



THE NADD BULLETIN

THE OFFICIAL PUBLICATION OF NADD

NADD

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

VOLUME 20 NUMBER 2
MARCH/APRIL- 2017



THE NADD

BULLETIN

The NADD Bulletin
is the official publication of NADD.

Copyright ©2014
ISSN 1065-2574

EDITOR:
Lucy Esralew, Ph.D., NADD-CC

MANAGING EDITOR:
Robert Fletcher, D.S.W., A.C.S.W., NADD-CC

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

132 Fair Street
Kingston, NY 12401-4802
(845) 331-4336
(800) 331-5362
FAX (845) 331-4569
E-Mail: info@thenadd.org
<http://www.thenadd.org>

Robert J. Fletcher, D.S.W., A.C.S.W., NADD-CC
Chief Executive Officer
FOUNDER

BOARD OF DIRECTORS

President

Daniel Baker, Ph.D., NADD-CC
Woodbury, MN

Immediate Past President

Donna Nagy McNelis, Ph.D., NADD-CC
Philadelphia, PA

Vice President

Peggie Webb, MA
Murrieta, CA

Secretary

George Zukotynski, Ph.D.
Pflugerville, TX

Treasurer

Terrence McNelis, M.P.A.
Erdenheim, PA

Bruce Davis, Ph.D.
Murfreesboro, TN

Mark Fleisher, MD
Omaha, NE

Eileen Elias, M.ED.
West Barnstable, MA

Jeffrey Keilson, M.A.
Framingham, MA

Susan Morris, B.S.W., M.S.W., R.S.W.
Toronto, ON, Canada

James Napolitan, Ph.D.
Chicago, IL

Julia Pearce
West Jordan, UT

Stephen Ruedrich, M.D.
Cleveland, OH

Hugh Sage, Ph.D.
Enid, OK

TABLE OF CONTENTS

What's an Advocate to Do? Social Workers' Role in Supporting Self-Advocates with Intellectual and Developmental Disabilities 23

An Introduction to the DM-ID-2 28

Neuroscience Reviews
Attention Deficit-Hyperactivity Disorder (ADHD) and Intellectual Disability (ID). 34

DSP Interests and Concerns
Trauma-Informed Care: Taking Action..... 35

NOTE FROM THE EDITOR

In this issue we promote advocacy, update our knowledge of dual diagnosis, build bridges, and offer practical support. Wendy Dorsy considers the role of the social worker as an advocate working with persons with disabilities. We are including in this issue an abridged version of the first chapter of the DM-ID-2 written by Drs. Rob Fletcher, Jarrett Barnhill and Sally-Ann Cooper. Jarrett Barnhill, MD updates us about the research regarding the genetic relationship between IDD and ADHD in the Neuroscience Review. Lynn Winters offers practical help for individuals who need trauma-informed care in the DSP Interests and Concerns column. Julia Pearce offers her thoughts on building bridges rather than creating silos between professionals and families in the Family Corner.

Spring comes as a welcome reprieve. Consider soaking up the sun while writing about your work and submitting it for our future issues.

Lucy Esralew, Ph.D., NADD-CC
drlucyesralew@gmail.com

Opinions expressed in the NADD Bulletin are not necessarily those of NADD or the Editors.

What's an Advocate to Do? Social Workers' Role in Supporting Self-Advocates with Intellectual and Developmental Disabilities

Wendy Dorsey, Virginia Commonwealth University

Self-Advocacy

Historical Context

It can be argued that disability is the original 'other' of the Western world, used in rhetoric to justify inequality of rights and treatment under the law for other non-dominant identities since the eighteenth century. This was particularly true concerning women's suffrage, the freedom and civil rights of Black Americans, and the rights of immigrants to the United States. Each of these groups has faced discrimination on the basis of biological, cognitive, and emotional inferiority. Minority groups have historically denounced any similarity to such characterizations, placing further distance between the disability community and the dominant culture. Even as Black Americans and women have been and continue to be oppressed by the dominant culture, the value of their circumscribed societal roles has remained intact (Baynton, 2000). Persons with disabilities, on the other hand, constitute a group that has been historically not only segregated but hidden from view without a unifying purpose or role in society. This became particularly problematic during the industrial era and was demonstrated formally through the practices of institutionalization and sterilization of "feeble-minded" Americans (Baynton, 2000). Specialized programs, self-contained classrooms, and restricted civil rights remain common practice for persons with disabilities in a patriarchal system that is significantly underfunded and effectively maintains the dependency of recipients.

The Self-Advocacy Movement began in Sweden during 1960's through the work of Dr. Bengt Nirje, director of the Swedish Association for Persons with Mental Retardation. Nirje organized a club comprising members with and without intellectual and developmental disabilities [IDD] to plan and go on outings and then meet to share their experiences. Club members without disabilities were instructed to allow those with IDD to make their own choices, even if mistakes would follow. By design, the club had no leader and was intended to provide persons with IDD "normal" community experiences. Profession-

als and parents were opposed to Nirje's proposal based on the assumed needs of persons with IDD to be protected from harm. Nirje responded, "To be allowed to be human means to be allowed to fail" (MGCDD, 2016, p. 2). Through this concept, Nirje identified the concepts now known as, *dignity of risk* and *normalization* that are key principles of self-determination and the self-advocacy movement (MGCDD, 2016).

The movement was brought to the United States in 1974, following Canada's first self-advocacy conference in 1973, which was attended by several self-advocates from Oregon. The first U.S. self-advocacy organization was named "People First" in 1974 in response to a call to action from one of the organization's inaugural members (MGCDD, 2016). Self-advocacy encompasses a range of activities from personal decision-making to collective advocacy efforts in the political arena (Chapman, 2014).

Theoretical Basis

It is important to consider multiple theories of disability across time and place, as these perspectives shape social policy and the daily lives of persons affected by disability. Reid-Cunningham and Fleming (2009) examine disability theories across the social sciences from the perspective of a collective individual-societal dichotomy. They describe individual models as those that define disability as being a problem within the person and include the medical model, social Darwinism, and the deficits model. Social policies and practice interventions based on individual models focus on "fixing" problems within affected persons and providing a minimum standard of custodial care.

On the other hand, social models view *disability* as deficits in environmental conditions that disadvantage groups of people, including those labelled with or having characteristics of someone with a disability. Social models include: the oppression model, which categorizes persons with disabilities as 'others,' resulting in their oppression and internalization of discrimination; the diversity model, which acknowledges persons with disabilities as having a cultural identity of

shared experiences and ways of understanding the world; and, finally, the social constructionist model, which defines disability as a problem of environmental and social barriers that reflects society's inability to meet the needs of certain groups (Reid-Cunningham & Fleming, 2009). The social constructionist model is consistent with the mission and philosophy of the self-advocacy movement, as well as self-advocates' reports of their own obstacles and barriers to leading a self-determined life (MGCDD, 2016).

Social Construction of Intellectual Disability

Gasker and Fischer (2014) draw from Nussbaum's capabilities perspective, proposing that it is the responsibility of social institutions to ensure constituents access to resources and to provide opportunities to make choices. The role of the social worker is to form mutual partnerships with clients as the basis for the helping relationship. The social worker can then work with the client to identify strengths and resources from which the client may choose to engage in order to accomplish personal goals. Practically speaking, this process requires social workers to engage with clients and systems, such that the view of justice represents the voices and contexts of those whom it claims to benefit (Gasker & Fischer, 2014).

