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# THE NADD

## BULLETIN

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## NOTE FROM THE EDITOR

The June issue of the Bulletin consists of diverse information, opinions, and clinical considerations. Ed Seliger overviews four interrelated NADD accreditation and certification programs. Lucy Esralew shares her thoughts about social pragmatic problems and autism in an inaugural column. Jarrett Barnhill, M.D., casts a backward glance at ideas that he previously presented about catatonia and looks towards treatment models. Jeffrey Keilson reminds us of the essential role of family in advocacy, policy, and service planning while acknowledging the daily stressors and challenges experienced by family members. Melissa Cheplic announces a scholarship opportunity for DSPs and the NADD DSP Award for Excellence. Julia Pearce shares with us the brave and moving account of her family dealing with the gifts and challenges of caring for someone with significant disabilities.

We welcome your submissions. Consider the Bulletin as an opportunity to share the work you are doing with persons with intellectual and developmental disabilities and co-occurring mental health or behavioral health issues

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

# NADD Accreditation and Certification Programs

*Edward Seliger, MA, NADD*

With the NADD Accreditation and Certification Programs, NADD, in association with the National Association of State Directors of Developmental Disability Services (NASDDDS), has established standards and benchmarks for services provided to individuals who have intellectual and developmental disabilities co-occurring with mental illness. Individuals with intellectual and developmental disabilities (IDD) and mental illness (MI) have complex needs and present clinical challenges to the professionals, programs, and systems that provide care to these individuals. The NADD Accreditation and Certification Programs were developed to raise their level of care, as well as to provide recognition to those programs and professionals offering quality care.

Charles Moseley, Ed.D., former Associate Executive Director for NASDDDS, said,

The NADD Accreditation/Certification Program is an important tool for state agencies, DD and MH, that are interested in expanding their community infrastructure to support people with co-occurring developmental disabilities and mental illnesses....NCI data have consistently documented over the years that approximately 32% of all people receiving DD services have a mental illness. The NADD Accreditation/Certification Program offers an important tool to states and providers interested in improving their efforts to serve this group of individuals.

The NADD Accreditation and Certification Programs are composed of four interrelated programs: Accreditation for programs, Competency-Based Clinical Certification, Competency-Based Dual Diagnosis Specialist Certification, and Competency-Based Direct Support Professional Certification.

## **The NADD Accreditation Program**

NADD developed the NADD Accreditation Program to improve the quality and effectiveness of services provided to individuals with a dual diagnosis through the development of competency-based professional standards and through promoting ongoing professional and program devel-

opment. NADD offers accreditation of programs serving individuals with a dual diagnosis, rather than the agency or organization that offers these programs.

A NADD Accreditation survey evaluates a program on the basis of eighteen competency modules:

- Medication Reconciliation
- Holistic Bio-Psycho-Social Approach
- Database/Outcome measures
- Protocols for Assessments
- Treatment/Habilitation Plans
- Basic Health Care
- Interdisciplinary Team
- Training / staff and family
- Crisis Prevention and Intervention
- Cultural Competency/Family Values
- Trauma
- Quality Assurance/Incident Management
- Evidence-Based Treatment Practices
- Ethics, Rights, Responsibilities
- Interagency and Cross-Systems Collaborations
- Long Term Living – Service Coordination
- Advocacy and Rights Health Informatics (Technology)

(Note: Only the standards that are applicable to the program will be evaluated.)

Details about these competency areas and what the NADD accreditation surveyors look for is available in the Accreditation Program Manual, which is available on the NADD website.

The Accreditation survey includes (1) interviews, (2) records review, and (3) policy and procedure review. The NADD surveyor(s) have face-to-face interviews with treatment team members, other staff involved in treatment of the individual, and program administrators. The NADD surveyors complete a records review and interview of the treatment team members on specific cases to ensure clear documentation that reflects the individualized goals of treatment plan as well as direct observation of the staff and persons receiving services. The NADD surveyor(s) review and assess whether the program practices reflect the best practice as established by the NADD accreditation standards.

One way that NADD Accreditation differs from almost all other accreditation programs is the

inclusion of a consultation component. Through their expertise, NADD surveyors are not only able to identify areas that are in need of improvement, but they are also able to offer concrete suggestions about how to improve the program. The consultation component takes place on site during the course of the survey.

Hugh M. Sage, PhD, Executive Director of Liberty of Oklahoma Corporation/Robert M. Greer Center in Enid, OK, the first program to receive NADD Accreditation, noted,

When NADD made its accreditation program available...we realized that objective evidence of compliance with those additional standards would be ideally suited to attest to the appropriateness and efficacy of Liberty's clinical and related practices for our highly specialized client population. And, in fact, our NADD survey...produced a number of helpful recommendations for strengthening our program.

After completion of the accreditation survey, NADD makes a determination about granting accreditation. The decision may be to grant accreditation for three years, two years, one year (provisional accreditation), or to deny accreditation. Programs which receive accreditation or provisional accreditation receive a certificate.

### **Competency-Based Clinical Certification Program**

The NADD Competency-Based Clinical Certification was developed to improve the quality and effectiveness of services provided to individuals with a dual diagnosis through the development of competency-based professional standards and through promoting ongoing professional development. Certification attests to the clinician's competency in providing services to individuals with a dual diagnosis.

NADD has identified five competency areas that applicants for Clinical Certification must demonstrate mastery of.

- Positive Behavior Supports and Effective Environment
- Psychotherapy
- Psychopharmacology
- Assessment of Medical Conditions
- Assessment

The NADD Competency-Based Clinical Certification Program Manual, available on the NADD website, lists benchmarks and performance indicators for these competency areas.

