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Mental Illness & Mental Retardation: Understanding Dual Disorders

Despite the unity implied in the phrase "mental health and mental retardation" the reality is quite different. There are two distinct service systems with few interfaces. This creates difficulty for developmentally disabled persons who suffer from a mental illness. Matters are made worse because they are at higher risk of emotional problems than the general population.

Of particular concern are individuals who suffer from both mental retardation and mental illness, who are sometimes referred to as "dual disordered." These individuals and their families turn to the "MR System" for a broad array of services and supports, but psychiatric treatment availability is very limited. In 1997 MCES created an outpatient psychiatric clinic for developmental disabled individuals. It remains one of the few resources of its type anywhere.

The incidence of psychiatric disorders among individuals with mental retardation is higher than the general community realizes. There is nothing mutually exclusive about mental illness and mental retardation. Learning disability does not exempt an individual from mental illness. Nonetheless mental health services remain an underserved need of dual disordered individuals.

> "People with mental retardation are susceptible to the full range of psychiatric disorders; indeed, their vulnerability to some disorders (e.g. adjustment, anxiety, and impulse-control disorders) is somewhat higher than for the general population. Although only a minority of people with developmental disabilities have major mental illnesses, the involvement of psychiatrists need not be limited to that minority."
>
> Mark J. Hauser, MD, Psychiatric Annals (1997)

An Overview of Mental Retardation

Individuals who suffer from mental retardation are distinguished according to their IQ and their degree of impairment as follows:

Borderline Mental Retardation (IQ between 70 and 85)
These persons can function in the community with some difficulty, mostly at times of stress, but who do not need special supports.

Mild Mental Retardation (IQ is between 50 and 69)
Persons in this group tend to think concretely, and can be quite verbal and function in regular employment with the support of others.

Moderate Mental Retardation (IQ is between 35 and 49)
These individuals speak only in short sentences or single words and may communicate through gestures. Those on this level need structure and supervision from others.

Severe Mental Retardation (IQ is between 20 and 34)
These individuals are usually non-verbal, perceiving the world through sensations. They are dependent on the care of others.

Profound Mental Retardation (IQ is below 20)
These individuals usually have severe organic impairment with physical manifestations. Typically there is great difficulty with any kind of communication and have a total inability to meet their own needs.

In the most severe levels of mental retardation, such as severe and profound, there is no ability to form intent. In moderate mental retardation there may be some comprehension of situations, but not an ability to modulate impulsivity and instinctional responses. In mild mental retardation there may be full comprehension of wrongdoing but a lack of judgment to modulate behavior.

"This issue outlines the co-occurrence of mental illness and mental retardation. The information shared in this Quest is the product of a one year monthly workshop I held with a group of interested mental retardation providers to discuss the interplay between mental retardation and mental illness. A thank you is extended to all who participated in that endeavor. The current information is to be further elaborated on and is copyrighted. I plan a more extensive treatment of this topic in a forthcoming book entitled **Minds of a Lesser God**. In the next issue we will look at the problems that individuals with mental retardation have when they become involved with the criminal justice system."

Rocio Nell, MD, CPE, CEO/Medical Director of MCES

The Pendulum of Sanity

For a full overview of the Pendulum of Sanity, please refer to the February 2004 MCES Quest which can be found at www.mces.org in the Reference Room.

The continuum of states of mind we all can encounter:

Healthy/Normal – The way a person goes through life seeking to be at their best or to compromise to fit in their environment.

Adjustment Disorders – An emotional reaction to a stressor that lasts less than three months. Adjustment disorders are common and can affect anyone. They occur when a person can not cope with a stressful event or accumulation of changes leading to the development of emotional or behavioral symptoms. Symptoms may include hopelessness, sadness, crying, anxiety, worry, headaches, withdrawal and inhibition among others.

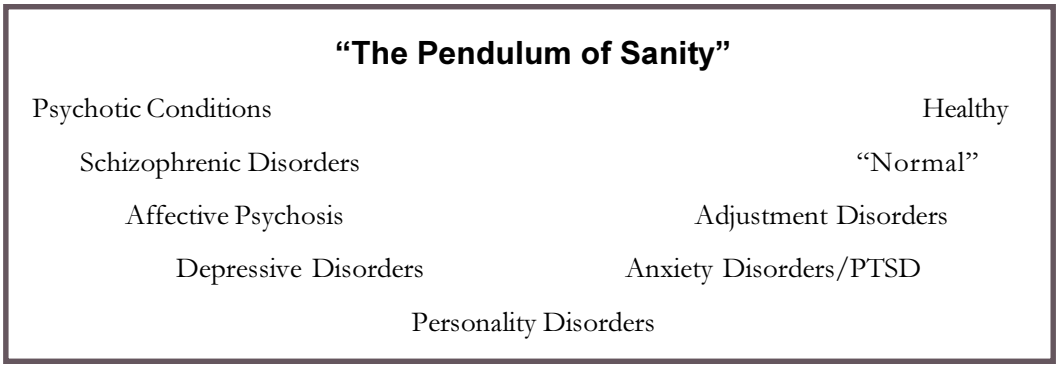
Anxiety Disorders – Anxiety disorders are the most common psychiatric illnesses and can involve variations of the feelings of anxiety and fear.

