

MENTAL HEALTH CLINICAL ASSESSMENT OF PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES: HISTORY

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Adequate psychiatric evaluation of persons with mental retardation and developmental disabilities (MR/DD) involves the same steps as adequate psychiatric evaluation of a neurotypical patient, with some modification of technique to take into account the exigencies imposed by the person's disability. The procedure resembles that used in child psychiatric evaluation because, like the child brought for psychiatric evaluation, the patient usually is not the one requesting evaluation and he or she is seldom able to furnish details of history. In some ways, the evaluation is also similar to geriatric psychiatry, especially when patients with dementia cannot give an adequate history. Also, the geriatric population, like much of the developmentally disabled population, tends to have multiple medical diagnoses and to be on multiple medications that can cause problems with drug interactions and side effects. This paper describes the method of gathering history from caregivers and documents, including the significance of symptoms most often displayed by persons with MR/DD and the differences in presentation of familiar symptoms as seen in this population.

Keywords: developmental disabilities, diagnosis, psychiatric evaluation

Diagnosis is the key to treatment and history is the key to diagnosis. In all fields of medicine, in fact in all fields of human services, only the history of how a problem evolved will reveal the nature of that problem. Knowing that a patient has, for example, hallucinations tells us nothing except where to start looking for a diagnosis. Only a history that reveals the slow, insidious loss of affect, interest and social judgment, or the disruption of sleep and appetite and onset of deep sadness and suicidal thoughts, or the onset of sleeplessness, overactivity, and grandiosity, will distinguish the source of the hallucinations in an episode, respectively, of Schizophrenia, Major Depressive Disorder, or Bipolar Disorder. The gathering of a history is a basic skill taught in the early years of medical school, with each specialty adding its list of things to look for and ask about. Psychiatry is no exception. Without a good history, the mental health clinician cannot easily make a diagnosis, because diagnosis relies on knowing the course and context within which the symptoms developed. This is especially true for the patient with mental retardation or developmental disability (MR/DD).¹⁴

Standard textbooks of psychiatry assume that the history will be obtained from the patient,

perhaps supplemented by a review of past hospital records if they exist.¹⁰ Diagnosis usually depends upon the patient's description of his or her mental experiences. This is less likely to be possible with the patient with MR/DD, for whom

“... information from informants may be crucial and the presence or not of mental state abnormalities or characteristic biological features, determined indirectly. For example, disturbance of sleep and appetite, poor concentration, loss of interest, and agitation and distress may enable a diagnosis of depression to be made in the absence of a clear understanding of whether the person is actually feeling depressed.”¹³

Because of the limitations in giving a verbal history for most individuals with MR/DD, the history must be gathered, with the patient's (and/or guardian's) participation and consent, from family and other caregivers, educational and habilitative agency records, and any other sources that can be found. The model for this process originates in the history-taking process taught in Child Psychiatry. Lewis⁹ notes:

“The psychiatric assessment of infants, children, and adolescents is both complex and subtle, requiring multiple sources of information, including the child, parents, teachers, pediatricians, hospital records, and previous evaluations, as well as observations of family interactions.” (p. 440)

This is the model for obtaining history from persons who may not be able to speak for themselves, and it is routinely necessary in the mental health treatment of persons with MR/DD, based on their developmental delay. This line of thinking is sometimes misinterpreted as a belief that adults with MR/DD are like children, and is seen as patronizing or paternalistic. This is not the case. In most respects, the adult with MR/DD has adult desires and needs and deserves the same rights as others. The point here is that, by virtue of their developmental disability, these adults function cognitively and emotionally at an earlier developmental level and that this affects their understanding of the world and ability to express themselves. To not take that into account leads to a misunderstanding of the presenting problem. In fact, many people with MR/DD are able to give at least some of their own history, although their developmental level should be taken into account when interpreting this information; Also important is how the information is elicited, such as the use of words appropriate to the level of understanding and avoidance of leading questions.¹¹ Much information can also be obtained by observation of nonverbal interactions.

This paper will describe the information most important to the accurate psychiatric diagnosis of persons with MR/DD, and offer suggestions as to where it can be found. (This information is just as important in the evaluation of neurotypical individuals, but can generally be more easily accessed).

The traditional way of organizing the history is to begin with the Presenting Problem (sometimes called the Chief Complaint). Set out the information relevant to the evolution of that problem, and proceed to a developmental history that describes the patient's pre-morbid functioning. The advantage of this approach is that it begins with the chief concerns of the referring parties and allows rapid focus on any crises and their precipitating events. An alternative, equally valid approach is to begin to gather a complete developmental history and later report the current concerns. The advantage of this method of presentation is that the current problem is presented in the context of a complete picture of the individual, making clearer the context of the current concerns. Presented below

is the traditional order of organization, but traditions can change. The goal is to have all the information required to make the diagnosis and communicate it convincingly to others.