In order to be considered for Clinical Certification, an applicant must meet certain pre-requisites. They must have one of the following licenses in the USA or Canada (equivalent accepted): state/province license, i.e. Ph.D., Psy.D., or Ed.D. Psychologist; state/province license, BCBA, or governing body recognition as an Applied Behavior Analyst; State/province license as a Physician, M.D., D.O., MBBS, or equivalent; state/province license as a Master's level Mental Health Counselor, Marriage & Family Counselor, Addictions Counselor; state/province license as a Licensed Clinical Social Worker; state/province license as a Physician's Assistant, Advanced Practice RN, or Nurse Practitioner (or clinical equivalent); or other similar credentialing; equivalent determination resides with the NADD Competency-Based Certification Program. Professionals with a Master's level in a related field or RNs are eligible with additional experience and a thorough explanation of the experience base. The applicant must have 5 years experience in support of persons with intellectual disabilities and mental health issues. This can include internships and externships. For applicants with a Master's degree in a related field and for RNs, 7 years is required.

Applicants are required to submit a work sample and then participate in a telephone-based interview/exam. The applicant is presented with a case vignette approximately 24-48 hours before the interview, about which he or she will be asked to verbally offer his/her thoughts and reflections (i.e., provide a case formulation and treatment plan). The interview also includes resolution of any questions raised during other parts of the application process.

Clinicians who receive NADD Clinical Certification are entitled to use "NADD-CC" as a credential.

The NADD-CC is being recognized by a wider and wider variety of different entities as a unique specialty, and we anticipate broader recognition as time passes. Individual municipalities such as the City of Philadelphia recognize the NADD-CC, giving specific preference in a Request For Proposals. Some third party payers, including managed care entities, recognize NADD-CC. Individual states, such as MN and NJ, recognize NADD-CC and are in the process of adopting NADD-CC into service qualifications and job class specifications.

One NADD Certified Clinician, Alyse Kerr, MS, NCC, LPC, NADD-CC, said,

The NADD competency-based clinical certification has provided me with an av-

enue to verify a dual diagnosis specialty. My ability to provide clinical supports to individuals supported both by medical assistance and private insurances has been expanded by allowing me to gain access to closed insurance networks. These networks had been closed to me prior to receiving this certification, allowing this population to remain largely unserved outside of community mental health centers.

As she observed in an article published in the July-August 2013 *NADD Bulletin*, thanks in part to her NADD Clinical Certification, she is now able to put together services that might not otherwise be available to individuals diagnosed with an intellectual/developmental disability who have mental health needs.

### **Competency-Based Dual Diagnosis Specialist Certification**

The NADD Competency-Based Dual Diagnosis Specialist Certification Program is designed for specialists in the field of dual diagnosis who deliver, manage, train and/or supervise services for persons with intellectual/developmental disabilities and mental health needs. Staff working in units of county, state or provincial government, QIDPs, RN's, LPN's, program directors, program supervisors, case/care managers, program specialists, supports coordinators, peer specialists, trainers, and others are examples of roles that can apply for this certification.

The specialist seeking certification is required to demonstrate mastery of the following six competency areas:

1. Multimodal bio-psycho-social approach
1. Application of emerging best practices
2. Knowledge of therapeutic constructs
3. Respectful and effective communication
4. Knowledge of dual role service delivery & fiduciary responsibilities
5. Ability to apply administrative critical thinking

The NADD Competency-Based Dual Diagnosis Specialist Certification Program Manual, which is available on the NADD website, lists benchmarks and performance indicators for these competency areas.

As in the Clinical Certification application process, once a candidate has been determined to meet the pre-requisites for Dual Diagnosis Specialist Certification, he or she is asked to submit a work sample. The instructions for submitting the work sample reflect the various job roles in-

cluded within Dual Diagnosis Specialist Certification. For example, the way that an administrator is asked to demonstrate ability to communicate effectively will be different from the way that a case manager or support coordinator would be asked to demonstrate the same competency. Through answering a series of questions, the work sample should demonstrate mastery of each of the competency areas.

The interview/exam, which is conducted telephonically, includes discussion of applicant's training and experience in dual diagnosis, jobs, position, program; review of capacity and work with (or support of) individuals with dual diagnosis; discussion of one project/program/service plan/training that involves dual diagnosis; discussion of change in the life (or lives) of a person with dual diagnosis; discussion of systemic change where the candidate works; discussion of work sample and resolution of specific questions arising from application materials. Candidates can expect the interview to include additional topics or areas that are consistent with current practice. Some topics might include: self-determination, consumer decision-making/problem solving, person-centered planning, assessment, financial implications, operational structure, etc.

Specialists who receive NADD certification are entitled to use "NADD-DDS" as a credential.

Susan Morris, MSW, RSW, NADD-DDS, commenting on the benefits of the process of applying for Dual Diagnosis Specialist Certification, said,

Overall it was a very good experience in two ways. The first was the opportunity it gave me to connect with my references and discuss my work with them in a way that I had not done before. This was particularly true with the family reference – as most of our conversations in the past had understandably been oriented toward their situation and broader issues. They were delighted to be able to have the opportunity to support my professional development. The writing of the work sample required me to also think in a different way (e.g., about communication, programmatic, and inter-system issues) as they applied to a particular area. This provided me with a fresh perspective on work that I had been doing for a number of years. While the time that such endeavors require is always hard to set aside, I feel quite proud of this accomplishment.

## Competency-Based Direct Support Professional Certification

In general, DSPs spend more time with the person with IDD/MI than any other professional. The competence of the DSP can make a big difference in the quality of life for people. DSPs are often the ones charged with supporting skill building. They help the person engage in recommended therapies on a day-to-day basis. This work requires an advanced level of skill and knowledge to do well. However, there is little available to guide DSPs and others in identifying the specific competencies a DSP should have for this work. As a result, many DSPs are under-qualified. Too often, they lack the support and training to do well. This lack of standards can make finding, hiring, training, and retaining qualified DSPs difficult. As a result, many people with IDD/MI do not have adequate daily support.

The NADD Competency-Based Direct Support Professional Certification is a program to certify the competency of DSPs who support people with a dual diagnosis. DSP competency-based certification validates and provides assurance to individuals served, colleagues, and employers that a direct support professional has met the standards established by NADD for providing services to individuals with IDD/MI.

NADD identified five competency areas that the DSP applicant must demonstrate competency in:

1. Assessment and Observation
2. Behavior Support
3. Crisis Prevention and Intervention
4. Health and Wellness
5. Community Collaboration and Teamwork

The NADD Competency-Based Direct Support Professional Certification Program Manual, available on the NADD website, provides benchmarks and performance indicators for these competencies.