Conceptualization

Persons with disabilities are characterized as different from the norm, in their "ableness," a status far removed from the United States' ideal of *rugged individualism* (Tharp, 2012). Although, ableness can be biologically-based, the appropriation of certain differences of ability as significant or relevant is socially and culturally constructed (Baynton, 2000). Persons with IDD have faced systematic segregation through placement in large institutions and limited availability and access to supports in the community, which continues to foster social isolation. This longstanding systemic discrimination is a reflection of the public stigma that socially constructs this population as incompetent, incapable, and an expenditure for the community at large. As a result of these norms, barriers to access and limited interaction with non-disabled peers, many members of the IDD community have internalized these stigmatizing constructs (Baynton, 2000).

Evolving Models of Care

The disability field has long been moving away

from individual-deficit and toward social models; however, this trend has been slow to be accepted by many of the social institutions with which the IDD community interacts. The discussions that follow will present both progress toward social inclusion and meaningful participation and the widespread challenges that remain (Reid-Cunningham & Fleming, 2009).

Health. Rooted in the deficits-based medical model, the healthcare system presents significant challenges for the most effective self-advocates. The complex Medicaid system, inexperience of providers, and lack of transportation create a system of care that is inaccessible to many persons with IDD (Ellem, O'Connor, Wilson, & Williams, 2013). In addition to these barriers are the health rights' violations faced by persons with IDD, including: practitioners use of professional jargon to describe patients' health information without clarification, refusal to treat patients on the basis of disability, or assumption of incapacity on the basis of disability (Feldman, 2012).

Helping professions/Social work. Helping professions and social workers, in particular, find themselves balancing the needs of multiple constituencies in their work with marginalized and oppressed populations in the larger social context. The social constructivist perspective is at times challenging to reconcile as practitioners navigate the paternalistic aspects of their roles. These responsibilities can be damaging to the therapeutic relationship and dually serve as protective and oppressive forces. Ellem et al. (2013) emphasize the need for social workers to approach practice with the IDD population using gentleness and respect, honoring the lived experiences of clients they serve. Social workers must practice self-reflection and creativity to navigate the challenging systems relied upon by members of this population.

Outcomes & Quality of Life

Inadequacies of current systems are evidenced by the poor outcomes of many persons with IDD in comparison to the general population. This population is overrepresented among persons experiencing homelessness and within the criminal justice system. They have higher incidence of isolation, unemployment, and preventable health problems. As large state institutions continue to close in favor of community options and individual freedoms, the already strained social systems across disciplines must face their inadequacies to improve the quality of life for the IDD community (Ellem et al., 2013).

Conflicts & Challenges to Traditional Models of Social Work

Social activism and political advocacy are not without risks, particularly of unintended consequences for oppressed groups. Gasker and Fischer (2014) attribute this vulnerability, in part, to the lack of consensus in the social work profession for the theoretical principles that guide practice in the name of social justice. They argue that the broad use of justice theory is insufficient for defining the role of social workers or social institutions in pursuit of social justice and equity that serves as a core value of the profession. Realities of the welfare state and the institution of “helping” demonstrate the conflicting roles of social workers, as agents for social change and social control – a duality that is heavily influenced by political climate (Sweifach, Linzer, LaPorte, 2015).

Concept of “Vulnerability”

In response to opposition from families and services systems, early self-advocates in the United States followed other prominent civil rights groups to organize at the local, state, and national levels. Self-advocates describe their most significant barriers to social inclusion as those placed by social relationships and institutions based on an assumption of incapacity, asexuality, likeness to children, or vulnerability to exploitation and abuse (MGCDD, 2016).

Protection vs. Empowerment

Through the *NASW Code of Ethics* (2015), social workers are faced with the dichotomous task of seeking social justice on behalf of clients while also supporting their self-determination. The task is further complicated by the profession’s mandate to enhance clients’ wellbeing within a cultural frame of reference that values protection of persons who are considered vulnerable. This is not only an ideological dilemma, as regulatory and legal guidance are relatively specific regarding the requirements of mandated reporting and protection from harm for persons with IDD.

The balance between protection and empowerment is aptly illustrated through the use of restraint during behavioral crises. One of the methods traditionally used across helping professions to protect persons with IDD from self-harm or aggression toward others is through some form of restraint. Even when techniques are applied properly, their use can evoke strong emotional reactions from both staff and the person being restrained, and utilization is associated with

increased risk of physical harm to all involved (Wilkins, 2012). Even so, the use of restraint can be the last option to protect someone from life threatening danger or resorting to police involvement.

Decision Making

The contradiction inherent to endorsing both protection and empowerment of persons with intellectual and developmental disabilities is particularly evident during discussion of decision-making authority for students approaching the age of majority. Too often, school personnel and other helping professionals recommend to parents the pursuit of substitute decision-making (i.e. guardianship) as the first-choice option to protect persons with IDD entering adulthood. Such recommendations are often made without understanding the immediate or long-term consequences of this determination, including the loss of rights associated with guardianship, the ongoing role of the court system in the parent-child relationship, or the parent’s inability, once deceased, to control future guardian appointments (Jameson, 2015; Rood, Kanter, & Causton, 2014). Assessment of capacity for guardianship purposes is highly variable by state and often by court, relying on assumptions of incapacity based on diagnosis, rather than individualized assessment (Jameson, 2015; Kanter, 2015; Rood et al., 2014). Research suggests that persons who are empowered to make decisions affecting where and how they live are more independent, more involved in their communities, have lower risk of abuse, better outcomes, and higher quality of life than those without such opportunities (Jameson, 2015; Rood et al., 2014).

The Virginia Department of Education (2015) technical assistance document related to the transfer of rights upon age of majority describes the purpose and process for obtaining guardianship over an adult student with a disability before describing other options. In addition, alternatives are each compared to legal guardianship with advantages to guardianship being convenience and cost. Responsibilities and long-term consequences associated with guardianship are not mentioned in the document, which is provided to school districts for guidance purposes. Overall, the Transfer of Rights document presents guardianship as a first-line option to protect students unable to make informed decisions. It does not attempt to inform educators or parents of the implications and long-term consequences of any option or of opting-out completely.

Self-advocates and disability rights organizations cite the United Nations' (2007) *Convention on the Rights of Persons with Disabilities* [CRPD], which recognizes the inherent right of persons with disabilities to make choices affecting their lives, to actively contribute to their communities, and to receive support needed to achieve these ends. The legal guardianship process exists in opposition to the spirit and intent of the CRPD, as well as the United States' Americans with Disabilities Act of 1990 and the Individuals with Disabilities Education Improvement Act of 2004 (Jameson, 2015; Rood et al., 2014). The potential harms and challenges associated with guardianship can be alleviated through alternatives that retain the voice and meaningful participation of persons with disabilities, including: powers of attorney, representative payee, special needs trust, and support decision-making (Jameson, 2015; Kanter, 2015). The supported decision-making model, which allows persons with disabilities to select a trusted individual to provide support in order to make informed decisions, continues to gain support among self-advocates and many policymakers (Kanter, 2015). A key difference between substitute and supported decision-making is the process and authority by which decisions are made (Jameson, 2015).

Current Roles of Social Workers in Direct Practice with Persons with IDD

Self-Determination

The concept of self-determination is fundamental to social work practice as defined by the profession's core value, "Dignity and worth of the person." Enacting this value requires social workers to empower clients to make their own choices and develop capacity toward independence (NASW, 2015). Ellem et al. (2013) describes a developmental model, utilizing collaboration and mutual respect between the social worker and clients with IDD, emphasizing the need to build on clients' capacities and develop skills in relationship building, identifying resources, and acquiring knowledge and skills in problem solving.

Health

Given the health and healthcare inequities faced by persons with IDD, social workers are in a key position to support self-advocates to address issues of health rights, accessibility, and healthcare quality concerns. Feldman (2012) studied the efficacy of a health self-advocacy training curriculum intended to build capacity of

persons with IDD related to health knowledge, self-advocacy, and recognition of health rights violations. The curriculum utilizes a multi-systems approach to provide opportunities to evaluate various situations and to support generalization of skills. Following participation in this program, the training group demonstrated an ability to evaluate and respond to a variety of situations related to knowledge of health information, health rights, and health advocacy. Considering the continued health disparities experienced by persons with IDD, social workers should be knowledgeable of such interventions and strategies to empower clients as self-advocates.

