THE NADD BULLETIN

NADD

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

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NOTE FROM THE EDITORS

We welcome you to *The NADD Bulletin*, 2011, being delivered electronically for the first time. We hope each of you had a wonderful holiday season. This issue marks the beginning of the 6th and final year of Dr. Dan Baker's co-editorship of *The NADD Bulletin*. We hope that this year continues to provide you with high quality articles related to our important and challenging work.

Watson and Hayes attempt to reframe family interactions and impact on individuals with ID. Traditional family approaches address the layers of multi-directional interactions and systems issues. The family is the nucleus for development and emerging vulnerability and resilience to "outside" influences. The authors shift this conceptual paradigm slightly towards the positive aspects of family systems. Rather than focusing on the family as a source of problems (e.g. dysfunctional, enabling, sabotaging treatment), this model redirects clinicians to work co-operatively and rely less on authoritative expertise or unidirectional models of treatment. Although a portion of Watson and Hayes's discussion is a part of many models of family therapy, they point out the need for families as joint problem solvers rather than subjects of all forms of intervention.

King focuses on the conceptual framework for the complex interaction between psychological trauma, physical/sexual abuse, and post-traumatic stress disorder. The widespread prevalence of abuse/neglect among individuals with intellectual disabilities sets the stage for PTSD as a major player in any diagnostic scheme. As King point out, many psychiatric diagnoses include the primary symptoms of PTSD. But we must remain equally vigilant for another brand of diagnostic overshadowing – assuming that a history of a traumatic event is responsible for every behavior or set of psychiatric symptoms. This brings us to the most intriguing part of this article – the link to the great "truths" of the Buddha, especially defining the source of suffering. Many individuals with ID are "trapped" by adaptive deficits, limited resiliency, and impaired communication in abusive situations that create both learned helplessness and intense distress. Most rely on us to be enlightened and recognize their signals of distress and not jump the gun to "intervening" based on a failure to understand their messages.

Barnhill takes another stab at bipolar disorder (BD) in individuals with ID. Focusing on childhood onset can provide clues into the complex interaction between ID, the impact of genetic risk factors, emerging or prodromal temperamental styles and gene-environment interactions and the probability of developing BD.

The U.S. Public Policy Update, by Hurley and Beasley, looks at the advantages of using web-based technology to offer consultation and training. In a new column, DSP Interests and Concerns, Seliger introduces the NADD Certification Program for Direct Support Professionals

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Does Having Hope Help? Resiliencies and Challenges of Families Raising a Child with Autism

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Introduction

Families of children with autism spectrum disorders (ASDs) are currently in crisis (Standing Senate Committee on Social Affairs, Science and Technology, 2007), arising from unique issues related to the nature of ASD, such as difficulties associated with accessing a diagnosis, specialized interventions, and adequate family support. Families of children with ASD experience higher rates of stress, as compared to families of children with Down Syndrome, intellectual disability, Cerebral Palsy, Fragile X syndrome, and typically developing children (e.g., Abbeduto, Seltzer, & Shattuck, 2004; Blacher & McIntyre, 2006; Estes et al., 2009). While adjusting to the idea of having a child with a disability can be stressful on its own, there are often additional struggles associated with accessing a diagnosis and subsequent treatment related to ASD. The diagnostic process is a critical point for the family and the child, as access to a diagnosis and care generally leads to the reduction of problematic behaviors. This paper presents preliminary findings from a study on families of children with ASD, addressing their strengths and challenges.

Theoretical Background

Although families of children with ASD report high levels of stress, it is also important to address strengths and resiliencies. Current trends in family disability research have shifted from the traditionally negative, deficit-based models of coping, to those which highlight positive, strength-based constructs of family functioning and thriving under stress, such as family resiliency (Watson, 2008). Family resilience focuses on the positive factors that contribute to a family's ability to recover from crisis (Seligman & Csikszentmihalyi, 2000). One such positive factor is hope. According to hope theory (Snyder et al., 1991), hope is a facet of a goal directed life and is characterized by having positive expectations for the future and working towards their attainment. Having hope is the ability to set goals and use both agency and pathways thinking in order to achieve goals and therefore overcome obstacles. Agency thinking is the motivational aspect of hope and relates to the initiation and sustained pursuit of a goal, which is fostered through one's past ability to achieve goals and the perceived ability to achieve current and future goals (Snyder et al.). Pathways thinking is the ability to strategize, plan, and implement multiple approaches to overcome goal-blockages and ultimately reach the desired goal. Together, agency and pathways thinking are necessary when recovering from crisis – as it is important to stay motivated and focus on the meaning of the goal (accessing a diagnosis or specific services) and to be able to generate multiple routes (working with various organizations or agencies to access additional respite funding).

Developmental disability and family functioning interact continually in a pattern over time. Families "go through repeated cycles of adjustment-crisis-adaptation" (Patterson & Garwick, 1994, p. 132), seeking to achieve balance, a state that is influenced by the meanings families attribute to their situation, as well as to their own identity as a family and their view of the world. According to Patterson and Garwick, "the meanings the family ascribes to what is happening to them (demands) and to what they have for dealing with it (capabilities) are critical factors in achieving balanced functioning" (p. 132). Such is the premise behind the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick*)*, which addresses how families deal with potentially stressful situations. According to this model, the family is a social system and thus attempts to maintain a balance by using its capabilities to meet demands. There are two phases in the FAAR, adjustment and adaptation, which are separated by a crisis. During the adjustment phase, only minor changes are possible as the family attempts to meet its demands with existing capabilities. However, a crisis emerges, where the demands exceed the family's capabilities and the imbalance persists (Patterson, 1988). After the crisis or several crises, families enter the adaptation phase, where they may acquire new resources, deduce the demands they must deal with, and/or change the way they view a situation. The FAAR highlights three important contributing factors to adjustment and adaptation: Demands, Meanings, and Resources. Reaction to a potentially stressful situation follows one of two spirals, with adaptation along a continuum from bonadaptation to maladaptation.

Research Questions and Methodology

This study addressed the following primary research questions, as informed by the FAAR model (Patterson & Garwick, 1994) and hope theory (Snyder et al., 1991):

1. What are the specific stressors and strains associated with having a child with autism?
2. What are the resiliency factors that contribute to adaptation?
3. Does having hope help in family adjustment to a diagnosis of autism?

A mixed methods approach was employed, consisting of interviews and standardized questionnaires. Employing a basic interpretive approach (Merriam, 2002), qualitative interviews were conducted with families of individuals with ASD. Primary caregivers also filled out five standardized questionnaires, including the Parenting Stress Index (PSI; Abidin, 1995) and the Hope Scale (Snyder et al. 1991).

Preliminary Results

Preliminary analyses were conducted on the questionnaires and interviews collected to date. Results are presented according to the research questions outlined above. All family names and identifying information have been changed to protect participant identity and theme names are quotes taken directly from parent interviews.