In order to be considered for certification, the

applicant must meet the following pre-requisites: (1) must have worked as a DSP in the developmental disability or mental health field for at least one calendar year and must have completed 1000 hours of direct support work; (2) must be an employee in good standing; and (3) must sign the Code of Ethics.

To demonstrate competency, the candidate takes an online multiple choice test and must achieve an overall score of at least 80% while the score for each of the competency areas must be at least 60%.

Direct Support Professionals who receive NADD DSP certification are entitled to use "NADD-DSP" as a credential.

Mischa B. Staton, NADD-DSP, from Meridian Health Services' Connxxions program said,

The NADD-DSP certification has allowed me to validate my dedication to provide the best service possible. Clients, families, and community partners are so grateful to learn about the process and know I am committed to upholding professional standards.

## Trainings

To assist candidates to prepare for applying for accreditation or certification, NADD is developing a number of web-based trainings. These trainings will not be required, but are intended to assist those candidates who feel they would benefit from the additional training. There will be training modules for each of the competency areas for each type of certification. Candidates will have the option to participate in as many of these trainings as they choose.

Live trainings in a couple of Dual Diagnosis Specialist modules have been offered several times.

For further information, contact Edward Seliger at [eseliger@thenadd.org](mailto:eseliger@thenadd.org).

## Consultation and Training

Keeping abreast of the latest developments in the study of dual diagnosis presents challenges to any organization. NADD provides state-of-the-art consultation and training to agencies, organizations and government entities across a broad spectrum of issues concerning persons with dual diagnoses. NADD's large network of experts is ready to analyze and assist your organization in the development of programs, treatments, and supports to better serve your clients. Our experts can help keep your organization on the cutting edge of the study of dual diagnosis.

## *Tales of an Itinerant Clinical Neuropsychologist*

# Autism and that Other Thing

*Lucille Esralew, Ph.D.*

*This is my inaugural column. The topics that I comment upon are clinical themes that I think about while driving between visits (hence the "itinerant" in my clinical handle). My purpose is to process my clinical experience, become more self-reflective and differentiated in my practice and stimulate thinking or questions among colleagues.*

Individuals on the autism spectrum present with interesting and complex challenges in terms of their social perception and social skills. There is a great deal of overlap between those individuals who exhibit social pragmatic challenges and are on the spectrum versus those individuals with similar social challenges who do not meet criteria for autism. Social pragmatic communication disorder (SCD) is a recent addition to DSM-5 nosology and denotes all the aspects of social cognition and social interaction problems which we attribute to higher functioning individuals with autism (such as Aspergers) minus the intense narrow band of interests or repetitive behaviors that are now regarded as hallmark distinguishing features between SCD and autism spectrum disorder (American Psychiatric Association, 2013). There appear to be several roads towards atypical social-emotional development and not all of them lead to autism.

Theory of Mind (ToM) problems which we have typically linked with autism is not, as it turns out, the exclusive province of individuals on the spectrum. In reality, none of us can be sure what others are thinking unless they have directly and truthfully told us. The ability to understand from another's perspective and infer their intentions and motivations from verbal and other behavior is an enterprise at which some of us are better than others. However, if we are typically developing, we have a fair idea of what is normative social motivation and social behavior within our own culture. Otherwise, all bets are off.

Individuals with intellectual disability may have a hard time inferring their own and other's intentions due to their limited understanding. Individuals who have personality disorders may have a difficulty replacing their own unique perception with an appreciation of the vantage point of others. Typically individuals with narcissistic personality disorder may have a difficult time

shifting from their self-perspective to entertain thoughts about the motivations of others, and individuals with borderline personality style have a distorted view of their own and others' motivations. So social understanding, which underlies Theory of Mind, appears to fall on a continuum. We also know that individuals with schizophrenia may exhibit ToM problems characterized by an inability to shift from their own perspective to take on another person's perspective. Again, not all roads towards Theory of Mind problems lead to autism.

Individuals with significant depression, social anxiety, or severe mental illness may all demonstrate social skills deficits. Whether or not there is an underlying brain disorder or structural deficit that leads to social dysfunction is beyond my ability to ascertain or the scope of this column; my point is that not everything that departs from what we consider typical age appropriate social cognition and social skills is attributable to autism.

Now, my clinical story...

There are people who eschew the diagnosis of autism and others who seek it. I was recently consulted by a family whose 22 year old relative had a history of social naiveté, broken relationships, and limited social cognition who was referred to me for evaluation. She had been living with her maternal aunt. Her parents had divorced when she was an infant, her mother died several years ago, and she had moved in with her aunt. She was academically successful in high school although she had no friends. She had failed college while living away on campus; at some point she was not attending classes nor handing in her assignments. She returned to her aunt with the idea of resuming college while living at home. She had never been able to sustain a job.

The young woman's aunt prefaced our initial intake for testing by saying "I just know you are going to tell me she is autistic" There was clearly a discrepancy between the young woman's capacity and her functionality. No one could figure out how someone with average to high average intellectual capacity could so consistently fail at work, living independently, college, or relationships. A co-worker of the aunt's, who herself has a child who is high functioning on the spectrum,

suggested that this young woman (my client) might also place on the spectrum and should be evaluated to determine if this was the case. Well, this is not the case, but I am ahead of myself in the clinical narrative.

I interviewed the young woman who was articulate albeit difficult to engage. She had average intelligence. Her stories on the Thematic Apperception Test (TAT) were logical, socially appropriate, but superficial. She looked and sounded visibly depressed. Her response to questions on the Autism Disorder Observation Scale (ADOS) revealed that she had limited friends and no interest in dating. She presented as disconnected from her emotions. She described what I would have thought were painful experiences in a flat and emotionless way. Overall, testing revealed that she was anxious, very depressed, self-isolative, and socially poorly equipped. It is likely that she had never adequately processed her grief related to the illness and death of her mother. She met criteria for major depression and generalized anxiety disorder. If her social skills deficits persist after treatment for affective spectrum disorder and relevant skills building, she will probably also meet criteria for SCD. She did not meet criteria for a diagnosis with autism.

