

Mission Impossible?: Developing an Accurate Classification of Psychiatric Disorders for Individuals With Developmental Disabilities

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There are a number of controversies in psychiatric classification. To begin with, it is important to consider why a system of classification is needed and what form the system should take. Cantwell³ reviewed several important conceptual issues in classification of child and adolescent psychiatric disorder that may be applied to a discussion of the same topic for individuals with developmental disabilities. Critical questions include: (1) Should classification be dimensional or categorical? (2) Are psychiatric disorders best characterized as discrete entities? (3) Are disorders quantitatively or qualitatively different from normal? Cantwell³ also discussed the importance of reliability and validity. Following review of the rationale and basis for developing a psychiatric classification system, these conceptual issues are discussed. Some ways in which a developmental approach might enhance a diagnostic system for people with developmental disabilities are explored.

Keywords: categorical approaches, developmental disabilities, developmental psychopathology, dimensional approaches, psychiatric assessment, psychiatric classification

It is important to consider why classification of psychiatric disorders is needed. There are several reasons to try to develop an accurate classification scheme. In medicine, discrete classification is used based on the notion that disorders will eventually be defined or described, etiology will be identified, and specific treatments will be developed related to this understanding. In the case of many disorders or illnesses, especially psychiatric disorders, this is a goal but not a reality. However, in general, a major reason to classify a health or mental health problem is to develop effective treatment.⁴

Another rationale for classifying disorders is to provide clear definitions so that communication about disorders can occur across a wide variety of settings, and for a large number of cases. To develop an effective treatment for depression, and to test the efficacy of the treatment, there must first be an agreed upon definition of depression. If depression is defined in one way at the University of Massachusetts and a different way at another center, it will not be possible to compare treatment approaches between the two sites. Clearly, this would hinder progress towards identifying effective therapies.

It is also important that classification be reliable and valid, so that at some point, causes can be determined. Getting to the root of the

problem will be much more difficult if every researcher defines the problem in a different way. Classifying problems also allows for social systems to be developed to provide care to individuals in need, and to provide appropriate care to individuals with specific types of need.³

To insure that a given clinical population will have the benefit of effective services and treatment, it is important that classification be reliable and valid for that group. One example of this is the debate over the use of adult diagnostic criteria for the identification of major depression in young children. Early on in the debate, many experts in child development held that depression could not occur in young children. This was in keeping with psychoanalytic models of depression at the time (late 1950's, early 1960's) suggesting depression involved "super ego" problems (i.e., guilt) that young children could not experience. In a similar fashion, people with mental retardation were also thought to be incapable of becoming depressed, at least until the landmark 1983 Sovner and Hurley³¹ article, "Do the Mentally Retarded Suffer from Affective Illness?"

In the child psychiatric literature, there was gradual acceptance that children suffered from depression, but theorists began to talk about "masked" forms of the disorder. It was suggested that depression in children was different from that seen in adults. Depressed children expressed

somatic complaints, had tantrums, ran away, refused to go to school, were restless, etc. These problems were seen as masking the depression, which lay hidden beneath the surface. The problem with this conceptualization soon became evident, as most every psychopathologic state or trait was seen as a possible “behavioral equivalent” of depression in a troubled child. As Cantwell³ observed, the term “masked depression” was “used so vaguely and so loosely that with time the concept lost all credibility...”

Eventually, researchers began to describe the effects of developmental stage (or age) on the surface features of depression.^{2,5,26} Children, depending on their developmental stage, might have some variable features, but there was no need to characterize a new disorder. Elements that help define a syndrome as a syndrome, beyond clinical phenomenology, such as family history studies and treatment outcome were examined. These external validators were found to be consistent with findings from the adult research. Based on these studies, there was general agreement that children could be diagnosed using the adult criteria with only minor modification.