Looking Forward

New Perspectives

It is interesting to note that in a systematic review of HBSE texts for graduate social work students there is some mention of disability, but little acknowledgement of disability theory to inform practice. Most discussions of disability within the studied texts focused on an individual, deficits-based model or through the lens of a conflict perspective, emphasizing the oppression and marginalization faced by this population. Little attention is paid to any strengths or empowerment theories of disability that characterize the self-advocacy movement (Reid-Cunningham & Fleming, 2009). This represents a significant gap in social work education that implicates practitioners lack of preparedness to work effectively with this substantial minority population, despite the social work profession's commitment to social justice, dignity and worth of persons, and competence (NASW, 2015). As such, practitioners must be open to professional development and self-reflection opportunities when working with new client populations, particularly those that are subject to a particular cultural frame-of-reference that is shared by the clinician. Insight into this gap may also serve as an opportunity for the profession to consider new perspectives to meet the needs of this growing population.

Implications for Direct Practice Social Workers

As a profession, social work requires an understanding of and deference to the individuals, groups, and communities whose unmet needs are the result of failure from social institutions to provide the essential resources needed for survival. Unfortunately, social problems amount to more than a lack of material goods, as the mechanisms by which such resources are lost and

gained amount to complex systems of power, belief, and ideology that have existed in this country since its colonization (Tharp, 2012). In order for interventions to reflect the needs and goals of persons with IDD toward social change, social workers must engage with self-advocates as informants to guide practice (Ellem et al., 2013). It is important for social workers to participate in self-reflection to gain awareness of the biases and social identities that they bring to the helping relationship and to be cognizant of power dynamics that can undermine the self-advocacy philosophy and clients' self-determined efforts (Chapman, 2014). Social workers must engage with clients effectively across systems levels and with other professionals through interdisciplinary collaboration in order to counteract elements of oppression for positive and sustainable social change.

References

- Baynton, D. C. (2000). Disability and the justification of inequality in American history. In P. S. Rothenberg, & K. S. Mayhew, Race, class, and gender in the United States (9th ed., pp. 94-103). New York, NY: Worth Publishers.
- Chapman, R. (2014). An exploration of the self-advocacy support role through collaborative research: There should never be a them and us. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 44-53.
- Ellem, K., O'Connor, M., Wilson, J., & Williams, S. (2013). Social work with marginalised people who have a mild or borderline intellectual disability: Practicing gentleness and encouraging hope. *Australian Social Work*, 66(1), 56-71. doi: 10.1080/0312407X.2012.710244
- Feldman, M. (2012). Health self-advocacy training for persons with intellectual disabilities. *Journal of Intellectual Disability Research*, 56(11), 1110-1121.
- Gasker, J., & Fischer, A. (2014). Toward a context-specific definition of social justice for social work: In search of overlapping consensus. *Journal of Social Work Values and Ethics*, 11(1), 42-53.
- Jameson, J. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons with Severe Disabilities: The Journal of TASH*, 40(1), 36-51.
- Kanter, A.S. (2015). Guardianship for young adults with disabilities as a violation of the purpose of the Individuals with Disabilities Education Improvement Act. *Journal of International Aging Law & Policy*, 8, 1-68.
- Minnesota Governor's Council on Developmental Disabilities [MGCDD]. (2016). *The self-advocacy movement*. Retrieved from Parallels in time: A history of developmental disabilities: <http://mn.gov/mnddc/parallels/seven/7a/1.html>
- National Association of Social Workers [NASW]. (2015). *Code of ethics*. Retrieved from <http://www.socialworkers.org/pubs/code/code.asp>
- Reid-Cunningham, A. & Fleming, V. (2009). Theories of disability: Findings from an analysis of textbooks on human behavior and the social environment. *Journal of Human Behavior in the Social Environment*, 19(1), 10-25.
- Rood, C., Kanter, A., & Causton, J. (2014). Presumption of incompetence: The systematic assignment of guardianship within the transition process. *Research and Practice for Persons with Severe Disabilities*, 39(4), 319-328.
- Sweifach, J. S., Linzer, N., & LaPorte, H. H. (2015). Beneficence vs. fidelity: Serving social work clients in the aftermath of catastrophic events. *Journal of Social Work Values and Ethics*, 12 (1), 3-12.
- Tharp, D. (2012). Perspectives: A language for social justice. *Change*, 44(3), 21-23. doi:10.1080/00091383.2012.672918
- United Nations General Assembly. (2007). Convention on the Rights of Persons with Disabilities. United Nations, A/RES/61/106, Annex I. Retrieved from <http://www.un.org/disabilities/>.
- Virginia Department of Education. (2015). Transfer of rights for students with disabilities upon reaching the age of majority in Virginia. Retrieved from http://www.doe.virginia.gov/special_ed/regulations/state/transfer_rights_students_disabilities.pdf
- Wilkins, D. (2012). Ethical dilemmas in social work practice with disabled people. *Journal of Intellectual Disabilities*, 16(2), 127-133. doi: 10.1177/1744629512444986

For further information, contact Wendy Dorsey at wendydorsey@gmail.com.

An Introduction to the DM-ID-2

Robert Fletcher, Jarrett Barnhill, and Sally-Ann Cooper

[Abridged from the first chapter of the DM-ID-2]

The Problem

Although psychiatric disorders in persons with intellectual/developmental disability (IDD) are common, they are often not appropriately identified (Reiss, 1994). The provision of adequate mental health treatment for people with ID continues to be lacking, in part, because reliable psychiatric diagnosis remains a clinical challenge. Determining an accurate psychiatric diagnosis becomes especially difficult at lower levels of intellectual functioning (Rush & Frances, 2000).

DM-ID-2 has been produced to help address this problem. In addition to adapting the *DSM-5* diagnostic criteria where appropriate, the *DM-ID-2* provides a wealth of information about and considerations for assessing and diagnosing individuals with ID and coexisting mental health needs. In some cases, it is not so much that the criteria need to be adapted as that a different method of eliciting the necessary information must be used. Information is provided in recognizing common behaviors of individuals with intellectual disabilities and in how to differentiate these behaviors from psychiatric disorders.

Review of Prevalence of Mental Illness in IDD

Individuals with IDD can experience the same mental disorders as the general population, as well as some disorders that are uncommon in the general population such as pica. Studies have indicated that psychiatric disorders in people with IDD are at a higher rate than in the neurotypical population. Studies on prevalence rates of psychiatric disorders have varied widely.

The variance of the data reflects a number of variables including: (1) the nature of the study sample, (2) the nature of the definition/classification system(s) used to identify psychiatric disorders and ID, (3) the particular tools used for assessment of potential psychiatric disorders, (4) the inclusion or exclusion of 'challenging behavior,' (5) the inclusion or exclusion of autism spectrum disorders under the general mantle of psychiatric disorders, (6) the inclusion or exclusion of biomedical conditions as a potential contributing/etiological factor in the presentation of behavioral or affective symptoms, and (7) the training and experience of the individual(s) ap-

plying assessment tools (Buckles, 2016), and the methodological quality of the study.

There have been a few studies that have employed rigorous methodological protocols. One such study conducted by Cooper, Smiley, Morrison, Williamson, and Allan (2007) used multiple measures. The method used a population-based adult sample (N=1023) with a comprehensive individualized assessment model. The data indicated a point prevalence of mental illness at 40.9% (clinical diagnosis); 35.2% (DC-LD); 16.6% (ICD-10); and 15.7% (DSM-IV-TR). Similarly, high prevalence rates have also been reported for children and young people with intellectual/developmental disabilities, in whom mental health problems are about four times more common than in the general population (Einfeld, Ellis, & Emerson, 2011; Emerson and Hatton, 2007).

