

Dual Diagnosis: Overview of Therapeutic Approaches for Individuals with Co-Occurring Intellectual/ Developmental Disabilities and Mental Illness for Direct Support Staff & Professionals working in the Developmental Disability System

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*“To say that a particular psychiatric condition is incurable or
irreversible is to say more about the state of our ignorance than
about the state of the patient.”*

Milton Rokeach

“The best way to get experience is to get experience!”

Julie Gentile, MD

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This work has been sponsored by the Ohio Mental Illness/Developmental Disabilities Coordinating Center of Excellence (MIDD CCOE). The MIDD CCOE promotes clinical best practices for individuals with mental illness and developmental disabilities. It is a collaborative effort involving the Ohio Department of Mental Health and Addiction Services, the Ohio Department of Developmental Disabilities, and the Ohio Developmental Disabilities Council. With the goal of providing appropriate treatment for individuals with co-occurring mental illness and developmental disabilities, the CCOE assists local systems throughout Ohio to increase their service capacity and foster collaboration.

The CCOE is based at the Wright State University Department of Psychiatry, near Dayton Psychiatry under the leadership of Dr. Julie Gentile. The Ohio MIDD CCOE provides comprehensive psychiatric assessments, educational programs, regional and local team consultation. In 2012, the CCOE also initiated Ohio's Telepsychiatry Project for Intellectual Disability which provides clinical consultation and mental health services to individuals in under-served areas of Ohio with co-occurring mental illness and intellectual disability.

About the Author

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Tricia Burke, LISW, was appointed as the President and CEO of Envision in 2012 in Cincinnati, Ohio. Envision provides a continuum of services to children and adults with developmental disabilities, developmental delays, and co-occurring mental illness. The organization was founded in 1963 and was formerly known as Resident Home Corporation.



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She has 40 years of experience in the mental health and developmental disability nonprofit sector. She served as Executive Director of the Colorado Developmental Disabilities Council and Director of Mental Retardation Services and subsequently Director of Mental Health Services for a large agency in Pittsburgh before moving back home to this area in 1989.

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I: PURPOSE

This paper is written for professionals in the mental health and developmental disability sectors who want to have a better understanding of adults and children who need the services of both. Individuals with Intellectual Disabilities (ID) have significant needs for mental health services, but too few therapists and psychiatrists are prepared to serve them well. Historically, individuals with developmental disabilities were routinely denied psychotherapy. However, there is a growing body of research to support its efficacy and an increasing numbers of experienced clinicians adapting traditional evidenced based best practices to successfully treat individuals with co-occurring conditions. For those who work in traditional DD services, there are many opportunities to provide services in a therapeutically supportive and trauma informed manner.

Three psychiatrists – Frank Menolascino, Irving Philips, and George Tarjan – began the “dual diagnosis movement” in the 1970’s by pushing beyond the narrow behaviorism understanding of individuals with Intellectual Disabilities. They were the first to broaden the clinical perspective that individuals with ID are vulnerable to the full range of psychiatric disorders. They faced significant opposition at the time but it launched new dialogue and research in the field. Evidence was collected to show that dual diagnosis is common. In the 1980’s, more appropriate clinical interventions and services emerged to demonstrate that individuals with ID could benefit from treatment. Over the years, numerous promising practices have emerged. However, there remains a great need to attract more professionals to this area of specialty practice and provide them with adequate training.

This report is meant to serve as a bridge for those professionals who are interested in exploring and expanding their understanding and skill set. It will provide an overview of the need, historical misunderstandings, guidelines and examples of traditional mental health practices that have been adapted for individuals with developmental disabilities, and an introduction to helpful books and resources that have emerged for this specialized area of practice. This paper will also be useful to DD professionals seeking a better understanding of the mental health needs of the individuals they serve and therapeutic interventions that might be helpful.

MY PERSPECTIVE

My perspective in writing this report comes from 20+years of experience as a CEO of a community mental health center in southwest Ohio. I moved to Ohio from Pennsylvania where the mental health and developmental disability services are provided within the same service system. I served as the Director of Mental Retardation and subsequently as the Director of Mental Health for a Pittsburgh community mental health center that had many specialized services for those with dual diagnosis – psychiatry, therapy, sex education, and partial hospitalization. Western Psychiatric Institute was nearby with an abundance of psychiatric residents and a specialized training program for dual diagnosis developed by Dr. Irene Jakab. I did not realize how unusual that was for the field in the 1980’s. As I worked in Ohio, I began to see how far apart the systems were here. Too often conversations focused on which system was responsible for paying for services as if the individual only belonged in one or the other. Most clinicians did not feel skilled to serve individuals with developmental disabilities or believed they could not benefit from treatment - a behavioral approach was deemed more appropriate.

I NEEDED A GUIDEBOOK

As an administrator, I knew we could do better. But I am not an experienced clinician. I know a lot about mental health and mental illness, but I could not personally show my staff how to do therapy. I wanted and needed a guidebook written by clinicians who had expertise that I could share with staff to help them build their skill set and comfort level. Given the day to day demands faced by most community mental health center staff, I had no time to do this research and little resources to spend on it. Learning about the CCOE and its resources provided helpful guidance in that journey. Having meaningful participation with the Co-occurring Collaborative that was formed in the Cincinnati region by Hamilton County Developmental Disability Services connected our two systems and deepened our learning. We benefited significantly from the resources made available by the MIDD CCOE. As a result of the CCOE's efforts, there are dual diagnosis teams all across Ohio that are working together to make specialized services more accessible and available. However, many gaps in services and misconstrued thinking persist.

Given that 1/3 of individuals with developmental disabilities also have a mental illness, the need surpasses the capacity of the current mental health system to serve them. We need leaders in the mental health sector to recognize this unmet need in their communities and make a commitment to build capacity to provide these needed services. We need clinicians and mental health case managers to become more educated and skilled in working with individuals with intellectual disabilities. We need to build relationships with professionals who work in the developmental disability side of the sector and learn how to talk together in ways that are helpful and collaborative.

This paper is written from that perspective. It is meant to give an overview of the state of the art today. There has been a fair amount of research and growing literature that has been produced on this specialized area of practice over the past twenty years. Using the National Association for Dual Diagnosis (NADD) website as my compass, I purchased and read the major books that were recommended to professionals in our field. This paper will introduce them to you in enough depth so that you may know which ones will be valuable to you as you deepen your expertise in this area.

II: PREVALENCE OF CO-OCCURRING MENTAL ILLNESS AND DD

1 out of 3 individuals with a developmental disability has a mental illness

For a long time, many mental health professionals believed that individuals with developmental disabilities did not experience mental illness, that their intellectual deficits somehow protected them from this experience. Or they believed that they could not benefit from treatment even if they were experiencing psychological distress due to their lack of verbal skills and capacity for insight. Their symptoms were seen as behaviors that should be addressed through behavior modification.

In 1983, Steve Reiss coined the term, “**diagnostic overshadowing**” to describe the tendency to assess individuals with intellectual disability less accurately. He noted that intellectual disability was such an obvious and important characteristic that it overshadowed professionals’ perceptions to the point that they couldn’t see the individual’s signs of emotional distress and illness. This refers to a bias impacting a clinician’s judgment regarding co-occurring disorders in individuals who have intellectual disabilities or other mental illness.

In fact, individuals with intellectual disabilities do experience the full range of mental illnesses and the incidence is much higher in the DD population than in the overall population. Nearly 1 out of every 3 individuals with a developmental disability will also have a mental illness. There is a 3 to 6 time increased rate of psychiatric and behavior problems in individuals with ID compared to the general population. In the general population, it is estimated that 1 out of every 5 individuals will experience a mental health problem in their lifetime. The prevalence of anxiety and mood disorders within the ID population is more than double that of the general population (American Psychiatric Association, 2000). When psychiatric disorders are more broadly defined to include the range of “behavioral disturbance” commonly seen in individuals with intellectual disabilities, prevalence rates have been reported to be as high as 80% (Razza and Tomasulo, 2005). The variance in these prevalence rates is related to the complexities of discerning and defining psychiatric disorders in individuals with ID. Exactly what constitutes a psychiatric disorder in individuals with intellectual disability is a subject of ongoing study.

If you think about what it must feel like to live in our society with a developmental disability, this high level of incidence makes sense, especially for those with mild and moderate disabilities. You are more vulnerable. You know you are different and can’t do what many others your age have achieved. You are highly dependent on parents and caregivers. If you live in a facility, you have endless people coming and going in your life. You have more limited receptive and expressive language. Your ability to make sense of your world is more impaired. Your sense of self esteem is more fragile. And yet, you long for what every other human being longs for – to be loved and accepted, to have friends, to have a purpose in your life, to feel safe and secure, to have some say in your life. You may have an intellectual disability, but you have the same kinds of feelings and emotions that all human beings experience. It is your vulnerability that leaves you more prone to be a victim – and unfortunately the abuse too often is inflicted by the very people that you are depend on for your daily care.

1 out of 3 will be sexually abused before the age of 18 5 times more likely to suffer sexual abuse

Children with intellectual disabilities may be 3 to 6 times more likely to suffer abuse than non-disabled children (Fletcher, 2011). In 1992, Richard Sobsey, known for his pioneering work with the Sexual Abuse and Disability Project, documented the higher than average rates of sexual abuse of individuals with disabilities; the negative sequelae of sexual abuse, such as withdrawal, aggression, inappropriate sexual behavior, and psychological distress; the paucity of appropriate and available treatment; and the rationale for the modification of existing treatment models to aid recovery in survivors with intellectual disabilities (Mansell, Sobsey, & Calder, 1992). Women with mild intellectual disability experience the highest levels of sexual abuse. They are about 5 times more likely to suffer sexual abuse than women without disabilities. Male victims are more likely to have severe retardation (Fletcher, 2011).

The National Child Traumatic Stress Network identifies the profound influences that abuse and neglect can have on brain development:

- The more prolonged the abuse or neglect, the more likely it is that permanent brain damage will occur. Not only are individuals with developmental disabilities more likely to be exposed to trauma, but exposure to trauma makes developmental delays more likely. The developing brain is exquisitely sensitive to stress. Persistent states of fear in children impair their capacity to benefit from cognitive, social, and emotional experiences (Perry, 2001). Exposure to trauma can modify the child's ability to access different levels of brain functioning, resulting in changes in their perception of time, cognitive style, affective tone, ability to develop solutions to problems, and ability to respond to and understand rules, regulations, and laws (Perry, 2001). Severe neglect can result in reduced brain size, density of neurons, and head circumference (Perry and Pollard, 1997).
- Individuals with developmental disabilities are trained to be compliant to authority figures. They are dependent on caregivers for a longer period of time for more types of assistance than a non-disabled child, and they are dependent on a larger number of caretakers. They are more likely than other children to be placed in residential care facilities. They are often unable to meet parental expectations and isolated from resources to whom a report of abuse could be made. Often they are impaired in their ability to communicate and sometimes impaired in their mobility. They are less prone to critical thinking than others which may result in it being easier for others to manipulate them. They are often not provided with general sex education, and caregivers may feel that individuals with developmental disabilities are asexual, although for individuals with mild to moderate mental retardation sexual development and sexual interest occur at approximately the same age as the typical population (Tharinger, 1990), and precocious puberty is 20 times more likely to occur in persons with developmental disabilities than in the typical population (Siddigi, 1999).
- Individuals with developmental disabilities may also experience cognitive and processing delays that interfere with understanding of what is happening in abusive situations, and feelings of isolation and withdrawal due to their differences, which may make them more vulnerable to manipulation because of their increased responsiveness to attention and affection. In addition, the effect of trauma is increased for individuals with developmental disabilities due to a predisposition

toward emotional problems and impaired resiliency before the abuse occurs (Burrows & Kochurka, 1995).

The lack of trained professionals and the long-standing belief that individuals with developmental disabilities cannot benefit from traditional verbally oriented therapies to help them in processing traumatic incidents has contributed to the lingering impact of unrecognized and untreated trauma for those with intellectual disabilities.