In a similar manner, some practitioners in the field of developmental disabilities have claimed that depression presents so differently in patients with intellectual disabilities, that new criteria are required. The phenomena may be similar to “masked depression.” In both instances, behavioral equivalents such as somatic complaints or tantrum behaviors are recommended. Some lessons might be learned from past classification dilemmas of the child psychiatric researchers. One approach investigators in the field of developmental disabilities might use to improve psychiatric diagnostic assessment is to describe the probable impact of developmental stage on the clinical manifestation of various psychiatric disorders,^{6,7} while maintaining use of the core DSM criteria. This tactic was adopted in DSM-III-R, and continued in DSM-IV, in which age related features of disorders are described while adult based diagnostic criteria are essentially retained.¹

BASIS FOR PSYCHIATRIC CLASSIFICATION

The most obvious basis for classification is etiology. However, to use etiology as a basis for classifying disorders, the state of the science must be such that the causes of illness or disease are known. In the case of mental health disorders,

causes are poorly understood. It should also be noted that etiology is not always the best basis for classification. Cantwell and Carlson⁴ cite the example of fractures. In this instance, a phenomenological descriptive approach is more useful. It is obviously more helpful (in determining treatment) to know that a fracture is simple versus compound, as compared with knowing only that it was caused by a misplaced hammer blow, or by a fall in the bathtub.

One difficulty in the area of assessment of mental health disorders is that current thinking would suggest that these disorders are usually multiply determined. There may be many pathways to the “chief complaint” of anxiety, or the problem that someone is aggressive. What then is the relationship between the classification of disorder and its treatment? If symptoms of a bipolar illness emerge in the context of velo-cardio-facial syndrome, will treatment differ from that which would be given to an individual with the same phenomenology of mood symptoms, who does not have a possible genetic basis for their difficulties? Should classification systems that are essentially descriptive differentiate between disorders with suspected etiologies and ones in which the pathways to disorder are less well understood?

SHOULD CLASSIFICATION BE DIMENSIONAL OR CATEGORICAL?

Both DSM and ICD are categorical or discrete classification systems.^{1,40} The advantage to such a system is that there can be characterization of a mental health problem in ways that help determine the most likely effective treatment and do not require that we know the “cause” of the disorder. In the example given above, if the cause is suspected (there may be a genetic component), this can be specified as well. But the bipolar disorder symptoms may be treated with mood stabilizing medications that have been found to be effective in controlled investigations of individuals presenting with a well defined set of problems that constitute the syndrome of bipolar disorder. Another advantage to a categorical system is that there can be discourse among investigators across many settings which can help further our understanding of classification of illness and its related treatments, even when investigators disagree about etiology.³

There are drawbacks to categorical systems, however. In particular, they may not be as precise as other types of taxonomy. Some investigators

have argued that syndromes should be empirically derived, and a “dimensional” approach would be a more effective way to classify psychopathology. Using a dimensional classification system, syndromes would be identified based on the use of factor analytic or other statistical analyses of inventories of psychopathology. Some have argued, since psychopathologic states might not be discrete entities, they may in fact be better characterized as occurring along a continuum of severity.^{22,34,38}

A large number of checklists and symptom surveys have been developed to assess psychopathology in individuals with and without cognitive disabilities. As Sturmey³⁴ points out, research regarding the reliability and validity of these measures has been more systematic than approaches used in studies applying categorical classification to the psychiatric assessment of individuals with developmental disabilities. However, despite the proliferation of numbers of assessment tools, none of the checklists appear to contain a full set of DSM symptom criteria for such disorders as major depression and bipolar disorder.

Some have argued that DSM-IV criteria cannot be applied to individuals with severe mental retardation.^{14,28} The argument may be premature, however, because so few investigations have systematically studied their application. Sturmey³⁴ reviewed studies that had employed either ICD or DSM criteria to establish psychiatric diagnoses in people with mental retardation and found that only one study failed to modify criteria in some way. Charlot *et al.*¹⁰ reviewed studies in which mood disorders were evaluated in individuals with developmental disabilities. Many of the investigations used substitute criteria and either added, or both added and deleted criteria for diagnoses of mood disorder. In some instances, behavioral equivalents were used as replacements for symptoms rarely seen or difficult to assess in people with severe cognitive impairment. For example, in one study, the authors omitted the symptoms of guilt, hopelessness, and depressed mood, using crying and aggressive behaviors as substitute symptom criteria.¹¹ Unfortunately, the modifications to criteria varied from one study to another, and did not appear to be empirically derived.