Personality Disorders – These are long-term maladaptive patterns of behavior and of internal perceptions that deviate from the individual's cultural norms and negatively affect functioning.

Mood or Affective Disorders – These disorders are the result of extreme changes in mood and very common in the US and affect twice as many women as men. They often co-occur with other disorders (e.g. schizophrenia, anxiety and personality disorders), substance abuse and other illnesses (e.g. cardiac disease). Depression with all of its subtypes belongs in this group.

Schizophrenia – "Schizophrenia" literally means, "split mind" which leads to a misconception of the illness. It is a very serious mental illness where there is a problem of perception and loss of contact with reality. Schizophrenia is a chronic psychotic disorder that primarily affects thought and behavior.

Organic Disorders – These are transient or permanent dysfunctions of the brain caused by a disturbance at any level of its organization (i.e., structural, hormonal, biochemical, etc.). This may be caused by aging or a variety of physical conditions.



Characteristics of Individuals with Mild Mental Retardation

- Speech – There is the ability to speak in full sentences and with good use of grammar.
- Thinking – Concrete, focusing on people, objects or situations (not ideas). They are able to use reality-based thinking and consider consequences. (When a low functioning person is able to speak about ideas and demonstrate abstract thinking, there is a need to consider the presence of learning disabilities instead of mental retardation.)
- Physical Characteristics – These vary according to the cause of the mental retardation. They may have congenital abnormalities to which the suffering person may be greatly sensitive to and have an awareness of any physical difference, i.e. Down Syndrome.
- Social Skills – These are variable. For the most part they are oriented towards interacting with others and many are capable of good social interactions. There is awareness of others and of playing a role in the community and with their families.
- Sexuality – This is usually confusing in the sense of the individuals not knowing their sexual identity or the appropriate expression of their sexuality.
- Interpersonal Relationships – Vulnerability to rejection. The lower the self-esteem the greater the vulnerability and the feeling of being rejected by others.
- Memory – For the most part that is good, and there is the ability to verbalize events from the past. At times able to recollect abuse.
- Self-Esteem – This may be variable. It may be affected by the feeling of being different and a desire to be like others. A tendency is to focus on desire for normalization, such as having a "normal" girlfriend, to have a driver's license, to have a regular job. Those in this group may be resistant to participate in programs that identify them as disabled.

The Psychiatric Pendulum for Mild Mental Retardation

Healthy – The key factor for wellness in persons with mild mental retardation is acceptance. If they are able to accept their differences and limitations, they may go through life functioning at their best and being able to enjoy it. This is facilitated when such individuals have experienced acceptance and love in their upbringing. They then reflect this experience in their later life.

Normal – This applies to individuals who are adjusted to their situation but who do not really obtain enjoyment from life or fulfillment in their actions. It is felt that routine becomes a major factor in these individuals' lives.

Adjustment Disorders – An event or accumulation of stressful situations that has triggered a reaction that can be manifested either with anxiety, mood changes or behavioral acting out. The stimuli usually happen within three months and gets resolved even if untreated within three months. Reasons for Adjustment Disorders in persons who are mildly mentally retarded may be difficult to identify since they may be vulnerable to situations and losses that do not affect non-disabled people. Examples include loss of staff members, changes in staff, job stress, medical problems, and family inconsistencies. The loss or death of relatives or staff members may be key factors in causing Adjustment Disorders that may lead to more permanent conditions. Unhappiness can be manifested with temporary depression, feelings of anxiety or acting out. Trying to identify possible triggers may suggest interventions that assist the person in "digesting" the stimuli that lead to the problem so that he or she does not become symptomatic and more permanently affected.