Although much of the prevalence data comes from Europe, and particularly the UK, the National Core Indicators from the USA has identified that a rate of 55% of people with IDD have a co-occurring psychiatric disorder (National Core Indicators, 2016). This study is based on patient charts from 30 states in the USA (N=13,466).

Another study that used a random sample (N=240) reported on different prevalence rates depending on the diagnostic classification system (Bailey, 2007). The data indicated that when using the DC-LD the rate was 57.0%; the ICD-10 reflected a rate of 24.8%; and 13.2% when using the DSM-IV.

These studies, as well as others, demonstrate that there is a higher prevalence rate when using diagnostic systems that are designed to assess mental disorders in people with IDD. Moreover, these studies indicate that the use of the DSM system reflects much lower rates than when using other diagnostic systems, even when compared to other nosology systems that are also not designed for assessing mental disorders in people with IDD (e.g. ICD-10). Hence the need for *DM-ID-2*, to consider and interpret how to use *DSM-5* specifically from the perspective of people with intellectual disabilities.

Classification and Diagnosis of Mental Illness: Historical Perspective

The clinician is faced with certain challenges when an individual with ID presents with disturbed or disturbing behavior. Since at least as

long ago as early Greek civilization, it has been acknowledged that not all abnormal behavior arises from a single, unitary cause. People might behave similarly or differently for a number of reasons, and knowing the specific reasons can be helpful not only in explaining the disturbing behavior but also in constructing an intervention that might alleviate the behavior. This is the reason that we attempt to classify behavior into discrete groupings, including syndromes.

Since the time of early Greeks, then, there have been a multitude of systems of nomenclature for mental disorders, each based upon underlying concepts of causation. Each of these systems was limited by the underlying theoretical and philosophical framework used to construct the system. It became increasingly difficult to clearly describe behaviors in terms that had some sort of common acceptance.

At the beginning of the twentieth century, Emil Kraepelin, a German psychiatrist, developed a systematic classification based upon manifest, observable behavior (Alexander & Selesnick, 1966). This classification system enabled psychiatrists from many different places to describe psychiatric disorders in a manner that could be duplicated elsewhere. Because the system was based on observable behavior, the theoretical approach of the psychiatrist would not determine the way he or she characterized the particular psychiatric disorder.

In the mid-twentieth century, the American Psychiatric Association (APA) published the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* (American Psychiatric Association, 1952) as a systematic document containing descriptions of each of the disorders contained within this classification system. Although this system used the terminology of “reactions” and “syndromes,” there was a clear effort to describe various disorders in behavioral and observable terms. In 1968, the *DSM-II* (American Psychiatric Association, 1968) eliminated the terminology of “reactions” in favor of such terms as Anxiety, Neurosis, and Schizophrenia, but in general there were few changes in the overall structure. Starting with the *DSM-III* in 1980 (American Psychiatric Association, 1980), diagnostic criteria sets were developed for each disorder, based whenever possible on observable phenomena. The *DSM-III-R* (American Psychiatric Association, 1987) and the *DSM-IV* (American Psychiatric Association, 1994) introduced some changes in individual categories, but in general the basic framework remained relatively unchanged.

The *DSM* diagnostic criteria are constructed to

be “generic”; that is, they should ideally be applicable to all patient populations, independent of the patient’s age, ethnicity, culture, gender, or the presence of comorbid medical or mental conditions. There have been many critiques of the *DSM*, however, arguing that developmental issues, cultural context, and other factors can affect the symptomatic expression of disorders.

Additionally, there has been controversy found in the literature concerning the issue of reliability in making specific *DSM* diagnosis in persons with ID, especially those with more severe impairment and intellectual function (Einfeld & Aman, 1995). Mickelsen and McKenna (1999) assert that as intelligence decreases the validity of psychiatric diagnosis for individuals with ID tends to decrease. They explain this as the result of both an increase in nonspecific organic factors and the relative inaccessibility of the individual’s inner life as productive speech decreases with the increased severity of impairment. Noting a general consensus that mental disorders can be diagnosed using standard diagnostic criteria for people with mild IDD and reasonably good communicative skills, Szymanski et al. (1998) acknowledge the increased difficulty for individuals with more severe IDD and poor verbal skills.

The *DM-ID* is not the first attempt to improve the diagnosis of mental disorders in individuals with ID. The Royal College of Psychiatrists in 2001 published a guide entitled *DC-LD [Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation]* (Royal College of Psychiatrists, 2001). The *DC-LD* is a classification system that has been developed in recognition of limitations of the ICD-10 Manual published by the World Health Organization (1992) and in its place the *DC-LD* reflects a consensus of current practice and opinion among psychiatrists from the United Kingdom and Ireland who specialize in ID (referred to there as *learning disabilities*). The *DC-LD* provides operationalized diagnostic criteria for psychiatric disorders and is intended primarily for use with adults with moderate to profound ID.

Recognizing the diagnostic challenges that clinicians face when attempting to arrive at an accurate psychiatric diagnosis for individuals with IDD co-occurring with mental illness, in 2007 the National Association for the Dually Diagnosed (NADD), in association with the American Psychiatric Association (APA), published *Diagnostic Manual—Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability* (Fletcher,

Loschen, Stavrakaki, & First, 2007). The *DM-ID* was designed as a companion to the *DSM-IV-TR* and aimed to assist clinicians to arrive at a more accurate *DSM-IV-TR* diagnosis for individuals with IDD. In 2013, the American Psychiatric Association published the *DSM-5*, thus necessitating revision of the *DM-ID* to incorporate the changes from the *DSM-IV-TR* to the *DSM-5*.

Diagnostic Challenges

During the past few decades, there have been important developments in the field of mental health care for people with IDD. The National Association for the Dually Diagnosed has been instrumental in marshaling national and international attention, providing education and training, and disseminating relevant clinical and research policy issues. In spite of these encouraging developments, however, there remain significant obstacles hindering appropriate care and treatment for this underserved population. One key problem has been the lack of a diagnostic system appropriate for clinical use with the diverse population of people with IDD (Sturmey, 1999). As a result, individuals may receive no psychiatric diagnosis even when a mental disorder exists, or they may receive an inaccurate or inappropriate diagnosis. Because treatments, services, and supports are tied directly to the accurate evaluation and diagnosis of people who have IDD coexistent with mental disorders, the absence of psychiatric diagnoses is a central issue.

Clinicians need a system whereby they can recognize the presence of *DSM-5*-documented mental disorders in persons who have limited expressive and receptive language skills. The DSM system relies primarily on self-report. Individuals report to the clinician their signs, symptoms, feelings, and experiences. A major advantage of the *DM-ID-2* is that it enhances the reliability of psychiatric diagnoses in persons with IDD which could ultimately improve treatment outcomes.

There are a number of factors associated with the difficulty of making an accurate diagnosis in people with IDD. The applicability of existing standardized classification systems (such as the *DSM-5*) for persons with IDD has been critically debated in professional literature (Sturmey, 1999). To determine whether a person within the general population has been experiencing psychiatric symptoms, a clinician typically relies on the person's description of his or her experiences and feelings. Individuals with cognitive impairments experience difficulties in receptive and expressive language to varying degrees. Mild

limitations in cognitive and verbal skills make it difficult, and severe limitations may make it impossible, for people with IDD to articulate such abstract or global concepts as depressed mood or to communicate subtle differences among emotional or motivational states.