OHIO NEED & PREVALENCE

The 2010 census found just over 11.5 million people residing in Ohio. Approximately 1.5% will have an intellectual disability and one third of these individuals will have a co-occurring mental illness. This means that there are approximately 172,500 children and adults with intellectual disability living in Ohio today of which 95% have mild or moderate intellectual levels of functioning. Approximately 1/3rd of them or 57,000 will have a co-occurring mental illness.

The magnitude of need is very high. The capacity of the mental health system is very low. As professionals, we receive little or no training to prepare us for this specialized area of practice. This paper will identify materials and resources to help with this preparation and summarize the ways in which traditional therapy practice can be modified to serve individuals with ID. As mental health centers plan for strategic growth, this specialty area offers much potential. The vast majority of these individuals have Medicaid benefits based on their disability so money is not the barrier.

The major barrier to overcome is one of willingness, enhancing skill sets, and building relationships with the DD sector. Agencies serving individuals with developmental disabilities struggle every day to get the mental health needs of their individuals served – they will welcome you with open arms. What has been missing most is a trained, interested, and skilled workforce and committed leadership at the management level.

III: DIAGNOSIS & ASSESSMENT

DEFINING INTELLECTUAL DISABILITY

Intellectual Disability (ID) is the preferred term for mental retardation. The United States Congress passed legislation in 2010 eliminating the term “mental retardation” from all federal laws and substituting terminology “an individual with intellectual disability” in all health, education, and labor law. Intellectual Disability affects approximately 1% to 3% of the population. The DSM criteria for ID include significant sub average intellectual functioning, onset before the age of 18, and concurrent deficits or impairments in adaptive functioning. In Ohio, the age range is extended to age 22. The ranges include:

	<u>IQ Range</u>	<u>% of ID Individuals</u>
Mild	50/55 to 70	85%
Moderate	35/40 to 50/55	10%
Severe	20/25 to 35/40	3-4%
Profound	Less than 20/25	1-2%

Individuals may be born with congenital, trauma induced, or illness-induced damage to the brain. Other infants and children will sustain enough brain damage through illness or accidents to prevent normal developmental growth.

Dr. Gentile does an excellent job of describing the cognitive and emotional capacities of individuals with ID using Piaget’s stages of development in her recently published book, Psychiatry of Intellectual Disability. These explanations will be very useful to therapists who are trying to understand the level of understanding of an individual with ID and how to adjust their own interviewing and therapeutic intervention. (Gentile, 2012, pp. 101-104)

Severe/Profound and Sensorimotor Stage

Piaget’s sensorimotor stage of development is defined as taking place from birth until the development of language. With the development of language, an individual understands the world by integrating sensory information with behavior and actions. Individuals with severe/profound ID have limited to no development of language and could be considered to be functioning at the sensorimotor stage of development. While the history is being taken from caregivers or others, the individual with severe/profound ID can be observed for appearance, relatedness to others, impulse control, activity level (voluntary and involuntary motor movements), expression of affect, attention span, any unusual ritualistic, stereotypic or repetitive behaviors and external signs of anxiety.

Moderate ID and Preoperational Stage

Individuals in the moderate ID range tend to function in the “preoperative stage” of cognitive development and will interpret their world in a concrete and literal manner. In children with typical intelligence, this occurs at approximately 2-6 years of age. Language development is a hallmark of this stage of development. They will have egocentric speech and will see things from their own

perspective not the viewpoint of others. They typically have difficulty in manipulating information and drawing logical conclusions from information. They will also tend to focus on one aspect of an object while ignoring other facets, and will usually have difficulty ranking the importance of various aspects of a situation or experience. That is why Likert-type scales are not useful for self report at this stage.

Mild ID and Concrete Operations

Those in the moderate to mild range tend to function at the level of “concrete operations” thinking logically about concrete events, but may have difficulty understanding abstract or hypothetical concepts. They are not able to use deductive logic, taking a general concept and using it to predict or determine the outcome of a specific event. They may have difficulty describing symptoms and providing subjective data regarding emotions – i.e., they may state they are “scared” instead of “mad”. Dr. Gentile suggests using pictorial representations of various emotions to help increase skill set both for use in the therapy session but also as a take home set. Once a therapeutic alliance is established, they are typically able to communicate in a very genuine and authentic way. They are less egocentric than the person with more severe ID and more capable of beginning to see things from other’s perspectives.

DD vs. MH APPROACHES TO ASSESSMENT

A person’s IQ is only part of the assessment process used by DD professionals. They also look at functioning levels or adaptive behavior and limitations. This helps define the level of supports needed by an individual to function in daily life. Mental health professionals need a current DSM diagnosis to bill their services. The DSM is a manual published by the American Psychiatric Association and covers all mental health disorders for both children and adults. It also lists known causes of these disorders, statistics in terms of gender, age at onset, and prognosis as well as some research concerning the optimal treatment approaches. The book is typically considered the “bible” for any professional who makes psychiatric diagnoses in the United States and many other countries. The numeral behind the DSM stands for which version or revision it is. With the fifth edition, numbers rather than roman numerals are used to indicate which edition. The DSM-5 was published in May 2013.

The traditional DSM diagnostic guides familiar to mental health professionals were not adequate to diagnose the mental health issues of individuals with developmental disabilities. To address this issue in 2007, the National Association for the Dually Diagnosed (NADD), in association with the American Psychiatric Association (APA), developed the Diagnostic Manual – Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability. This is a useful guide to mental health professionals to determine an accurate psychiatric diagnosis with considerations given to the lower levels of intellectual functioning. There is also a companion textbook that provides of a description of each disorder, a summary of the DSM-IV diagnostic criteria, a review of the research and an evaluation of the strength of evidence supporting the literature conclusions, a discussion of the etiology and pathogenesis of the disorders, and adaptations of the diagnostic criteria for persons with Intellectual Disability (ID). For each disorder, there is descriptive text and details of how to apply diagnostic criteria, as well as tables of adapted diagnostic criteria.

In addition to adapting the DSM-IV diagnostic criteria where appropriate, the DM-ID provides advice about and considerations for assessing and diagnosing individuals with ID and coexisting mental health needs. In

some cases, it is not so much that the criteria need to be adapted, as that a different method of eliciting the necessary information must be used. Information is provided in recognizing common behaviors of individuals with intellectual disabilities and in how to differentiate these behaviors from psychiatric disorders. Both of these books can be purchased on Amazon or through NADD. There is a discount for NADD members.

Diagnostic Manual-Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability \$120 in paperback \$95.00 for NADD Members

Diagnostic Manual-Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability \$80 in paperback. \$65.00 for NADD Members

DSM-5 CHANGES: Intellectual Disability

The new edition of the DSM-5 was published in May 2013. The significant changes address what the disorder is called, its impact on a person's functioning, and criteria improvements to encourage more comprehensive patient assessment. It is now available on Amazon:

Diagnostic and Statistical Manual of Mental Disorders, 5th Edition \$85.73

Name Change to Intellectual Disability

"Intellectual disability (intellectual developmental disorder)" as a diagnostic term replaces "mental retardation" used in previous editions of the manuals. In addition, the parenthetical name "(intellectual developmental disorder)" is included in the text to reflect deficits in cognitive capacity beginning in the developmental period. Together, these revisions bring DSM into alignment with terminology used by the World Health Organization's International Classification of Diseases, other professional disciplines and organizations, such as the American Association on Intellectual and Developmental Disabilities (AAIDD), and the U.S. Department of Education. AAIDD fought hard to have the term "disability" used rather than "disorder." For individuals with developmental disabilities, "disability" is much less offensive than "disorder" and vastly improved over "mental retardation." And as mentioned earlier, intellectual disability is also the term used to replace the term "mental retardation" in all federal education, health, and labor laws with passage of legislation in 2010.

Single Axis

The revised disorder also reflects the manual's move away from a multi-axial approach to evaluating conditions. Using DSM-IV, mental retardation was on Axis II to ensure that clinicians identified associated impairments alongside other mental disorders. With DSM-5, all mental disorders will be considered on a single axis and given equal weight.

Characteristics

The DSM-5 defines these characteristics. Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:

- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning. The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder.

Comprehensive Assessment

DSM-5 emphasizes the need to use both clinical assessment and standardized testing of intelligence when diagnosing intellectual disability, with the severity of impairment based on adaptive functioning rather than IQ test scores alone. By removing IQ test scores from the diagnostic criteria, but still including them in the text description of intellectual disability, the DSM-5 attempts to ensure that IQ is not overemphasized as the defining factor of a person's overall ability, without adequately considering functioning levels. This is especially important in the development of a treatment plan.

DSM-5 CHANGES: Autism Spectrum Disorder

The new edition introduces two fundamental changes in the diagnosis of autism spectrum disorder. First it collapses previously distinct autism subtypes – including autistic disorder and Asperger syndrome – into one unifying diagnosis of autism spectrum disorder (ASD). Second, the current three symptom domains of social impairment, communication deficits and repetitive/restricted behaviors will become two – social communication impairment and repetitive/restricted behaviors.

DEVELOPMENTAL DISABILITY ELIGIBILITY DEFINITION IN OHIO

In the interest of clarity for mental health professionals, it may be useful to clarify how the terms Intellectual Disability and Developmental Disability are used in Ohio under eligibility standards established by the Ohio Department of Developmental Disabilities. In addition to intellectual disabilities, developmental disabilities also include individuals with cerebral palsy, traumatic brain injuries, autism spectrum disorder, epilepsy, learning disabilities and other syndromes if they also meet the functional limitation criteria described below. Eligibility for DD services in Ohio is done by each county board. Some counties use a more liberal interpretation of the definition than others and this can be confusing to mental health providers who work across county systems. Ohio also expands the age of onset to 22 compared to the federal definition of occurrence before the age of 18.

A developmental disability is defined as a severe, chronic disability that is characterized by all of the following:

- Is attributable to a mental or physical impairment or a combination of mental and physical impairments, other than a mental or physical impairment solely caused by mental illness
- Is manifested before the person attains age 22
- Is likely to continue indefinitely

Results in one of the following:

- In the case of a person under age three, at least one developmental delay
- In the case of a person at least age three, but under age six, at least two developmental delays
- In the case of a person age six or older, a substantial functional limitation in at least three of the following areas of major life activity, as appropriate for ones age: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and, if the person is age 16 or older, capacity for economic self-sufficiency

Causes the person to need a combination and sequence of special interdisciplinary or other type of care, treatment or provision of services for an extended period of time that is individually planned and coordinated for the person

IMPACT ON THE FAMILY

It is understandably difficult for family members to accept and adjust to having a child diagnosed with a developmental disability. The “perfect” or “typical” child they expected is now replaced with a child who may be very different and who will need lifelong help and support or even continual care. They also face the stigma that comes with the diagnosis which sometimes causes friends and extended family members to pull away. Their other children face similar challenges with their friends and peers. As their non-disabled children mature and celebrate the many milestones of growing up, both parents and the child with a disability experience the sadness that they have not or may never achieve the same. The impact on siblings of having a brother or sister with disabilities can also create a sense of being “left out” if the large share of attention is constantly focused on the sibling with a disability. This often goes unrecognized within the family since they are seen as being so lucky to be “normal.”

This stress is exacerbated when a child also suffers from a mental illness, especially when it is expressed in significant behavioral changes. For an individual with ID who may have limited ability to communicate distress and pain, these symptoms may manifest as behavioral problems such as aggression, insomnia, self-injurious behavior, and social isolation. These behaviors can be very troubling to parents and family members.

Parents face a daunting task to find professional help for assessment and helpful intervention. They also face the challenges of coping with two major conditions and two complicated systems of services and care.