From what I could reconstruct from the young woman's narrative, her mother's illness and death came at critical points in her development when she did not have the opportunity to engage with same aged peers. She lacked coping skills and age appropriate social experience, and she experienced significant anxiety and depression, which caused her to avoid social situations. She was emotionally overtaxed and ill-equipped to deal with others in an age appropriate manner; she relied upon fantasy and wishful thinking instead of coping skills. As a result, she was not dealing adaptively and realistically with her situation.

Does this young woman have problems? Yes... but none of them have anything to do with placing on the autism spectrum. When I debriefed the aunt about the testing, she appeared a bit disappointed. Apparently, she had heard of social pragmatic communication disorder. She said, "So, you are telling me she does not have autism, she has that other thing." No, I was not really telling her that her niece had "that other thing."

I was telling her that her niece needed treatment for her significant anxiety and depression.

So what is the "take away" for me as a clinician who works to understand brain-behavior relationships, particularly among individuals with intellectual and developmental disabilities with co-occurring mental health problems? From my vantage, this experience underscores the importance of good assessment that identifies individuals' relative strengths and weaknesses and serves as a basis for an action plan for the individual and his or her family. On innumerable occasions, I have met individuals who have been misdiagnosed or poorly evaluated. As a result, they are linked with services they do not need and do not get the relevant services and supports they do need in order to enhance their mental health, overall well-being, and life outcomes. There is a tremendous need for education, which helps individuals and their families realistically plan for services and supports and understand how to best utilize limited resources. I honestly do not know what a child or an adult with social pragmatic communication disorder (not attributable to autism) can obtain in the way of relevant services. It is a new diagnosis in the communications disorders category of the DSM-5 listed alongside phonological disorder and stuttering. This may be a helpful placement for speech and language therapists, but it has limited utility for those of us who are clinicians providing therapy and psychosocial supports. Has anyone been reimbursed for treating this disorder? If so, I would like to hear from you and how you managed this.

So, what did I recommend? I recommended psychiatric evaluation to commence active treatment for depression and anxiety, non-pharmacological treatment approaches such as Dialectic Behavior Therapy with its heavy emphasis on skills building, increasing the young woman's social opportunities, and building her social network.

All for now, clinically speaking.

## Reference

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.) Arlington, VA: Author.

For further information, contact Dr. Esralew at [lesralew@trinitas.org](mailto:lesralew@trinitas.org)



*Neuroscience Reviews***Catatonia – A Treatment Model***Jarrett Barnhill, MD, DFAPA, FAACAP, NADD-CC, UNC School of Medicine*

Over the last several articles we focused on developing an understanding of catatonia in individuals with IDD and ASD. It is apparent that we are much better at describing catatonia than we are at explaining it. In spite of these shortcomings, several ideas emerged:

1. Catatonia is a collection of state-related changes that are difficult to reduce to single neurotransmitters or specific brain lesions (Coffey, 2012).
2. Like many other neuropsychiatric disorders, catatonia represents a form of disconnection syndrome that co-ordinate homeostatic regulatory systems. These mainly involve the top-down cortical regulation of subcortical, limbic, and stress response systems (Fink & Taylor, 2009; Friedman, 2007; Geschwind & Levitt, 2009).
3. The clinical phenotype of catatonia represents the convergence of many traumatic, metabolic, neurobiological, and neurophysiological pathways (final common pathway).
4. The clinical picture of catatonia best fits the stress-diathesis model. The stressors include ecological, physiological, or co-existing psychiatric disorders (Coffey, 2012; Strober, 2001)

In most circumstances these ideas are not included in the process of diagnosis or treatment planning. Taken together, they can provide a broad framework for assessment and differential diagnosis. Contrast this non-personalized treatment approach with those used to treat common infectious diseases. Streptococcal pharyngitis is defined by specific symptoms and clinical findings. It is triggered by a known species of bacteria and generally “cured” by antibiotic therapy. But there are problems:

1. Resistance to some previously effective antibiotics. Resolution-specific testing to identify the sensitivity of the bacteria to specific antibiotics.
2. Are there ecological and genetic vulnerabilities that increase the likelihood of “catching it” or shaping severity or clinical course?
3. Variability among bacteria (epitopes) that trigger more complex immunological reactions in genetically vulnerable individuals

– PANDAs, Sydenham’s chorea, rheumatic fever or heart disease (Singer, 2007).

Both catatonia and strep throat are acute or state-related disorders. PANDAS, AND rheumatic fever are disorders that occur when a vulnerable individual is exposed to a particular type of strep infection. For catatonia, these vulnerability factors can be other neurodevelopmental disorders like some subtypes of autism spectrum disorders; genetic vulnerability to autoimmune or underlying metabolic disorders. Catatonia develops when that vulnerable individual is exposed to a specific trigger. Both provide examples of the stress diathesis model. Genes can set the stage for vulnerability (diathesis) and in some cases, may be changed by repeated exposure. Unfortunately many of our standard medical, psychological, functional behavioral, genetic, neurobiological, and neuro-diagnostic tests for catatonia do not provide the level of certainty found in rapid strep tests or cultures for beta-hemolytic streptococci (Singer, 2007).

Although we have a growing evidence-base, there are still major gaps in our ability to predict treatment response for even our best behavioral, psychotherapeutic, or pharmacological interventions. Why is this so? One neuroscientist once lamented that he “picked the wrong organ to study” Many of our treatments are directed at either a specific phenotypic expressions or a co-occurring neuropsychiatric disorder. For example, reinforcing incompatible behaviors or prescribing a dopamine antagonists to treat auditory hallucinations does not explain their underlying neurobiology. Empiricists might argue that knowing “why” is less important than knowing that it works. There is also comfort in the availability of evidence-based data or established treatment algorithms. This comfort fades when they are not effective. Under these circumstances, many clinicians turn to faith-based (the opinions of experts), theological-based (internet or theories about treatment), or desperation-based (throw everything at it and hope something works) for treatment approaches. This brand of empirical desperation is not uncommon when treating individuals with IDD or ASD.