The patient and all the available caregivers must be present. They must bring with them all possible written records from family, school and agency files. The clinician, in turn, must be prepared to interview all the caregivers and review all the records. There can sometimes be situations where the clinician has limitations on the amount of time he/she can spend on the evaluation, such as in a clinic based on direct reimbursements. In these situations, it can be helpful for a family member or caregiver to summarize the relevant information prior to the initial evaluation. This requires educating the individual on what information is necessary and important, and carries the risk of important information being missed. One helpful tool can be an intake template such as that presented in Sovner and Hurley.¹³

HISTORY OF THE PRESENTING PROBLEM (CHIEF COMPLAINT)

The Presenting Problem, or Chief Complaint, is the reason for consultation or initial psychiatric evaluation appointment. An old joke has it that, "No child ever asked to see a child psychiatrist." While this is not entirely true, it points up the fact that persons who do not make the decisions in their own lives, which includes the vast majority of persons with MR/DD, are referred for mental health evaluation by others. This means that a caregiver has noticed either a change in functioning or a problem behavior, or the patient has run afoul of legal or educational systems. Before approaching the question of whether or not there is a psychiatric disorder, and if so which, in Lewis⁹ words,

"...it is important to consider the goals and context of the referral. Diagnosis of a psychiatric disorder may be just one of many possible reasons for [parental] referral; other reasons, sometimes covert, may include marital problems, child custody conflicts, problems in the school..." (p. 440)

To these, for persons with MR/DD, we can add problems with residential, vocational and other habilitative systems. Again, Lewis:

"Sometimes the child's symptoms reflect more a problem of 'fit' between parent and child, or between the school and child, rather than a psychiatric disorder." (p. 440)

Such systems problems are a constant in the lives of persons with MR/DD. However, it is important not only to elicit the Presenting Problem, but to state who has defined the problem, how long it has been observed, in what environments it is observed, and if it is of long

standing, why evaluation is being sought at this time. It is crucial that the person or persons making the referral for evaluation are present to explain their concerns.

The clinician must from the outset begin to understand the Presenting Problem as part of a constellation of changes in the patient's functioning, and must ask caregivers about the onset and chronology of changes in any or all of the following, which will comprise the History of Present Illness.

HISTORY OF PRESENT ILLNESS

KNOWLEDGE OF ANY CHANGES OR PRECIPITATING EVENTS

The most important information to be supplied is that of any environmental, life, or medical changes known to occur prior to the onset of the "chief complaint." For example, if a person had a drastic change in mood or behavior, or increase in the frequency or severity of an existing problem, related to any changes, that must be known. Some changes may have precipitated an episode of a psychiatric disorder. For example, loss of a parent may precipitate an episode of depression. In addition, many medical conditions may cause psychiatric symptoms, such as thyroid disorders, instability in seizure disorders, or head injury. Most importantly, the psychosocial stressors experienced by persons with MR/DD may be causative in behavioral or emotional reactions that are mistaken for psychiatric disorders. It is essential that caregivers be knowledgeable about potential stressors which may include:

- changes in routine at school/work
- changes in routine at home
- changes in staff at home and work
- changes in interpersonal relationships
- moving of work or residence

- changes in family structure
- changes in family frequency of visits or quality of interactions
- loss or death of friends or family
- anniversary dates of losses
- transitioning from educational system to adult residential/vocational system

The chain of events leading to evaluation may have been set in motion by a change in life or environment easily recalled by caregivers as significant (death of a parent, promotion and therefore loss of a favorite caregiver or friend) or by a seemingly insignificant (to caregivers) event (promotion and therefore loss of a friend at work, offer of promotion, criticism of performance, new roommate). The DSM-IV multiaxial system² has two axes relevant to this issue: Axis IV: Psychosocial and Environmental Problems, and Axis V: Global Assessment of Functioning. Axis IV lists most of the sorts of environmental stress that can cause developmental crises. Axis V calls for a subjective assessment of the patient's highest "level of functioning" in the past year, and the current level. Neither scale is normed for persons with MR/DD.

While it is optional whether one includes these axes in the formal diagnosis, it is crucial for the clinician to understand and record in narrative form the significance of recent life and environmental changes to the evolution of the patient's current problem. The existence of a stressor or precipitant does not rule out the presence of a major psychiatric disorder. This can only be determined by the symptom picture presented by the entire history and mental status examination.⁸ Both adjustment disorders and episodes of major psychiatric disorders can be precipitated by environmental stressors. Neither will respond to treatment unless attention is paid to relief of the stressor. It is crucial to have caregivers knowledgeable about sources of stress in the patient's life present at the gathering of the history.

UNWANTED BEHAVIORS

Where the Presenting Problem is an unwanted behavior, usually aggression, self-injury, property destruction, or management problems ("non-compliance") it is important to note all of the above, the antecedents of the behavior, the

environmental responses to the behavior, and the patient's responses to any interventions already attempted. Symptoms of psychiatric disorder may wax and wane in intensity or vary with level of stress, but will be observed throughout the day and in all environments. A behavior or symptom that occurs only at home, only at school or work, only on one shift, or only with specific caregivers is more likely to be either a systems problem or to be complicated by a systems problem.