Anxiety Disorders – Persons who are developmentally disabled are very susceptible to feelings of anxiety. The dynamics of anxiety may differ in the sense that instead of

"Adequate epidemiological data regarding persons with both mental illness and mental retardation have yet to be gathered; however, clinical experience has shown that the full range of psychiatric disorders may be found among individuals with mental retardation. This includes co-occurrence with schizophrenia, affective disorders, obsessive-compulsive disorder, anxiety disorders, and behavior disturbances with injurious and aggressive behavior directed towards self, others, or objects. Proper identification and effective treatment of these mental disorders are especially important for people with mental retardation. In fact, while it is usually not possible to correct and reverse the underlying cognitive deficits, treatment of the behavioral and emotional problems that can be associated with mental retardation can significantly improve functioning and quality of life."

National Institute of Mental Health (NIMH) (2000)

being a manifestation of internal conflict, it can be a manifestation of sensitivity and conflict with the outside world. Symptoms of Obsessive Compulsive Disorder (OCD) are frequently seen and become reinforced by the need to have a sense of control in their lives.

Personality Disorders - People with mild mental retardation will frequently manifest character traits consistent with disorders that originate in the oral stage of development; such as dependence, histrionics or antisocial acts. Still the following is a review of manifestations of personality disorders in persons with Mild Mental Retardation. Seldom are Schizotypal or Schizoid Disorders diagnosed. If these clinical presentations are noted, the individual most likely will be looked at as autistic or be considered more severely impaired than what they may be given their lack of communication and involvement with others.

- People who are dependent or histrionic are attention seeking. They require others to fulfill their needs for reassurance and attention. If this does not happen, they tend to escalate either by becoming symptomatically depressed or acting out in a dramatic manner.

- People with antisocial tendencies will act in response to their needs without any consideration for others. Much effort must be made by others to help them realize that their behaviors may have consequences not to their liking.

- When the issue of control comes into play, then other clinical features may be seen, such as passive aggressiveness and less commonly paranoia. The tendency of the developmental disabled person is to interact with others. Unless there is a post traumatic component, the paranoid aspect is seldom seen.

- Borderline Personality is seen mostly in clients who have learning disabilities. When this is the case, they usually will be quite dramatic in their way of going through life. When caregivers find themselves in conflict over what interaction to use or how to relate to a person, the possibility that the client may have a borderline personality needs to be considered.

- Obsessive-Compulsive – In general when these symptoms are present it is a manifestation of the disorder and not a personality style. Many times it is related to the concreteness and organicity and should be accepted. Medication intervention will be crucial in the presentation of true OCD.

- Narcissistic – Frequently narcissism is a factor in developmentally disabled individuals and must be expected. The more fixed the narcissism, the less specific will their interactions with others be. Truly narcissistic people need others to respond to them, but it is more of a "generic other" rather then a "specific other." In contrast, dependent or histrionic individuals may attach themselves more to specific caregivers.

Depressive Disorders – This can be seen as part of reactive depression or endogenous depression. This clinical picture at times goes underdiagnosed. It is important to identify it as a possible factor in people that start functioning at a lower level than what they used to in the past. When regression is seen, the possibility of an underlying depression needs to be considered. Regardless of origin, it is strongly recommended that antidepressants be utilized since the patients do usually respond to them.

Affective Psychosis – This is overdiagnosed as a cause of behavioral problems in individuals who are mildly disabled. There is a need to make the diagnosis in the following manner:

- Consistency of Symptoms - Symptoms are present in all aspects of the individual's life, such as at home with parents, at the place of residence, and at place of employment or workshop. If symptoms are manifested only in one aspect of the person's life it usually is a sign of conflict with the environment and not of a mental illness.
- Nature of Symptoms – To diagnose the disease there must be a presence of symptoms such as hyperactivity, inability to sleep, pressured speech, constant activity, or high impulsivity, in a pattern that is not consistent with the prior lifestyle. The psychotic component needs to be looked at by a lack of contact with reality, but not based on delusions or hallucinations that may be fabrications or just verbalizations of a vivid imagination or manifestations of other psychiatric conditions such as a histrionic personality.

Schizophrenic Disorder – This condition is overdiagnosed. Many people get labeled as psychotic without a firm basis for it. Secondary symptoms alone such as hallucinations and delusions are not grounds for the diagnosis of Schizophrenia, since they can be seen in an array of other conditions, such as organicity, mood disorders or just be a form of self-expression. There is a need to identify the illness by the presence of primary symptoms such as through disorganization and misperception.

Organic Psychosis – Organicity is a given factor in individuals with mental retardation. The criteria for organic personality, which is no longer valid in DSM IV, does fit the clinical picture of many of these clients. The key factors being impulsivity and the inability to delay gratification. This is a direct manifestation of brain damage, mostly in the frontal lobe. Currently these symptoms are labeled as impulse control disorder but it is important not to forget the underlying organic component.