Family Stressors and Strains

According to the FAAR model, demands are conditions that call for a change in the family system. Three kinds of demands exist, including stressors, strains, and daily hassles. Stressors are life events that occur at a discrete period of time and that produce change. Strains, on the other hand, are conditions of felt tension associated with a need or desire to change something. Daily hassles are minor irritants that we encounter throughout our day-to-day functioning (Lazarus & Folkman, 1984), such as waiting in traffic. Parents of children with ASD face all three kinds of demands, but strains and stresses appear to be the most relevant demands to the present study. Furthermore, according to the FAAR, demands can come from three sources, including individual family members, the family itself, and the larger community. Families in the present study described the diagnostic process as a discrete stressor, and strains included the challenging behaviors associated with autism and the resulting management required, the multiple roles family members must take on, and struggles to access services.

"I think I always suspected that there was something": Diagnostic process. All families described struggles in receiving a diagnosis of an ASD for their child. Family members discussed suspecting for a long time that there was something "going on" with their child, but medical professionals, friends, or extended family members discounted their concerns. Nine-year old Michael's mother, Charlotte, recalls being called a "refrigerator mother" by her son's physician while seeking a diagnosis, while Carol remembers, "I felt so validated that someone finally is telling me YES that it is something more than my parenting skills, his behavior." Similarly, Sara, mother to 16-year old Brian, recollects,

> …because one of my master's degrees is in Child and Development Studies I knew something was amiss and yet most of the folks around me were dissing my thoughts – thinking that, you know, he'll outgrow it, or boys ripen different times than girls and really discounting how I felt, so there was a struggle trying to get my voice heard that clearly we were looking at some developmental problems. So, it took probably 3 or 4 years to really figure out what was going on with his development and get a diagnosis.

This quote also speaks to lengthy assessment processes, with parents reporting a range of 6 months to 5 years in accessing a diagnosis of an ASD for their child.

"You have to learn to deal with a lot when you walk into our house": Autism behaviors. All family members described the specific challenging behaviors displayed by their children. These behaviors ranged in severity from perseverative interests to anxiety and severe tantrums. Regardless of the particular behavior, all family members described at length the routines and strategies required to manage their child's presenting issues in order to minimize anxiety and facilitate family functioning. Anna describes a typical evening in her home:

> … and then I sleep with him, because he can't sleep. He can never be alone anywhere, at anytime. He's very paranoid, very anxious, so if he's alone for a minute, he panics, he can't be on the same level if there's nobody there - you know top, middle, basement, he can't be on any level if there's nobody with him. So he always has to be with somebody, and, especially at night – he's extremely anxious at night, his anxieties are a little bit better during the day. The oncerta helps a little

bit with his anxiety, but at night he's not on it, and it's extreme at night.

"So he doesn't qualify": Struggles to access services and supports. Regardless of the severity of the autism, all family members described having to advocate strongly to receive services for their children. Carl, the father of 10-year old Caleb, tells other parents to "be patient and you have to not take no for an answer when you're dealing with the school. Push, push, push." Mothers and fathers described the frustration at being on waiting lists for services such as Intensive Behavioral Intervention (IBI), getting an Individualized Education Plan (IEP) for their children in school settings, and struggling to receive respite. Jackie, a mother of 3 children with ASDs, demonstrates this theme nicely:

> …with various testing he was diagnosed with autism and went on a wait list for autism therapy. So Jordan went through IBI twice actually; the first time was about an 11 month wait and he received less than a year of treatment, and then at age 6 he was kicked out of the program, put into school, 3 years later, after severe behaviors, he was re-assessed by [psychologist], to get back into IBI because the school was putting their hands in the air, ready to send him home. So we got him back in for another year of treatment…

Parents faced challenges in qualifying for services when their child's intelligence level (IQ) exceeded 70 or their challenging behavior was not challenging enough to qualify for therapy or intervention.

"I'm really great at multi-tasking!": Multiple roles. One of the most striking themes to emerge was the number of roles parents needed to take on while having a child with an ASD. Parents described being mothers and fathers, but also advocates, researchers, case managers, teachers, therapists, employers, and doctors.

Despite all of these stressors and strains, most families were dealing well with their demands and showed great resiliency, as discussed below.

Resiliency Factors

In the FAAR model capabilities are competencies or traits of the family system, its members, or the larger community. Capabilities include resources and coping behaviors and can be used to manage stressors and strains. Self-esteem and a sense of mastery have been named as important personal resources that facilitate adaptation. Parental control dealing with medical professionals would thus be a relevant competency applied to this study. Finally, community resources are one of the strongest protective factors associated with family resilience (Patterson & Garwick, 1998). These resources include the quality of the relationships families have with medical professionals, as well as access to funding bodies and intervention services.

"I'm very lucky to have my husband": Resources. Family members in the present study described a range of supports that facilitated adaptation to having a child with an ASD. All of those who participated in the study were intact families and both mothers and fathers discussed the importance of a strong marital relationship with good communication. Although dealing with multiple professionals was often described as a strain, each family member described at least one practitioner who had been particularly helpful in supporting their family. Danielle, mother to 7-year old Don, commends many of the practitioners who have helped her family, "those people are truly gifted, especially Dr. Sullivan, he was amazing, oh absolutely amazing."

"It's a balance game": Coping Behaviors. Mothers and fathers reported an assortment of ways to deal with their stressors and strains, but family members who seemed to be faring better discussed the importance of taking time for themselves. Danielle stresses, "I think the biggest thing that I've learned is that I have to take care of myself. You know, without me taking care of myself I can't take care of my kids." Reframing was another coping behavior that contributed significantly to adaptation, meaning that parents took a step back and learned to prioritize. Carol, for example, recounts, "He was very tactile defensive when he was younger – VERY… To this day, his nails are very long, because he doesn't like them cut, but I, you know, pick my battles". It is also important to note that coping behaviors are largely affected by one's overall approach to life and feelings of hope, which are discussed in the final research question.

Does Having Hope Help?

Hope theory is based on the premise that "where there is a will, there is a way" (Snyder et al., 1991). This construct is important to families with children with autism because of the obstacles and challenges they face when trying to recover from crisis. As discussed above, the two main components of hope theory reflect both the will (agency thinking) and the way (pathways thinking) and can be measured using the Hope Scale (Snyder et al., 1991). Therefore it follows that people with higher levels of overall hope, agency, and pathways thinking would report ex-

periencing less stress, as measured by the Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995), as they would be better equipped to recover from crises.