MOOD

Most important is to elicit whether the current mood represents a change from a pre-morbid baseline state. Changes in mood may be the presenting problem or may be an associated finding. Sadness and tearfulness typical of depression, elation, euphoria and *lability* (rapid changeableness) of mood typical of mania, irritability that can occur with either, fearfulness observed in many types of Schizophrenia, must all be questioned. Aggression, destructiveness and management problems might all be linked to a mood disorder. *Explosiveness* (violent response to minor provocation) may occur together with or independent of a background of irritability. Note that symptoms that appear to be cyclic are not necessarily evidence of a bipolar disorder. There are many other possible explanations.¹²

SLEEP DISTURBANCE

Psychiatric disorders frequently disturb sleep, often profoundly. Anxiety may cause occasional or situation-related fitfulness of sleep. Major Depressive Disorder may cause a characteristic *early morning waking*, but may also cause *sleep interruption* (difficulty falling to sleep or maintaining sleep), or may cause *hypersomnia* (excessive sleep). During a manic episode of Bipolar Disorder there may be days of complete or partial *sleeplessness*. Schizophreniform Psychosis or acute episodes of Schizophrenia may be accompanied by sleep disruption as well. Persons with severe obsessive-compulsive symptomatology may wake in the night to pursue compulsive activity. Caregivers may or may not have kept a *sleep log*; this is something that could be made routine for all evaluation referrals or requested for a follow-up appointment. Certain medical conditions and medications can cause sleep disturbances.

APPETITE DISTURBANCE

Major Depressive Disorder may cause profound appetite and weight loss, or *hyperphagia* (excessive appetite and weight gain) may be seen. During a manic episode a person may be too overactive to eat full meals, resulting in appearance of poor appetite, and even weight loss. Delusions of poisoning may disrupt food intake, as might severe obsessive-compulsive rituals involving food. Many residential care systems keep *weight charts* which can be reviewed. Certain medical conditions and medications can cause appetite and weight loss.

ACTIVITY LEVEL

Overactivity or *underactivity* may occur in, respectively, mania or depression. These in turn might change a pre-existing pattern of ritualistic activity in persons with Autism Spectrum Disorders. Apparent underactivity might be seen in schizophrenia, but this is less a motoric phenomenon than a *withdrawal* from activities. Certain medical conditions and medications can cause similar changes in activity levels.

HALLUCINATIONS AND DELUSIONS

Hallucinations (perceptual experiences generated within the central nervous system with no current external sensory basis for the experience), common in all psychotic disorders, may be difficult for caregivers to distinguish from *illusions* (misprocessed or misinterpreted real sensory stimuli common in delirium and states of mild intoxication, including intoxication caused by anticonvulsants and some other medications in common use by persons with MR/DD, and in withdrawal states), or for that matter from *auditorization of thought* (hearing one's own thoughts as a voice inside the head) or simply *soliloquizing* (talking to oneself), both of which are common in persons with MR/DD and no psychiatric disorder. Various types of *hallucinations* are described in detail elsewhere.⁸ When inquiring about any history of hallucinations, a detailed explanation must be given to caregivers as they might frequently report developmentally normal behavior as hallucinations or delusions. True auditory *hallucinations* are unpleasant, usually frightening, bizarre or critical in content, and heard through

the ears, as if from outside. Caregivers may be able to report that the patient appears conscious but preoccupied, or talking when there is no one present, or carrying on elaborate conversations. Caregivers might report or be able to describe suspected *visual hallucinations* when the patient seems to be responding to things not seen by others. One type of *hallucination* that should be questioned whenever there is a change in level of consciousness suspected is *olfactory hallucination*, seen in partial-complex seizure disorder. Caregivers may be asked if the patient reports

and if this is followed by alteration in consciousness, confusion or combativeness.

All reports of *hallucinations* must be confirmed by the patient directly. Persons functioning as low as the moderate range of retardation can answer reliably when asked if they sometimes hear someone talking to them when no one is there, and identify the source and content. Given the desire to please or to give "the right answer" displayed by so many persons with MR/DD, if the patient answers "Yes" to a question about hallucinations he or she must ALWAYS be asked whose voice it is, and the content. *Overcompliance* may be checked by asking later, "You don't hear voices do you?" Persons with extensive experience of psychiatric hospitalization or even previous evaluation may falsely report *command hallucinations* as reasons for an explosive outburst or other problem. It may not be possible to definitively diagnose hallucinations in individuals with severe or profound MR/DD (S/PMR). In such cases it is probably best to consider hallucinations an explanation of last resort, only after other possible causes for the presentation have been ruled out.

Delusions are fixed, false beliefs, not shared by others in a patient's family, subculture, ethnic, national or religious group, rigidly held despite all evidence of their falsity. These might be reported by the patient or by caregivers. They cannot be inferred from behavior but might be suspected by caregivers if the patient reports or acts on them. No type of delusion is any more than indicative of any disorder; none is diagnostic. All may occur in

any disorder, or be missed or misdiagnosed in persons with MR/DD. Persons with MR/DD may express ideas easily mistaken for delusions because they cannot support these ideas with evidence, or may report experiences thought to be beyond their level of ability. Only a complete history, and a review of such statements with knowledgeable caregivers, can prevent such errors. Delusions must be distinguished from such things as magical thinking and other thought processes that can be normal in persons functioning at early developmental levels.⁴

In persons with MR/DD, *grandiose delusions* may take the form of statements or acts suggesting to caregivers the belief that the person is not mentally retarded, or no longer in need of services. This must be distinguished from the testing of limits by persons with Personality Disorders. Another form that *grandiosity* might take is a stated belief that the person can drive, buy a car or an apartment, get a job—all normal, everyday skills for a neurotypical person, but beyond the abilities of most people with MR/DD. Similarly, delusional guilt may take the form of a belief, or acts suggesting the belief, that one will, or has, run out of money, or bankrupted the family or residential program, that one is a failure at work—all within the realm of possibility and not bizarre in any way. One can only determine the delusional nature of such beliefs by reviewing their basis with knowledgeable caregivers, and observation of the patient's response to confrontation or reassurance.