One systematic approach involves parsing the stress response diathesis model by more focusing

on bio-behavioral observations and data drawn from a convergence of functional behavioral and ecological analyses: genetic and neurobiological risk factors and rethinking treatment options to match these observations. This approach recreates a personal algorithm and provides nodal points for treatment. For example reducing the intensity of psychophysiological responses to specific stressors may diminish the likelihood that these will trigger catatonic states. Of course this is not as easy as it sounds on paper. To date we have few treatments that focus on altering core vulnerabilities to catatonia (dysregulation of excitatory-inhibitory systems in the brain), but we can take steps to modify their intensity and probability of triggering the cascade to severe dysregulation (Coffey, 2012; Northoff, Eckert, & Fritze, 1997).

Many current treatments focus on symptomatic relief. We are less certain about ways to reduce risk: define and minimize stressors, replace missing neurotransmitters or repair dysfunctional networks, and minimize or protect against relapse or continued vulnerability. For example, it appears that treatment of catatonia differs from the usual approaches to schizophrenia spectrum and mood disorders (Coffey, 2012; Fink & Taylor, 2009). Successfully treating the primary psychiatric conditions may not necessarily eliminate catatonia (Coffey, 2012; Fink & Taylor, 2009). With the exception of ECT, high dose lorazepam or Zolpidem, amantadine, and NMDA modulators may improve catatonic symptoms but may not be as successful for co-occurring mental disorders (Levy, 2007; North et al., 1997). In addition, we reduce the doses or eliminate antipsychotics or add amantadine for neuroleptic-induced subtypes (Sethi & Morgan, 2007); eliminate neuroleptics or combinations of serotonergic treatments and symptomatically treat NMS or serotonin syndrome-like catatonia; avoid neuroleptics in established cases of NMS; minimize anticholinergic drugs in delirious catatonia, or use (Lee, 2010; Penland, Weder, & Tampi, 2006; Sethi & Morgan, 2007). Electroconvulsive therapy can ameliorate all of the above (Coffey, 2012; Fink & Taylor, 2009).

But even our best treatments noted above are not 100% effective. ECT as a rescue treatment can be lifesaving. So does ECT temporarily alter the specific causal mechanism; disrupt the final common pathway; treat comorbid neuropsychiatric disorders or various combinations? But some causes of catatonia may contraindicate ECT – elevation intracranial pressure, stroke and some

drug induced states (Carroll et al., 2007; Fink & Taylor, 2009). Other approaches may depend more on the subtype of catatonia:

1. High dose benzodiazepines (Ativan or Zolpidem); drugs that correct Glutamate over activity systems – general approaches (Carroll et al., 2007; Coffey, 2012; Fink & Taylor, 2009; Penland et al., 2006)
2. Reduce intracranial pressure, treat infectious disease, correct metabolic disorders, etc. (Schapira, 2007; Smith, Smith, Philbeck, & Kumar, 2012; Young, 2010)
3. Ameliorate auto immunological or auto-inflammatory disorders (Coffey, 2012; Fink & Taylor, 2009; Singer, 2007).
4. Interrupt ongoing overt (status epilepticus), or covert (nonconvulsive status) seizure activity (Kang & Barnes, 2013; Spence & Schneider, 2009);

Someday treatments may be directed at individual vulnerabilities (personalized medicine) that may be more preventative than our current treatment models. (Fink & Taylor, 2009; Kruger, Bagby, Hoffer, & Baunig, 2003),

For most of us, having a high index of suspicion, developing a good description of observations and time line, medication review and a thorough medical history are starting points. It is imperative to develop a good working relationship with medical and mental health providers who will listen to you. It behoves us to develop an understanding of catatonia and its treatment at multiple levels.

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For further information, contact Dr. Barnhill at [Jarrett\\_Barnhill@med.unc.edu](mailto:Jarrett_Barnhill@med.unc.edu)

## US Public Policy Update

# A Personal Perspective – Health Care Reform for People with Intellectual Disabilities: Critical Role of the Family Caregiver

Jeffrey Keilson, Advocates

*NOTE: Some of the names of individuals and families have been changed to protect their privacy.*

I've spent over 40 years as a human services professional and a leader. Early in my career, I came to understand that individuals and families are the best experts on their lives and in the best position to understand needed resources and supports. I learned a tremendous amount

on what individuals with intellectual/developmental disabilities (IDD) and their families need from working with them, and I pride myself on being an advocate with them. This is why I spent nearly 2 decades helping, with others, to bring the principles of self-determination to bear on disability policy and legislation in Massachusetts and nationally.

With all I have learned over the past four decades, I still don't fully understand the magni-

tude of the challenges families face every day. Recently, I experienced a glimmer of what it is like when I spent the afternoon at the beach with my girlfriend's teenage daughter, Rosie, who has autism, an intellectual disability, and a seizure disorder.

Rosie and I went to the shore while her mom spent the day helping her own mother. I soon realized that relaxing, reading, and watching the waves was not going to happen. No lifeguards were on duty, so one hundred percent of my attention had to be on Rosie. She loves being in the water but has no awareness of its potential dangers. I sat in my chair at a safe distance from the water's edge because, unlike Rosie, I do not enjoy cold water. Naively, I believed I could keep an eye on her while staying warm and dry.

As Rosie moved deeper into the water and farther from the shore, I repositioned my chair to see her. I feared I wouldn't be able to reach her in time if something happened. I repeatedly called and motioned for her to come closer. Rosie finally heard me, came back to the beach, and sat beside me. I tried to explain that she could remain in the water as long as she stayed close to the shore, but my explanations did not reach her. Feeling guilty and frustrated for spoiling her time at the ocean, I gave up. We left and went for her favorite treat of Italian ice. I was emotionally exhausted after just a few hours as Rosie's caregiver. It's hard to imagine what it would be like to care for someone with similar or more significant challenges, every minute of every day. We are only beginning to recognize the negative impact of stress on the caregiver's health and wellness. With more than 44 million family caregivers in the country, not recognizing the importance of supporting them in comprehensive ways is not good public policy. The estimated cost of the informal (unpaid) care is more than \$500 billion, greater than all Medicare spending in 2013.

