, and integrating life events; and sources of anxiety. In short, the development of top-down self-regulating systems.

But as we shall see, this series of steps still leaves considerable variability within the Anxiety Disorders. The residual heterogeneity may partly explain our current problem with limited treatment responsiveness. In this context, our next steps will involve narrowing our focus to mainly treatment nonresponders. This diagnostic protocol will require a different approach that includes a search for shared genetic, epigenetic (gene environment interactions), neurobiological, neuroimaging and neuropharmacological intermediate endophenotypes. This level of analysis applies a more systemic and systematic process to a smaller group of treatment resistant individuals.

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Family Corner

Thoughts About Bears

Julia Pearce

I attended a session at the NADD 2018 conference in Seattle titled A Consumer, Parent and Professional Perspective on Anxiety. It was presented by three well-spoken and honest people: a daughter, mother and uncle – Emilie Corthell, Sue Gamache, and John Gamche

One part of the presentation mentioned an article by Leigh Merryday from August 8, 2014 called “Bears in the Park,” which talks about stress and anxiety felt by parents of children with disabilities. This article states, “So we rarely leave that park. And we stand—fight or flight response at the ready—clutching the hands of our children all the time. While trying to live our lives in all the necessary ways.” I now find myself still standing, fight or flight at the ready and continue to be pounced on by bears all around. The difference is that I now DO NOT have my Dallin’s hand to hold or his eyes to look into to ask, “Are you okay.”

The bears with Dallin were many. Seizures, fall risk, dementia, muscle wasting, doctor appointments that gave us no new information. Digging deep to find resources for someone who did not fit in any system. Surviving an unknown illness at two years old? Good luck with that... dementia symptoms at age 18? Should not have happened and yet.... Trying to find mental health supports? Looks like you need to create your own.

And then Dallin passed away. And the bears remained. People who said unbelievable things: “You must be happy to be an empty nester,” “What a relief to have time,” “You don’t know what it’s like to have a child since yours is gone,” “Do you remember what it was like to hold an IEP, go to the doctor, do a meeting, talk to another parent?” It was like all of my legitimacy was suddenly taken and what remained was the pit of an empty space in our lives.

The bears are now even more surprising as my work has brought me back to working directly

with families who have children/youth with disabilities. Recently I found out that some people are surprised that I work where I do because my child is not alive. As if my 22 years of experience left with him. And my additional 6 years of advocacy and policy work for system change does not count because I do not have Dallin with me at the meetings. Do we lose the knowledge we have gained? Are other advocates not able to help families because their child is not in the exact moment at that exact time? You can’t help a parent of a preschooler if your child is not in preschool? Ridiculous and yet....

The bears do not go away. They seem to loom even larger.

At the end of the session in Seattle, the presenter shared the idea that it’s not that our loads are heavy, it’s that we need to lift more weights to learn to tolerate it. I am still not sure what I think about that concept and yet I am beginning to understand that it may be that it is through continually gaining additional skills that I will get stronger, to be able to come back from the never-ending comments and experiences. Which, in turn, will give me the ability to do what is needed next. Maybe it is gaining strength by lifting the weights that will get us all through. Even now.

Even while I, with Leigh Merryday, “remain perpetually on watch for bears.”

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Family Corner is an ongoing column in The NADD Bulletin and is published under the auspices of the NADD Family Voices Committee. We welcome your comments, suggestions, and submissions for this column. To learn more or to contribute to this column, you may contact Julia Pearce, Editor of Family Corner runnamokk@hotmail.com

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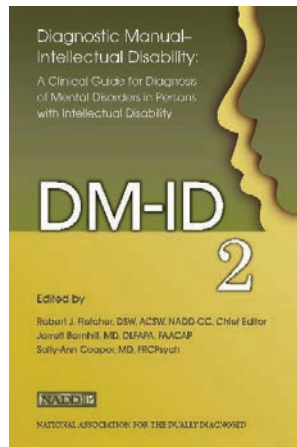
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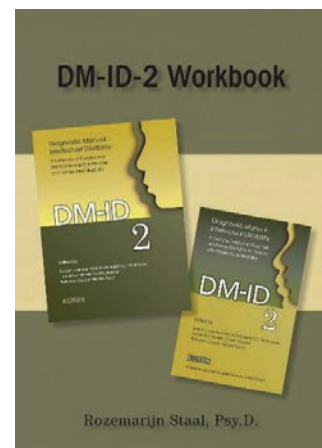
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NADD 36th Annual Conference and Exhibit Show

October 23-25, 2019 * New Orleans, Louisiana

Visit the NADD website at www.thenadd.org for more information on upcoming conferences and trainings. Updated information is posted as available.