Somatic delusions may take the form of constant minor complaints and clinging, constant pain, repeated demands to see medical personnel, and other vague complaints suggestive of a somatization disorder. In persons with mild mental retardation (MMR) and Major Depressive Disorder they may take the form of a belief that the person him or herself is dead or dying, that loved ones and other important persons in the patient's life are dead or dying, that caregivers, friends and partners no longer love or care for the patient. Somatic delusions also must be distinguished from *somatizing* that occurs because the individual is not able to recognize or label emotional states and therefore tends to express them in the form of a physical symptom; this is also common in children.

Persecutory delusions may take the form of simple insistence that others are “bothering” the patient. The belief is well within the realm of possibility and can only be seen to be false if checked with caregivers, who may be able to verify that the people “bothering” the patient are nowhere nearby or have never been observed to have any interaction with the patient. Some individuals may be expressing that others are bothering them because they are projecting their own unacceptable internal feelings onto others; this can also be seen in children.

Erotomaniac delusions occur when a patient believes that he or she is loved by another person when there is no evidence of this being true. This has been reported in people with MR/DD and can occur alone as a singular delusional disorder or can arise during the course of a psychiatric illness. Caregivers must report the history of the delusion, when it began, any precipitating events, and any threats or stalking of the loved person.⁵

SUICIDAL OR HOMICIDAL IDEATION

Persons with MR/DD are perfectly capable of forming ideas for, or even plans for, killing self or others. Threats may be *manipulative* (designed to change the response of others, usually associated with Personality Disorders) or genuine (associated with a psychotic illness), although harm can come from both if ignored. The clinician must question the events surrounding any such threats or acts, and explore them with caregivers and the patient. Any credible plan must be investigated for its feasibility; a threat to shoot or overdose oneself is of different significance depending upon whether a patient does or does not have access to a gun or drugs. Sometimes an individual engaging in apparently nonspecific aggression or self-injury may actually be expressing suicidality or homicidality.

CHANGES IN LEVEL OF FUNCTIONING

Patients with mood disorders or schizophrenia may withdraw from activities to the point of loss of interest in usually enjoyed activities, or to the point of loss of previously-independent skills or self-care (in the case of depression), or may increase activity and productivity, sometimes to the point of disorganization of daily activity (in the case of mania). Reports of changes in ability level at work sites or residential homes should be

provided and may document an acute or slow decline in skill level.

AUTONOMIC AROUSAL

The “Fight or Flight” response is mediated by the autonomic nervous system. Sudden aggression or running might be observed; if so, caregivers should be asked about the presence or absence of flushing, pallor, *tachypnea* (rapid breathing), *diaphoresis* (severe sweating); the patient can be asked about heart racing and subjective feelings of fear for no reason. Sometimes persons with anxiety disorders have an elevated resting pulse, which can be measured at interview or noted on past electrocardiograms or physical examinations. A small percentage of individuals may be displaying rage attacks which occur “out of the blue,” but this is often mislabeled due to a lack of critical evaluation looking for antecedents.

OBSESSIONS AND COMPULSIONS

Caregivers may report, or recall when asked, that the patient **must** perform certain repetitive activities (rituals; most commonly washing, cleaning, ordering and reordering possessions, hoarding, throwing things away), conform to a rigid schedule, keep lights on or off, doors open or closed, arrange a table before sitting down or eating, touch things or people, and react catastrophically to any attempt to interrupt these behaviors. Some patients also engage in obsessive thoughts and perseverative speech on certain topics. Such *obsessive-compulsive behaviors* can occur independent of, or as part of, an *Autism Spectrum Disorder*. They may be the reason for evaluation or an incidental finding; often caregivers have observed these behaviors for so long they are accepted as part of the patient’s personality rather than a symptom, and so must be specifically asked about.

SIGNS OF NEUROPATHIC PROCESSES

Behavioral disturbance may be a part of a more widespread neuropathic process. Motor abnormalities and subtle changes in level of consciousness may be so mundane a part of life with persons with MR/DD that they or their significance are overlooked by caregivers, and can only be elicited by questioning.

Disorientation is loss of ability to locate oneself in space or time; when more severe, there can be loss of self-recognition. *Confusion* is inability to respond appropriately to familiar stimuli or environment. Both may be noticed by caregivers or elicited on questioning. A person with MR/DD might suddenly be lost in familiar places, attempt to go through a weekday routine on a weekend day, wake at night and act as if, or insist it is, day. The patient may be urinating or defecating in inappropriate places, mixing inappropriate items of clothing, or wandering off. *Incoordination* and *lethargy* may be observed by caregivers. It is important to note the duration of these phenomena, and whether constant, as in a progressive or chronic process, such as endocrine or neurodegenerative disorders (often associated with a decrease in level of independent functioning), or intermittent, as in a metabolic or drug-induced delirium, or voluntary intoxication.