IV: ADAPTING PSYCHOTHERAPY

FACTORS CONTRIBUTING TO HIGHER RATES OF PSYCHIATRIC DISORDERS

A broad array of factors have been found to contribute to the higher than average rates of psychiatric disorders experienced by individuals with intellectual disabilities. They are very similar to the factors that are contributory to depression and other psychiatric disorders: (Razza-Tomasulo, 2005)

- Low levels of social support
- Poorly developed social skills
- A sense of learned helplessness and correspondingly low sense of self-efficacy
- Low socioeconomic level
- Increased presence of physical disabilities, especially epilepsy
- Heightened family stress and heightened maternal stress
- Increased likelihood of central nervous system damage
- Increased presence of reading and language dysfunctions
- Decreased opportunities to learn adaptive coping styles
- Increased likelihood of chromosomal abnormalities, metabolic diseases, and infections
- Increased likelihood of experiencing early trauma and abuse

They also experience more loss and stress over the course of their lifespan as they engage with their world. They are often ridiculed by others. They long for what their siblings can do and the milestones they reach. They often long for independence beyond their reach. Even positive milestones are mixed blessings. Graduating from school, they may experience the loss of a familiar setting and friends. Completing therapy, they lose a trusted relationship. Moving away from home to different living arrangements, they face the loss of day to day contact with family and the familiarity of the home setting. In their new living arrangements, they often experience the frequent turnover of staff and starting over with new. At times, they are vulnerable to less than trustworthy staff and may not be able to express what has happened to them under their watch. Unfortunately, they experience higher than average rates of exposure to sexual abuse. They have more difficulties learning new skills and experience more failures as a result. They are very dependent on staff and family for the quality of their life and loss of a family member to illness or death can be a very difficult loss.

Hollins and Sinason (2000) outline the following organizing principles which apply to all individuals with ID, regardless of the severity of cognitive deficits:

- The existence of the disability itself -including the conscious and unconscious fantasies that accompany it
- Loss of the normal self who would have been born
- Sexuality - internally distorted by the impact of the disability
- Dependency - not being able to live autonomously
- Fear of death - being part of a group that society does not reliably accept and protect.

Symptoms of psychiatric disorders have frequently gone undetected in individuals with ID because of a tendency on the part of professionals to attribute symptoms to the intellectual disability itself – “diagnostic overshadowing.” Clinically significant psychological symptoms have been misunderstood as mere behavioral components of cognitive deficits. Even such severe symptoms as suicide attempts have been misconstrued as self-abusive behavior (Kaminer, Feinsten, & Barrett, 1987). Despite early misunderstandings and unfounded assumptions of many mental health professionals, individuals with intellectual disabilities experience the same types of psychiatric illness as they nondisabled counterparts (Charlot, 1998; Nugent, 1997).

SYMPTOMS MAY BE EXPRESSED DIFFERENTLY

Charlot’s research provides descriptions of symptoms that may vary from those more commonly seen in the nondisabled population – for example, individuals with intellectual disabilities experiencing depression frequently talk to themselves out loud rather than ruminate silently. In assessment of depressive symptoms, it is important to bear in mind that individuals with ID may be more likely than non-impaired adults to experience irritable rather than sad moods when depressed. Angry, aggressive, and self-injurious behaviors may also be displayed by depressed individuals with ID. Many referral problems are initially presented by staff as noncompliance, temper tantrums, self-abuse, or going off with no provocation. Individuals with ID who exhibit such behaviors are often depressed and frequently, although not always, have histories of traumatic exposure. (Razza-Tomasulo, 2005, p. 138).

CONSIDERATIONS FOR ADAPTING PSYCHOTHERAPY

There are a number of issues that must be addressed when providing psychotherapy to individuals with co-occurring mental health problems and ID. Some of these include:

- The individual’s level of intellectual functioning
- The presenting symptoms that led to the referral
- How the symptoms compare to the individual’s previous level of functioning
- How mental health symptoms interact with behavior that is typical for the individual’s ID or DD
- What types of stressors the individual is facing
- What skills the individual has used to manage similar stressors in the past
- The therapists own biases about ID and their ability to engage in the treatment process

There is an excellent chapter in Dr. Gentile’s book, Psychiatry of Intellectual Disability, co-authored by Carroll Jackson, LISW that describes the unique challenges that clinicians face in adapting the psychotherapy treatment process in working with individuals with intellectual disabilities. The book by Razza and Tomasulo, Healing Trauma: The Power of Group Treatment with People with Intellectual Disabilities also explores these issues in great depth with many case examples of how they have navigated them in doing group as well as individual therapy. The case examples illustrate the concepts with specific language that was used with their individuals which I found very helpful.

EXPLAINING WHAT THERAPY IS & THE MEANING OF CONFIDENTIALITY

Typically, individuals with ID are not self-referred. Most come into treatment referred by someone else concerned about their maladaptive behavior – a parent, caregiver, etc. They may not have any idea about

what therapy is. They may not see the problem as an area of concern for them, or they may see the referral as punishment or as a consequence for their behavior. They may not have any input into the choice of the therapist or who will even be present with them during the appointment.

The majority of individuals with ID have many professionals involved in their care – case managers, habilitation providers, job coaches, behavior support specialists, and a variety of direct support professionals. Individuals with ID may have no understanding of how the therapist's role is inherently different than all of the other members of their team. They may have no idea about what therapy is and what confidentiality means. They frequently experience the free sharing of personal information between multidisciplinary team members and may have concerns that the information disclosed in therapy will be treated in the same manner. This can also be true about some of the team members as well who may expect to know what is shared with the therapist in the therapy sessions.

This is complicated by the fact that the therapist often needs collateral information from care providers, as individuals with ID are poor historians. Their caregivers and parents may be able to provide valuable information about sleep records, weight changes, appetite changes, medical conditions, documentation of unexplained sadness, isolative behavior, etc. They are often able to help when the individual has very limited language skills as they are more familiar with their speech patterns. The care providers are also valuable in helping ensure that the treatment recommendations are followed and homework is completed.

INITIAL INTERVIEW

Nancy Razza and Daniel Tomasulo offer these suggestions for conducting the Initial Interview in their excellent book on Healing Trauma. A generally helpful strategy is to give a brief explanation to the individual on what the meeting will be about. Some simple examples they give that must be tailored to the individual's level of comprehension include: "This meeting is a chance for us to talk about things that bother you; you can also talk about good things, and things you like to do. Is that okay with you?" They recommend this approach even if the individual has a legal guardian who has already given consent for treatment. It is important to establish that the relationship with the therapist may likely be very different than the ones they are used to with people in positions of authority.

They note that for many individuals with ID, a lifetime of compliance has preceded the first meeting with their therapist. Thus it is often necessary to tell the person directly that although you believe the session will be helpful to them, they do not have to stay and talk to you if they do not want to. You can also make clear to them that they can change their mind later if they want to stop, even if they have signed a "consent for treatment" form. (Razza-Tomasulo, 2005, p. 133) They go on to recommend that if you are unsure whether the individual fully understands you, ask them to repeat back what they heard you say by introducing a "checking back" as a regular part of the process. Be praising of their efforts to feed back your communication. Similarly, check out your understanding of what was said to you, asking if you "got it right." Dr. Gentile often uses the phrase, "can you fix it for me" if she has not quite gotten what they are communicating to her. For individuals who have difficulties with their communication, this can help to enhance comprehension as well as to convey a sense of genuine interest in them.

COMMUNICATION ISSUES

Most individuals with ID experience receptive and expressive language limitations. Some may have better receptive language but be unable to express themselves well. Depending on their level of cognitive deficits, they may not be able to self-report their symptoms. It is important for the therapist to explore their individual's degree of understanding and to ensure that the individual feels comfortable telling the therapist if, and when, information is presented in a way that is confusing or unclear. This can be done by establishing that the cognitive deficit is a legitimate and neutral topic and discussion from the beginning, so that issues regarding communication can be addressed openly. This is crucial to establishing the therapeutic alliance.

An overestimate of an individual's abilities will prevent them from fully understanding what is being presented. Underestimating their abilities may cause them to feel patronized and frustrated. Individuals with ID may also struggle with the expression of emotions and feelings. They may not have the necessary problem-solving skills to manage stressors appropriately when they occur. An inability to do this can be extremely debilitating and they can feel overwhelmed and frightened by intense emotional responses that they do not understand.

The ability to identify and label feelings provides a sense of control and comfort that can increase an individual's capacity to appropriately manage their feelings. It is impossible to process emotions and to understand the connection between thoughts, feelings, and behaviors without the ability to identify them.

ASSISTIVE TOOLS TO LABEL FEELING STATES

The therapist may need to interpret behavior for an individual with ID by identifying and labeling the emotions that are tied to the events discussed in the session. For example, "you look sad when you talk about how sick your grandmother is." Other activities that can facilitate the labeling of feelings and emotions include: (Gentile, 2012, p. 286)

- Use of pictorial representations of faces to facilitate identification of emotions
- Use of journaling if they have the capacity
- Use of picture journaling as a substitute for writing – drawing pictures or putting pictures into a journal
- Expressions through music

Universal Facial Expressions of Emotion

Paul Ekman is an American psychologist who has been a pioneer in the study of emotions and their relation to facial expressions. He classified six facial expressions which correspond to distinct universal emotions: disgust, sadness, happiness, fear, anger, surprise. It is interesting to note that four out of the six are negative emotions.

The cues for facial expression as suggested by Ekman are in the table below.

EXPRESSION	CUES
Happiness	raising and lowering of mouth corners crinkles appear around the eyes cheeks raised
Sadness	lowering of mouth corners eyes may tear raise inner portion of brows
Surprise	brows arch eyes open wide to expose more white jaw drops slightly
Fear	brows raised eyes open mouth opens slightly
Disgust	upper lip is raised nose bridge is wrinkled cheeks raised
Anger	brows lowered lips pressed firmly eyes bulging

USEFUL GUIDELINES FOR SPEAKING/ INTERVIEWING WITH INDIVIDUALS WITH ID

The following guidelines were developed by Dr. Gentile for use when speaking with individuals with intellectual disabilities. They are more fully described in her book in Chapter 6 on "Interviewing" (Gentile, 2012, pp. 90-120). The following are suggestions that I found helpful.

- Be honest when you do not understand an individual's speech or communication and feel free to ask them to repeat the response or enlist the help of collateral sources in the room when appropriate.
- Ask permission to involve collateral data sources.
- Use "who," "what," and "where," questions rather than "when," "how," and "why."
- High yield accurate information will most likely be gained from the use of pictorial multiple-choice and factual yes/no questions, closely followed by subjective yes/no questions.
- Avoid hypothetical or abstract future-oriented questions.
- Avoid jargon or slang, as well as other technical language.

- Use concrete descriptions and avoid figurative language.
- Avoid conversational punctuations such as “really” and “you know” because they may be taken literally.
- Frequently check understanding of conversation with the individual with ID.
- Ask what particular words mean to the individual, and use their words when possible.
- Match questions and answers with the individual’s expressive language.
- Avoid double negatives.
- Use words that they use for body parts.
- Avoid abstract concepts.
- Use alternative language systems – picture and line drawings as adjunct when needed.
- Match the interviewee’s mean length of utterance.
- Use plain language or language less than 6th grade level.
- Use single clause sentences.
- Use active verbs rather than passive ones.
- Use present tense whenever possible.
- Use time anchors when discussing the past.
- Avoid idioms – i.e., do not say “you can’t teach an old dog new tricks.”
- Avoid direct comparisons – i.e. How do you like your new home and job - ask each as separate questions.
- Yes/no questions are higher yield when used regarding activities and events, but they are not as accurate with feelings and emotions.
- Avoid confrontational or potentially embarrassing yes/no questions.
- Avoid leading questions - “you knew what you were doing was wrong, didn’t you?”
- Use caution with “why” questions.
- Exercise caution with use of humor.
- Eliminate irrelevant stimuli in the office which may steal the attention or create attraction.
- Use assistive devices used by individuals as part of the interview whenever needed.
- Learn the basics of sign language for commonly used words – thank you, bathroom, please, sad, happy, good, and bad.

BEWARE of ACQUIESCENCE

Acquiescence is the tendency to agree with any statement that the interviewed individual is given. This is relatively common in individuals with ID, especially if they are answering to an “authority figure.” This is less likely with the person with more severe cognitive deficits. The tendency towards acquiescence makes it a challenge to determine whether an individual’s responses are truthful and real information. They may fear consequences, or a negative response, or disappointment from the interviewer. You may need to cross question and ask the question in different ways to clarify the response. Ask for examples. It can also occur if the questions being asked are too complex and beyond the cognitive ability of the individual.