Other factors that increase the difficulty in making psychiatric diagnoses include the tendency for some people with IDD to attempt to hide their disabilities (to adopt a "cloak of competence"; Edgerton, 1967), the tendency not to be forthcoming with respect to self-descriptions, and the tendency for some to try to please the evaluator by answering falsely or in a manner that is inaccurate ("acquiescence bias"). Additionally, the symptoms of diverse psychiatric disorders are often expressed differently in people with IDD. Sovner (1986) has identified four processes that are common in persons with IDD that can influence the diagnostic decision-making process: (1) baseline exaggeration, (2) intellectual distortion, (3) psychosocial masking, and (4) cognitive disintegration.

Another diagnostic challenge is diagnostic overshadowing (Reiss, Levitan, & Szyszko, 1982). Having a diagnosis of IDD can overshadow coexisting mental disorders and may predispose practitioners to overlook the presence of psychopathology because unusual or anomalous behavior is attributed by the clinician to being artifacts of developmental or social delay. For example, a person with profound IDD who is very withdrawn and asocial might be less likely to be labeled as depressed than would a person with average intelligence (Sturmey, 1999). Adding further to this risk of diagnostic overshadowing is the considerable amount of physical disorders, impairments, and multimorbidity that people with intellectual disabilities experience (Cooper et al, 2015).

Accurate diagnosis is important because it provides a sound basis for effective treatment. Positive treatment outcome is based on an accurate diagnosis. Just as this is true concerning physical health, it is equally true in psychiatric health.

Severe behavioral disturbance in the form of verbal or physical aggression toward others, self-injury (aggression toward self), and property destruction frequently motivates referrals for diagnosis and treatment prescription. Such severe disturbance occurs at a clinically significant rate among people with ID, often threatens the stability of family living or the continuation of community living in a relatively nonrestrictive setting, and can precipitate admission to a public mental health or ID facility. Severe behavioral disturbance of various types occurs among people with

mild to profound ID. However, it is important to understand that severe behavioral disturbances are not part and parcel of a diagnosis of ID. The presence of clinically significant behavioral disturbances mandates a thorough clinical diagnostic evaluation to determine the presence of comorbid mental and physical disorders that may be responsible for the behavioral disturbance. The extent to which behavioral disturbances represent symptom equivalents for symptoms such as depression and anxiety, especially in individuals with severe and profound ID, has been the subject of considerable debate, which remains to be elucidated by further research.

Diagnosis for an individual within the population without IDD generally relies upon the person's description of his or her experiences and feelings. Individuals with IDD have limited receptive and expressive language, thus limiting their ability to describe their symptoms. They may also lack the self-reflection to describe internal states. Furthermore, individuals with IDD who are experiencing mental illness may present in very different ways than their peers without IDD. The *DM-ID-2* provides guidance for assessing and diagnosing specific disorders in individuals with IDD and provides information on recognizing challenging behaviors of individuals with IDD and how to differentiate between behavioral problems and psychiatric disorders. The *DM-ID-2* is designed as a companion to the *DSM-5* and aimed to assist clinicians to arrive at a more accurate diagnosis for individuals with IDD.

The DM-ID-2

The publication of the *DSM-5* (American Psychiatric Association, 2013) necessitated that the *DM-ID* be updated. NADD began putting together work groups to revise the *DM-ID* during the summer of 2012. One hundred and four experts from around the world were recruited to work in 26 work groups. A chairperson was identified for each work group.

Changes from *DSM-IV* to *DSM-5* reflect developments in genetic research and neuroimaging as well as efforts to promote ease of use. The disorders included in *DSM-5* have been reordered into a revised organizational structure, reflecting the fact that mental disorders do not always fit completely within the boundaries of a single disorder and that some symptom domains involve multiple diagnostic categories. *DSM-5* recognizes developmental issues utilizing a lifespan approach and including descriptions of how the disorder presentation changes across the lifespan. The multi-axial

approach has been dropped. A number of disorders that had been distinct in *DSM-IV*, such as autistic disorder, Asperger's disorder, and pervasive developmental disorder, have been consolidated in *DSM-5* and the *DM-ID-2* into autism spectrum disorder (ASD). Trauma- and stressor-related disorders in the *DSM-5* and *DM-ID-2* is an umbrella diagnostic area that now includes reactive attachment disorder, disinhibited social engagement disorder, posttraumatic stress disorder (PTSD), acute stress disorder, and adjustment disorder. The classification for bipolar and depressive disorders has been streamlined. Disorders previously referred to as "dementias" are now designated as major or mild neurocognitive disorders and have enhanced specificity.

Added Value Chapters

In addition to all the major diagnoses that are found in the *DSM-5*, the *DM-ID-2* includes two additional chapters. Following this chapter, there is a chapter on assessment and diagnostic procedures. This chapter is important as it assists the reader in understanding the biopsychosocial developmental approach to conducting a psychiatric assessment with individuals who have an intellectual disability. Another added value chapter informs the reader about behavioral phenotypes that are associated with genetic disorders, which is intended to aid in the understanding of how a disorder's genotype affects its behavioral phenotype.

Neurodevelopmental Disorders

The *DSM-5* changes the "Disorders with Onset during Childhood and Adolescence" (*DSM-IV-TR* and *DM-ID*) to a new category "Neurodevelopmental Disorders." The reorganization adds stereotypic movement disorders and tic disorders to the neurodevelopmental disorders. There are major components of neurodevelopmental disorders: age of onset during the developmental period; diagnosis based on assessment based on a deviation from expected lines of development and differentiation from other medical or neurodegenerative disorders. Even when these basic criteria are met, there is still a high rate of overlap between them. This pattern of high rates of comorbidity also applies to other psychiatric disorders (American Psychiatric Association, 2013; Fletcher et al., 2007).

Because of these boundary issues, many affected children may have multiple developmental diagnoses. For example, child can have autism spectrum disorder, severe intellectual disability;

attention deficit hyperactivity disorder and a tic disorder. The relationship between these neurodevelopmental disorders, challenging behaviors, and primary psychiatric disorders can also be complex (American Psychiatric Association, 2013). In the *DM-ID-2*, intellectual disability is already established and serves as a starting point in the diagnosis. As a result, the diagnostician must consider how the severity of IDD limits our ability to clearly recognize many neurodevelopmental disorders (e.g. specific learning and communication disorders in nonverbal individuals). The presence of severe IDD can also affect the developmental trajectory of emerging motor coordination, communication, and specific learning disorders as well as the validity of many diagnostic instruments crucial to defining these disorders (Barnhill, 2014).

In recent years, it is becoming increasingly obvious that many primary psychiatric disorders are also neurodevelopmental in nature. The risk for early onset psychiatric disorders is related to gene-environmental interactions, the timing of early developmental stressors (e.g. trauma), and history of learning experiences and in some cases, the presence of a specific behavioral phenotype. In addition, the presence of IDD or autism spectrum disorder also alter the development, assessment, and treatment of schizophrenia, bipolar, depressive, anxiety and obsessive-compulsive/related disorders. Lastly, severity of IDD and autism spectrum disorder plays a critical role in the development of challenging behaviors (aggression, self-injury, and disruptive and destructive behaviors) that frequently accompany primary psychiatric disorders (Barnhill, 2014). In order to negotiate these issues, the diagnostician needs a good working knowledge of diagnostic overshadowing, baseline exaggeration, and vulnerability to cognitive, emotional, and behavioral disorganization and cognitive distortions (Barnhill, 2014; Fletcher et al., 2007; Gardner, Griffiths, & Hamlin, 2012).

Other Disorders

While neurodevelopmental disorders emerge in childhood and persist into adulthood, a large number of other types of disorders more typically have onset in youth, adulthood, or at older age. Chapters on these are presented in the DSM-5 after the neurodevelopment disorder chapter. Key changes include the streamlining of bipolar disorders and depressive disorders, the elimination of substance abuse and substance dependence which are replaced with a new overarching category of substance use disorders, and the enhanced specificity for major and mild neurocog-

nitive disorders (formerly known as the dementias) to reflect scientific advances in this area. The categorization of personality disorders remains similar to that in DSM-IV, but section III of DSM-5 presents an alternative hybrid model of impairments in personality functioning and pathological personality traits.