The PSI-SF measures stress experienced by a parent of a child with a disability and provides an overall stress score as well as subscale scores for the following: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Commonly used to identify families in need of support services, a higher PSI-SF score indicates greater stress in the area indicated (Abidin, 1995). When correlated with the Hope Scale, the PSI-SF provides us with some meaningful information about the experience of families. Most notably, there is a significant, negative correlation between the Parental Distress subscale which includes stress related to the parents' perception of their own parenting competence, access to social and spousal support, and constraints due to life roles with both the agency thinking subscale [$r(1) = -.698, p < .01$] and overall hope [$r(1) = -.655, p < .01$]. This finding suggests that as hope and agency thinking increase, the experience of parental distress decreases. It is also valuable to note that the Difficult Child subscale, which relates to the parent's view of the child's behavior as stressful, is not significantly correlated with hope, suggesting that the relationship between parental distress and hope is not influenced by the perceived severity of the difficult behaviors associated with having a child with autism.

Conclusion

Awareness of how other families have adjusted to their child's disability is valuable to new families and may enable a more supportive and goal directed approach to accessing a diagnosis and intervention services. Understanding what families do in order to transform from a family in crisis to a functioning family with a disability is important when implementing family support programs. Moreover, developing a collaborative relationship between families and professionals strengthens not only research, but also practice.

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Complex Post-Traumatic Stress Disorder: Implications for Individuals with Autism Spectrum Disorders

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Several decades ago, the second son of a Ukrainian speaking couple who had emigrated from Eastern Europe was born in Israel. At the age of three this child was diagnosed with an Autism Spectrum Disorder (ASD). The family subsequently immigrated to Canada when their child was six years of age. Psychometric testing completed on three occasions demonstrated the presence of a mild degree of intellectual disability concurrent with an ASD. Despite his challenges, by grade five, this child was speaking in short but intelligible sentences, was playing the piano with joy, and was proudly described by his father as "quiet and polite." At age fourteen it was suggested that the child would benefit from a high school summer program at the end of grade nine, to allow his social skill repertoire to expand. By June of the next year, his mother lamented that "my son's spirit has left his body, he is broken." Unsupervised during lunch breaks during the summer school program, this child had been physically, emotionally, and sexually assaulted by his peers. Admitted to a tertiary care children's hospital at age fifteen, he was able to articulate that he was experiencing initial insomnia and described seeing ghosts and clowns, which were formulated by his mental health team to represent auditory and visual hallucinations. His speech deteriorated, he stopped answering questions, and completely withdrew from interactions with others.

Hospitalized ten times, over the next few years, including a four month admission to a tertiary care dual diagnosis service, this child retreated. He was afraid to go to sleep, he covered his eyes and ears, running for the family room of his parents home when company visited, and he experienced panic attacks, was noted to demonstrate "odd postures,, and engaged in increased stereotypies (which were misinterpreted as pathology rather than a self-survival mechanism). Neurological consultations failed to reveal any abnormalities nor did metabolic screens, EEGs, and CT scans of his head; genetic karyotypes and a FISH analysis for the number 22 Q 11.2 deletion (DiGeorge syndrome) were unremarkable. His psychiatrists developed a consensus that the provisional diagnosis in this case was schizophrenia, resulting in the prescriptions of Perphenazine, Rispiradone, Quetiapine, Olanzapine, Clozapine (which induced neutropenia), Divalproex Sodium, Clonazepam, and Lorazapam. During one admission to the hospital this child also received nine treatments of bilateral electroconvulsive therapy.

Most clinicians attending to him listened but did not hear. During his first admission to hospital, a month after the swift onset of a significant change in his mental status behavior, in the absence of the use of alcohol or illicit substances or a family history of psychiatric illness, this child although mute, wrote on a clipboard that a peer had hit him in the leg and 'private parts.' Despite this, the diagnosis remained that of schizophrenia. Shortly thereafter his parents were informed by the school Principal that two fellow students had in fact been arrested for assaulting their son. A referral to an internationally renowned sexual trauma team was recommended but not initiated. In 2002, a psychologist who did listen, wrote that: "the most parsimonious explanation is that this child is suffering from Post-Traumatic Stress Disorder (PTSD), given the fact that the shift in his presentation followed in close proximity to his victimization at summer camp." A recommendation for psychotherapy was met by resistance by his parents in the context of their increasing frustration, confusion, and fearfulness at the myriad of medications which had been prescribed with various adverse effects experienced by their son. They became completely untrusting of a system which, after supporting their child in a group home for four years, determined that he was capable of living on his own with marginal support, only to watch him repeatedly set fires, aggress against his parents, and be apprehended by the police after eloping from a group home. Finally in 2009, this individual was admitted to a state-of-the-art treatment home run collaboratively by a Tertiary Care Psychiatric Facility and a Community Living Association. Unfortunately even in this environment the child remained aggressive and was charged with sexually assaulting a staff member (grabbing her breasts impulsively) and now awaits court proceedings.

In his book, *Healing Trauma*, *Pioneering Programs for Restoring the Wisdom of Your Body,* Peter Levine (2008) outlines the twelve-phased healing trauma program, an extension of his exploration into the evolutionary roots of how animals and humans process, and are reunited and heal, or continue to suffer from traumatic experiences (*Waking the Tiger*, 1997). Levine's premise is that "most organisms have an innate capacity to rebound from threatening and stressful events" (2008, p. 30).

He argues that there is hope for the wounded child in our case description. As Levine states, in virtually every spiritual tradition suffering is seen as a doorway to awaking (p. 4). He cites the Four Noble Truths of Buddah.

The **First Noble Truth** is that suffering is part of the human conditioning and that avoiding painful experiences creates the very conditions that promote and perpetuate unnecessary suffering.

Complex Post-Traumatic Stress Disorder (CPTSD), a constellation of symptoms, was first described by Judith Herman in her groundbreaking work *Trauma and Recovery, the Aftermath of Violence from Domestic Abuse to Political Terror* (1992). Symptoms of this disorder are listed in Table I.

Table I. Signs and Symptoms of Complex Post-Traumatic Stress Disorder

A. Alterations in:
1. Regulation of affective responses.
2. Attention and consciousness – intrusive symptoms.
3. Self-perception.
4. Perception of the perpetrator(s).
5. Interpersonal relationships.
6. Systems of Meaning.
B. History of subjection to totalitarian control over a prolonged period of time.

These symptoms can present in a variety of ways, leading as it did in our case study to prolonged unnecessary suffering for the survivor and his or her family, despite well-intended but misdirected efforts of many mental health and developmental sector professionals in a system ill-prepared to actually diagnose this condition in individuals with ASDs.