Another problem when using assessment tools or inventories to classify psychopathology is that the factors identified will always be comprised of the items (symptoms or behaviors) that are put

into the instrument (“garbage in, garbage out”). If assessment tools do not contain all of the relevant DSM items required to diagnose a disorder, then it will not be surprising when factors are identified that do not correlate strongly with DSM syndromes, or with each other.²⁴

Related to this concern is the fact that content validity and criterion validity serve opposing functions. To ensure that an assessment tool has criterion validity, only those items correlating highly with the criterion are retained. Unfortunately, in the early stages of investigating the clinical features of a syndrome (using a psychopathology instrument), items that have been dropped may have been important to a complete understanding of the nature of the disorder within the group under study.¹² Developing a comprehensive picture of the clinical phenomenology of DSM identified disorders may be the most important goal in the early stages of building a valid classification for this population.

MORE ON THE DISCRETE VERSUS DIMENSIONAL DEBATE

In the childhood psychiatric literature, a good example of the discrete versus dimensional classification question has arisen in the area of diagnosing Autistic disorder, Asperger’s disorder, and Pervasive developmental disorder not otherwise specified (PDD NOS). In a review of this literature, Szatmari³⁶ provides a compelling argument for changing the current scheme. This group of disorders (PDD NOS, autism, and Asperger’s disorder), taken together, can be differentiated from other emotional and behavioral disorders arising in childhood, usually with good reliability. However, within the broad category of PDDs, there is generally poor agreement among clinicians who attempt further differentiation to a sub category (PDD NOS versus Asperger’s). A better resolution of the available data may be to view the broad category of the three disorders taken together as a discrete syndrome. However, within this larger group, a dimensional approach could be used to further classify individuals who have a more or less severe variant of the disorder.

In children and adolescents, reliability of DSM categorical classification of psychiatric disorders is reasonable for broad categories, but is less robust for specific subtypes of disorder (i.e., anxiety disorder versus panic, social phobia, etc.).^{19,23} This is especially true for small children, and for internalizing types of disorders. One interesting possibility is that disorders in young

children are actually broader spectrum in nature, and that the clinical phenomenology only becomes more specific with age (or with developmental progress).¹⁹ If true, this might have implications for the psychiatric assessment of individuals with developmental disabilities, in particular for people with more severe cognitive delay.

Some investigators studying adult psychiatric disorders have also raised questions about the problem of using a discrete classification system.³⁸ Van Praag³⁸ notes the fact that patients often do not fit neatly into discrete categories. The more common experience is that patients have symptoms from a variety of syndromes. In biological psychiatry, symptom clusters or behavioral domains have been identified for which there appear to be common neurophysiologic or neurochemical pathways. Pallanti²² discussed the recent interest in neurobiological personality traits and “behavioral tendencies” or temperament including Cloninger’s dimensions of temperament as well as Zuckerman’s proposed “sensation seeking” tendencies, that may predispose to bipolar affective disorder and antisocial personality disorder. The basic premise is that there are inherited behavioral tendencies, and that these “character dimensions” have neurofunctional substrates.

A number of “final common pathways” for various behavioral tendencies have been described. Rats who prefer alcohol to water have fewer D2 receptors in certain areas within the limbic system. Others have noted 5HT dysregulation in impulsive aggression. Following along these lines, Van Praag³⁸ has suggested a “functional psychopathology” approach in which classification would involve “tiers.” Syndromes, once identified, could be further “dissected” into “psychological domains” that are disturbed. These include disturbances in the regulation of mood, aggression, motor activity, information processing, memory, perception and others.

Van Praag³⁸ summarizes advantages to a functional psychopathology model, noting in particular that comorbidity can be better explained using this type of system. The actual phenomenon of comorbidity may be an artifact of the way we currently classify mental disorders. Data from recent epidemiologic investigations suggest that many individuals appear to suffer from multiple disorders. For example, it has been argued that depressive spectrum disorder may better be characterized along a dimension of severity. A milder form may be one that occurs

without anxiety or other associated features. In the more severe variant, there may be features of several different anxiety disorders.³⁵