Dr. Gentile offers 4 techniques from Finlay and Lyons (2002) to detect acquiescence in an interview:

- Questions where the correct answer should be “no,” e.g. Does it snow in summer here? Can you fly an airplane?
- Pairs of questions that are opposite in meaning. Are you happy? Are you sad?

- Pairs of questions in which the same question is asked in different formats, i.e., yes/no and either/or.
- Informant checks.

It is always important to say more than once that there are no wrong answers and to demonstrate affirmation for all efforts to respond. When individuals make the effort to give information that is obviously difficult for them, acknowledgement for that effort is essential.

ADAPTING THE THERAPEUTIC PROCESS

Therapy is typically about individuals “telling the story of their life” –either past or present – to a therapist. This is usually because there is something troubling them in their life that they cannot understand or change. Often they may not even know what exactly is troubling them. They may be unable to express their difficulties verbally, but these difficulties are being both experienced and expressed through how they live their lives. The therapist will encourage the individual’s self-expression until these troubles reveal themselves and can be understood. Thus, the dialogue and the relationship to the therapist nurture the individual’s self-expression and in turn self-reflection. (Cottis, 2009, p. 30) One can see how therapy has become deeply reliant on narratives as a means to explore the individual’s experience. For many individuals with intellectual disabilities, narrative based self-reporting is difficult. Poor memory, struggles to make cognitive connections between feelings and behaviors, and limited language and communication skills are the reasons typically cited as the reasons they are poor candidates for therapy.

However, it is heartening to see the success that willing therapists have been able to achieve by adapting their practice to incorporate alternative means of creative expression that are accessible to individuals with intellectual disabilities, including individuals who have very significant impairments. This paper will give an overview of their work and point the reader to the appropriate resources to learn more about these adaptations in more depth. In general, these suggestions are found in all the adaptations:

- Use simple concrete language and simpler sentence structure.
- Take a slower pace over a number of sessions – be willing to go at their pace.
- Use shorter sessions.
- Take time to provide education about vital concepts.
- Use a more directive approach helping individuals to identify and express feelings – i.e., it looks like you feel pretty bad, upset, sad when you remember what happened...is that right?
- If the individual is unable to respond when talking about a difficult topic, affirm the effort. If they remain silent, try to convey understanding of the silence by saying that right now this seems to be hard to talk about.
- With an individual who is able to express their emotions, continue to clarify those emotions and affirm the individual for being able to talk about them.
- When maladaptive coping strategies are identified, do not rush in and pressure the individual to change; affirm your understanding of the feelings and behaviors for now, and ask the person if he or she wants to change such behavior having experienced negative response to it. Let them know they will have the chance to learn how to make changes as they continue in therapy.
- Repetition is essential – review and practice skills.
- Use homework and review of homework to reinforce learning.
- Augment learning in therapy with art therapy, role-play, and therapeutic games.

- Include use of psychodrama techniques – doubling, role reversal, etc. to draw out clarity about feelings and practice of coping responses.
- Use laminated skill cards to reinforce learning between sessions.
- Include participation and assistance of care providers with consent of the individual.

WHEN ABUSE IS INVOLVED

As noted earlier, individuals with intellectual disabilities experience abuse at a much higher rate than the nondisabled population. It is estimated that one out of three will have experienced sexual abuse before the age of 18. Young women with mild intellectual disabilities are about 5 times more likely to suffer sexual abuse than women without disabilities (Fletcher, 2011). Razza and Tamasulo have very helpful suggestions in Chapter 7 of their book, Healing Trauma for investigating symptoms and how to respond when abuse is involved. They note the importance of bearing in mind that sexual abuse, like exposure to other forms of trauma or extreme stress, can affect individuals across many dimensions: somatic, emotional, cognitive, behavioral, and characterological.

There is increasing support for the notion that traumatic exposure can lead to the development of a variety of disorders, including eating disorders, substance abuse, self-mutilation, dissociative disorders, personality disorders, as well as post traumatic stress disorder (PTSD). Many factors are thought to influence the development of any particular disorder and it is overly simplistic to assume that the development of a disorder is due solely to the experience of any one traumatic event. Their suggestions for therapists interviewing someone who is brought to therapy with abuse as the presenting problem include:

Begin addressing the individual's feelings directly after they tell you about the abuse – i.e., “How does it feel to you to be talking about what happened?” For individuals who are able to verbalize their feelings, it is important to affirm them for doing so, saying something such as, “I am glad you can tell me how you feel.” If the person has indicated that they feel bad in some way about discussing or remembering the event, add, “I am sure you do feel bad (or sad, or whatever word they used), these things are not easy to talk about.”

When the individual is not able to tell you how they feel, it can be useful to check out with them their perception of their feeling state. For example, “I notice you looked down at the floor just now and go quiet. It looks like you felt kind of sad. Is that right?”

In keeping with the focus on respect for the individual's limits, it is a good idea to ask permission to continue this line of questioning. It is important, however, to tell the individual your rationale for continued questioning, as this may help him or her to go on with the process. You might say something like, “I know this isn't easy to talk about, but if it's all right with you, I'd like to ask you some more questions. I'd really like to understand what you went through, and how you feel about it. Also, if you and I look at what's been going on, we might be able to figure out what you can do to feel better. Is that okay with you?”

Remember that it is better to go slowly and continue this checking process, repeating your understanding of what you have heard for verification. This demonstrates your interest in truly understanding the person, which is therapeutic in its own right, as well as being helpful for individuals who have speech or language difficulties. As with all trauma victims, establishing safety and trust is essential to the treatment process.

SYMPTOMS MAY BE DIFFERENT

In your assessment of depressive symptoms, bear in mind that individuals with ID may be more likely than non-impaired adults to experience irritable rather than sad moods when depressed. Angry, aggressive, and self-injurious behaviors may also be displayed by depressed individuals with ID. Many referral problems are initially presented by staff as noncompliance, temper tantrums, self-abuse, or going off with no provocation. Individuals with ID who exhibit such behaviors are often depressed and frequently, although not always, have histories of traumatic exposure. (Razza-Tomasulo, 2005, p. 138)

Razza and Tomasulo go on to suggest simple ways to inquire about symptoms of anxiety by using words such as “jumpy,” “nervous,” or “scared.” They note that it can be helpful when asking about any symptom experience to clarify it with concrete, real-life examples. “Sometimes, after a bad thing happens, people feel kind of scared. Do you feel scared sometimes, like you’re nervous and it’s hard to calm down?”

If they answer affirmatively, they follow with increasingly concrete questions to assess the frequency and specificity of these experiences. For example, “Do you feel nervous when you lie down to go to sleep at night, or when you wake up in the morning? Do you feel nervous at work? Do you ever feel nervous at home? What happens at work that makes you nervous? Note that the questions suggested are simply examples of the types of questions that might be used to encourage the individual to describe their symptoms. It is important not to barrage the individual with questions but rather to affirm and nurture the person along as they begin to respond (Razza-Tomasulo, 2005, p. 139).

If you believe the individual may also be suffering from PTSD, you may also want to ask questions to discern if they have intrusive memories, flashbacks, or nightmares. It can be useful to ask them if they have “bad dreams.” You might also ask, “Do you ever feel like you can’t stop thinking about what happened, even when you want to?” and “Do you have to try really hard not to think about what happened?” The re-experiencing aspect of PTSD intrusive memories, flashbacks and nightmares can also show up as “trauma-specific reenactments,” especially in children where they act out behaviorally the traumatic episode experienced with themselves, with toys, or with other children. In adults, these are more typically expressed as head banging, picking at their skin, or biting themselves. This is particularly true in adults whose cognitive limitations are severe (Razza-Tomasulo, 2005, pp. 139 -140).

Individuals with ID often have a lowered sense of self esteem and personal power because of their experience growing up with a disability. Therefore it is important to remember that this diminished sense of self may manifest itself through the victim’s belief that what happened was in some way their own fault. Unfortunately, this is often reinforced by angry responses by well-meaning parents and caregivers who respond to an incident by asking questions or making comments such as “you know better,” “how could you have not yelled when he grabbed you?” etc. It can be helpful for the therapists to add comments such as “Often people who have been abused like you feel it might have been their own fault, even though it wasn’t. Do you sometimes feel like that?” “Now that the abuse is over, is life pretty much the same as it was before, or is it different somehow?” The most important thing to look for is how the person really sees themselves.

In assessing who is accessible to them for good social support and secure attachment, it can be helpful to ask questions such as, “Who can you tell if you have a really bad problem?” “Is there anyone who would

help you even if you made a really bad mistake?" For individuals who need more concrete examples, you might try something like, "If you had to go the hospital to have an operation, who would you want to go with you?" (Razza-Tomasulo, 2005, p. 142).

Always remember that the assessment of a person need not begin or end with first interview. All individuals need to feel a measure of safety and trust before they are willing to disclose their traumatic histories. Individuals who appear to be in distress and who exhibit symptoms deserve the opportunity for treatment, even if clear information concerning the details of the trauma cannot be obtained or verified that it took place.

V: TRAUMA INFORMED CARE & POSITIVE CULTURE INITIATIVE

TRAUMA INFORMED CARE

Given the high incidence of abuse by individuals with intellectually disabilities, it is important that MH & DD service providers understand the concept of trauma informed care and create service environments that are sensitive to the needs of individuals who have experienced trauma in their lives. As the National Center for Trauma-Informed Care notes, “traumatic experiences can be dehumanizing, shocking or terrifying, singular or multiple compounding events over time, and often include betrayal of a trusted person or institution and a loss of safety.” Trauma can result from experiences of violence. Trauma includes physical, sexual and institutional abuse, neglect, intergenerational trauma, and disasters that induce powerlessness, fear, recurrent hopelessness, and a constant state of alert. Trauma impacts one’s relationships with self, others, communities and environment, often resulting in recurring feelings of shame, guilt, rage, isolation, and disconnection. Although exact prevalence estimates vary, there is a consensus in the field that most consumers of public mental health services are trauma survivors and that their trauma experiences help shape their responses to outreach and services.

Trauma-informed care is an approach to engaging individuals with histories of trauma that recognizes the presence of trauma symptoms and acknowledges the role that trauma has played in their lives. Trauma informed care seeks to change the paradigm from one that asks, “What’s wrong with you?” to one that asks, “What has happened to you?” In a 2008 presentation to the Florida Association of Drug and Alcohol providers’ conference, Joan Gillece, PhD, Director of the National Technical Assistance for the National Association for Substance Abuse and Mental Health Program Directors summarized and compared elements of Trauma Informed Care (TIC) with those in non-trauma informed settings. She gives concrete examples that are helpful in understanding what it means to be trauma informed.

TRAUMA INFORMED	NON TRAUMA INFORMED
What happened to you?	What is wrong with you?
Recognition of the high prevalence of trauma	Lack of education on trauma prevalence & concept of “universal precautions”
Recognition of primary and co-occurring trauma diagnoses	Over-diagnosis of Schizophrenia and Bi-polar, Conduct Disorder and singular addictions
Assess for traumatic histories and symptoms	Cursory or no trauma assessment
Recognition of culture and practices that are re-traumatizing	“Tradition of Toughness” valued as best care approach
Power/control minimized - constant attention to culture	Keys, security uniforms, staff demeanor, tone of voice, excessive use of restraints
Caregivers/supporters - collaboration	Rule enforcers - compliance
Address training needs of staff to improve knowledge and sensitivity	“Patient-blaming” as fallback position without training

Staff understand function of behavior (rage, repetition-compulsion, self-injury)	Behavior seen as intentionally provocative
Objective neutral language	Labeling language as manipulative, needy, "attention-seeking"
Transparent systems open to outside parties	Closed system - advocates discouraged
Asking individuals how they prefer to be addressed	Calling individuals by first name without permission or last name without title
Quietly making rounds and informing people of schedule	Yelling "lunch" or "medications"
"Let's talk and find you something to do"	"If I have to tell you one more time..."
"May I help you?"	"Step away from the desk"

Trauma Informed settings also pay great attention to avoid “triggering events” for their individuals. These can include a wide range of things including yelling, not being listened to, large men, restraints, being isolated, being touched, darkness, people too close, loud noises, feeling lonely, contact with family if that is associated with their abuser. The triggers will differ for individuals according to their own experience. Successful treatment centers and service agencies must pay attention to these kinds of factors in order to create a sense of safety and a place where the healing process can begin.