The **Second Nobel Truth** suggests that we must discover why we are suffering. Given this child's world view and the innate growth used by many individuals of ASDs, as well as relative insensitivities to the religious and cultural tenants of the family of the subject of our case history, how was he to begin to understand the suffering he experienced immediately after being traumatized and more pointedly in the context of the system which denied him psychotherapy, did not listen to his words, and trivialized his behavioral response to the suffering? It is well known that for those suffering from it, CPTSD is more closely related to how we deal with the effects of these traumatic events. In this paper we will discuss evidence-based recovery therapies emerging with great promise for neurotypical individuals in this context; we will then review the limited literature regarding modified trauma cognitive behavioral therapy (TCBT) and mindfulness in individuals with intellectual disabilities (ID) noting the complete absence of literature regarding treatment projects for complex PTSD in individuals with ASDs.

Research is critically needed to allow the realization of the **Third Noble Truth** that suffering can be transformed and healed. Finally we will ponder the **Forth Noble Truth** that states that once you have identified the cause of the suffering you must find the appropriate path to recapture the simple wonders of life.

This begs the question, in the unique lives of individuals with ASDs, particularly in the lives of those who are non-verbal; are we truly able to understand sources of happiness in individuals with ASDs, given variations in neuropsychological thinking styles, dysfunctional and altered autonomic nervous systems, and unique hypo and hyper sensitivities? In addition, we are attempting to understand the process of their trauma and methods to assist in healing the lives complicated by an extremely high rate of lifetime prevalence's of co-morbid mental health concerns (Bradley & Bryson, 1998; Ghaziuddin, 1998). Levine suggests that we become traumatized when our ability to respond to a perceived threat is in some way overwhelmed (p. 9). He describes the trauma as a loss of connectiveness to our bodies, to families, to others, and to the world around us.

The life histories of individuals with ASD are characterized by the following facts:

1. Thirty percent have a friend who is not a family member or a care giver.
2. Ten to fifty percent are homeless.
3. Seventy-seven percent live in poverty.
4. Fifty percent living in the community are prescribed psychotropic medications.
5. Twenty-five percent have unattended dental needs.
6. Forty-three percent have undiagnosed health problems.
7. As children they are five times more likely to be abused than neurotypical individuals (The National Council on Health and Family Violence) and have a lifetime prevalence of IDs of 50-70%.
8. They age earlier and have higher mortality rates than the general population.
9. The vast majority are living with parents who are aging and becoming increasingly frail and unable to address the support needs of their children. Families spend 50-60 hours per week caring for their child with an ID or ASD. (Roebuck, 2008).

As care providers, are we capable of adequately understanding the distortion and already unique world view in self perception in the life of an individual with an ASD exposed to repeated trauma? What modifications are necessary in establishing a positive therapeutic alliance which counters testimony heard at the National Council and Disabilities Hearing (1998) that has "pointed to the inescapable fact that people with mental illnesses are systematically and routinely deprived of their rights and are treated as less than full human beings?" (2000). This would resonate with our Canadian autism self-advocate Michelle Dawson who has written in *An Autistic Victory: The True Meaning of the Auton Decision* (May 13, 2005). "Everything that is said, done, and decided about autism in Canada enriches the lives of autistic Canadians. Daily we live tactical and emotional consequences of having our fate in the hands of non-autistic factions quarrelling over our treatment."

We begin with three principles expressed by Herman (1992) with respect to the engagement phase of the psychotherapeutic treatment of complex PTSD and her work with neurotypical individuals. She stresses the need to address issues sequentially and to assist in the acquisition of therapeutic skills to deal with emotional-laden issues, in a hierarchal order.

Suggested Modifications to the Psychotherapeutic Process in Assessing and Supporting Individuals with ASDs and CPTSD

The establishment of emotional stability and safety is deemed essential for successful outcomes, enhancing the individual's abilities to endure extreme arousal states, and enhancing the abilities to master rather than avoid bodily, affective states. Herman also emphasizes the need to identify, if possible, external events triggering intrusive cognitive, emotional, and physical experiences while providing psycho-education regarding the body's response to repeated trauma and increasing an awareness of the sense of self in relational capacities.

Phase 1. Recognizing the uniqueness of the individual.

Under and over reported symptoms because of cognitive profile of individuals with ASD (theory of mind, systematizing alexithymia, lack of central coherence, lack of understanding of emotional vocabulary, poor emotional recall, and poor understanding of typical levels of anxiety) complicate the initial assessment and establishment of the therapeutic alliance in this context (Stoddart, Burke, & King, in press).

Phase 2. Personal empowerment.

The therapist functions as an active, empathic, responsive listener, creating relational conditions in which the client is emotionally validated. Inherent power differences in this relationship must be acknowledged; all attempts at collaboration are optimized.

With reference to individuals with ASDs, even prior to exposure to repeated trauma, O'Neill (1999, p. 18) notes that in individuals with ASDs "not all are shy, but all need to feel the calm of their inner experiences. It centres and soothes some of the anxiety that comes from outside confusion. It is comfortable to know that you have a portable sanctuary (your home)."

Phase 3. Professional training, ongoing supervision and consultation.

The concepts of readiness for therapy and modifications to therapy which are applicable to all forms of psychotherapy have particular relevance to trauma CBT (TCBT). Ways to address inherent power inequalities in the relationship between all therapists and an individual with an ASD are the subject of current research. Table II depicts methods to prevent an abrupt termination in the early phases of psychotherapy.

Table II Methods to Prevent an Abrupt Termination in the Early Phases of Psychotherapy.

1. Ensure appointments start and end on time.
2. Offer regular appointment times, predictability, and sameness, reducing the client's anxiety.
3. Reduce the duration of appointments.
4. Use humor.
5. Use radiant scales as visual aids to gage degrees of emotion on a gradient.
6. Provide written psycho-educational material and/or use pictorial aids.
7. Set an agenda in a truly collaborative manner, following the client's lead with a degree of flexibility.
8. Have sensory-friendly waiting rooms.
9. Provide access to objects or encourage clients to utilize objects of their own as a component of a sensory dyad or toolkit directly during psychotherapeutic sessions.
10. Allow various seating arrangements.
11. Increase the number of therapeutic sessions.
12. Engage in and discuss directly the client's areas of interest.
13. Gradually introduce emotionally-laden topics.

(Stoddart, Burke, & King, in press)

In discussing the use of CBT in individuals of ID in general, Gaus (2007) argues with strong conviction based on years of clinical practice that it is a myth that individuals with ASD are not capable of psychological insight, of benefiting from any therapeutic relationship to effect change in their lives, or of thinking reflectively about their lives and the future.

Sheila Mansell (2003) has suggested the following guidelines in establishing and maintaining a positive therapeutic alliance and psychotherapeutic relationship with individuals with ID:

a. Ensure therapy is developmentally appropriate. Explore suggestions from various clinicians from a practice-based evidence perspective regarding methods to modify TCBT to address individual needs.

b. Foster an active client role in therapy.