Involuntary movements (movements not under the patient's voluntary control) must be questioned. *Tremors* may be indicative of metabolic disorder, drug toxicity, or long term ("tardive") medication side-effect. *Tics* are sudden, repetitive, simple movements like blinks, shrugs, grimaces, or there may be more complex mixtures of multiple simple movements. Tic disorders and stimulant side-effects are among the causes of tics. Movements with alteration in level of responsiveness suggest *partial seizures*. All of these movements must be distinguished from *stereotypies* (repetitive voluntary movements) common in Autism Spectrum Disorders.

SIGNS OF PERSONALITY DISORDER

Incontinent anger, self-mutilation (conscious and deliberate acts involving tissue damage, e.g., infliction of burns or superficial cuts on forearms) or *manipulative self harm/suicide threats* characteristic of *Borderline Personality Disorder* might be the focus of evaluation or an incidental finding from past history. Caregivers can be asked about *staff splitting* (playing one caregiver against another, fomenting quarrels among caregivers and/or peers) and *intolerance of perceived abandonment* (occurrence of any or all the problem behaviors when more than comfortable levels of self-care are required, e.g., during vacation of an important caregiver, a promotion

resulting in separation from an important caregiver or peer). *Narcissistic Personality Disorder* might be detected in grandiose expectations of self, relatives or relationships, and rage at perceived slights. *Histrionic Personality Disorder* might be seen in reports of self-dramatization and exaggeration of any complaints. *Antisocial Personality Disorder* might present as systematic disregard of laws, disregard of the rights of, or exploitation of, others.

Personality disorders can occur along with other psychiatric symptoms and can be comorbid with other psychiatric disorders. One should not assume that everything in the life of an individual with a Personality Disorder is due to the personality disorder and label it as "just manipulative."

SEXUAL DISORDERS

Sexual dysfunction is unlikely to be part of a chief complaint brought by caregivers, but might be alluded to by patients on medication that can cause such side effects (antipsychotics, many antidepressants). A more likely cause for evaluation is a sexual disorder causing community problems such as *voyeurism* or *pedophilia*. In these situations the clinician will require access to all documentation of incidents including any records from the legal system.

PAST HISTORY

The goal of the past, or developmental, history is to construct as complete a picture as possible of how the patient became the person he or she is at the time of the evaluation. Biological, psychological and social contributants must all be explored to the extent permitted by access to current caregivers, family members, and historical records. The availability of any and all of these will vary from patient to patient; what must not vary is the clinician's commitment to find and examine all that can be found.

Parents are the ideal historians. Other caregivers who have known the patient for significant periods, siblings and teachers are all valuable sources of history. Relationships crucial to the patient's treatment may be forged in the shared task of gathering history. Often one non-familial caregiver is the most important person in the patient's life, and it is that individual who is most likely to have the most accurate information

(and be the most crucial ally in treatment). It is important to educate people about what information is important to discuss and what records are important to bring. It is also important to take into account during the assessment the situation that the parents and/or caregivers are in. Many times, they are under a great deal of stress dealing with very difficult situations and may be fearful that clinicians will judge them and therefore be reluctant to speak freely. There can be underlying feeling of anger or guilt. There may also be preconceived notions about the causes of symptoms that color their presentation of information. It is helpful to try to make the parent/caregiver feel comfortable and to encourage as objective a description of the situation as possible.

Documents most valuable in assembling a developmental history include the earliest developmental and psychological evaluations, earliest school evaluations, and earliest medical evaluations. These are most likely to contain pregnancy, birth and infancy histories, histories of developmental milestones and early relatedness, histories of family responses to the diagnosis of developmental disability, and history of early physical signs of neurological or genetic disorders. Family history of developmental and psychiatric disorders may be mentioned. Later psychiatric disorders may be mentioned. Later psychological, developmental, medical, school and child study team evaluations present a chronological story of growth and development. Any past psychiatric evaluations and any legal system documents can be critical to accurate diagnosis. Initial agency, state eligibility, or institutional admission documents may gather or summarize earlier reports no longer available.

Past medical evaluations, beginning with the earliest developmental evaluations, may note signs and symptoms of important medical causes or comorbidities of mental retardation such as seizure disorders, head trauma, and genetic disorders, as well as independent medical issues important to diagnosis and treatment such as diabetes, hypertension, hypothyroidism and porphyria. What is ruled out is as important as what is ruled in by previous evaluations. A patient may already have had EEG, brain imaging, karyotype, Fragile X DNA, or FISH.⁷ Where conclusions are based on obsolete diagnostic

methods (e.g., skull X-ray vs. magnetic resonance imaging, Fragile X karyotype vs. Fragile X DNA), probable accuracy of the earlier conclusions must be weighed, as must the possible benefits of testing these with modern diagnostic studies.