OHIO DODD POSITIVE CULTURE INITIATIVE

Mental health professionals should also be aware of a highly trauma informed initiative that has been under way within the DD sector for many years. John Martin, the Director of the Ohio Department of Developmental Disabilities serving under Governor Strickland and continuing under Governor Kasich formed the **Positive Culture Initiative**. His administration has focused on strengthening cultures throughout their provider sector to create environments where individuals can truly thrive. This Initiative and thinking is very significant in a sector that makes extensive use of behavior supports to also focus on the whole person.

The Initiative defines positive culture as “an intentional way of supporting all people within our communities that focuses on creating healthy relationships and acknowledging the unique gifts that each brings to those relationships. It is about making the shift in thinking away from power, control and coercion in language and actions, and toward affirmation, unconditional acceptance and encouragement.” Cultivating a positive culture includes making the conscious decision to move away from beliefs and actions that contribute to violence or emotional harm, focus solely on the person’s compliance, or maintain a social system that pushes people who are different to the fringes.

The Positive Culture Initiative partnered extensively with John McGee and his **Gentle Teaching** practices to train staff across the state of Ohio until his untimely death in 2012. The central focus of Gentle Teaching is to express unconditional love. It is the framework around a psychology of human interdependence. The main idea of gentleness is not to get rid of someone else’s behaviors, but to deepen one’s own inner feelings of gentleness in the face of violence or disregard. **Gentle Teaching** is also a

teaching approach. As such, it has four initial teaching purposes—***to teach others to feel safe, loved, loving, and engaged***. These are taught through repeated acts of love. Gentle caregivers learn to use their presence, hands, words, and eyes as their primary teaching tools to uplift and honor others.

For mental health professionals, I found the material exceptionally useful to update and broaden my perspective about working with individuals who have a developmental disability and build needed sensitivity to the most current thinking in their field. **People First Language** is essential for those who want to be successful in co-occurring partnerships but the following credo conveys very helpful and important nuances to be aware of when building relationships with individuals who have a disability.

A Gentle Teaching Primer

John J. McGee, PhD and Marge Brown, MS

- Do not see my disability as the problem. Recognize that my disability is an attribute.
- Do not see my disability as a deficit. It is you who see me as deviant and helpless.
- Do not try to fix me, because I am not broken. Support me. I can make my contribution to the community in my own way.
- Do not see me as your client. I am your fellow citizen. See me as your neighbor. Remember, none of us can be self-sufficient.
- Do not try to modify my behavior. Be still and listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.
- Do not try to change me, you have no right. Help me learn what I want to know.
- Do not hide your uncertainty behind “professional” distances. Be a person who listens and does not take my struggle away from me by trying to make it all better.
- Do not use theories and strategies on me. Be with me. And when we struggle with each other, let that give rise to self-reflection.
- Do not control me. I have a right to power as a person. What you call non-compliance or manipulation may actually be the only way I can exert some control over my life
- Do not teach me to be obedient, submissive, and polite. I need to feel entitled to say “No” if I am to protect myself.
- Do not be charitable towards me. Be my ally against those who exploit me for their own gratification.
- Do not try to be my friend, I deserve more than that. Get to know me. We may become friends.
- Do not help me, even if it does make you feel good. Ask me if I need your help. Let me show you how you can best assist me.
- Do not admire me. A desire to live a full life does not warrant adoration. Respect me, for respect presumes equity.
- Do not tell, correct, and lead. Listen, Support, and Follow.
- Do not work on me. Work with me.

VI: OVERVIEW OF SPECIFIC TREATMENT MODALITIES ADAPTED FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

The following is an overview of traditional evidenced based mental health therapies that have been successfully adapted for individuals with intellectual disabilities. Each summary will identify helpful resources for learning more about each practice in detail. The books that I found most helpful were these:

Psychotherapy for Individuals with Intellectual Disability, 2011

Authors: Robert J. Fletcher DSW and Steven Reiss PhD

Excellent overview of many practices written by individual authors

Available in paperback on Amazon: \$40.25

NADD Bookstore: Member Price \$49.95 Non Member \$54.95

Healing Trauma: The Power of Group Treatment for People with Intellectual Disabilities, 2005

Authors: Nancy J. Razza and Daniel I. Tomasulo

Interactive Behavioral Therapy – adapted for group and individual treatment

Excellent chapters on adapting for sex offenders

Good resource on adapting language and techniques with many case examples

Currently out of stock on Amazon: \$27.54

Available from NADD: Member Price \$54.95 Non Member \$59.95

Psychiatry of Intellectual Disability: A Practical Manual

Authors: Julie P. Gentile and Paulette Marie Gillig

Excellent and practical guide to assessment, interviewing techniques, and specific disorders

Good chapter on Psychotherapy written by Dr. Gentile and Carroll Jackson, LISW-S

Available in hard cover on Amazon: \$70.00

When considering one approach vs. another, it is also important to reflect on the large body of research which finds that despite therapist's beliefs or preferences for certain models of therapy, research comparing the relative efficacies of established models consistently finds no appreciative superiority of any one model over the others. In fact, the evidence suggests that it is not the particular model, but what the individual brings to the therapy, that is most important to the final outcome. What successful therapies – and therapists – have in common is their ability to tolerate the individual's pathology while mobilizing the individual's strengths (Duncan, Miller, & Sparks, 2004).

DIALECTICAL BEHAVIOR THERAPY

Dialectical Behavior Therapy was developed by Marcia Linehan in 1993 to address the needs of individuals diagnosed with borderline personality disorder who were chronically suicidal and not benefiting from traditional treatment. DBT is based on the premise that the combination of exposure to an invalidating environment, along with unknown biological factors, contributes to the development of emotional instability and abnormal reactions to emotional stimulation. The goal of DBT is to validate that the individual's behaviors and reactions are understandable, without agreeing that they are the best or only approach to solve the problem. DBT focuses on helping them learn to regulate their emotions and improve their ability to cope with stress and their interpersonal relationships. It postulates that some people have a higher than typical baseline arousal level and are highly emotionally reactive to their environments and that they have a harder time returning to a baseline arousal level. (Fletcher, 2011, p. 18)

The treatment has been expanded to address the needs of a wide variety of individuals with a range of disorders in a variety of settings – suicidal adolescents, eating disorders, treatment resistant depression, individuals who repeatedly injure themselves, individuals with multiple treatment failures, adolescents with bi-polar disorder, etc. (Fletcher, 2011, p. 14) Margaret Charlton, Ph.D. and Eric Dykstra, Psy.D have adapted it for the DD population (DBT-SP). SP refers to Special Population. This model is described in the first chapter of the book, Psychotherapy for Individuals with Intellectual Disability edited by Fletcher and Reiss. The original work outlining the model developed by Dr. Linehan is in two books, Cognitive-Behavioral Treatment of Borderline Personality Disorder (1993) and Skills Training Manual for Treating Borderline Personality Disorder (1993),

The dialectical perspective focuses on the intentional bringing together of two seemingly conflicting sides to promote multiple ways of looking at one's experiences from many sides. It reduces rigidity, excessive judgment, and blame. DBT is not aimed at reducing or getting rid of ordinary pain or discomfort, nor on ridding oneself of particular thoughts or feelings, but rather is focused on reducing unnecessary suffering. Oftentimes individuals increase their suffering by struggling against that which they cannot change, such as trying to rid themselves of their respective histories. In contrast, the focus of DBT is on reducing unnecessary suffering through skillful means, namely managing urges and emotions in the service of pursuing valued life directions despite feeling pain, experiencing negative emotions, or thinking negative thoughts. DBT advances the dictum that "no matter what, I choose how to act."

DBT is based on these working assumptions:

- Individuals are doing the best they can in the moment.
- Individuals need to do better, try harder. Wanting to change is not enough.
- Individuals have not caused all of their problems but they have to solve them anyway.
- Individual's lives are unbearable as they currently are.
- Individuals must learn new ways of being in all relevant situations.
- Individuals cannot fail in treatment – either the treatment failed or the treaters failed.
- Treaters need assistance and support when working with individuals with intensive problems.

DBT uses a combination of weekly individual therapy sessions and weekly group therapy sessions that focus on internalization of skills from four different modules: core mindfulness skills, distress tolerance

skills, emotional regulation skills, and interpersonal effectiveness skills. As a team based model, the team adopts the following agreements to provide a good foundation for working together. (Fletcher, 2011, pp. 20-21) I include them here because they are useful to all teams working in our sectors:

- **Dialectical Agreement:** Because disagreements, differences of opinion, and conflict arise, we agree to search for the synthesis in these situations as opposed to “THE TRUTH.”
- **Consultation to the Individual:** Just as we cannot “save” the individuals we work with, it is unhelpful to try and solve all of their problems for them. We use skills in our interactions with others and we coach our individuals on how to approach various approaches with others to find skillful ways of relating.
- **Consistency Agreement:** We agree that consistency is important AND real life happens. We concurrently agree to help individuals cope with failures and inconsistencies. We strive ourselves to be consistent and we acknowledge that this will not occur 100% of the time.
- **Empathic Orientation:** In order to be successful in our roles, we must be mindfully empathic toward those we work with. We agree to search for non-pejorative and non-judgmental interpretations and understandings of individual’s behaviors. We also agree to approach each other in a non-judgmental way and validate each others’ experiences.
- **Fallibility Agreement:** We agree that we are all imperfect and have permission to fail. We agree to keep each other accountable and treat each other gently and with empathy.

DBT-SPECIAL POPULATIONS

Charlton and Dyksta note that the current effort in developing DBT-SP to meet the needs of individuals with DD/ID is just beginning. They believe that DBT’s focus on the often seen constellation of multiple difficult to treat problems, vulnerability to stress, and need for intensive and long term interventions make it a good fit for the dually diagnosed. The main tenets of DBT remain unchanged; however the presentation and language were adjusted to a level that persons with ID/DD can more easily comprehend. They paired down some of the concepts or simplified them to allow for better comprehension and ability to apply the material. They also rewrote the handouts in order to increase attention and aid in understanding. Finally, they use generous amounts of individual feedback, repetition and rehearsal to aid the learning, retention, and generalization processes. Because the group skills training material was the most formalized and structured in standard DBT, they started with adapting these.

A video of a presentation given Eric Dykstra at the annual conference of National Association for the Dually Diagnosed in October 2009 can be viewed at www.CEQuick.com for \$15.00. The course focuses on the adaptation of DBT for individuals with developmental or intellectual disabilities. A paper authored by Dr. Charlton and Dykstra in 2008 about their adaptations is included in the index.

In Ohio, LifePoint Solutions has been using and adapting DBT for individuals served by Hamilton County Board of Developmental Disabilities for several years. They recently received funding through the Hamilton County DD Services from the Ohio Strong Families / Safe Communities grant to further adapt this model for individuals with intellectual disabilities.

IBT: INTERACTIVE BEHAVIOR THERAPY

As noted earlier in this paper, individuals with intellectual disabilities suffer higher than average rates of trauma, sexual abuse, and psychopathology. Nancy Razza and Daniel Tomasulo have authored a book, Healing Trauma: The Power of Group Treatment for People with Intellectual Disabilities that describes the IBT group treatment model that is based heavily on traditional models of group therapy and psychodrama modified for individuals with intellectual disabilities. IBT is based on traditional psychotherapy, not a curriculum based social skills training approach. It is process-oriented method that allows for a wide variety of curricula to be used and focuses on the rich group interactions that occur between and among members.