Jahoda et al. (2009) describe that a collaborative relationship is the cornerstone of successful CBT in individuals with ID, acknowledging the potential for power and inequalities in the client-therapist relationship arising from:

1. Expressive and receptive language difficulties.

2. Client histories with a difference between them and those perceived in power and decisions of authority.

3. Concerns regarding passivity, acquiesce, biases, and a tendency to say yes to complicated questions.

Using a novel method of interactual analysis in a group of fifteen individuals with borderline to mild degrees of ID, a review of verbatim transcripts of CBT therapy sessions conclusively demonstrated that a relative equal power distribution between the client and therapist is achievable; therapists were noted to ask more questions than clients, but clients were confirmed to be able to contribute to the flow of the conversation and play an active role in therapy.

Using a method of interactual analysis developed by Linell, Gustavsson & Juvonen (1988) and the *Cognitive Therapy Skills for Psychosis* (Haddock et al., 2001) a measure of fidelity to the key structural and process elements of CBT (agenda, feedback, understanding, interpersonal effectiveness, collaboration, guided discovery, a focus on key cognitions, and the choice of interventions and the use of homework) Haddock et al. concluded that CBT therapists:

1. Were able to achieve high levels of adherence to CBT principles while working with individuals with ID.

2. Were able to establish interpersonal, empathic, collaborative approaches.

3. Were able to convey understanding through rephrasing and summarizing.

4. Were able to acknowledge the client's point of view as important.

5. Were able to facilitate guided discovery.

6. Asked questions to show interest without being demeaning.

7. Were able to use appropriate questions to reframe the meaning clients attach to events.

The authors conclude "collaboration does not just mean that the therapist is able to communicate effectively as an expert, but that the client

must feel he or she is properly heard and understood" (p. 7). The focus in therapy should be on real life experiences (issues in the here and now).

Interventions in complex TCBT attempt to provide clients with a means of shifting their inner experience of themselves to their sense of interpersonal relationships. The identification that these symptoms of CPTSD (see Table III) are arising from traumatic events rather than from perceived character flaws, can liberate the client from the paralyzing sense of shame. Goffman suggested that "we believe the person with stigma is not quite human, with this assumption we exercise varieties of discrimination to which we effectively, if often unthinkingly, reduce life chances." (Goffman, 1963).

Spindel (May 2005) has suggested that the power of stigma results in a demeaning denial of natural human rights of choice and removes the essence of what makes a person human (p. 1).

Given the immense vulnerability to stigma and discrimination to which individuals with ASDs and histories of repeated trauma undoubtedly are exposed, it is understandable that they engage in experiential avoidance resulting in the constrictive and intrusive symptoms of CPTSD, layered on a pre-existing sense of alienation and disengagement from society.

After completing phase one in the therapeutic process as proposed by Herman (1992), the establishment of an active sense of personal and environmental safety and stabilization, phase two, the prolonged exposure to traumatic memories in a gradual way through mindfulness and acceptance strategies combined with exposure exercises, begins the process of explicitly identifying and labelling the signs and symptoms most often present following an exposure to trauma and beginning to address a destabilizing sense of internal shame.

The potential task of confidently establishing a diagnosis of CPTSD is formidable in neurotypical individuals. This task is further complicated in the lives of individuals with ASDs. Formal diagnostic guidelines are not yet in the *DSM-4-TR* (American Psychiatric Association, 2000). The symptom presentation involves affective, somatoform, obsessive-compulsive behaviors, comorbid substance abuse issues, and symptoms such as dissociation, an under-recognized symptom of CPTSD; this results in an extreme challenge to the therapist to recognize this disorder in individuals with ASD with severe expressive-communication deficits. Traumatic events often occur during developmentally vulnerable stages

in the individual's life and in this process become intertwined with the child's bio-psychosocial development. How easy it would be to dismiss this in a child with an ASD, who, by definition, is struggling with development of a sense of self and is already, by definition, uncomfortable in an alien world even prior to repeated exposure to trauma.

Herman (1992) suggests that the constructive and intrusive symptoms of CPTSD lead to a reduction of normal social and emotional capacities causing a stunting of the development of self esteem, an impairment in daily life routines (so important in the lives of individuals with ASDs attempting to modulate pervasive levels of anxiety in a confusing world). Herman describes the development of

> self-deregulation, an impairment of modulation of arousal, attention, cognition and related behaviors. Therapeutic attempts directed towards integrating these capacities, such as the emotion, cognition, and bodily experiences are unified in a single response and lead to self-directed and purposeful behavior. It would be a reasonable formulation to suggest that this process in an individual with ASD would result in deterioration in acquired or mastered ADLs and extreme withdrawal or aggression and self injury.

Herman suggests, "it is as if time stops when trauma happens" (p. 37).

Individuals with ADSs may also develop CPTSD through what Maria Root (1992) describes as

> insidious traumatization which occurs when an individual is repeatedly negatively targeted for some aspect of their identity, resulting in a chronic state of over arousal and stress, a response society often directs towards individuals with ASD, already attempting to modulate chronic states of autonomic nervous system over arousal through sterotypies, insistence on sameness and predictability and the utilization of challenging behaviour, to express distress arising from unpredictable changes in their daily life routines. What world view would a therapist guide an individual with ASD toward, to provide a sense of security and attachment, when the individual's world view has been so distorted, sometimes to the point of accepting and believing the world view of the perpetrator of the re-

peated abuse? An acceptance that they are inhuman objects to be manipulated, exploited and endure a sense of powerlessness?

The third and final stage of therapy proposed by Herman aims to re-establish a connection on many levels between the individual and community. She believes that sharing the traumatic narrative and recreating a grossly distorted chronological personal narrative is a precondition for the reconstitution of a meaningful world, necessary to rebuild a sense of order and pride (and to remove shame, guilt, embarrassment, and humiliation). Rather than using power and inequalities in the therapeutic relationship, she suggests the therapist cannot take sides or direct the patient's life dreams, but rather "is called upon to bear witness to the trauma." In the third phase of therapy forging a new pathway from disconnection and fear to safety, the victim is faced with the double challenge of rebuilding his or her own shattered self assumptions about meaning, order, justice and finding a way to resolve the differences and free him or herself from the adopted beliefs of the perpetrator of repeated abuse.

In sitting with an individual with an ASD who has CPTSD the therapist is called upon to bear witness to the trauma and therefore must spend much time attempting to understand the individual's unique world view. Signs of symptomatic resolution are noted in Table III.

Table III Signs of Symptom Resolution

1. Being able to bear feelings and come to terms with traumatic memories.
2. Establishing authority and autonomy over traumatic memories.
3. Bringing symptoms to manageable limits.
4. Allowing traumatic memories to become a coherent, chronological narrative.
5. Restoring self-esteem.
6. Reestablishing interpersonal relationships.
7. Establishing or recreating a coherent sense of meaning and self.

(Herman, 1992)

The therapist plays the role of a witness and an ally; in his presence the survivor can speak of the unspeakable (Herman, 1992, p. 175). The therapist assists to restore a sense of continuity with the past through guiding the client to rewrite the trauma narrative.