Information about previous medication trials can also be beneficial. This should include the dose given, the length of time given and the response to treatment. Many times, a person is listed as not responding to a medication trial when a careful evaluation reveals that a full therapeutic trial never occurred. Likewise, many times a person is listed as being "allergic" to a medication, when further information reveals that the "allergy" was actually a medication side effect.

The clinician must at all times be aware of sources of inaccuracy in these documents. It is well to remember a lesson from the classics. Herodotus (IV,42) describes an account of a Phoenician circumnavigation of Africa which he found unbelievable because the sailors claimed "to have the Sun on their right." The observant Phoenician sailors, who had crossed the Equator, were correct; Herodotus was led astray by theories of the day, which did not know of the Equator and the Sun's position relative to it when seen from southern latitudes. Today we believe the Phoenicians' account for the exact reason Herodotus disbelieved it—the detail the good historian Herodotus included. Observations are valuable but diagnostic conclusions may be colored by theoretical considerations no longer supported by current belief or practice.

This is particularly true of diagnoses of "Childhood Schizophrenia." Currently, this term is reserved for children who meet virtually the same diagnostic criteria for Schizophrenia as adults. As late as 1980 it was applied to persons we would easily recognize today as having an Autism Spectrum Disorder. Diagnostic criteria for Schizophrenia and Bipolar Disorder have changed radically over the past 25 years; diagnostic conclusions from old histories and other documents are less valuable than the observations that led to them and would lead to a different diagnostic conclusion today. Many diagnostic entities described in DSM-III¹ and IV² were not formulated, or had different diagnostic criteria, before 1980 (most notably Pervasive Developmental Disorder Not Otherwise Specified).

Often, a psychiatric diagnosis has been made without clear criteria, partly because of the difficulty in accessing information about subjective internal states. At times, it appears that diagnostic conclusions were arrived at based on a response to treatment; i.e., if there is some response to an antipsychotic, the individual must be schizophrenic. These diagnoses are often carried for years or decades because they have not been critically re-evaluated. Similarly, outdated theories about the psychodynamic origins of Autism Spectrum Disorders often led to quite pejorative descriptions of parents and family dynamics.

Diagnoses were often used to justify courses of treatment (often medication use) or educational placement. The seriousness and intensity of behavioral problems, including even allegations of abuse, were often exaggerated to justify medication use or residential placement not otherwise available in an overburdened system. Historical documents should always be read with due appreciation of the time and context of their creation, and checked against the living memory of their sources if available. The credibility of living informants must also be weighed against credible historical accounts.

Individual Educational Plans (IEP's), Individual Service Plans (ISPS), and Individual Habilitation Plans (IHP's) seldom provide information that is useful for the psychiatric history. Most are mechanically created to fit with the deemed educational goals and objectives, and do not provide information that is accurate and relevant for psychiatric purposes. The exception occurs where the IHP or IEP includes professional evaluations.

DEVELOPMENTAL HISTORY

Developmental history is the personal history of the individual and the family events that shaped the current situation, beginning with what we think of as heritable factors and encompassing everything that might bear on the premorbid functioning.

Pregnancy: One must ask, or research in documents, about the course of pregnancy: uneventful vs. complicated by hemorrhage, threatened miscarriage, exposure to TORCH infection (the fetal *encephalitides*: Toxoplasmosis, Rubella, Cytomegalovirus and Herpes), *teratogens*

(drugs or other substances capable of causing fetal malformations and mental retardation, including alcohol, other intoxicants, phenylalanine due to untreated maternal phenylketonuria, Coumadin, anticonvulsants and abortifacients), premature or postmature delivery. Details of labor (length, difficulty) may be asked about or found. Breech presentation (currently thought to be an effect, rather than a cause, of developmental disorder) should be noted. Delivery by C-section, and presence or absence of *respiratory distress* and need for resuscitation (oxygen) should be noted. Birth weight is important; many genetic disorders are characterized by Intrauterine Growth Retardation (*IUGR*, or "low birth weight"). Normal birth weight is 5 lbs 5 oz. or above. *Apgar scores*, a measure of physical fitness at birth, should be found where possible. These are customarily taken at 1 and 5 minutes and measure such things as strength of cry, oxygenation and muscle tone. Scores below 8 on the 0-10 scale may be associated with future developmental problems. The 5-minute measure is the more predictive. Any abnormalities seen at birth should be noted, with any necessary treatment or NICU admission. A great deal of sensitivity is required here; too great an emphasis was in the past placed on minor events of pregnancy as causes of retardation. Review of this information can be an opportunity to relieve a parent of unjustified guilt.

Infancy: The question "What was (the patient) like as a baby?" can elicit a wide range of responses. Many babies with MR/DD are "easy"; that is, undemanding. Babies with Autism Spectrum Disorders are often difficult from early in life; it must be determined whether the baby cuddled, made eye contact and smiled responsively. *Gaze avoidance* may be present from birth or develop much later. *Developmental milestones* (age at achieving head support, sitting, walking, speech) should be established. Severe medical problems, especially any associated with slowing of development or loss of developmental milestones, onset of seizures, episodes of dehydration and head trauma with change in level of consciousness should be searched for. Children with Autism Spectrum Disorders may display *toe-walking, twirling, rocking, headbanging* and *motor stereotypy* (repetitive voluntary movements and

posturing) early, others later. Hyperactivity and sleep disturbance may also be seen early in life.