Characteristics of Individuals with Moderate Mental Retardation

- Speech – These individuals can use speech, but mostly in words or short sentences. They may use words in a neologistic manner which may give the wrong impression of psychosis. Sentences may be memorized without being a manifestation of the ability to use grammar correctly.
- Thinking – This is very concrete, with the focus on oneself. They are serial thinkers rather than parallel thinkers. They focus on the here and now, and the main object is "me." It is recognized that given the pattern of thinking, consistency of approach by different caregivers is crucial. Thinking occurs not in words, but in pictures. Individuals in this group may be stimulated by images and this creates a stronger emotional response. These images may become somatic and this may become a pre-learned behavior. It is important to understand the different ways of thinking through the five senses. Most people are accustomed to thinking verbally, but in people who have difficulty with verbal understanding and expression then somatic perceptions and images become the mode of thinking. Interventions are better done through images because this may reduce ambiguity and a broader ability to cope with concepts.
- Physical Characteristics – These are related to the seriousness of the disability. It is felt that this group is not as sensitive about personal differences as the mildly disabled, but still at times some may become aware of their differences and may become resentful of them. Thinking is based on the primary process mode and is oriented to seeking immediate gratification.
- Social Skills – Behavior is usually need-based rather than socially interacting. There is a desire to be noticed, to be validated. They usually seek interactions with caregivers rather than peers, who are often perceived as rivals.
- Sexuality – This is usually manifested through physical expression. It may be quite instinctual and may lead to behaviors that are not socially acceptable, such as public masturbation. Infatuation with caregivers can happen. There is a need to see this as a manifestation of normal sexual attraction that at times may have to be dealt with by avoiding the interaction.
- Interpersonal Relationships – These too are need-based for emotional and personal validation. There is a strong need for approval.
- Memory – This may be quite selective, and can be somatic and visual.
- Self-Esteem – This is dependent on the validation of others and may be very fragile.

"Although mental retardation is classified as an Axis II disorder in **DSM-IV**, it is not considered a mental illness as such, with its own unique signs and symptoms. It is a system of identifying groups of people who need social support and special educational services to carry out tasks of everyday living."

C. Simon Sebastian, MD, Medical College of Georgia (2002) (E-medicine)

The Psychiatric Pendulum for Moderate Mental Retardation

Healthy – This applies when there is a sense of being loved and the person has enough emotional fulfillment that helps them cope with unpleasant situations.

Normal – Theses individuals require more effort from others and may have more manifestations of poorly adaptive reactions at the times when their needs are not met.

Adjustment Disorders – These are very common and may arise with issues that may be missed by the family or caregivers.

Anxiety Disorders – The mechanism is not present as in the classic neurosis of internal conflict, but the symptoms of anxiety or its substitutions can be present as a manifestation of ego failure to cope due to learned behaviors. As an example, anxiety is quite common, mostly in situations where there may be insecurity, separation or loss. Phobias

may be present and may become a way of avoidance or a manifestation of Post Traumatic Stress Disorder. OCD may be present, frequently as a manifestation of insecurity.

Personality Disorders - People who are in this level of development disability usually are by nature in the cluster of oral personality styles, such as dependent and histrionic.

- People who have difficulty in interpersonal relationships and are of normal intelligence would be considered Schizoid. In this group there would be a tendency to consider them autistic.
- When paranoid tendencies are present there is a need to consider a Post Traumatic Stress Disorder.
- Borderline Personality characteristics are quite normal for this group. Needs met: means good; needs not met: means bad.
- Narcissistic – Self-centeredness is the normal way of interacting with others and the world among these individuals.

Depressive Disorders – These are extremely common and frequently underdiagnosed. They may be manifested by a regression and less capacity to do tasks.

Affective Psychosis – These are overdiagnosed. There is a need to rule out underlying organic factors such as thyroid problems or any endocrinological factor, such as menopause. Again, as with mild mental retardation, look for the consistency and the nature of symptoms. Look at the mood and the enjoyment of activities to differentiate between an agitated depression and mania. When the clinical picture is not clear it is better to start with a mood stabilizer first and then consider an antidepressant.

Schizophrenic Disorder – This is overdiagnosed. Gather history and see if there has been deterioration, inability to relate to others and poor functioning in late teens or early adulthood. Asperger's Syndrome needs to be considered.

Organic Psychosis – These are conditions to be considered. There is the need to differentiate between dementia, delirium, and organic psychosis.