A number of evidence-based therapies helpful for neurotypical individuals with CPTSD have emerged (Courtois & Ford, 2009). This is comprehensively described in the text *Treating Complex Traumatic Stress Disorders - An Evidence-Based Guide*. These therapies include:

1. TCBT (a combination of CBT, acceptance, and commitment therapy).
2. Contextual-based trauma therapy.
3. Experiential and emotion-focused therapy (including accelerated, exponential, dynamic psychotherapy and emotion-focused therapy for trauma).

We will focus on TCBT, given emerging evidence-based practice that with appropriate modifications this particular therapy appears to have value for individuals with ID and ASDs (Jahoda, 2010). Jahoda has explored methods of preparing (readiness) clients with ID for therapy through the use of motivational interviewing based on the principles of:

1. Empathic listening.
2. Acceptance without judgment.
3. Avoidance of direct confrontation.
4. The belief that change cannot be forced.
5. Supporting self-efficacy.
6. The essential intervention to create and amplify in the client's mind a discrepancy between past and present behaviors.
7. Changing the content of therapy – optimizing the fit between client and therapist, involving additional caregivers in portions of the therapy, and offering therapy in home-based settings.
8. Modifying therapy – modification would include;
   a. Using simple language and visual aids.
   b. Re-scripting the traumatic narrative with happier endings (this correlates well with the documented effectiveness of social stories, narratives, and role-playing in therapy involving individuals with ASDs (Courtois, Ford, & Cloitre, 2009).

It is recommended to be alert to the need to distinguish between cognitive distortions and cognitive deficits while empathically listening to survivors of complex trauma with ASDs. An attempt must be made to address potential deficits in the processing of trauma to which information during the traumatic process has been acquired and now

is contributing to the clinical presentation. This may lead to themes contributing to relative reliance on the identification of strengths to highlight and build on. Teaching people to understand that emotions, particularly anger, sadness and anxiety, may be being appraised as 'crazy thoughts.' This often becomes an integral part of the social behavior analysis conducted on the individual suspected of having complex PTSD, leading to emotional regulations and skill building in adaptive environmental modifications. This critically stresses that the therapist be aware that many people with IDs, despite having familiarity with various emotions, have a poor understanding of their relationship between beliefs and emotions. It is important to recognize that supporting the development of self efficacy, the belief in one's capacities to manage emotional states in an individual with ASD, will be occurring in the context of the individual's developmental experiences in which there have been many events in which the individual's views were invalidated or in which the individual was exploited.

Minna Mettinen, a powerful Canadian self-advocate with ASD, has commented "our society is very quick to judge people's beliefs in all kinds of shallow and totally frivolous manners, but won't even try to understand the origin of these unusual or even unacceptable methods of thinking." (Personal correspondence, 2006).

Jahoda (2006) offers advice regarding the manner in which CBT can be made meaningful for people with ID. He has also examined the elements of systemic resistance to the provision of psychotherapeutic modalities to individuals with ID and ASD. These include therapeutic disdain – the belief that this group of individuals are "not clever enough." He notes that there has been a very slow paradigm shift from those who have worked in institutional settings but acknowledges an emerging recognition of the person within the individual with ID. In therapists' minds there may still be persistence of social stigma and isolation and resistance to the idea that the individuals with ID and ASDs do indeed need and want meaning and purpose in their lives. He recognizes that CBT cannot be of assistance to all persons; even with optimal modifications he suggests alternative methods of support may be more helpful for:

1. Individuals unable to hold a conversation.
2. Individuals who have verbal IQ's less than 50 (Wilner, 2002).
3. Individuals who have significant persistent difficulties linking antecedents to beliefs and consequences.

4. Individuals who have specific cognitive or behavioral attributes such as extreme impulsivity.
5. Individuals who are unable to be taught to recognize and articulate felt emotion.

Studies involving the use of CBT and depression (Mason, 2007; Wilmer, 2005) and aggression (Taylor, 2002;, Jahoda et al., 2006) support the potential advocacy of CBT for people with ID and ASDs.

Jahoda (2010) also emphasizes the importance of distinguishing between cognitive deficits (a lack of cognitive control of emotions and beliefs) and cognitive distortion, the latter being critical thought content to be identified and made explicit to the client in the therapeutic process. He convincingly argues that the use of self-monitoring, pictorial techniques, social problem solving techniques, psycho-education, and acknowledgment of verbal self regulation are helpful in demonstrating that individuals with ID and ASD are indeed capable of altering the way in which they think about the world (challenging underlying cognitive distortions and diminishing automatic negative thoughts leading to distressing emotional feelings).

The interest in modifying CBT to support individuals with ID, ASD, and mental health concerns was highlighted by the establishment of a national network of like-minded professionals, funded by the Dally Thomas Foundation (and the publication in the UK of two special editions of the *Journal of Applied Research in Intellectual Disabilities*, 2006). This edition includes both outcomes of evidence-based studies and practice-based evidence. Lindsay et al (2006) reported that the assessment of individuals with ID and histories of perpetrated rape and sexual assaults against children showed specific, consistent patterns of cognitive distortions with these offenses, and were potentially amenable to reframing and psychotherapy and psycho-education in the context of CBT. Oathamshaw & Haddock (2006) have stressed the importance of the verbal communication abilities of clients using a task design which demonstrated that potential CBT clients with ID could differentiate between positive and negative feelings.

Sams, Collins and Reynolds (2006) developed a novel task which was used to distinguish potential CBT clients based on their abilities to differentiate between thoughts, feelings, and behaviors. Jahoda et al. (2006) demonstrated that individuals with ID could be identified according to their ability to recognize and label emotions, link

events and emotions, and understand the mediating role of cognitions. The editions editor (Willner 2006) has reviewed the existing evidence-based literature, including recommendations to increase motivation and address systemic barriers to accessing and engaging individuals with ID and ASDs in psychotherapy.

Whitehouse, Tudway, Look and Stenfert Kroes (2006) reviewed, as was discussed previously, the therapeutic need to distinguish between cognitive deficits and distortions. Stenfert Kroese & Thomas (2006) reported in a case study the successful treatment of post-traumatic nightmares using imagery retrieval therapy as a component of CBT. Jahoda, Dagnan, Jarvie and Kerr (2006) have examined the role of life experiences influencing the self-perception of individuals with ID, as follows: the correlated increased vulnerability to depression in this population, and the mediating role of cognitions, which could be therapeutically identified and reframed in CBT. Dagnan and Jahoda (2006) have used the diagnosis of social phobia to demonstrate the impact of social context on the core thought schema of individuals with ID. An emphasis on the critical need to modify mainstream cognitive models of mental health problems to incorporate issues such as stigma, social-economic status, and self-determination was highlighted.