If a functional psychopathology model is used, there may be greater potential for quantification of data regarding psychopathologic states, and in turn, to develop more targeted treatments. One disadvantage at this time is that the functional approach has not gained wide acceptance. As a potential model for use with individuals with developmental disabilities, a danger may be that many people presenting for psychiatric care will be categorized as having problems with impulsivity and aggression. This could provide a rationale for using the same intervention (i.e., neuroleptic medications) for individuals with widely varying causes for aggressive behavior which is frequently a diagnostically non specific surface feature of an acute psychiatric disorder.^{9,16} Further exploration of this model could be exciting though, if subtypes of cerebral dysfunction linked with mental retardation are examined. For example, we know that some individuals have mood changes secondary to seizure foci in specific brain areas that make them more vulnerable to develop a mood disorder.³⁷ Seizure disorders occur at higher rates among individuals with developmental disabilities, and in specific relation to certain syndromes associated with mental retardation.¹³ How often are these conditions linked? And, are there differences related to the pathways involved?

ARE DISORDERS QUANTITATIVELY OR QUALITATIVELY DIFFERENT FROM NORMAL?

Werry and Quay³⁹ studied a very large cohort including all of the children in kindergarten through second grade in a Midwestern university town. An interesting finding was that virtually all of the children displayed behavior problems of some kind. Researchers began to question, if so many young children present with behaviors usually considered pathologic, what really constitutes an “abnormal” behavior? With additional research, it became increasingly clear that many psychiatric disorders were comprised of behaviors or emotions that are normal at some time in development, within certain situations, or when displayed to some degree. Psychopathologic states could be understood as excesses of normal behavior, at least in many instances. One way to help define a behavior as pathologic or symptomatic is that psychopathologic behaviors interfere with normal functioning and cause

significant distress. Predictive validity is enhanced when severity measures are used, and level of impairment is considered.

It is now recognized that a variety of psychosocial stressors impact on the occurrence of psychiatric disorder, and understanding these can enhance a system of classification.³ There has been limited research on the topic in people with developmental disabilities, but data suggest a wide array of stressful life events may either trigger or exacerbate mental illness for these individuals. There may be a tendency for clinicians to underestimate the impact of losses and changes in the lives of people with more severe intellectual disabilities.²⁵ Certain personality traits and tendencies of individuals with developmental disabilities may place them at greater risk for psychiatric disorder. For example, people with developmental disabilities often expect to fail. This tendency may play a role in the development of learned helplessness, and could increase vulnerability to depression.¹⁷

Some psychiatric disorders do not appear to be comprised of problems or behaviors that are simply quantitatively greater than normal (i.e., psychotic disorders). In any case, it is important that thresholds for classifying a symptom as pathologic be clearly outlined within the classification scheme, as well as providing information about how the phenomenology is affected by different contexts.^{3,20} Possibly, the use of a tiered system, such as the one recommended by Van Praag³⁸ would incorporate the best of both approaches. In this model, broad categories are discrete. A range of symptoms or symptom clusters are seen within these larger classes. These functionally related symptoms could then be quantitatively described.

RELIABILITY

It is vital that any classification system have reliability.³ If one clinician uses the system, and makes a particular diagnosis, it is important that most any clinician would apply the scheme assessing the same patient and arrive at the same conclusion. A system must be reliable or its

validity cannot be established. Spitzer³³ described a number of common sources of unreliability in psychiatric assessment, most of which can be applied to any clinical population, but are particularly salient for individuals whose assessment is heavily dependent on informant reports. Spitzer's³³ observations regarding

unreliability in diagnostic assessment are summarized in Table 1.

Information variance may result from different information being given on the same case. It may be that different clinicians will tend to elicit different information. Observation variance occurs, even when clinicians have the same information, because they make different observations on the data they are given. Criterion variance refers to the fact that clinicians will use different thresholds to make a diagnosis, even when using the same classification system. So at Clinic A, Attention Deficit Hyperactivity Disorder or ADHD is diagnosed frequently, and at Clinic B, the disorder is far less commonly identified, though both clinics use DSM-IV. Subject or occasion variance, although not a true source of unreliability, can be an apparent one. This type of variation occurs when the patient has an actual change in clinical presentation when evaluated at different points in time. Psychopathologic states are not static, and this variation reflects a true variation in the phenomena being assessed.