In the mid-nineties, when managed care was on the rise as an answer to sky-rocketing health-care and behavioral health costs, many of us were rightly concerned that individuals and families would be left out of decisions about their health-care and long-term services and supports. With leadership and funding that stimulated innovation from the Robert Wood Johnson Foundation, federal and state governments and others, the self-determination movement grew. Self-determination promoted the imperative that individuals and families have a central role in decision-making about services and control the dollars used to purchase services. Self-determination for community services was also viewed as a viable

alternative to managed care.

Since, we've made important inroads in how services are delivered. Individuals and families in many states have more opportunities to manage resources, hire their own staff, and choose providers and types of support best suited to their needs. We have a long way to go. As health-care reform renews and expands the emphasis on managed care, to control costs and improve outcomes, it is of utmost importance that we not lose sight of the unique needs of people with IDD and the crucial role of the family caregiver. As high as 80% of people with IDD live with a family member. It is critical that we build on the achievements of the self-determination movement and pay heed to the expertise of individuals and families.

Federal, state, public schools, and human service provider bureaucratic regulations or agency driven policies and practices too often trump real needs and desires of individuals and families. Decisions are often made by managed care staff and other professionals with an eye on short-term costs or what they think is best rather than on real needs and best results for individuals or family caregivers. This is especially true for children and adults with co-occurring IDD and behavior disorders, whose families must navigate disparate systems with complex bureaucratic layers.

An example is the O'Neil family's struggle to access services for their son, John, who has IDD and behavior disorders. Early in childhood, John became eligible for state-funded services for his IDD, but when it came to mental health services the family battled for 7 years, appealing numerous denials, before he was deemed eligible for services.

For John, this process led to a revolving door of residential school placements and emergency hospital stays. For his mother, Ellen, it entailed thousands of dollars spent on appeals and thousands of hours completing paperwork and attending meetings. It meant re-living the painful struggles in John's childhood to obtain the services he needed. Now, Ellen is gearing up for another battle since John was denied adult services for his IDD. She awakes at 4 a.m. to attend to paperwork, researching the barriers and potential opportunities for assistance, and, because of complex service system, the demands of advocating for John's services before heading off to her job.

The stress and daily toll on family caregivers such as Ellen are inconceivable to most professionals. The cumulative impact of this stress is

known to negatively affect the health of family caregivers, resulting in an estimated \$13 billion of increased healthcare costs. Loss of productivity for family caregivers is estimated to be more than \$30 billion. Neglecting needs, wishes, and perspectives of individuals and family caregivers is unsound policy.

When professionals, despite best intentions, get caught in a complex web of budget and regulatory priorities, we lose sight of the plight of families who turn to us for understanding and assistance. We lose sight of the unique knowledge and expertise families bring.

In the 2015 *NADD Bulletin* May issue, Sue Gamache reminds us of the vital nature of families' expertise:

When systems are fragmented, parents/guardians are the only ones who see our children as whole. I am the one who knows how my daughter interacts at school, with family and socially, who her other health care providers are and what their plan of care is, what will work in

Emilie's life and what won't.

As professionals, policy makers, and politicians recreate our nation's system of healthcare and social services so that it yields cost-efficiencies and best outcomes, we must ensure that essential perspectives of individuals and families are included. More importantly, their voice must be the strongest. The NADD position statement, *Including Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illness: Challenges that Must be Addressed in Health Care Reform*, outlines a path forward. This principle is critical for individuals and families. If we don't, the parts will never add up to the desired results.

For further information, contact Jeffrey Keilson at [jkeilso@advocatesinc.org](mailto:jkeilso@advocatesinc.org).

*The "U.S. Public Policy Update" is an ongoing column in The NADD Bulletin. We welcome your comments and submissions for this column. To learn more or to contribute to this column you may contact Eileen Elias, Editor of the U.S. Public Policy Update at [eelias@jbsinternational.com](mailto:eelias@jbsinternational.com).*

## *DSP Interests and Concerns*

# **NADD Conference Scholarship Opportunity for Direct Support Professionals and The NADD DSP Award for Excellence**

NADD continues its commitment to Direct Support Professionals who provide support to individuals with IDD and mental health needs by offering (1) the NADD DSP Award for Excellence and (2) scholarships to assist DSPs to attend NADD Annual Conferences.

## **Conference Scholarship Opportunity for Direct Support Professionals**

NADD is committed to improving the workforce of Direct Support Professionals (DSPs) who are supporting people in our communities with intellectual/developmental disabilities and mental health needs. In appreciation of these hard working and committed DSPs, NADD is supporting an annual scholarship opportunity. Two DSPs will each receive a free full conference registration for the NADD 32<sup>nd</sup> Annual Conference & Exhibit Show, *Equality/Recovery/Access: Integrating Treatment & Services for Persons with IDD/MI*, November 18-20, 2015 in San Francisco, CA.

This scholarship is open to any DSP in good standing who supports individuals with developmental/intellectual disabilities and mental health needs and who would benefit from an opportunity to advance his/her involvement and knowledge in the field by attending The NADD 32<sup>nd</sup> Annual Conference & Exhibit Show.

Please visit the NADD website to complete application information and to respond to the following questions.

1. Describe the work you do in the community and the individual(s) you support. Include an illustration of how your work in the field has improved the quality of life and mental wellness for someone you support. (Please exclude personal identifiers and protected health information.)

2. Explain how you hope to benefit from attending the NADD Annual Conference and how you plan to use the experience to enhance your work in the field.

### **The NADD DSP Award for Excellence**

The NADD DSP Award for Excellence is given annually to acknowledge a Direct Support Professional (DSP) whose contribution to supporting people who live in our communities has resulted in significant improvement in the quality of life for individuals with intellectual and developmental disabilities and mental health needs. The award is given to a Direct Support Professional whose dedication, advocacy, compassion, competence, person-centered approaches and collaboration results in improved quality of life, health, and wellness, and/or opportunities for person(s) with intellectual disabilities and mental health needs. The 2015 award will be presented at NADD 32nd Annual Conference & Exhibit Show on November 20, 2015 at the Fairmount in San Francisco, San Francisco, CA.