Methodological challenges to the presentation of CBT were also reviewed, including: issues of capacity and consent; the ongoing need to refine and optimize methods of the assessment of presenting psychopathology; and the appropriate role of promoting performance and research studies. In addition, clinical challenges, including the need for more opportunities for advanced training for clinicians, the lack of studies addressing the validity and reliability of assessment tools, the lack of stable research and infrastructure funding, and the inability to establish clinical trials to demonstrate with sufficient statistical power the efficacy and effectiveness of CBT in individuals with ID and ASDs were openly acknowledged. All of these issues are particularly germane to people with ASDs, constituting a spectrum of individuals with core similarities but significant variations in sensory profiles, cognitive strengths and styles, and co-morbid mental health concerns. All of these issues are highlighted in our case study which stresses the need for bio-psychosocial assessments, the need to reformulate the diagnosis if the individual appears treatment refractory, the limitations of support programs primarily based on the use of psychotrophic medication and

containment, and a relative systemic absence of knowledge regarding the vulnerabilities of abuse experienced by individuals with ASD. Skilled clinicians, however, have published practice-based evidence regarding the provision of CBT to individuals with ASD to allow passionate and creative skilled clinicians to proceed therapeutically with compassion, while awaiting evidence-based practice. Gaus (2007) has emphasized the need to confirm an individual's acceptance and knowledge of ASD traits as a critical issue to consider before engagement in therapy. She stresses ten key antecedents and perpetuants of the clinical presentation of individuals with ASD to be included in both a review of the appropriateness of CBT and combinations in the provisions of CBT as listed in Table IV.

Table IV.

1. Poor social skills and social insight.
2. A relative inability to understand emotions.
3. Sensory processing difficulties (seeking or avoiding behaviors).
4. Alterations in executive function.
5. Isocratic learning – information processing styles.
6. Restrictive and repetitive interests.
7. Poor fine and/or gross motor skills.
8. Problems of emotional modulation.
9. Resistance to change and an inflexible cognitive style.
10. Difficulties in navigating transitions.

It is essential that we proceed with compassion while awaiting the evidence regarding the most appropriate modalities of therapy for the most clinically-marginalized and stigmatized individuals in our societies. We need to act with a vision to create a future better than the past and present experienced by those whom we support.

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Neuroscience Reviews

Bipolar Disorder: There's More Than Meets the Eye, Part II

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Dickstein, D.P., Brazel, A.C., Goldberg, L.D., & Hunt, J.I. (2009). Affect regulation in pediatric bipolar disorder. *Child Adolescent Psychiatric Clinic of North America,18*(2), 405-420.

This article addresses a weak spot in our conceptual models of dual diagnosis (MI-ID): the lack of integration between genetics, neurobiology, functional behavioral analyses and descriptive/categorical classification of mental disorders. Due to our incomplete understanding of complex behaviors, we tend to fall back on familiar models. For example, we tend to lump aggression into a single functional typology of challenging behavior. Mental health clinicians may follow a different tact and try to squeeze aggression into a *DM-ID* heterogeneous category such as Intermittent Explosive Disorder. Relying exclusively on single approaches creates an interesting problem. Both mental health and behavioral clinicians rely on inclusive approaches that encompass most forms of aggression. For researchers, this level of heterogeneity is largely unacceptable. Neuroscientists attempt to define more specific subgroups or endophenotypes based on differences in neurochemistry, neurophysiology, past learning experiences, comorbid psychiatric disorders, and neurodevelopmental risk factors. Unfortunately this level of specificity is not practical in many clinic settings.

For example, let us address one subgroup of aggression behaviors – function as a means of escaping demands. If we stop our analysis at this point, we have failed to consider the differences created by behavioral excesses (mania) versus skill deficiency (language deficits or social isolation); role of variability in level of affective arousal; impulse control and the degree of foresight; intensity of urges to aggress or the neurobiological forces driving this goal directed versus nondirected aggression. Overlooking these weaknesses creates gaps in understanding that Bill Gardner attempted to fill with a more comprehensive bio-behavioral model.

Among mental health clinicians and psychopharmacologists the empirical approach is far more useful than a detailed bio-behavioral analysis and treatment – unless this approach proves less than optimally ineffective. In this situation we can make several assumptions: we have made an error in our hypotheses about function, underlying cause (depression) or postulate a neurotransmitter dysfunction; our models of reinforcement or drug effects are incorrect, or perhaps both. For the pharmacologist, drug treatment is based on hypothetical neurotransmitter abnormalities (low serotonin turnover associated

with aggression, etc); brain dysfunction (frontal lobe injury or epilepsy, etc); or psychiatric diagnosis-specific (mania, intermittent explosive etc). Based on a superficial combination of behavioral and "biological" interventions (using the same data collection systems) may demonstrate this lack of efficacy but provides limited data to assist in understanding why this happens. Analogue methods may zero in on factors that maintain the behavior but may not tell us what is unique about the differences or what underlying neurobiological principles are in play. A single neurotransmitter or syndrome generic explanations present similar limitations.

In their article, Dickstein, Brazel, Goldberg & Hunt do not address aggression in terms of functional behavioral or neuropharmacological analysis. They focus instead on the heterogeneity of aggression in general and defensive aggression in particular – main in terms of modifying operations such as negative affective, pain, threat perception, and viability in impulse controls. These factors are intertwined with the developmental trajectory of affect regulation. This brings us to a current dilemma- the relationship between defensive aggression, irritability, and pediatric bipolar disorder (BPD). These authors explore this relationship by comparing a subgroup of children with euphoria, cyclical mood changes, and narrow phenotype mood disorder (narrow phenotype) and those who present with irritability, chronic and noncyclical moodiness and anger, hyperarousal, symptoms of accelerated thought but lack a family loading for BD (broad phenotype) and proneness to develop adulthood Major Depressive Disorder (MDD) not BD.

There is a movement to reclassify this group of children as "severe mood dysregulation" (SMD). Adapting this model to MI-ID requires that we fine tune our approaches to irritability, impulse dyscontrol, and nonspecific variation assumed to represent mood cycles. For this to be successful we need to account for mixed bipolar states and the impact of IDD on the development of affect regulation. I suspect that we are overdiagnosing BD among individuals with IDD. But how do we deal with high rates of irritability, noncyclical moodiness, and hyperarousal. Although Dickstein et al. do not address this problem, I suspect we need a combination of functional behavioral and neurobiological strategies that transcend one-factor thinking. We need methods of modifying the threshold, intensity of affective responses (behavioral excesses), and capacity to help regulate impulse control (skill deficits). Since each of these factors are maintained by associative and operant learning, we also need to blend these two models and try to minimize pharmacological approaches that may impede the new learning (extinction) of these pre-potent conditioned responses.