The special considerations and needs of group treatment for trauma and sexual abuse survivors and offenders are covered in detail in the book, but the model described is a useful one for processing a wide range of issues that individuals bring into treatment. While the book is largely focused on group treatment, it also illustrates how many of the same techniques used in group based IBT are equally helpful in doing individual treatment with individuals with intellectual disabilities.

This work was honed by the authors in the 1990's at the YAI/National Institute for People with Disabilities in New York City and the Arc of Monmouth in Tinton Falls, New Jersey. In 1993, the Robert Wood Johnson Foundation awarded the ARC a grant to provide mental health services to individuals with intellectual disabilities with specific funding for sexual abuse issues. The authors presented the IBT model at the American Psychological Association's national convention in 1998, the first continuing education workshop ever to be presented to this group at a national level focused specifically on providing psychotherapy to individuals with intellectual disabilities. Their book published in 2005 is based on their extensive practice experience and a review of the growing literature in the field. As such, it is a very practical and useful book for therapists.

The IBT model is carried out in the same way with offenders, sexual abuse survivors, and individuals with no known trauma history who display psychological symptoms – depression, agitation, anxiety, self-injurious behavior, and physically aggressive behavior. They also find that groups are successful with a range of membership – for instance, groups for survivors including members with and without known sexual abuse and a range of diagnosable disorders. Some of the specific differences unique to sex offenders are covered in a later section of this paper.

The theoretical formulations and many of its techniques are drawn directly from psychodrama as originated by J. L. Moreno and were adapted by the authors for their work with individuals with intellectual disabilities. Moreno believed that therapy ought to engage the person as completely as possible, and therefore the interactions between therapist and individual should not be limited to simply thinking and talking. He believed that action needed to be added in order to engage the individual behaviorally and emotionally. Since individuals with intellectual disabilities have a cognitive impairment, traditional “talk” therapies ask them to do therapeutic work in the area in which they are most limited. By engaging them through

behavioral and emotional means as well, the authors found success in increasing their opportunity to do meaningful therapeutic work.

IBT is also based on the work of group psychotherapy pioneers who shared the underlying philosophy that an individual's personality, and thus the individual's particular psychopathology, develops through personal experiences with other people. Logically then, changes in these styles can best be brought about in connection with others as well. The group therapy format allows for a controlled connection with others in which each individual's style of interrelating can be examined and altered. (Razza-Tomasulo, 2005, p. 43)

IBT STAGES OF TREATMENT

In traditional psychodrama, a session is composed of three stages: the warm-up, the enactment, and the sharing. The authors found that a longer, more intense preparation for the enactment was necessary and changed the traditional sharing stage because of its reliance on abstract thinking. They replaced it with a stage called affirmation and used it as an opportunity to reinforce each member for the productive work done in the session. Following is a summary of the 4 stage group process that they evolved – orientation, warm up and sharing, enactment, and affirmation.

Orientation Stage

When beginning a new group, the facilitators present the basic rules of group: safety and confidentiality. The authors explain that in order for the group to be a safe place for each member, there can be no physical violence or threats. They give concrete examples of the concepts and ask members to feed back what they have heard until it is clear that they understand what is meant. Violence or threats of violence toward group members in or out of sessions are grounds for termination from the group. In terms of explaining confidentiality, they take great pains to clarify that members cannot talk about what other members say outside of the group. To concretize this idea for lower functioning members, they stress that they should not repeat the names of other members outside of the group. They also stress to the members that they can, if they wish, talk about their own group experience with others – but not about other's experiences.

In new groups, the authors present the information on safety and confidentiality over the first few sessions and repeat it when a new member joins. The authors devote an entire chapter to inevitable trouble spots that will occur when interpersonal conflicts arise or confidentiality is broken. They give many examples of how they process these breaches with the individual involved and within the group. Generally, they end up imposing a one session suspension on a member who breaks one of the two primary rules (safety and confidentiality) after a session in which the issue has been processed with the remaining group members. They have found that members with intellectual disabilities, a working comprehension of the group rules often comes only through experience – and that experience entails making mistakes. They retain the right to terminate a member if their continuation would be damaging to the other group members. This is particularly true if an individual with sociopathic tendencies that were not picked up in the initial interview violates a group rule (Razza-Tomasulo, 2005, pp. 171-179).

Typically members begin the orientation stage by sharing information that does not have powerful emotional meaning for them and may be rather superficial. Deeper, more emotionally meaningful material comes later once a sense of acceptance and safety is established. These initial disclosures during the orientation stage are used to build an agenda for the day's session, with each member having an

opportunity to present what he or she would like to work on. Typically each group is started by asking if anyone would like to speak first, or if anyone has anything left from the last session that they feel needs more time. The therapist generally asks each member who has presented an issue to then choose another member and ask that person if they would like to present next. Ideally, there are two therapists to facilitate the group process.

The focus during this stage is on strengthening communication skills. The authors found that most beginning members are not accustomed to be listened to or good at listening to others, particularly to their peers. Once a member begins speaking, the facilitator needs to interrupt that person's discourse early on (usually within 15 to 20 seconds of their talking) and ask the group, "Who heard what (speaker's name) said." This feedback loop provides an opportunity for members to strengthen their listening skills while allowing the sender of the information an opportunity to clarify their remarks. Once satisfied that one or two members of the group have adequately heard them, the sender is then asked by the facilitator to choose the next person to send information. This allows for the interaction between members to begin as soon as possible while keeping the facilitator out of the choosing process. This process continues until each member in the group has had the opportunity to share, while along the way, the facilitator asks the members to orient toward one another by demonstrating eye contact and appropriate body positioning.

The primary task of the facilitator is to identify behaviors that represent therapeutic factors and reinforce members at the time of their emergence. For example, "Ellen, I noticed you looked at Carmen the whole time she was talking today. You are really getting to be a good listener." In addition, the facilitator should repeat this specific accomplishment, and others that may have occurred, during the affirmation stage.

Warm-Up and Sharing Stage

The warm-up and sharing stage is characterized by a shift to deeper self-disclosure. The goal for this stage is for each member to clarify his or her agenda item or issue to be worked on for the day. The facilitator's job during this phase is to acknowledge each individual's honesty or courage in bringing up their issue, supporting it as a viable agenda item, and checking to see who heard it.

Enactment Stage

In the enactment stage, one or more of the issues presented is moved into action. The member whose issues will be addressed in the enactment is referred to as the "protagonist." Other members who help by playing supporting roles are called "auxiliaries." A general guideline for the facilitator to use in choosing a protagonist is to look for someone who has a pressing need to work on that day, and who appears to have the interest and attention of a good number of group members.

During this stage, a variety of action techniques are used to stimulate multiple senses, and as such, enhance both attention and memory. For example, a "double" is used to create support for the protagonist by having another member, or the facilitator, stand behind the protagonist's chair and say the thoughts and feelings the protagonist may be having. The opportunity for change is greatly enhanced if the double can create an atmosphere in which the protagonist feels supported and understood. Two doubles may also be used to verbalize two conflicting feelings the protagonist may have. Any number of group members may be asked to double in an effort to help the protagonist experience such therapeutic factors as acceptance and universality with other members.

The enactment stage accelerates the emotional involvement of the members. Emotional involvement, as well as behavioral engagement, greatly enhances the power of the group, getting member's attention, facilitating memory of the experience, and allowing for an opportunity to experience an altered or enhanced

sense of self for all members participating. At the tail end of the enactment stage, great care is taken to affirm the protagonist for their effort in the group. Others are encouraged to say what was good about what the protagonist just did. Also, it is important to affirm each of the doubles as well as each of the members who gave their time and attention to the enactment.

Other techniques that may be used in the enactment stage include the empty chair, role reversal, representational dramas, and the use of split doubles to represent internal conflicts. Also, auxiliaries can assist protagonists by playing the roles of other key people from the protagonist's life. The book gives many examples and details about the use of these techniques in the chapters about their groups with offenders, survivors, and abuse avoidance.

Affirmation Stage

The affirmation stage allows for feedback to be given to each member pertaining to his or her participation in the group. The therapist provides each member with strong verbal acknowledgements for behaviors they displayed that reflect positive therapeutic factors or show evidence of psychological growth. During this phase, the facilitator is highly directive, allowing no negative feedback to be given to any member. Each member should be able to take away at least one positive piece of an enhanced self-concept, e.g., "I am getting to be a good listener" or "better at controlling my temper."

In addition to affirming enhanced self-concept and helping members clarify specific strengths, the affirmation stage also serves to contain the affect generated during the enactment stage. The therapist brings a sense of closure to the day's emotional material. It is not a time to bring up new material or to allow for controversy or criticism.

THERAPEUTIC FACTORS

Therapeutic factors are components of group therapy that emerge during the group process. They are the specific components that benefit a member's condition. Generally speaking, the more these factors are present in a group, the more therapeutic power the group has. The authors provide detailed summaries of each therapeutic factor including (Razza-Tomasulo, 2005, pp. 53-64)

- **acceptance and cohesion** - a sense of belonging and being valued by the other
- **universality** – common acknowledgement of an experience by group members
- **altruism** – spontaneous helping another without the need to have that help reciprocated
- **installation of hope** – positive changes that occur as a result of having worked through an issue
- **catharsis** – purging of emotions or witnessing a catharsis
- **modeling** – the impact of watching others struggle with important issues in their lives and learning something for oneself
- **self-understanding** – learning important things about oneself in various ways, especially through feedback from others and experiences had during enactments.
- **learning from interpersonal action** – learning that takes place as a by-product of trying to adapt to and relate constructively to the group
- **self-disclosure** – providing for emotional release and the opportunity to experience being accepted by others even when one has bared "shameful" experiences. For others, it can be a helpful warm-up to beginning disclosures of their own

- **corrective recapitulation** of the primary family – working through feelings established in the family of origin to come to a corrective understanding of those feelings within the group
- **existential factors** – sharing the common bonds of death, loneliness, suffering, and loss
- **impacting of information** – introducing specific didactic information and using “teachable moments” that occurs as a result of the therapeutic work because of the emotional state evoked
- **development of social skills** – feedback available to members concerning social interaction from the facilitators and eventually from other members in the group

USE OF INDIVIDUAL THERAPY

The authors recommend that every effort be made to create therapy groups that can accommodate a majority of individuals with intellectual disabilities. The group format and use of psychodrama techniques is well suited to this population. They recommend individual therapy for those patients who are not a good fit with existing groups and for severely paranoid or sociopathic individuals. They also recommend individual treatment as a first course of action toward the following ends:

- further assessing an individual to determine treatment needs – individual, group, behavioral intervention, need for family member/caregiver involvement
- orienting the individual toward the therapy process
- helping the individual to identify treatment goals.

Individuals whose cognitive understanding is so low that they are completely unable to describe any of their experience in words are generally referred for behavioral intervention. However, individuals whose verbal ability is extremely limited (such as a tendency toward accurate but one-word responding) and who need consistent direction for fundamental interpersonal skills may still be accepted for group therapy. The authors recommend keeping a number of groups running so that a range of needs can be accommodated. An individual whose interpersonal skills are severely limited and requires a great deal of work on skill development to function in a group is generally accepted into a group in which other members have similar needs. In both “lower functioning” and “higher functioning” groups, however, the authors include individuals across something of a range, finding that the members at the upper levels of skill development in relation to others in their group, offer potent models for less developed members and positively influence the evolution of the group’s functioning. The more skilled members benefit from the expanded sense of self they develop as a result of making those contributions.

OVERCOMING RESISTANCE TO GROUP

It is not uncommon for individuals who are good candidates for group to be anxious and resistant to efforts to include them. This is generally true for all people, irrespective of their level of intellectual functioning. The authors use a limited number of individual sessions to explore the specifics of the fear and to dispel misconceptions. They then present the individual with a plan to test out the group that includes a safety valve. They are asked to attend 4 sessions and make a decision after that time. In general, talking about a group is no match for actually experiencing it, and the authors find that for most individuals, the experience puts an end to the anticipatory anxiety. The freedom to opt out after 4 weeks gives the individual an important sense of control.