<http://thenadd.org/about-nadd/awards/nadd-dsp-award-for-excellence/>

To nominate a DSP for this prestigious award, please submit:

1. A one to two page statement indicating rea-

sons for nominating candidate for consideration for this award, for example: how has this individual's role as a DSP been exemplary, what makes him/her special.

2. The candidate's resume or employment/education history
3. Candidate's contact information, including name, address, telephone number, fax number, and email address
4. Nominator's contact information, including name, address, telephone number, fax number, and email address

Nominations should be submitted by September 1, 2015 to NADD, 132 Fair Street, Kingston, NY 12401-4802. Email: [info@thenadd.org](mailto:info@thenadd.org)

For further information, contact Melissa Cheplic at [Melissa.Cheplic@Rutgers.edu](mailto:Melissa.Cheplic@Rutgers.edu)

*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 [Melissa.Cheplic@Rutgers.edu](mailto:Melissa.Cheplic@Rutgers.edu)*

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## **Family Corner**

# **Joy, Grief, and Relief**

*Julia Pearce*

Joy, grief, and relief.

There are moments that are defined in my head with such clarity.

The first is when our son, Dallin, was born 23 years ago. The joy that we felt at that time was incredible and new. The moments of each day went by with such ease that we were beginning to think we understood what was coming to us in the coming years. The joy of each day was brought to us as Dallin learned to walk and talk and start to become a fun and adventurous toddler.

The next moment started the week before Dallin turned 2 years old: he started to have seizures with no known reason. The sudden grief at possibly losing our son to an unknown illness was overwhelming. Nine days were spent in the hospital doing blood tests, multiple

MRI tests, CT scans, EEG test and neurological evaluations while Dallin was losing all his developmental skills including sitting up, eating, drinking, walking, and talking. He had become like an infant and was not expected to survive the illness. And then, he was walking the day after the doctors had stood around his crib in the hospital and said he would not be able to so again. At this moment we began to understand how strong and determined he was! An equal amount of relief was felt as this fact was sinking into our hearts and understanding: the relief of having Dallin with us still, the relief that he had survived a catastrophic illness, and the relief that we were going home as a family despite the seemingly huge grief of having lost the little boy we had before. The joy of having this new Dallin was, again, overwhelming.

When we were sent home with Dallin, the seizures had been controlled with multiple medications, and he was given the following diagnosis at discharge: post infectious encephalopathy and ataxia. We were told that all of his skills would return in about the next 6 months and good luck. He wore a helmet while he was re-learning to walk and started to learn sign language so he could tell us what he wanted, like asking for the ever important cracker.

The following years included years of outpatient therapies, physical therapy, occupational therapy, and speech language therapy. Dallin was able to gain back many skills with hard work in those one-on-one settings, and then he let us know that he would rather learn in the 'real world' of doing things with other people than in the clinical settings. The fun we had playing as a form of therapy was joyful. He learned how to go horseback riding, downhill snow skiing, climb mountains, and ride adapted bikes. He liked to go to the store and follow a simple shopping list, interact with friends at school, help others who he felt needed even more help than himself, and we loved the moments and laughter that came to him and also, by association, us. Thirteen years after his initial illness, he started having difficulty with his muscles. As he had been progressing in so many areas in his life, this new obstacle was another thing we felt ill prepared to understand. This change in muscle strength not only affected his ability to do the many things he had enjoyed for years, but it also started to affect his mental health. We were seeing subtle signs of anxiety and occasional moments of what appeared to be depression.

Dallin's loss of muscle strength led us to a new group of specialists including an additional neurologist who focused on muscle disorders, a blood specialist, a psychologist, a psychiatrist, and then back to genetic research. The diagnosis had then expanded to include static encephalopathy, intractable epilepsy, Factor VII blood disorder, anxiety, depression, osteoporosis, signs of early dementia, and still being non-verbal. The muscle wasting problem seemed to mimic a muscular dystrophy but one could not be found that matched the symptoms. More questions came as we asked how this could be happening? What could be the cause? Who could help us find a way to stop it? There were many times we asked ourselves what to do next and what really was important. Many times we would do another procedure looking for an answer only to receive yet another phone call with inconclusive results.

Each time we thought we found an answer to why Dallin could be losing muscle mass, we were met with unanswered questions and moments of grief as we considered what the future may hold for him. There were times that we would ask the 'what if' questions: What if Dallin needed a wheelchair at some point? What if we could not find a way to reduce his anxieties? What if he was not able to do the things he enjoyed? What if what if what if ... Finally this brought us to the moment when we remembered that Dallin was still with us and that we needed to and got to hold on to each incredible moment! Dallin was the one who helped us, again. He would literally hold our faces in his hands and look directly into our eyes as if to say: are you paying attention? Do you see that this moment is the one to be in? At last, we were back on track in seeing the joy that was right in front of us.

The next few years were given to us as a time to find a bit of relief in the stressors that had built up. We were able to find medications that helped with new seizures and ones that helped with Dallin's anxieties and depression. We were able to create a partnership with the school IEP team that allowed Dallin to receive home/hospital education services for the days when his loss of strength and endurance did not allow him to attend school. At one point, we knew it was time to find a home that was wheelchair accessible. Dallin had started falling and had missed steps while going into the lower level of our home. In a matter of months we were able to find a home that was exactly the size we needed, including the size of hallways to support wheelchair use, bath rooms that had grab bars, and the ability to know those who could make other small accommodations to the stair way safety. The relief of being able to work with others in our family, community, and disability organizations we know was immense and powerful. At each step during this time we would sometimes look at our little family and again realize there were great things happening around us in spite of the muscle loss and moments of confusion that were still in Dallin's world.