Dementia is the loss of the ability to function as a consequence of some chronic organic brain syndrome. Delirium is the response to acute clinical symptomatology as a consequence of medical problems. Organic psychosis is just a loss of contact with reality based on some kind of brain damage.

Characteristics of Individuals with Severe Mental Retardation

- Speech – Communication is extremely limited, for the most part, consisting of just a few words or simple sentences. When a sentence is used, it is meant to express a message like a long word but not with the understanding of sentence complexity and grammar. Frequently speech may be echolalic or demonstrate perseverance.

  Many times people are diagnosed with severe mental retardation when this is not the case. There are people who are able to understand and obviously able to think in words, but have an expressive aphasia becoming limited in their verbalization for that they are considered severely mentally retarded when this is not the case. So it is important to assess mental retardation by the level of functioning and ability to comprehend and not the ability to express one's self verbally.
- Thinking – Thought is very simplistic, rigid and reflects basic needs. Expressions are usually self-centered and thinking is based on primary process, meaning expecting immediate gratification of needs. Frequently thinking is on images or sensations. Activities such as self-stimulation may represent repetitive thinking as ruminating on an idea or perseverating on an act can be. They are capable of understanding and responding when one thought at a time is presented; not able to register and follow several commands at one time. Able to respond to the immediate input, but not to store information to attend to later.
- Physical – Usually abnormal physical characteristics accompany the disability. In this group there is no awareness of the disability and at times there are complications with physical health. It is very important to attend to the physical environment and to their physical health in a consistent manner.
- Social Skills – Very limited with a need for approval and above all of nurturing. Interactions are mostly with caregivers and based on need for care and nurturing. No peer interactions except for basic competition. Interaction is best on a one-to-one basis.
- Sexuality – This occurs mostly as a manifestation of the pleasure principle involving immediate gratification and self-stimulation. At times, it may be too open which can create conflict since there are no inhibitions and the caregivers may have difficulty coping with this. It is important to redirect the behavior. It may be appropriate, when this causes anxiety and difficulty coping, to use medication that may decrease sexual drive.

- Memory – A crucial component since most skills are learned through memory and many may have it quite preserved.
- Self-Esteem – It is totally dependent on external approval and accumulation of experiences.

The Psychiatric Pendulum for Severe Mental Retardation

Healthy – A healthy person with severe mental retardation needs an environment that is consistent, emotionally supportive, and nurturing. There is the need to give great attention to physical health and possible causes of discomfort and pain. The environment is crucial for well being. Issues such as weather conditions, temperature, or clothing must be addressed and taken into consideration when the person shows signs of discomfort or manifests behavioral changes.

Normal – There will be people who do not show the features cited above consistently. They may have more difficulty adapting to the environment, or may have conditions that cause more impulsivity and make adapting more difficult. There are congenital conditions where self-injurious behavior is seen, which also make adaptation more difficult.

Adjustment Disorders – These are very common for reasons that may not be noted by others. They are usually manifested with changes in behavior.

Anxiety Disorders – These are seen, mostly as a pure manifestation of anxiety. This can just be because the person is not well connected to the environment or just simply uncomfortable with whatever the situation is. It is felt that they respond well to medication that decreases anxiety, but it is important to be aware that benzodiazepines can disinhibit and aggravate the possible manifestation of negative behavior.

Personality Disorders – These are usually not a factor. People in this group are, for the most part, by their nature, dependent and narcissistic. The world revolves around them and the issue is being taken care of. Some people may learn skills in manipulating others and getting their needs met, in this way coming across as controlling or passive-aggressive. At times out of the pleasure principle and the direct discharge of instincts, elements of meanness can be seen and this needs to be understood as basic human nature being manifested without editing or filtering by social consciousness.

Affective Psychosis – This may be present at times and it is important to keep in mind the consistency of the symptoms in all environments. Insomnia and agitation remain symptoms to identify.

Schizophrenic Disorder – This is very difficult to diagnosis. It is important to look at regression and loss of ability to function as factors. Important to remember is that this illness makes its presence in late adolescence/ early adulthood.

Organic Psychosis – This is frequently present by nature of condition, although new organic factors can get superimposed due to the process of aging or to some other deterioration. It is important to look at the decreased level of functioning.

Depressive Disorders – This may be a manifestation of loss or just lack of nurturing and can be manifested through behavior or lack of interest in activities. It is often under diagnosed.

"Mental health is a goal for all people, including those with mental retardation, not just those having difficulties. Mental health is an essential ingredient in the quality of life. The two main aspects of mental health are emotional well-being and rewarding social and interpersonal relationships. Emotional well-being is an important part of the gift of human life. Good social and interpersonal relationships are important for a rich and fulfilling life. People who have mental retardation are not in any way handicapped with regard to these human qualities —people with mental retardation are capable of a rewarding emotional life."