US Public Policy Update

Using Web-Based Technology in Consultation and Training for the National START Teams

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Due to a national expansion of the Center for START Services, we are using the Internet for web-based meetings, consultations, and seminars. We are able to decrease costs of our services in travel time as well as costs to agencies for their employee's travel. In addition, this venue increases the participation of families, individuals, and developmental agency personnel. It is also a way to involve our community mental health partners in assessment and treatment planning, while increasing their knowledge about intellectual disability and mental health needs (IDD/MH).

START (Systematic, Therapeutic, Assessment, Respite and Treatment) is a system linkage model of providing community services, natural supports and mental health treatment to people with IDD/ MH (Beasley, 2002; Beasley & Kroll, 2002). This model, first developed in 1988 and cited by the Surgeon General's Report (U.S. Public Health Service, 2002), has been used as a basis for the development of services

in Maine, Connecticut, Massachusetts, Minnesota, Oregon, Tennessee, Texas, and Washington (Jacobstein, Stark & Laygo, 2007). At the UNH - IOD, we are currently working with two counties in Ohio, a region in Connecticut, North Carolina, and New Hampshire with a major focus on transitional youth. We are utilizing the latest technology to conduct meetings, consultations, and trainings of not only START staff, but also their community partners.

The virtual "meeting" is efficient because it eliminates travel while saving time, money, and resources lost in work hours out of the office. Continuing advances in technology have made these venues easy to use. The meeting leader can present documents, power point presentations, videos, or conduct brainstorming sessions on the white board. Each person in an individual's linkage network can log on from his or her office (or home). Participants can talk in the meeting either by telephone or through their computers. This flexibility can accommodate, for example, staff at a hospital discharge meeting in discussing the treatment plan with team members and our START consultant. Our Internet services are closed networks and confidentiality is maintained.

In addition, we have conducted formal trainings for the START linkage network with CEUs available. Due to their success, and practicality of the webinar, we are now expanding our formal trainings with a series of 8 sessions available to all current START Teams. New Hampshire START, North Carolina START (East, West and Central), Butler County-Ohio START, the RHC Children's Retreat in Hamilton County-Ohio, the Children's Home of Connecticut START program, and the state of Missouri are cosponsoring this effort. It will be accessible to 350 locations via computer. START programs can invite any of their community linkage network members to learn more about IDD/MH.

The webinar also allows us to invite a wide range of speakers working from their office or home. We are enthusiastic about our national training schedule for this year: Nancy Razza, Ph.D. / trauma; Robin Friendlander, MB, FRCPC / psychosis in youth; William Gardner, PH.D. / self-injury; Anne Hurley, Ph.D. / autism spectrum disorders; I. Leslie Rubin, M.D. / medical aspects; Anne Hurley, Ph.D. / cognitive limitations. In addition, Joan Beasley Ph.D. will conduct 2 national START Team meetings.

Finally, it is critically important for anyone working in the field of IDD/MH to have adequate training in the unique issues of our population.

In Missouri, for example, Jarrett Barnhill, M.D. was able to offer hundreds of MDs and other clinicians training while they were at their desks during lunch break. Because so few psychiatric practitioners have the specialized opportunity to learn about or treat patients with IDD/MH during their residency, providing expert training is very important (Ruedrich, Dunn, Schwartz, & Nordgren, 2007).

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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 Joan Beasley, Editor of the U.S. Public Policy Update at joan.beasley@unh.edu.

DSP Interests and Concerns

Competency-Based Certification Program for Direct Support Professionals

Edward Seliger, M.A., Project Coordinator, NADD

As part of NADD's recognition of the critical role that Direct Support Professionals (DSPs) play in providing support to individuals who have mental illness and intellectual/developmental disability (MI/IDD), we are committed to welcoming DSPs into NADD. One reflection of this commitment will be an ongoing column in *The NADD Bulletin* focused on the needs and interests of DSPs. This first column introduces the NADD DSP Certification Program, an important segment of the NADD Accreditation/Certification Program which will begin operation this year.

Why Is Credentialing for DSPs Important?

Traditionally, DSPs have been overlooked and undervalued by policy makers, employers, and community members. Credentialing will allow DSPs to demonstrate their skills, knowledge, and commitment to providing quality service to the individuals with dual diagnosis they support. Credentialing DSPs will ensure that people who pursue careers in direct support share a common knowledge base and skill set.

- Credentialed DSPs will feel valued and take pride in the direct support work
- Credentialed DSPs will be recognized for the skills and knowledge they have acquired and the work they do
- Employers will benefit by an increase in the consistency of high quality supports delivered by credentialed DSPs.
- The people who use support services will lead better lives because the DSPs who support them have the knowledge, skills, and attitudes needed to support their individual preferences and personal goals

It is also hoped that a valued credential will influence workforce development.
- DSPs will benefit by wage enhancement programs for those who seek credentials
- Employers will benefit by a reduction in DSP turnover when they hire credentialed DSPs

Eligibility
- Completion of 1,000 hours of direct support work in MH or IDD field (DSP, student, trainee), either paid or unpaid over a one year period
- Employment status
  - In compliance with all agency and state/provincial requirements
  - Completed required pre-service/pre-employment trainings
  - Not under disciplinary review or probation

Certification Procedure
- Provide summary of experience and education
- Sign off on Code of Ethics
- Provide a letter of recommendation/reference from a person supported, family member, or personal advocate
- Provide a letter of recommendation/reference from a person in a professional role (coworker, supervisor or management, therapist, behavior specialist, nurse, etc.) who has substantial direct observation knowledge of the applicant's ability to work with people with dual diagnosis
- Complete an on-line multiple-choice test in which the questions are based upon scenarios concerning work with individuals with a dual diagnosis. Applicants will have to demonstrate competency in five areas: (1) Observation & Assessment, (2) Community Collaboration and Teamwork, (3) Behavior Supports, (4) Crisis Prevention and Intervention, and (5) Promoting Health and Wellness

For additional information, contact Edward Seliger at eseliger@thenadd.org.

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 Kathleen Olson, Editor of DSP Interests and Concerns at kolson@ku.edu.

Upcoming NADD Conferences

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Massachusetts One-Day Symposium - 2011
June 16, 2011 (Th)
Sheraton Framingham Hotel & Conference Center
Framingham, MA

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Ohio State 9th Annual ID/MH Conference - 2011
September 19 & 20, 2011 (M & T)
Crowne Plaza Columbus North
Columbus, OH

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NADD 28th Conference & Exhibit Show-2011
November 2-4, 2011(W-F)
Loews Vanderbilt Hotel- Nashville
Nashville, Tennessee

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NADD 29th Conference & Exhibit Show-2012
October 17-19, 2012 (W-F)
Omni Interlocken Resort
Broomfield, CO

For further information on upcoming conferences/trainings, consultation services, and products, visit our website at www.thenadd.org. Updated information is posted as available.

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