What happened next was almost a blur and yet another set of moments that will always stay with me. Dallin continued to lose muscle, his anxieties increased as he seemed to lose cognitive skills, he had moments when he did not know who we were and it looked like dementia was being added to his list of things to be aware of, seizures increased and were triggered in almost every way including his favorite thing to do: going

for a car ride to look for school buses and trains. It seemed that our world was getting smaller and more controlled by the medical changes in Dallin ... and yet! We were truly finding the moments to pay attention to the things that mattered, being incredibly okay with the smaller world we were living and not being a part of many of the things we thought had been important before. Why would this be happening? A palliative care team had asked me one powerful question during an appointment. The question was: How long do you think you can do this? Meaning, how long can you make changes to your home, work, daily schedule, extended family interactions, community involvement? The answer that came to me was that I could do all of that and more for as long as it was necessary to help Dallin. And then the real question came to me: how long could Dallin's body do all that is was going through? At that moment the most intense feeling of grief washed over me as we all realized that Dallin was almost done. Maybe weeks, maybe months but his incredible being was almost done.

Within days we were in touch with hospice care and doing what we could to reduce the anxieties of this next phase of our journey with Dallin. We had planned for what would happen if Dallin outlived us with a special needs trust but now we had to plan what we would do as we outlived Dallin. Of all the absurd thoughts to have come to us! 80 weeks ago a new reality did come to us. Our Dallin woke up one morning, gave a huge hug to his dad and used sign language to tell us that he was finished. What else do you say to this except that this was ok and not ok all at one time. Dallin was always in charge and had always been the one to tell us when he was done. Dallin passed away that evening, and we were

able to be there with him at home for the entire experience. And then it was like the oxygen was sucked out of the room.

The thought that has been with me and my husband since then is yet another sense of relief and not one that will sound reasonable to most people, but it may sound familiar to a few other family members of a child with a disability. The relief that we feel is not about having our time back, not about being able to sleep 6 hours in a row, not about being done with caring for a person who needs total care. It is the relief of having been able to be the ones to have cared for our amazing Dallin for all of his life. The ability to do all that was necessary for as long we got to was incredible and powerful. The unbelievable amount of grief that has come to us since Dallin passed away has been life altering. The realization that the years of joy with Dallin were what it was all about helps us to do what we need to now for ourselves and others. The memories of the fun and hard times along with the things we learned from Dallin about joy, grief, and relief will stay with us forever.

For further information, contact Julia Pearce at [runnamokk@hotmail.com](mailto: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 at [lraymond@portresources.org](mailto:lraymond@portresources.org).*

## Share Your Expertise in Treatment and Services for Individuals with a Dual Diagnosis

### Submit an Article for the NADD Bulletin

*The NADD Bulletin* welcomes submissions of articles from practitioners, academics, managers, policy makers, family members, and Direct Support Professionals, who are involved in delivering care to people with intellectual disabilities and mental health needs. Manuscripts of interest include articles related to clinical application, policy, training, and perspectives related to supports for persons with intellectual or developmental disabilities and mental illness. Details about manuscript submission are available at <http://thenadd.org/nadd-bulletin/submitted-articles-for-the-nadd-bulletin/>.

Inquiries or submissions may be submitted to Lucille Esralew, Ph.D., Editor, at [lesralew@trinitas.org](mailto:lesralew@trinitas.org).



## New Webinar Trainings Available in NADD Store

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**DA14-1269C - Understanding Behaviors Associated with Traumatic Brain Injury (TBI)** Stephanie Young, LMFT, Stephanie Young Consultants, San Diego, CA

**ST14-1270C - The Role of the Behaviorist** - Kimberly Smith, LMFT, Stephanie Young Consultants, San Diego, CA

**SY14-1271C - Fetal Alcohol Spectrum Disorders, "The Invisible Disability"** - Robin Van Eerden, MS, NCC, LPC, NADD-CC, Consultant Integrative Counseling Services, Scranton, PA

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**R14-1268C - Research Made Easy** - Patricia Oliver, PhD, DMS, Worldly-Wise Consultancy LLC, Manistee, MI

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**PM14-1275C - Developing the Skills to Join in Community Activities** - Deirdre Hickey Sturm, Clinical Director, Special Kids Crusade, Monterey, CA

**DA14-1276C - Trauma and Neural Integration: Everyday Strategies** - Lara Palay, MSW, LISW-S, Center for Systems Change, Columbus, OH

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## **NADD Ohio State 13th Annual IDD/ MI Conference**

### **Mental Health Aspects: Treatment & Support**

September 21 & September 22, 2015

Crowne Plaza Columbus North Hotel, Columbus, OH

### **Keynote Address Presenters**

#### **Craig Erickson, MD**

Cincinnati Children's Hospital Medical Center, Cincinnati, OH

*Topic: Genetic Causes of Developmental Disability*

#### **Jarrett Barnhill, MD, DLFAPA, FAACAP, NADD-CC**

University of North Carolina School of Medicine, Chapel Hill, NC

*Topic: The DM-ID-2: The Growing Pains in Our Understanding of Psychiatric Diagnoses in Persons with Intellectual Disabilities*

### **Concurrent Session Topics**

Ohio's Employment First Initiative

Competency Through Conditional Release and Developmental Disability Boards

Practical Psychotropic Drug Management in Developmental Disabilities

The NADD Accreditation & Certification Programs (ACP)

Autism, Catatonia and Tic Disorders: Are They Relatives?

Dialectical Behavior Therapy (DBT): An Adapted Approach

Improving Preparedness for Ohioans with Disabilities

Offenders with IDD/MI: Research and Practice

Co-Occurring Treatment—What Actually Works & Why (2 Parts)

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# **NADD 32<sup>nd</sup> Annual Conference & Exhibit Show**

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### **Keynote Speakers**

Dave Hingsburger

Vita Community Services, Toronto, Ontario, Canada

Topic: TBA

Brian King, MD, MBA

Center on Human Development and Disability

University of Washington, Seattle, Washington

Topic: Equality/Recovery/Access: The Future Is Now

### **Pre-Conference Sessions**

Certification/Accreditation for IDD/MH: Raising the Bar

Policy Updates in Addressing Challenges in Health Care Refer for Individuals with Intellectual/Developmental Disabilities and Co-Occurring behavioral Health Disorders

Emotion Regulation Skills for Individuals with Dual Diagnosis: Complicating Factors, the SKILLS System, and Implementation

Forensics with People with IDD/MI Including Civil and Criminal Issues They May Face

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