Steven Reiss, Ph.D., Director, Nisonger Center UAP, Ohio State University

Characteristics of Individuals with Profound Mental Retardation

- Speech – There is none generally and most times only sounds.
- Thinking – This takes place mostly in images and touch and based on immediate gratification.
- Physical – Besides possible physical characteristics that indicate the presence of the disability, there are accompanying severe medical problems that need attention from others, such as being fed, having diapers and other physical issues that need attention and a consistent approach.
- Social Skills – These are very limited and are mostly based on the need of getting nurturing from others.
- Sexuality – This is not as pronounced and not as predominant as with higher functioning individuals.
- Interpersonal Relationships – There is a need for nurturing from others. These individuals respond well to affection.
- Memory – There is the ability to learn from past experiences and in this way to develop expectations. Memory is based on sensation. Smell and touch can be memory triggers.
- Self-Esteem – This is not a self-concept that they may have. There is total dependence on the outside world.

The Psychiatric Pendulum for Profound Mental Retardation

Healthy – This is a person who is well adapted to an environment and appears content with the nurturing received by others.

Normal – This is a person who does not have such a consistent environment and may have components in their psychological make up that makes adaptation more difficult.

Adjustment Disorder – This is very frequently found and most of the time it is related to changes in the environment or the caregivers. Physical problems need to be considered anytime there is a regression of behavior.

Anxiety Disorder – This can be manifested as restlessness and just reflect a discomfort with the environment.

Personality Disorder – This is not a factor. These individuals may have the characteristics of being self-centered and dependent, but this is to be expected given mental make-up.

Depressive Disorder – This can be manifested with just a lack of interest like refusing to eat and definitely often present and most likely under diagnosed.

Affective Psychosis – This can be present and needs to be observed through changes in behavior in all areas of his/her life. Diagnosis is made based on the consistency of symptoms.

Schizophrenic Disorder – This is extremely difficult to diagnose and may be recognized by deterioration of an individual who was able to relate at a higher level previously. This happens mostly in adolescents and young adults.

Organic Psychosis – This may be manifested as deterioration in later stages of life, mostly can be noted by loss of memory and regressive behavior.

Suicidality and Developmental Disability

Just as mental retardation and other developmental disabilities do not spare those they afflict from mental illness, neither do they remove them from the risk of suicidal behavior. Risk of suicidality may occur in individuals with mental retardation, epilepsy, Cerebral Palsy, and autism. This risk is higher when serious mental illness is present. Risk factors for suicidal behavior that characterize these individuals include chronic disability, self-care and self-direction limitations, and co-morbidities and dual disorders. Others include low self-esteem, poor social integration, stigma, and rejection. Triggers may include experiences such as interpersonal loss; changes in residence, school, or employment; neglect and abuse; and exploitation and bullying. It must be remembered that risk factors for suicide related to age, gender, race, and ethnicity do not discriminate on the basis of intellectual functioning. Service providers and caregivers must be aware of the risk factors for suicide cited above and be alert to warning signs such as talking about dying or hurting oneself, and threatening or looking for ways to harm oneself.

Anthony Salvatore, MA
MCES Development Director

MCES Developmental Disability Clinic

By Rocio Nell, MD, CPE; MCES CEO/Medical Director

In 1997, in response to a community need, MCES developed a developmental disability clinic. The Office of Mental Health/Mental Retardation identified that there was a need in the County for psychiatric care of individuals who were in the mental retardation system. Molly Frantz, Administrator; Nancy Wieman, Deputy Administrator of Mental Health and Marianne Roche, Deputy Administrator of Mental Retardation took it upon themselves to expose me to the best known practices in the treatment of mental retardation. Together we traveled to New York and New Jersey to meet with practitioners who were considered to be the best in this field and, in addition, we attended lectures on the topic. Who made the most impact on me was Dr. Andrew Levitas from the University of Medicine & Dentistry of New Jersey, School of Osteopathic Medicine, Department of Psychiatry, Division of Developmental Disabilities in Stratford, New Jersey.

In the meantime, the County Office of Mental Retardation sent an inquiry to all providers to identify the individuals who were not doing well and could benefit from a psychiatric assessment or second opinion. When the clinic opened, people were scheduled according to the urgency of their situation. Consults were done to clarify diagnosis and identify appropriate intervention. Since then 400 people have been evaluated at MCES with 95 currently active in ongoing treatment at this facility.