Problem behaviors commonly present in children and adults with intellectual disabilities. *DSM-5* does not consider these as disorders, and hence it is essential to consider the underlying causes of the problem behavior and code accordingly. *DM-ID-2*, therefore, also follows this approach.

Summary

The *Diagnostic Manual – Intellectual Disability 2 (DM-ID-2): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability* is designed to provide state-of-the-art knowledge of mental disorders and IDD. It provides a series of chapters that corresponds closely to the *DSM-5* classification system, with specific directions for applying the existing criteria to make them apply to persons with dual diagnosis. The authors of the chapters were selected largely from among professionals who had made international contributions to the field of dual diagnosis. The *DM-ID-2*, therefore, represents a multicentered, multicultural, and multifaceted collaborative effort of many experts, an effort aimed at an improved understanding of mental disorders and their unique expressions in persons with IDD.

References

- Alexander, F. G., & Selesnick, S. T. (1966). *The history of psychiatry: An evaluation of psychiatric thought and practice from prehistoric times to the present*. New York: Harper and Row.
- American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders (DSM)*. Washington, DC: Author.
- American Psychiatric Association. (1968). *Diagnostic and statistical manual of mental disorders (DSM-II)* (2nd ed.). Washington, DC: Author.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders (DSM-III)* (3rd ed.). Washington, DC: Author.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders (DSM-III-TR)* (3rd ed., revised) Washington, DC: Author.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental*

- disorders (DSM-IV) (4th ed.) Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)* (5th ed.). Washington, DC: American Psychiatric Publishing.
- Bailey, N.M., 2007. Prevalence of psychiatric disorders in adults with moderate to profound learning disabilities. *Advances in Mental Health and Learning Disabilities*, 1, 36-44.
- Barnhill J. (2014), Child development and intellectual disabilities: The challenge of hitting a moving target. In D. Baker & E. Blumberg (Eds.), *Mental health and wellness supports for youth with IDD* (pp. 223-237). Kingston, NY: NADD Press.
- Buckles, J. 2016. The epidemiology of psychiatric disorders in adults with intellectual disabilities. In C. Hemmings & N. Bouras (Eds.), *Psychiatric and behavioral disorders in intellectual and developmental disabilities*. Cambridge, UK: Cambridge University Press.
- Cooper, S.A., Smiley, E., Morrison, J., Williamson, A., Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. Mental health services for adults with learning disabilities. *British Journal of Psychiatry*, 190, 27-35.
- Cooper, S-A., McLean, G., Guthrie, B., McConachie, A., Mercer, S., Sullivan, F. & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice*, DOI: 10.1186/s12875-015-0329-3.
- Edgerton, R. B. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded*. Berkeley, CA: University of California Press.
- Einfeld S.L. & Aman, M.G. (1995). Issue in the taxonomy of psychopathology in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders*. 25: 143-167.
- Einfeld S, Ellis, L. & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability*, 36, 137-43.
- Emerson E, & Hatton C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493-99.
- Fletcher, L., Loschen, E., Stavrakaki, C., & First, M. (Eds.). (2007). *Diagnostic manual-intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. Kingston, NY: NADD Press.
- Gardner, W. I., Griffiths, D. M., & Hamlin, J. (2012). Biopsychosocial features influencing aggression: A multimodal assessment and therapy approach. In J. K. Luiselli (Ed.), *The handbook of high-risk challenging behaviors: Assessment and intervention* (pp. 83–102). Towson, MD: Brookes.
- Mikkelsen, E. J. & McKenna, L. (1999). Psychopharmacologic algorithms for adults with developmental disabilities and difficult-to-diagnose behavioral disorders. *Psychiatric Annals*. 29 (5): 302-314.
- National Core Indicators. (2016). Mental illness or psychiatric diagnosis. Retrieved from www.nationalcoreindicators.org/charts/.
- Reiss, S. (1994). *Handbook of challenging behavior: Mental health aspects of mental retardation*. Worthington, OH: IDS Publishing Corporation.
- Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance in mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency*. 86, 567-571.
- Royal College of Psychiatrists. (2001). *Diagnostic criteria for psychiatric disorders for use with adults with learning /mental retardation (DC-LD)*. Occasional paper OP 48. London: Gaskell.
- Rush, A. J., & Frances, A. (Eds.). (2000). Treatment of psychiatric and behavioral problems in mental retardation (Special issue). *American Journal on Mental Retardation*, 105(3).
- Sovner, R. (1986). Limiting factors in using DSM-III criteria with mentally ill/mentally retarded persons. *Psychopharmacology Bulletin*, 22, 1055-1059.
- Sturme, P. (1999). Classification: Concept, progress and future. In N. Bouras (Ed.), *Psychiatric and behavioural disorders in developmental disabilities and mental retardation* (pp. 3-17). New York: Cambridge University Press.
- Szymanski, L. S., King, B., Goldberg, B., Reid, A. H., Tonge, B. J. & Cain, N. (1998). Diagnosis of mental disorders in people with mental retardation. In S. Reiss & M. G. Aman (Eds.). *Psychotropic and developmental disabilities: The international consensus handbook* (pp. 3-17). Columbus: Ohio State University, Nisonger Center.
- World Health Organization (1992) ICD-10 International classification Diagnostic. 10th edition (ICD-10).

Neuroscience Reviews

Attention Deficit-Hyperactivity Disorder (ADHD) and Intellectual Disability (ID).

Jarrett Barnhill, MD, DFAPA, FAACAP, UNC School of Medicine

In a February 2017 article in the *Journal of the American Association of Child and Adolescent Psychiatry*, Faraone, Ghirardi, Kuja-Halkola, Lichtenstein, and Larsson, (2017) updated our understanding of the genetic relationship between ID and ADHD. The authors extracted their data from the Swedish Medical Birth Registry of nearly 2,150,000 infants born between 1987-2006 and included nearly 4,180 monozygotic twins, 12,655 dizygotic twins, and both first and second degree relative and half siblings. Although this data is not based on a review of records involving the presence of ADHD in youth, the purpose of this massive study was to address the contribution of genetic factors associated with increased co-occurrence or ADHD and ID. In descending order of genetic relatedness, we begin with MZ twins >; DZ twins and siblings >= parents; >second degree relatives and “step siblings.” This distribution of genetic risk suggests a polygenic pattern of inheritance in which multiple genes are involved. This pattern of inheritance may also reflect a threshold effect (number of genes present required to express the full clinical syndrome), help determine its severity, or, as in many neurodevelopmental disorders, or a gender bias towards males (affected females require greater genetic loading) (Faraone et al., 2017).

Most complex psychiatric and neurodevelopmental disorders are the result of polygenic patterns of inheritance, gender dimorphism, presence of comorbid conditions like epilepsy, and the extent and timing of complex gene-environment interactions. Each of these epigenetic effects contribute to the considerable heterogeneity among these co-occurring conditions.

The authors also adjust for the effects of the severity of ID in this type of genetic study. As a result, the authors limit their study to individuals with mild ID and the exclusion of those with severe-profound ID. The rationale behind this exclusion relates to the higher rates of complex epilepsy and other known neurogenetic and metabolic disorders in individuals with severe-profound ID. Many of the known genetic disorders associated with severe-profound ID most likely involve Mendelian (autosomal dominant, recessive or X-linked) and not polygenic patterns of

inheritance. In addition, there is less certainty in the recognition and the diagnosis of ADHD in this population (Hellings et al., 2016).