TERMINATION as GRADUATION

The authors note that treatment for trauma survivors and offenders requires long term treatment, often requiring treatment over several years. They acknowledge this is not popular in terms of managed care, but the group therapy format is a pragmatic way to keep the overall costs low. The cost must also be weighed against the costs of not providing adequate treatment – financially, emotionally, and socially. In the vast majority of cases, the authors found that long-term group therapy led to decreased problematic behaviors and symptoms, as well as gains in self-control, self-efficacy, and self-esteem.

The criteria to determine readiness for termination include:

- significantly reduced symptoms
- a moderate sense of self-efficacy (especially with respect to one's improvement)
- a reasonably well-functioning support network

As the authors approach termination, they secure the individual's permission to touch base with significant others in their lives – parents, group home managers, job coaches, social service staff who may have referred the individual – to get their feedback about the individual's behavior and to determine if there are concerns about which the therapists were unaware. It is important to assess an individual's social system's ability to maintain support, and for the individual's ability to make use of his or her system.

In general, group members with intellectual disabilities are less likely than non-disabled individuals to initiate termination from treatment. Razza and Tomasulo find it helpful to refer to termination as "**graduation**" to emphasize the effort and achievement of the individual in getting to this point. Within the group, the termination process for an individual begins with a review of that member's accomplishments. This is generally done at the end of a group session after an enactment or instead of an enactment. They put an empty chair in front of the graduating member. Then each member and the therapists take a turn sitting in that chair, facing the member directly and saying their goodbyes. Usually one of the facilitators goes first to provide a model for the members. The termination process also highlights the specific ways in which the graduating member has helped the group, such as by having offered support to others and taking on roles during enactments. At the end of this enactment, one of the facilitators presents the graduating members with a certificate of accomplishment to reinforce a sense of pride in the individual for their achievement.

It is essential that the member feel a sense of self-efficacy with regard to their improvement, and not attribute it to the group or to the facilitators. This is important so that they do not feel dependent on the group or others to sustain their improvement and to overcome a self-concept that has often been shaped by an intellectual disability that encourages a passive role in life. When members leave, whether through planned or unplanned terminations, the authors make a point of explaining that the member is always welcome to come back. When a second round of treatment is needed, the return to group is framed as an additional growth step representing the individual's motivation to further improve his or her life.

IBT TREATMENT FOR SEX OFFENDERS

This overview of the book by Razza and Tomasulo does not begin to convey the depth of specific information it contains on working with sexual abuse victims and offenders. The book contains specific chapters on both and will be a highly valuable resource to therapists working with these individuals. (Razza-Tomasulo, 2005, pp. 71-110) Individuals with intellectual disabilities who commit sexual offenses typically have poor psychological functioning, a damaged sense of self, inadequate interpersonal skills, and a need for treatment that improves their overall functioning. Many come from homes in which a parent was alcoholic, abusive, or both. They have an identity that has been compromised not only by their failure to be "normal" which is a shameful life experience for many individuals with intellectual disabilities, but also by the experience of growing up amid chaos and witnessing and surviving physical brutality.

Their groups for offenders typically include members with aggressive and non-aggressive sexual offense behaviors, other aggressive behaviors, and a range of diagnosable psychological disorders. In the chapter devoted to treatment for offenders (Razza-Tomasulo, 2005, pp. 91-110), they address additional factors that must be considered in the intake process and involvement of all parties involved with the individual. During the initial interview with the individual, it is necessary to inform the individual that, because he has a problem that hurts other people, his admission into the group rests on his agreeing to a team meeting to discuss his treatment. It is essential to have the individual sign releases at this time to allow for communication between the treating clinician and other team members.

During the initial meeting of all parties, each team member's responsibility in supervising the individual is clarified and agreed upon. The team may include family members or group home staff, job coach, case manager, and legal guardian if the individual has one. If they have lost a job because of their offense behaviors, it should be made clear that they are no longer working at their job because of their behavior. They also use this meeting as an opportunity to make clear to the individual the exact relationship between their behaviors and consequences. Often, individuals with intellectual disabilities are not legally charged with their offenses. Thus the team member closest to the problem is in the best position to deliver this information. In any case, the authors note it is a poor strategy for the clinician beginning treatment with the individual to be the first to confront him with the reality of his behavior and its consequences. However, they find that staff members, teachers, and family members frequently think the treating clinicians will completely take over the job of talking to the individual about his offense behavior.

The book also addresses differences from typical sex offender treatment that stress admission of guilt as the very foundation of treatment requiring such admission prior to starting treatment. The authors' experience however has found that this acknowledgement and becoming fully aware of the problem and being able to own up to and verbalize the problem is a therapeutic accomplishment that often evolves as a result of psychotherapy. They treat the denial as part of the group process and discuss some specific examples. As long as the individual agrees to allow communication among clinicians and other team members and participates in the initial team meeting in which his offense and supervision are discussed, the authors consider them as a viable candidate for psychotherapy.

The chapter also addresses the difficulties offenders face with intellectual disabilities in generalizing the learning to other situations or understanding all the implications of the law. The offender with intellectual disabilities often has difficulty understanding that if something is wrong in one situation with one person, it

may also be wrong in another situation with another person. The book gives detailed examples of how they work to improve this generalization.

SEXUAL ABUSE AVOIDANCE TRAINING

Given the individuals with intellectual disabilities are at greater risk, especially females, this training is widely needed. The authors have adapted the IBT therapy model to an interactive behavioral training program. Groups are conducted for approximately 8 members at a time who attend 12 sessions of training. This is different than the open-ended therapy groups. The authors recommend the training be limited to adults, with the youngest end of the range being those in the last years of a special education high school program (ages 18 to 21). They have also found members to be most comfortable when the age range within their sexual abuse training group is only moderate. At the time of the book's publication date in 2005, they were still experimenting with the optimal number of sessions and closed vs. open-ended groups. The 4 stage format for the IB/SAAT is "sociodramatic", rather than "psychodramatic." This distinction changes the role of the facilitator and is explained in detail in their book (Razza-Tomasulo, 2005, pp. 111-128).

MINDFULNESS-BASED PSYCHOTHERAPEUTIC PRACTICES

Bronwyn Robertson provides a helpful chapter within the book authored by Robert Fletcher, Psychotherapy for Individuals with Intellectual Disability, on the adaptation and application of mindfulness-based psychotherapeutic practices for individuals with intellectual disabilities (Fletcher, 2011, pp. 91-106). In general, mindfulness-based psychotherapy utilizes self-regulative practices to enhance attention, awareness, acceptance, and emotion regulation. In the past two decades, mindfulness-based practices have become increasingly more integrated within mainstream psychotherapy and adapted to and applied to varying populations. However, very little has been published on the adaptation and application for individuals with intellectual disabilities despite their high risk for developing anxiety and mood disorders and difficulties with self regulation, anger, and stress management.

Mindfulness skills have much in common with those that are utilized in more traditional psychotherapies – observing, noticing, describing, labeling, and participating are similar to those used in cognitive behavioral therapy (CBT). Mindfulness based psychotherapies are essentially newer or alternative approaches to CBT that may vary in their components, but generally involve behavioral practices, cognitive strategies, and practices which enhance concentration. The main approaches to mindfulness-based psychotherapy include:

- Acceptance and Commitment Therapy (ACT)
- Mindfulness-Based Stress Reduction (MBSR)
- Dialectical Behavior Therapy (DBT)
- Mindfulness-Based Cognitive Therapy (MBCT)

Mindfulness is an acceptance-oriented psychological process of relating openly with curiosity and receptivity, to one's thoughts, sensations, and emotions. Studies indicate that the practice of acceptance skills, which counter the suppression of unwanted thoughts, feelings, and sensations, leads to the alleviation of short-term distress and enhanced emotion regulation (Masicampo and Baumeister, 2007). Acceptance involves the noticing, observation, and letting go of unpleasant experiences rather than challenging and reframing them. The experiential exercises involved in mindfulness-based approaches offer a more accessible intervention model for individuals with intellectual disabilities than traditional CBT models based on verbal reasoning skills.

Although there are few published studies on the adaptation of mindfulness-based treatment for individuals with intellectual disabilities, mindfulness-based, mind-body relaxation practices have been used effectively with this population for many years. Uma, Nagarathna, Vaidehi, and Seethalakshmi (1989) pioneered the use of yoga as a therapeutic tool for children with ID. They found that sustained yoga practice resulted in decreased anxiety, enhanced social skills, and improved focus of attention.

Recent studies have explored the adaptation and application of a specific mindfulness-based meditation practice, known as "Meditations on the Soles of the Feet," for use with individuals with moderate ID at risk of losing their community placements (Singh, Lanciono, Winton, et al, 2008). Participants were taught to redirect, or shift, their focus from the object of their anger to a neutral spot on the soles of their feet. The training encourages participants to "stop and think before acting" by redirecting their attention from anger to

a neutral emotion and to focus on a neutral part of their body so that they can calm down before reacting. Results showed a substantial decrease in physical aggression by adult offenders with ID.

In preparation for mindfulness-based treatments, individuals benefit from training in vocabulary and basic skills needed in the identification and rating of emotional states and sensations. Materials, such as emotion identification and mood charts that have been modified for individuals with intellectual disabilities are very helpful.

Case Examples

Robertson gives several case examples in his chapter in Fletcher's book on how he has used mindfulness-based treatment practices in the treatment of anxiety, depression, physical aggression and self injury for individuals with intellectual disabilities. By combining elements of ACT, expressive therapy, mind-body relaxation, and meditative exercises based on everyday activities such as breathing, exercising, and playing, he has adapted practices for individuals functioning in the lower moderate to mild range of ID, in both individual and group therapy formats. He has also been successful in the integration of individuals with ID into mainstream mental health psychotherapy groups once they have been oriented to the basic techniques.

He teaches simple relaxation practices through modeling and experiential exercises. Simple deep breathing and self-soothing techniques are taught to manage physical aggression and self injury. In one case example, a young man at risk of losing his day support services due to periodic explosive physical aggression, self injury, and property damage, Robertson taught him to utilize a deep breathing technique similar to silent "whistling," humming, and simple yoga poses to self soothe, calm, and redirect himself. Staff was trained to cue him to use these techniques periodically throughout the day and during times when he was exhibiting signs of distress or agitation. These techniques were taught in weekly sessions over 6 months and then tapered to twice monthly as incidents of serious aggression and self injury decreased. Incidents of serious aggression and self injury decreased from twice weekly to less than once monthly, and the individual was able to maintain his day support services.

In another case example, Robertson worked with a young woman with mild ID and an early childhood of severe sexual and physical abuse by her biological parents and multiple foster care providers. She experienced nightmares, flashbacks, insomnia, isolation, and frequent passive suicidal ideation. She was at risk of losing both her community supportive living arrangement and employment due to her severe, explosive physical aggression which often resulted in injury to staff and was causing high staff turnover.

She participated in individual therapy sessions for 11 months, beginning with twice weekly sessions for the first two months. During the first two months of therapy, the focus was on creating rapport, trust, and a safe therapeutic environment. During this time, she was also introduced to deep breathing techniques, guided imagery and expressive arts exercises such as mandalas and "creating a safe place" drawings and journaling. Deep breathing was introduced via modeling and use of woodwind instruments, pinwheels, and blowing bubbles. Guided imagery involved metaphors and images associated with safety, security, calmness, and peace. The young woman was guided in finding her own images, sensations, places, colors, aromas, textures and objects associated with safety and peace. These were then used during relaxation exercises while in session and placed throughout her apartment and at her work station.

After completion of the first two months of therapy, she began to work on identifying her triggers, observing, noticing, and letting go of intense, unpleasant thoughts, feelings, and sensations and redirecting her

attention to “safe, calm” images, thoughts, experiences, and emotions. She was given daily mindfulness practice homework which she eagerly completed. Incidents of aggression increased to twice weekly during the first few weeks of treatment but with less intensity and tapered over the course of treatment. No staff sustained injuries during this time. By the sixth month of treatment, there were no reported incidents of aggression in the individual’s work environment and incidents at the residence decreased to less than once monthly. She no longer reported suicidal ideation and her nightmares decreased from nightly occurrences to an average of twice weekly. Robertson’s two year follow up showed she had maintained both her employment and supported living services.