When considering a system of classification of psychiatric disorders for people with developmental disabilities, it will be important to deal with the problem of reliance on informant reports. Research to date suggests that when informant reports are used, externalizing types of problems are more likely to be emphasized.^{2,19} Conversely, anxiety, depression and other internal types of psychopathology may be underestimated. Although there may not be any simple solution to the problem when evaluating individuals with limited language skills, some steps can be taken. Multiple sources of clinical information can be used to arrive at a diagnosis. Using clear operational definitions of symptoms and behavioral criteria can be helpful, as well as having concrete guides regarding thresholds for labeling a behavior a symptom.^{21,29,30} Symptom severity criteria could also be used. Psychiatric evaluations need to be longer when informants must provide a substantial proportion of the clinical data.³²

TABLE 1. SPITZER'S SOURCES OF UNRELIABILITY IN PSYCHIATRIC ASSESSMENT AND RECOMMENDATIONS FOR PSYCHIATRIC ASSESSMENT OF PEOPLE WITH DEVELOPMENTAL DISABILITIES (DD).³³

Information Variance	Different information is given on the same case. Different clinicians may elicit different information from patients, or informants.	Multiple sources of information should be used. Clinicians need to be aware that informants may focus on externalizing types of problems.
Observation Variance	Different clinicians, even given the same information, may draw different diagnostic conclusions.	There is need to develop improved reliability in the psychiatric assessment of people with DD. The use of behavioral equivalents could greatly improve reliability.
Criterion Variance	Clinicians use different thresholds to make a psychiatric diagnosis, even when using the same classification system.	There is a need to establish valid classification of psychiatric disorder for people with DD. One approach would be to develop modifications to DSM for use with people with DD, and to promote their use among mental health clinicians.
Subject or Occasion Variance	An "apparent source of unreliability" – the patient may have actual changes in presentation when evaluated at different points in time since psychopathologic states are not static.	Clinicians should consider the impact of true variations in psychopathologic states when assessing their patients with DD.

VALIDITY OF PSYCHIATRIC SYNDROMES

Validation of psychiatric syndromes includes several steps.³ First, there must be a comprehensive description of the phenomenology of the syndrome and its associated features. A means to reliably assess for the presence of these phenomena must be developed. Developmental effects should also be described. Studies of family history, laboratory findings, and treatment outcome can then provide external validation. It is not until these steps have been taken, that rates of disorder within a given population can be established.

Most DSM-IV psychiatric syndromes have not been validated in individuals with developmental disabilities. Validation of syndromes with core features that are more "internalized" is likely to be more difficult than for externalizing disorders.¹⁹ It will be important to deal with the fact that psychiatric evaluation of people with developmental disabilities often relies heavily on the use of informant reports which in turn results

in an increased emphasis on externalizing behavior problems.² In individuals with developmental disabilities, a further challenge will be to examine the extent to which genetic syndromes commonly resulting in mental retardation and other developmental disabilities, are also associated with specific psychiatric sequelae. Individuals with developmental disabilities may also be at risk for missed medical diagnoses, with high rates of physical health and medication side effect problems that mask or mimic acute psychiatric illness.^{8,27} Some challenges in making accurate psychiatric diagnoses in people with developmental disabilities are outlined in Table 2.

A conservative approach to developing a clear description of psychiatric syndromes in people with developmental disabilities would be to use DSM-IV criteria. These criteria could be expanded and minor adjustments made based on the existing literature regarding the phenomenology in the population. In Great Britain, a consensus

TABLE 2. CHALLENGES IN MAKING ACCURATE PSYCHIATRIC DIAGNOSES IN PEOPLE WITH DEVELOPMENTAL DISABILITIES	
PROBLEM AREA	RECOMMENDED APPROACH
Patient cannot provide reliable self -report	Use multiple sources of info: interview patient, observe patient, interview multiple caretakers, review records, look for objective sources of data must have longer appointment time for complete evaluation.
Most information comes from informants	Recognize tendency of informants to emphasize externalizing problems – probe for observations of vegetative symptoms, episodic patterns of illness, and facial expressions or behaviors that may give signs of internal state changes. Use behavioral equivalents to help identify the presence of DSM symptom criteria.
Developmental deficits may alter surface features of psychiatric disorder	Adults with intellectual disabilities appear to have similar phenomenology to children without cognitive delays. When evaluating patients with intellectual disabilities, consider the ways in which cognitive limitations may impact on the clinical picture.
Clinical population is heterogeneous	Due to the heterogeneity of population, one needs to know this individual’s baseline functioning to assess departures suggesting an acute psychiatric disorder. Although etiology of MR varies greatly, developmental features are similar for people with mild, moderate, or severe MR.
Medical problems often drive surface features of agitation, vegetative and mental status change but are hard to diagnose frequently missed	Thorough medical evaluation to assess possible medical problems causing altered behavior, mood, sleep, and appetite is critical. Common findings include: medication side effects (i.e., EPS, akathisia), constipation, infections (otitis, UTI), pain- fracture, thyroid, abnormalities, etc.