The authors conclude that the major portion of the relationship between ADHD and mild-moderate ID are due to genetics factors and not dependent on a model that relies upon differences in ADHD related measures that are commonly attributed solely to developmental rather than chronological age.

Treatment studies are also affected by similar factors. Until recently, individuals with ID were excluded from most psychopharmacological treatment studies. More recent studies that include or focus on the treatment of ID and ADHD confirm much of the clinical experiences of many in the field. In general, these factors included: inverse relationship between treatment response and level of ID, associated neurological, genetic, and metabolic comorbidities, and vulnerability to overstimulation or other factors associated with diminished cognition and brain development. When contrasted with neurotypical patients, those individuals with ID and ADHD are less likely to respond, more likely to experience adverse medical, and remain more vulnerable to behavioral side effects (depressed, irritability, appetite suppression).

The emergence of personalized medicine and pharmacogenomics has led to an increased numbers of studies focusing on neuro-biological and gene markers that influence both pharmacokinetic and pharmacodynamic factors. Drug responsiveness is addressed in term of gene effects on absorption and distribution: allelic variability in binding and activity of receptor sites; intracellular pathways; gene regulation; and patterns of metabolism and elimination. The etiology, severity, and patterns of comorbidity associated with a heterogeneous condition like ID also influence the efficacy and mode of action of many pharmacological agents used in the treatment of the ADHD and ID population.

This brings us to a brief overview of a chapter in Cryan and Reif's *Behavioral Genetics* published in 2012. Much of this book requires that you become genetic nerd. So this brief intro describes the major points. The final article in this

series will be a primer in basic molecular pharmacogenomics genetics. For now, we will stay at 30,000 feet and look down on the bigger picture. We will lay the pharmacogenomic foundation for personalized medicine.

The principle text comes from a chapter written by Hart, deWitt and Palmer that addresses the genetic factors that influence stimulant drug response in individuals with ADHD. These authors did not address the effects of ID on their findings. The use of stimulants in children and adults with ADHD and ID may in part relate to the observation that ADHD, ID, ASD, epilepsy, and other neurodevelopmental disorders share many genes. The ID population may also share the same cytochrome P450 glucoronidation and esterase pathways for stimulant metabolism and elimination. Thus the pharmacokinetic side of the story seems relatively understudied but on a more solid footing. The certainty of pharmacodynamic activities is more fluid. Many syndromes may influence the activity or integrity of drug binding sites, post-synaptic receptor activity, intracellular actions and influence of gene expression and metabolic pathways, and effects on brain circuits associated with both challenging behaviors and psychopathology (Hart, deWitt, & Palmer, 2012). Going through this at great depth would be your worst nightmare but in a later paper we will attempt to do this at a very basic level.

Consider yourselves forewarned. Now is the time to escape. The next paper in this series will shift the relationship between autism spectrum disorder (ASD) and ADHD.

References

- Cryan, J.F., & Reif, A. (Eds). (2012). *Behavioral neurogenetics*. New York: Springer.
- Faraone, S.V., Ghirardi, L., Kuja-Halkola, R., Lichtenstein, P., & Larsson, H. (2017). A family co-aggregation of attention-deficit/hyperactivity disorder and intellectual disability: A register based family study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 56(2), 167-174.
- Hart, A.B., deWitt, H., & Palmer, A.A. (2012). Genetic factors modulating the response to stimulant drugs in humans. In J.F. Cryan & A. Reif (Eds), *Behavioral neurogenetics* (pp. 537-614). New York: Springer.
- Hellings, J.A., Reiersen, A.M., Arnold, L.E., Mao, A.R., Pearson, D.A., Aman, M.G.,... McLaren, J.L. (2016). Attention-deficit/hyperactivity disorder. In R.J. Fletcher, J. Barnhill, & S.-A. Cooper (Eds.). *Diagnostic manual- Intellectual disability* (pp. 139-156). Kingston, NY: NADD Press.

For further information, contact Dr. Barnhill at Jarrett_Barnhill@med.unc.edu

DSP Interests and Concerns

Trauma-Informed Care: Taking Action

Lynn Winters,, LCSW, Bureau of Behavioral Support, Developmental Disabilities Division, New Mexico

Years ago, I was sitting through my umpteenth workshop on trauma. I could barely contain my frustration. Eight hours of describing what trauma is, and not a minute on how to help or what to do. More recently, amazing information is coming out on trauma-informed care and I finally feel like I have some practical tools to help.

When I was asked to write this article for Frontline Initiative, I went to my colleagues, Cynthia Alvarado, LBSW, and Jacqueline Valencia, BA, to brainstorm. Cynthia and Jacqueline run a family-based shelter program for homeless children and youth. They work directly with people receiving supports, their families, and the shelter parents that care for them. Often the chil-

dren that come into their program have extensive trauma histories and are often in emotional crisis.

Here are a few items from the bag of tricks we've developed over the years working with children, youth, and their families.

1. Always look at a trauma survivor's challenging behavior as perfectly understandable given what he or she has been through (National Council for Behavioral Health Learning Group, 2012).
2. If you don't know if the person you are supporting has a trauma history, it's better to assume he or she does. (This technique works great with anyone who is upset.)

3. Don't think, "What's wrong with you?" Instead, think, "What happened to you?"¹
4. People with trauma in their history tend to fear being rejected or pushed away. So, instead of "time out" try a "time in." Keep the person nearby. Stop what you're doing, and pay attention to the person (not the behavior). Speak quietly and calmly. If they respond well to touch and are not too escalated, try a hand firmly on the shoulder, or holding their hand. Always ask permission before touching. Sit quietly together.
5. Use the word "safe." Use it a lot. "I'm going to keep you safe. This is a safe place for you. Are you feeling safe?"
6. Help the person use their words if he or she has them. If the person doesn't have words, speak for him or her. Based on your observation, validate and normalize those feelings. "You seem to be very frustrated now, and that's OK. I would be too, if I were you." (Forbes, 2012)
7. Check for sensory needs. Is the person too hot? Too cold? Hungry, tired? Is it too bright? Too loud? Adjust the environment (Purvis, Cross, & Sunshine, 2007).
8. Offer an alternative activity; one that usually calms them. Try offering repetitive movement such as swinging on a porch swing, or rocking in a rocking chair.
9. Avoid the temptation to argue, lecture, nag, and remind. A trauma survivor in crisis cannot hear any of that, and it is likely to backfire.
10. After everyone is calm, look for the success.

"Thanks for not hurting yourself," (even if they smashed all the plates). "You used your words really well!" (Even if they called you every name in the book).

11. First and foremost, take care of yourself.

References

- Forbes, H.T. (2012). *Beyond Consequences L/ve [DVD]*.
- National Council for Behavioral Health Learning Group. (2012). <http://www.thenationalcouncil.org/>
- Purvis, K.B. Cross, DR., & Sunshine, W.L. (2007). *The connected child. Bring hope and healing to your adoptive family.* New York: McGraw-Hill.

For additional information, contact Lynn Winters at (575) 556-1693 or lynnwinters@yahoo.com.

Reprinted with permission from Winters, L. (2016). *Trauma-informed care: Taking action.* Frontline Initiative, 13, p. 9. Retrieved from https://ici.umn.edu/products/Frontline_Initiative/FI_13_1.pdf.

DSP Interests and Concerns is an ongoing column in The NADD Bulletin. We welcome your comments, suggestions, and submissions for this column. To learn more or to contribute to this column, you may contact Melissa Cheplic, Editor of DSP Interests and Concerns at cheplima@rwjms.rutgers.edu.

Family Corner

Family and Professional Perspectives

Julia Pearce

I have had many opportunities to volunteer with parent-to-parent organizations and to work in the disability field for over twenty years. I have been able to continue to learn new ways to support people with disabilities. I have been able to talk with people from across the United States and Canada, and I have found new perspectives from those I work with each day. We all come from different backgrounds and different regions, and the people with disabilities in our lives have different diagnoses. And yet, many times there is a word that comes up again and again.