POSITIVE PSYCHOLOGY PRACTICES

Positive Psychology is an emerging field of practice and research that focuses on the experience of positive emotion and the roles of healthy emotions in daily life (Seligman, 2005). Dr. Martin Seligman is credited with the upsurge of interest in this area noting that psychologists have studied illness for too long, ignoring focus on happiness and wellbeing. Positive Psychology interventions are designed to increase an individual's experience of positive emotions, engagement with life, and discovery of meaning in life. Positive psychology researchers have amassed data over the past 25 years to show that therapeutic interventions based on positive emotion produce rapid improvements in mental health.

Positive psychology approaches align well with the focus in the DD field to help individuals identify their strengths and interests and pair them with supports and resources. The supports that a person uses often are arranged to increase their sense of wellbeing and improve the quality of their life.

Positive psychology merges with the concept of self determination in that it assumes that people with and without disabilities can take control of their lives, make choices based on their preferences, and with support, make decisions that lead to positive futures (Wehmeyer & Mithaug, 2006). The clinical practice of Positive Psychology does not ignore the real challenges that individuals with disabilities experience as they attempt to live fulfilling lives, but seeks to balance the traditional focus of psychotherapy on pathology and disability with a focus on positive emotions and building individual strengths (Park & Peterson, 2008).

Kaufman (2006) identifies four techniques for integrating concepts of Positive Psychology into conventional forms of individual or group therapy:

- **Shift the individual's focus from the negative to the positive.**
Since most individuals seek therapy to obtain relief from the problems they are experiencing, they tend to focus their attention on negative events, and the process of traditional therapy may encourage this. To change this pattern, individuals can be instructed to keep a daily record of positive events or interactions. They can record lists of accomplishments, instead of the number of times they performed "problem behaviors."
- **Identify a personal strength and use it each day.**
Just as we exercise our bodies to become stronger, using personal strengths regularly can improve our life functioning. In this technique, the therapist, family members or care providers can serve as coaches, to remind, encourage, and reinforce the use of strengths.
- **Find a balance between the negative and positive.**
In this case, it is important for the people who interact with the individual to actively recognize the person's strengths, while providing constructive feedback regarding problems the person experiences. All too often, it is the reactions of others that keep the focus on the problems and ignore the many ways the individual attempts to improve him or herself.
- **Promote feelings of hopefulness.**
Feelings of hopefulness may increase the ability of individuals and family members to deal with problem they encounter. Individuals seeking therapy may have come to feel overwhelmed by the

duration, scope, or intensity of the problems. In this case, the therapist works to make the problem more manageable, by creating incremental, achievable goals. One way this can be done is by breaking down the problem into smaller parts and addressing the parts sequentially.

Within the field of Positive Psychology, conceptual frameworks have emerged that have relevance for the treatment and support of individuals with intellectual disabilities. Frederickson (2002) has suggested that negative emotions such as anxiety narrow a person's responses to an event, making it more likely that the person will engage in limited, self protective behaviors. Conversely, positive emotions broaden a person's responses, creating opportunities for personal growth and increasing repertoires of positive, adaptive emotion, cognition, and behavior. This "**broaden and build**" theory of positive emotions suggests that positive affective experiences contribute to personal well being, growth, and development, helping individuals develop a variety of adaptive behaviors including greater persistence, flexibility, and resourcefulness in problem solving.

Often the dominant narratives in the lives of individuals with intellectual disabilities are complaints about the quality of care-giving that they receive or lack of access to desired items or activities. Often caregivers encourage this behavior by the quality and content of their communication. If a caregiver asks, "How are you feeling today," the individual with ID soon learns that answering "I'm feeling great is likely to yield less sustained attention than the expression of problems (Fletcher, 2011, p. 74).

When asked to think of important life events, they may often speak of disappointments or abuse. Often this too is unintentionally reinforced by caregivers and helping professionals. Positive Psychology Interventions can be adapted to and supported by caregivers and others to refocus attention and recall on more positive emotions and events in their lives. Simple accommodations such as having someone else write down the positive events in a Three Good Things journal as the person speaks them or using a tape recorder to keep a log of them, can help a person with intellectual disabilities achieve the benefits of this exercise. The important thing is that the person spend some reasonable and regular time focusing his or her attention and recall on positive events in his or her lives and the good things that others have done to display affection and support for them. Examples of Positive Psychology Interventions that can be adapted for individuals with intellectual disabilities include:

Signature Strengths

An individual's signature strengths can be identified by taking a free online inventory at www.authentichappiness.org to receive individualized feedback about their top five signature strengths (Seligman & Peterman et al, 2005). There is also a separate survey for children. Individuals are encouraged to broaden and build on these strengths by using these strengths in a new and different way every day for a week. This exercise can be adapted for individuals with intellectual disabilities by having caregivers or family members completing the assessment with them or for them. Examples of past uses of these strengths can be used to illustrate their meaning.

You at Your Best

Seligman developed this exercise in 2005 in which participants were asked to write about a time when they were at their best and then to reflect on the personal strengths in the story. This can be adapted for individuals with intellectual disabilities using caregivers to give examples, giving a camera to the individual with ID to enable them to identify good things via pictures, using forced choice options, pointing out when they are at his or her personal best, keeping an ongoing log.

Count Your Blessings & Acts of Kindness

This technique was developed by Lyubomirsky et al. in 2005. Participants were asked to either count their blessings once per week or three times per week. Some were asked to perform 5 acts of kindness all in one day or spread out over one week. All of these activities increased participants' level of happiness. This exercise can be adapted by assisting individuals with intellectual disabilities to volunteer, participate in family and community rituals, keep a fun to do list, and participate in service learning projects. Caregivers can be encouraged to create opportunities for a more meaningful life and teach individuals how to engage in them more fully. These positive experiences can be captured through photos that are displayed or kept in a gratitude or happiness journal.

Case Examples

E. Richard Blumberg gives several case examples from his therapy practice in the chapter on Positive Psychology in Fletcher's book on Psychotherapy for Individuals with Intellectual Disability (Fletcher, 2011). In one example, Robert was referred for therapy by his group home. He was 28 years old with a diagnosis of mild MR with problems of anger and aggression. He had recently begun to refuse to go to his workshop program and on days when he did attend, he often refused to work and frequently argued with co-workers. His support provider reported that Robert made unreasonable demands on staff and typically refused to participate in scheduled activities. He was difficult to get up in the morning and often refused to go to work. Behavioral programs, such as contingent reinforcement, did not seem to work. Staff were frustrated with Robert and felt helpless to improve the situation.

Robert stated that his reason for coming to therapy was because he didn't like his job, the place he lived, or his housemates. He reported that he didn't have any activities outside of his day program and that his group home staff wouldn't take him anywhere. He made numerous complaints about staff at this day program, group home, and housemates. He appeared to be a young man who experienced few positive emotions and was not engaged in his life.

In response to the therapist's questions about things he liked to do, Robert responded that he liked to spend his own money, but quickly responded that staff wouldn't let him. He liked to visit his parents but added that he often fought with his brother. He liked to visit his girlfriend but again fought with her. He reported he was good at house and office cleaning and that he enjoyed the feelings of accomplishment when he was able to make things look "nice." He was not able to identify other personal strengths. Provided with some examples of strengths his therapist had observed during the session, Robert agreed that he was a tireless self-advocate, that relationships were important to him, that he liked orderly and clean environments, and that he had high standards for quality when it came to his work.

Robert was instructed to meet with his residential support staff each evening before bedtime and to think of 3 good things that had happened that day. The staff member would help him reflect on these positive events and record these for him. The therapist told Robert they would discuss these at their next weekly session. Robert's parents and support providers were invited to the next session. It began with setting an agenda, with input from Robert, his parents, and support providers. The agenda began with a discussion of the good things that happened during the past week, a discussion of Robert's strengths, his relationship with support staff and his roommate, visits to his parent's home and goal setting. Robert's support provider read the list of positive events and experiences and Robert commented on them. The good things included eating foods that he liked, watching favorite television shows, shopping, and several incidents when Robert had been kind to someone else. The staff and family reviewed Robert's strengths from the previous session and added that he was good at recognizing other people's needs and providing

help; he was very good at conversation and had a big vocabulary; he excelled at managing his money; and he had an excellent memory being able to remember details of conversations, birthdays, and other personal information about people in his life. The information about positive events and signature strengths were summarized, recorded, and shared with the team.

The next topic was goal setting and the therapist suggested that the team consider building on Robert's strengths and the events he had experienced that provided him with positive emotion. The team considered ways in which Robert could use his strengths in different ways throughout the week. A brainstorming list was created that included volunteer opportunities, finding a new job in home or office maintenance; sending birthday and holiday cards to family and friends; creating a "happiness book" of pictures of friends, family, vacations, and trips; can creating a picture menu of favorite foods to use when shopping for groceries. Robert agreed to continue his journal of good things that happened each day and that he and his support provider would call his parents at least once a week to share these with them.

In subsequent sessions, Robert, his parents, and support providers continued to review the positive events in his life. Robert continued to complain about various people and events, but his complaints steadily decreased. He began volunteering at a nursing home in the afternoons by assisting the nursing home staff, delivering mail and talking with residents about current events, sports, or other topics. At home, he became responsible for taking inventory of food and household supplies, and using pictures and labels, developed the bi-weekly shopping menu. His happiness book evolved into a "happiness wall" in his bedroom. He took up "power walking" with one of his housemates and began to lose excess weight.

Robert's story is typical of many individuals with intellectual disabilities who become dissatisfied with the lack of pleasure and meaning in their lives. His attempts at self-advocacy had become a problem for others and eventually for him, keeping him locked in an emotional state of frustration and anger. The Positive Psychology interventions shifted the focus of Robert's attention and the attention of those around him from negative events and emotion to positive feelings and activities (Fletcher, 2011, pp. 82-84). Given that the interventions are simple, they can be performed by an individual without the assistance of a therapist, unlike many traditional therapies. Care providers, educators, or family providers can be enlisted to provide these supports.

CONCLUSION

I hope that this white paper has been useful for those who want to deepen their practice and broaden their learning about individuals with developmental disabilities and their mental health needs. The most important step is a commitment to learning and getting comfortable in the “learning as you try” state of being. The sector is evolving and growing from the lived experience of therapists who are making that journey.

The research has give me a much deeper appreciation of the underlying power of relationships, trust building, safety and listening as the essential tools that are universally valuable to working with all people. These skills strengthen the therapeutic impact of all staff working in the mental health and developmental disability systems and are essential to the cultures we create in every setting in which individuals with disabilities live, work, and play.

If you are interested in learning more, continue to reach out to the MIDD CCOE and Positive Culture Institute. They are committed to ongoing trainings and initiatives to expand the knowledge and skills of professionals who want to do this work. Connecting with other professionals on this learning journey has been enriching and well worth the investment of time and energy. I hope to meet more of you in my own journey.

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Authors: Robert J. Fletcher DSW and Steven Reiss PhD

Excellent overview of many practices written by individual authors

Available in paperback on Amazon: \$40.25

NADD Bookstore: Member Price \$49.95 Non Member \$54.95

Healing Trauma: The Power of Group Treatment for People with Intellectual Disabilities, 2005

Authors: Nancy J. Razza and Daniel I. Tomasulo

Interactive Behavioral Therapy – adapted for group and individual treatment

Also address special needs of sex offenders

Good resource on adapting language and techniques with many case examples

Currently out of stock on Amazon: \$27.54

Available from NADD: Member Price \$54.95 Non Member \$59.95

Psychiatry of Intellectual Disability: A Practical Manual

Authors: Julie P. Gentile and Paulette Marie Gillig

Excellent and practical guide to assessment, interviewing techniques, and specific disorders

Good chapter on Psychotherapy written by Dr. Gentile and Carroll Jackson, LISW-S

Available in hard cover on Amazon: \$70.00

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Authors: Tamsin Cottis

British based; psychoanalytic approach

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