approach was used to develop a companion guide to ICD-10, emphasizing suspected differences in phenomenology of psychiatric disorders in people with intellectual disabilities, although behavioral equivalents were not routinely used.^{15,40} A developmental perspective could be helpful in deciding how to modify DSM for individuals with cognitive delay. For example, in the current DSM, core symptoms of depression are the same for different age groups, but there are variations which are described in terms of “age effects.” For individuals of different ages, there may be variations in the constellation of depressive

symptoms seen, typical associated problems, and at times, differences in the actual manner in which a core mood symptom is manifested. These variations may be driven, at least in part, by differences in cognitive functions or developmental stage.^{18,26}

In keeping with this perspective, it may be helpful to avoid using symptom substitutes. Rather, symptoms could be clearly operationally defined in ways that reflect how they might look in different groups of people. Using behavioral equivalents for DSM symptom criteria could then be systematically studied in individuals with

developmental disabilities. Charlot *et al.*¹⁰ have proposed modified DSM criteria for major depression and bipolar disorder. Modifications recommended included: use of behavioral equivalents as proposed by Sovner and Hurley^{29,30} and Lowry and Sovner,²¹ without dropping any of these criteria or using substitutes; use of irritability as an acceptable mood criteria (as currently established for children), and lowering the overall number of symptoms required by one symptom for individuals who have severely limited expressive language skills.

Modification of any proposed set of criteria is likely to be necessary over time, based on trial applications. In the first stage of investigating the reliability and validity of a set of proposed modified DSM criteria for people with developmental disabilities, a somewhat higher rate of false positives might be desirable. Since a first step in validating a syndrome is to develop a clear definition of the clinical phenomenology and commonly associated problems, during preliminary investigations, it may be helpful to "cast a wide net."¹² Further refinements aimed at increasing specificity of the proposed system could occur at later stages of research. Once clear definitions are available, reliability in their application must be established. Only then can prevalence studies and other external validators be examined.

SUMMARY

It is important to have a reliable and valid classification system to correctly identify psychiatric disorders in individuals with developmental disabilities. Improving accuracy in classification can help to maximize access to effective treatments and services. Classification can be discrete or dimensional, and there appear to be advantages and disadvantages to both approaches. Psychiatric disorders sometimes appear to be comprised of behaviors and feeling states that can and do occur in normal states. In other instances, psychopathologic symptoms appear to be qualitatively different from normal, as in the example of some symptoms of autistic disorder.

Classification of psychiatric disorders in individuals with developmental disabilities might begin with application of DSM-IV criteria with some modifications based on research describing clinical features of common psychiatric problems in this population. Also, research about the ways developmental stage might impact on the surface

features of psychiatric disorder could be useful in determining how DSM-IV criteria could be amended or modified. It will be important to use behavioral equivalents for each symptom criteria, to outline behaviors likely to be displayed by individuals who do not have expressive language skills. This has already been done by Sovner and Hurley^{29,30} and Lowry and Sovner²¹ for mood disorders. The behavioral equivalents methodology could greatly enhance reliability in psychiatric classification in people with developmental disabilities.

Validity would need to be established. Studies of the prevalence, usual clinical course, family history, laboratory findings, and treatment outcome could be conducted using modified or expanded DSM criteria with behavioral equivalents. For some disorders, it may be helpful to characterize one broad category (i.e., anxiety disorder). Within the larger group, a dimensional approach could be used to further classify individuals who have a more or less severe variant, as was recommended by Szatmari³⁶ in the case of autism spectrum disorders. In the case of other disorders, it may be possible to use current DSM-IV criteria with only minor modifications (i.e., major depressive disorder).¹⁰

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