The assessment is done with the participation of all involved in the care of the individual. A form was developed to identify the symptoms, past treatment and current circumstances, and likes and dislikes of the individual in an attempt to get the full picture of the person. This form is to be filled out by the different providers of care prior to the evaluation, including representatives of the home and workshops, in order to identify consistency of symptoms. Then in a brainstorming meeting, and open-minded environment, the symptoms are identified, discussed and the client assessed with the participation of family and those who provide the care.

An attempt is made to identify the core problem; for that, the analogy is used that it is like finding the grain in wood. With the belief that wood is carved following the grain, wonderful results can be obtained, but if not, everyone gets their hands full of splinters and the wood can be chipped away or even destroyed.

A "thinking out of the box" approach is used in identifying interventions, which mostly end up being simple to implement (once the core problem is identified) and, for the most part, just common sense. The result is that many individuals who lived in despair and who sometimes created situations difficult to handle by their caregiver, have been able to obtain a better quality of life and give great gratification to others. As for me, prior to 1997 I shied away from treating individuals who were disabled, acknowledging my ignorance of the topic and my feeling of inadequacy when confronted with a situation I was apprehensive about approaching. Once I gained knowledge and confidence in the matter, I recognized that it was a calling. I have found great joy in the provision of this service and fulfillment in my quest to be of help to others. I will be forever grateful to Molly Frantz, Nancy Wieman and Marianne Roche.

Consults are done either as a second or primary assessment. At times of special need, follow-up treatment is required at MCES. When this happens it is tailored to the needs of individuals. On some occasions it consists of a med check with the patient and at least one staff member present who brings the report from the rest of the team. Other times it consists of an interagency meeting with a multitude of participants, including family to discuss ongoing problems and to problem solve. Frequently there is a need to breach the miscommunications that, at times, exist between parents and providers. Ongoing education is offered to the staff on resolution of identified issues and encouragement of consistency of approach. In addition, MCES offers a community outreach team, and in some cases, a MCES case manager is assigned to the treatment team who becomes a source of support in the community. A MCES outreach nurse participates, when needed, in treatment doing home visits and medication assessment as needed. Frequently, treatment is coordinated with intensive outpatient programs, workshops and other services provided in the community. The key factor is communication and everyone using the same approach. For this, ongoing dialogue of all involved is needed.

Thinking Out of the Box

By Rocio Nell, MD, CPE; MCES CEO/Medical Director

Mary

Mary was presented because of frequent episodes of agitation when she came home from her workshop. The staff described that she was extremely disruptive at that time and difficult to redirect. I requested them to describe their schedule. They explained that she lived in a CLA with two other individuals and when she arrived home from the workshop, she was expected to watch TV while the staff prepared dinner.

The assumption was made that by being non-verbal behavior was her language and the intrusiveness and negative behavior was her way of expressing that she wanted staff attention and her meal. It was suggested that the staff cooks the evening before and leaves the meal prepared for the next day. This way when she gets home she would get full staff attention and eat early. She could have a snack in the evening before going to bed and the staff could prepare the next days meal once she was calm and settled.They agreed to try it and come back if the problem remained. I never heard from them again.

Ann

Ann was described as full of anxiety. She came into my office shaking and appearing extremely insecure. Staff described how she would get fixated on touching objects. Once she found something she wanted to touch, there was no way of removing her from that situation.

It so happened that Ann was legally blind and deaf mute; touch was her way of thinking and relating to the world. It was suggested to staff that they communicate with her through touching and make her world as predictable as possible through routine sensory sensations. Her perseveration in touching objects was a manifestation of the perseveration seen in people in thinking. She was treated with medication for OCD, which along with the staff change in their way of relating, led to a marked improvement.

Lillian

Lillian came in clicking her tongue. What I noticed was that her mother and staff encouraged her to say words. She was full of scars from her self-inflicted injuries. Staff said she frequently acted impulsively in a self-abusive manner. When I asked why they didn't click back. They said they thought that was encouraging her low level of functioning, promoting regression.

I considered that she might be frustrated and I clicked back. A dialogue developed with her clicking in different tones and sounds. I encouraged the staff to communicate with her that way; for her, clicking was her language. Now, as soon as she walks in my office she starts clicking, occasionally she will say hello and good morning. It so happens that once she related in a way she knew how, she became receptive to learn words and relate in the way others were expecting her to do. Medication to reduce impulsivity helped, but so did the way others interacted with her.

Giovanni

Giovanni was placed in a CLA after his Italian mother's death. She had dedicated her life to his care. He was non-verbal and appeared to be in the severe range of mental retardation. He was described as very unhappy and at times refusing to eat.