Silos. Silos between agencies. Silos between

professionals and family.

Not a very exciting word and yet one that has held our collective attention at conferences, meetings, and dinner with friends.

There have been times when the talk of working to build bridges between agencies starts, and then the reality of different funding streams, agency directors who may have different views on how services should be delivered, legislative oversight, restrictions about which people with which diagnosis can access services, and suddenly the best intentions of a group can be derailed. The power comes when each of these concerns

and realities is discussed with input from families and professionals.

Recently, I have been involved with meetings in our state to talk about ways that our Human Services and Mental Health state agencies can work together to provide needed services to children and youth with intellectual/developmental disabilities and mental health needs, also known as having a dual diagnosis. This group of focused and dedicated families and professionals is working to create a training curriculum and a system to support individuals with a dual diagnosis in urban and rural areas. This is an exciting and hopeful development as conversations continue with families and professionals as we work together to find solutions to current needs for people with disabilities, including those with a dual diagnosis.

Silos between professional and families.

There is a feeling or a thought that I have been watching develop for over ten years. It takes place in almost every meeting or conference or event where parents of children or adults with intellectual and/or developmental disabilities are in attendance with professionals in the disability field. The start of most of these events includes a registration table, a sign in sheet, or introductions where the following choices are requested: Name, Contact information, the Organization you are with, and then a box to check if you are 1) Parent 2) Professional 3) Student 4) Person with a disability 5) Other. What I have seen is that each of us check the box for the area that we most identify with at that time of our lives. And yet many attendees could check more than one box. The question that comes to me is: why is only one box checked? Many times, we have family members who are professionals and professionals who are family members in attendance.

There is an underlying feeling from both the family perspective and the professional perspective that has had an impact on many of us. It often happens that a professional in the disability field is also a parent or family member of a person with a dual diagnosis. I have been in meetings where the discussion includes topics that are important to all in the room. If we go back to the sign in, the roles we sign is as how we contribute in that setting. I have been in meetings where I find myself wanting to put on both 'hats.' Sometimes I, and others, have 'changed hats' to talk about both perspectives.

Other times, I have come out of a meeting and been met by someone who did not feel they were able to do the same. When I have had an opportunity to talk with them, this is what I have been told. There have been times when putting on the family perspective 'hat' had been met with constraints on future conversations as a professional. I was told that wearing both 'hats' would somehow reduce their knowledge and legitimacy in their work. This is something that I did not understand completely until recently. A few years ago I changed jobs from being with a group who knew my son and his multiple disabilities to working at an agency where only one or two of my co-workers know that I had been a parent to a young adult with changing medical and mental health needs. I would be in meetings and conferences where both hats were on but no one knew it. I then found myself saying less with my family hat on, and saying more with my agency hat on. It took a few months to realize that my perspectives as both a family member and a professional were welcome, and I also found that many at the agency were open to talking about both perspectives as we created plans to support people with disabilities.

The experiences of life with our son have led me to learn about and work with many good people in volunteer organizations and state agencies in different silos. The realization that has come is that silos may be in place in some areas of our work, but we can create new ways to work with any and all interested family members, parents, and professionals to find the best next steps for the people with disabilities and mental health needs that we love and serve each day. Our collective experiences and perspectives are the power we have to start where we are, use what we have, and do what we can.

For further information, contact Julia Pearce at runnamokk@hotmail.com.

Family Corner is an ongoing column in The NADD Bulletin and is published under the auspices of the NADD Family Issues Committee. We welcome your comments, suggestions, and submissions for this column. To learn more or to contribute to this column, you may contact Laurie Raymond, Editor of Family Corner lraymond112@gmail.com.

Mark your calendars...
**34th NADD Annual Conference and
Exhibit Show**



AUTISM

By: Lauren Turner–Brown, PhD
Assistant Director, UNC TEACCH Autism
Program

Assistant Professor, Departments of
Psychiatry and Psychology
University of North Carolina at Chapel Hill

DM-ID-2

By: Robert Fletcher, DSW,
NADD–CC

NADD Founder & CEO
Kingston, NY

Theme: Reaching your Potential & Beyond: IDD/MI

Conference Includes: a Pre–Conference Symposium, Variety of Concurrent Sessions, Poster Research Reception, and Breakfast Consultation Sessions with the Experts

Conference Chairperson:

Christina Dupuch, MSW (formally Carter), MSW, Vaya Health, Asheville, NC

Updates regarding this conference will be on
the NADD website:
www.thenadd.org

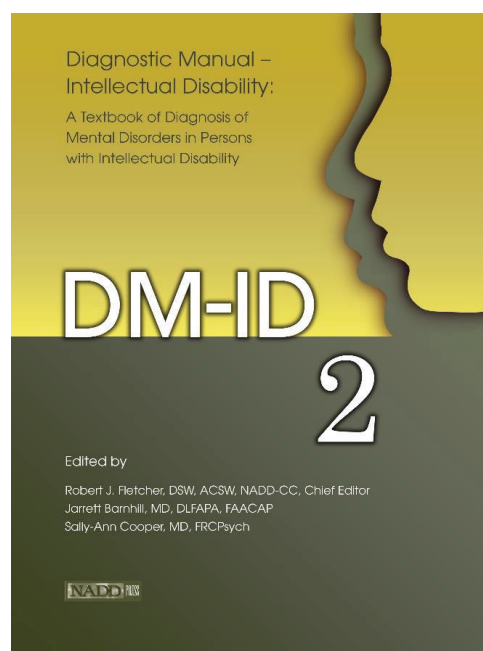
DM-ID-2

Edited by

Robert J. Fletcher, DSW, ACSW, NADD-CC, Chief Editor
 Jarrett Barnhill, MD, DLFAPA, FAACAP
 Sally-Ann Cooper, MD, FRCPsych

Improved outcomes for individuals with co-occurring intellectual/developmental disability (IDD) and mental illness depend upon effective psychiatric treatment. Effective treatment requires an accurate psychiatric diagnosis. Obtaining that accurate psychiatric diagnosis for individuals with IDD has been, and remains, very challenging. This book was written to address this challenge.

The groundbreaking publication of the *Diagnostic Manual-Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability* in 2007 gave clinicians and providers in the field of dual diagnosis (IDD/MI) the resource they needed to provide a more accurate psychiatric diagnosis for individuals with IDD. It has become the “gold standard” in psychiatric diagnosis for individuals with IDD.



More than 100 experts from around the world have now updated the DM-ID to accompany the *DSM-5*. The *DM-ID-2* was developed to facilitate an accurate psychiatric diagnosis in persons who have intellectual disabilities and to provide a thorough discussion of the issues involved in reaching an accurate diagnosis. The *DM-ID-2* provides state-of-the-art information concerning mental disorders in persons with intellectual disabilities. Grounded in evidence based methods and supported by the expert-consensus model, *DM-ID-2* offers a broad examination of the issues involved in applying diagnostic criteria for psychiatric disorders to persons with intellectual disabilities. The *DM-ID-2* is an essential resource for every clinician who works with individuals with a dual diagnosis (IDD/MI).

Member Price: \$105 • Non-member Price: \$135
 Product #: DA16-061B

Upcoming Conferences/Trainings

International Certificate Programme in Dual Diagnosis Summer Institute 2017

May 29-June 9, 2017 * Brock University, St. Catharines, Ontario

11th European Congress of Mental Health in Intellectual Disability

September 21-23, 2017 * Luxembourg

State of Ohio 15th Annual MI/DD Conference

September 25-26, 2017 * Columbus, Ohio

NADD 34th Annual Conference & Exhibit Show

November 1-3, 2017 * Charlotte, North Carolina

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