Early Childhood: The most important developmental milestone of early childhood is speech. Delay in speech and idiosyncrasies of speech are both important. The latter include *echolalia* (echoing instead of answering) *delayed echolalia* (repetition of whole sections of overheard dialogue) *pronominal reversal* (calling oneself "You" instead of "I") or *third-person self-reference* (calling oneself by name instead of using "I"). Mixture of any or all of these with communicative speech is indicative of Autism Spectrum Disorder. Normal motor milestones followed by failure to develop normal speech may point to communication and Autism Spectrum Disorders. Response to peers can be assessed; children with Autism Spectrum Disorders may ignore peers and toys. *Self-injury* may have its onset in early childhood or later.

It is usually in early childhood that MR/DD is suspected and first evaluations are sought. Records of these are very valuable. Discussion of parental response will elicit family reactions to the diagnosis of a developmental disability which may be crucial in the assessment as well as treatment planning.

Preschool/School: Classroom placements and responses to them are the first exposure to authorities and perhaps to cognitive deficits. Later there may be interactions of all kinds—favorable and less so—with neurotypical peers, and with other children with MR/DD. These may set the stage for future responses. This may be the setting for the first formal cognitive testing and other ongoing professional evaluation and treatment (Speech, Physical and Occupational Therapies). Attention Deficit-Hyperactivity Disorder and Tic Disorders may have their onset at this time, as well as Panic Disorder and the ritualism and *obsessive-compulsive* features of Autism Spectrum Disorders. Depressive episodes, and, rarely, manic episodes, can begin this early.

Adolescence: Where applicable, the clinician will want a history of onset of puberty, and the patient's and family's responses, dating and sexual experiences if any, experiences of independence and travel, extra-curricular activities, responses to siblings' emancipation, and responses to the ending of school and the beginnings of vocational involvement. Residential placement may take place during adolescence.

Mood disorders and Schizophrenia often have their prodrome or onset during adolescence and early adulthood. There may be exposure to intoxicants. Seizure disorders may begin or change their features during adolescence.

Many persons with MMR may be able to give crucially important accounts of their adolescence.

Adulthood: Many features of adolescence may be experienced in what is chronologically the young adulthood of persons with MMR (and in some cases in later adulthood). By this point siblings may have left the family, and many significant persons may have died. History of adjustment to residential and vocational involvements, ongoing social involvements, and other features of life noted in adolescence should be sought from informants and the patient.

The clinician should always be in search of history of onset of medical problems, physical and sexual abuse, other trauma, divorces deaths and other losses, and other, earlier, episodes of behavioral or psychiatric problems.

It is important to also get a substance use history. Many people assume that persons with MR/DD could not be using substances of abuse. In fact, many individuals with MMR are exposed to these substances and some use them.

Information about the use of over-the-counter medications and herbal remedies is also necessary since these can also have side effects and drug interactions.

Family History: The history of medical, developmental, and psychiatric disorders in immediate and second-degree maternal and paternal relatives is very important to potential diagnostic categories as well as possible medication response. Many medical conditions and mental retardation syndromes are genetic or have strong family histories. Mood disorders, Tic Disorders, and Autism Spectrum Disorders all have strong familial occurrence; Schizophrenia less so. Alcoholism in a family history may point to undiagnosed mood disorder; in a mother, to Fetal Alcohol Spectrum Disorders. A patient with MR/DD who presents a diagnostically difficult array of psychotic symptoms, and who has a family history of a diagnosed psychotic disorder, is more likely than not to share the family diagnosis (but this is subject to cautions about the accurate diagnosis of family members!). If known, drug responses of first degree relatives

can be valuable guides to eventual medication treatment choices as well as diagnostic clues.

HISTORY OF COGNITIVE AND COMMUNICATION EVALUATION

Formal cognitive testing is a field fraught with controversy as to its validity, reliability, and predictive value. For purposes of understanding an individual it is at best a source of rough approximation, since it is heavily influenced by verbal ability and interactive ability, placing many persons with aphasiess, motor impairments and Autism Spectrum Disorders at a severe disadvantage. However, educational and habilitative systems frequently use formal cognitive testing as a benchmark for service provision, and, however useful or accurate, IQ measures become an important factor in the lives of persons with MR/DD. For persons with developmental disabilities, it is essential that assessments of adaptive behavior are made as these measures balance formal IQ scores and represent more of the "gold standard" in deciding upon a level of developmental disabilities (mild, moderate, severe, profound).⁶

The numbers themselves can be diagnostically revealing. A 15 point disparity or more between Verbal IQ (VIQ) and Performance IQ (PIQ) may reveal Learning Disorder instead of or in addition to MR/DD. It is generally agreed that a VIQ/PIQ disparity of 15 or more points renders the resulting Full Scale IQ (FSIQ) invalid; persistent use of such results to determine service provision may indicate a systems problem, as would services aimed at a VIQ or PIQ level without taking into account the other. The FSIQ, VIQ and PIQ might correlate poorly with adaptive abilities measured by such instruments as the Vineland Adaptive Behavior Scales (VABS), or there may be *splinter skills*, abilities such as musical or memory skills beyond ability as measured by standardized IQ tests, or standardized testing might show functioning in the Severe or Profound range of mental retardation (S/PMR) in an individual with normal motor developmental milestones, all situations often pointing to Autism Spectrum Disorder.