It was suggested that the staff learns basic Italian language and cards were given to them with sentences in English and the Italian translation. In addition, it was suggested that they play cheerful Italian music for him every day at set times so he would have a routine he could expect and that he be fed mostly Italian-like food. Giovanni became much happier and there was no need for further psychiatric intervention.

Developmental Crisis Triggers

- Diagnostic changes
- Birth of a sibling
- Starting school
- Onset of puberty and adolescence
- Sex/dating issues
- Surpassed by younger siblings
- Emancipation of younger siblings
- End of education
- Out of home placement
- Establishment of staff/client relationship
- Inappropriate expectations of others
- Aging illness/death of parent
- Death of peers
- Onset of medical illness

Concluding Comments

We as human beings are part of nature. Our society determines how we categorize people and everything around us. Society shapes our understanding of mental retardation. However, we need to remember that the reality is as we all were born; we all will die and at the end all our differences are but our illusion. A daisy is just as beautiful as an orchid and an orchid is but a weed in the tropics.

According to Freud, there are two ways of thinking; one is following the primary process principle, meaning "I want what I want now." There is no concern for anything else. This is the mode of thinking of people whose IQ falls in the moderate to profound range. By the nature of their minds, they are self centered and they go about life pursuing what they want at each moment of time. When they have grown in an environment of love and understanding they can be quite easy to relate to. But at times, possibly because of over indulgence by others or the nature of their organic impairment, they can test limits constantly and try to be the center of attention. It is important to realize the nature of the thinking, here and now, and how it affects us, in order to approach this person in the most constructive way.

The other way of thinking is the secondary process principle, meaning the person does not want to suffer later so he/she reacts to situations by considering the consequences and not the immediate gratification. We all go through life learning the art of balancing the two tendencies. Persons with mild mental retardation may be able to learn the second type with support of others and to consider outcomes. They are expected to reason out the way to handle situations.

People who are mentally healthy go through life doing their best within their circumstances. We can see many people who are considered mentally retarded full of smiles at the Special Olympics and at other activities in the community. The key is the sense of self and the feeling of security. Nurturing and acceptance by others plays a role, but there are many factors that may come into play when the adaptation is not good and symptoms develop. Some are genetic, others come from the environment or circumstances. When addressing a developmentally disabled person with emotional problems, the key is to have an open mind and try to see the world from their eyes. More than that, we should attempt to understand their way of thinking and perceiving so then we can comprehend their behavior which most of the time is their way of communicating a manifestation of their language.

Lastly, it is important that those concerned about mental health and mental illness in the community consider the needs of those with mental retardation in their advocacy and program planning. As we have tried to show above, these needs may be difficult to assess in some cases, but their effects are similar to that experienced by someone without a developmental disability. Treatment is available and can significantly enhance the quality of life and relationships with caregivers and service providers. Likewise the recovery model has implications with individuals who are dual disordered. Their recovery options may often be more limited but they are entitled to enjoy as fulfilling a life as they can have. Services should be positive and caring and focus on strengths rather than deficiencies. Mental wellness must be fostered regardless of the nature of an individual's disability.

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News About MCES

In September 2006, MCES had a JCAHO survey. Now the process is different and there is an opportunity to dialogue about the findings of the surveyors and to have matters clarified. The end result was that MCES had a very successful survey as we have in the past with our crisis residential program, outpatient and inpatient programs being fully certified.

Changes to the Table of Organization

Since its inception, 33 years ago, MCES has had a Criminal Justice Department. This department has grown through the years to where now a multitude of services are provided under an umbrella larger than the criminal justice component. For this reason, the Table of Organization has been modified to reflect the changes and now MCES has a Community Outreach Service under which we have Criminal Justice Services, a Transition Specialist and Crisis Outreach. This department works not just on jail diversion, but in promoting the stability of the people we serve in the community. Frequently crisis workers are involved in the treatment of the developmentally disabled clients we serve at MCES. Efforts are made to prevent the criminalization of developmentally disabled individuals and lectures are given to provide education on this topic.

MCES Lecture Series

MCES offers lecture series that cycle through the spring and fall. Lectures consist of weekly presentations of three-hour duration on different topics intended to increase the understanding of psychiatric related topics. Of relevance to this Quest are the lectures on Dual Disorders: Mental Illness & the MR Population, Criminalization of the Special Needs Population, Recognizing and Dealing with Brain Injury, Psychiatric Interventions: Part 1 & 2, and many others. If you want information on the lecture series, please contact Sharon Bieber at (610) 279-6100.