There may be a significant difference between a person's measured performance and resulting estimated ability, and the person's *level of comfort*, that is, the level of ability, cognitive and adaptive,

at which he or she functions with the greatest ease and satisfaction. Often mismatches between levels of ability measured on standardized tests and level of comfort produce developmental crises when an individual is asked to function at the former rather than at the latter.

Serial IQs, that is, IQ measures across years, may reveal decreases due to onset of major psychiatric illness or other life crisis. Cognitive abilities measured by the Wechsler Intelligence Scales for Children (WISC) are considered valid through age 16; from this point the Wechsler Adult Intelligence Scales (WAIS) are used. For statistical reasons there is often a 10 point increase in IQs as measured by the WAIS series over those measured on the WISC series. This may be less so with the more recently revised WAIS-III. Habilitative and educational goals changes may be changed on this spurious basis, again the source of possible developmental crisis.⁶

As important as—perhaps in many instances more important than—the measured IQ are the evaluator's observations of the patient's behavior at testing. Even without any other available history, reports of gaze-avoidance, stereotypy, twirling, echolalia and other signs of Autism Spectrum Disorder may confirm a suspected diagnosis; such observations are recorded even in reports by alert clinicians that predate Kanner's 1943 description of Autism. Similarly, hyperactivity, compulsions, delirium, hallucinations, delusions, depression and elation/euphoria or irritability may all be noted in reports of psychological testing.

Speech and nonverbal communication styles may also be reported, and caregivers should always be asked about a patient's ways of making his or her needs known. Long-time caregivers may be aware of subtle signaling systems used by persons with no oral language. Sign language and alternative communication systems must always be inquired about; if possible interview should be conducted with sign translation or with use of augmented communication (picture exchange, electronic vocalizers, etc) when available. (**Note:** "Augmented communication" is not the same as Facilitated Communication, a technique advocated for use with this population for which there is no experimental support.) Patients for whom English may not be the primary or only language should be interviewed when possible in

their other language. Too often cognitive functioning may be incorrectly inferred from language and communication skills.

In summary, formal IQ test results should always be viewed skeptically. It should be noted whether correct instruments for the range of reported IQ were used, whether the patient was tested in a language he or she understands, whether sensory handicaps such as blindness or deafness, motor deficits such as cerebral palsy, were taken into account, and whether testing took place during an episode of an acute psychiatric or other disorder that could have distorted the results.

MEDICAL HISTORY

It is obviously of critical importance to know the patient's current medications, their doses, and where relevant current serum levels. This includes all medications prescribed, not just those prescribed for psychiatric treatment (the body does not know the difference). There can be important side effects and drug interactions. Many medications prescribed for general medical conditions can cause psychiatric symptoms. Recent medication changes, might be crucial, especially if they have occurred rapidly. Many medications can precipitate withdrawal symptoms if discontinued or tapered too rapidly. This frequently occurs with medications that many do not recognize can cause withdrawal, such as antipsychotics.

Laboratory studies may not be available to caregivers. Where current (within the past two to four weeks) laboratory studies are unavailable they should be ordered (as baseline: comprehensive metabolic panel, complete blood count with differential, thyroid function tests, relevant drug serum levels).

Persons with MR/DD can, of course, have any medical condition anyone else can have. Many, such as seizure disorders, meningitis, encephalitis, and traumatic brain injury, are indicative of, or consequences of, genetic, traumatic or infectious causes of MR/DD.

It must always be remembered that medications prescribed for both psychiatric and medical conditions, herbal preparations and over-the-counter drugs can all cause symptoms that mimic depression, mania, anxiety disorders, hallucinations, delusions, disorientation,

confusion and involuntary movements—any and all of the signs and symptoms described above.

SUMMARY AND FORMULATION

The task of the clinician is to integrate the fragments of available historical information with the Mental Status Evaluation⁸ into diagnosis and a coherent narrative understanding of how present events interact with past development to create the current problem, and use this understanding, or *case formulation*, to propose treatment. No one element described above will by itself make or confirm a diagnosis; only integration of the whole will yield an accurate diagnosis and a successful therapeutic intervention. The process of obtaining the history will create an active relationship with the patient and caregivers that will begin to make that intervention possible.

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CHECKLIST OF HISTORICAL INFORMATION NEEDED FOR THE PSYCHIATRIC EVALUATION

- Pregnancy, Birth
 - Early Development
 - Behavioral Adjustment in Early School Years
 - Level of Educational Interventions
 - Behavioral Adjustment in Adolescence
 - Level of Educational Interventions in High School Years
 - Occupational History
 - Substance Abuse History
 - History of Marriage or Children
 - Psychological Evaluations
 - Intelligence Testing (IQ)
 - Adaptive Behavior Testing
 - Medical History
 - Illnesses in Childhood
 - Disabilities, Visual, Hearing, Physical
 - Seizure Disorder
 - Surgical Procedures
 - Current Conditions
 - Accidents
 - Guardianship Information if applicable
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